AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

A.C.N. 087 155 780

FINANCIAL STATEMENTS

FOR THE YEAR ENDED
30 JUNE 2009

AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

DIRECTORS REPORT

The Directors present their report on the society for the financial year ended 30th June 2009.

The Directors in office during this period were as follows:
Dr Lilian Johnstone (Chairman), Dr Fiona Mackie (Honorary Secretary) and Dr Paul Henning (Honorary Treasurer). The Directors have been in office since the 5th August 2006 to the date of this report.

The principal activity of the Association during the financial year was to foster and develop the study of paediatric nephrology in Australia and New Zealand. No significant change in the nature of these activities occurred during the year.

The figures in the financial statements are for the twelve month period ending 30th June 2009. The surplus of the company for the financial year was $3,012.48.

Nil dividends were paid or declared since the start of the financial year. No options over issued shares or interests in the company were granted during or since the end of the financial year and there were no outstanding options at the date of this report.

No indemnities have been given or insurance premiums paid, during or since the end of the financial year, for any person who is or has been an officer or auditor of the company.

The Association's operations are not regulated by any significant environmental regulation under a law of the Commonwealth or of a State or Territory. At this time the Directors are not aware of any other developments likely to have a significant effect on the Association's operations.

This declaration is made in accordance with a resolution of the Directors.

Dr Paul Henning
Director
Honorary Treasurer ANZPNA

October 2009

AUSTRALIAN & NEW ZEALAND
PAEDIATRIC NEPROLOGY ASSOCIATION

DIRECTORS DECLARATION

The Directors have determined that the company is not a reporting entity and that this special purpose financial report should be prepared in accordance with the accounting policies outlines in Note 1 to the financial statements.

The Directors of the company declare that:

1. The financial statements and notes, presents fairly the company's financial position as at 30th June 2009 and its performance for the year ended on that date in accordance with the accounting policies outlines in Note 1 to the financial statements.

2. In the Directors opinion there are reasonable grounds to believe that the company will be able to pay its debts as and when they become due and payable.

This declaration is made in accordance with a resolution of the Directors.

Dr Paul Henning
Director
Honorary Treasurer ANZPNA

October 2009

SHEARER
+ ELLISS
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Financial Strategies

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AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

A.C.N. 087 155 780

INDEPENDENT AUDITOR'S REPORT

SCOPE

We have audited the financial report of **AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION** for the year ended 30 June 2009. The elected committee of the Association is responsible for the presentation of the financial report and the information contained therein, and have determined that the cash basis of accounting used is appropriate for the needs of the members. We have conducted an independent audit of the financial report in order to express an opinion to the members of the Association on its preparation and presentation. No opinion is expressed as to whether the basis of accounting used is appropriate to the needs of the members.

Our audit has been conducted in accordance with Australian Auditing Standards to provide reasonable assurance as to whether the financial report is free of material misstatement. Our procedures included examination on a test basis, of evidence supporting the amounts and other accounting estimates. These procedures have been undertaken to form an opinion as to whether, in all material respects, the financial report is presented fairly in accordance with the cash basis of accounting so as to present a view which is consistent with our understanding of the financial position of the Association and the results of its operations. Statements of Accounting Concepts and position of the Association and the results of its operations. Statements of Accounting Concepts and Accounting Standards are not applicable to the cash basis of accounting adopted by the Association.

The audit opinion expressed in this report has been formed on the above basis.

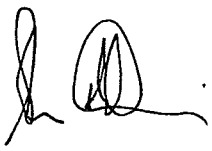
QUALIFICATION

As is common for organisations of this type, it is not practicable for the Association to maintain an effective system of internal control over registrations subscriptions and other fund raising activities until their initial entry in the accounting records. Accordingly, our audit in relation to income was limited to amounts recorded.

QUALIFIED AUDIT OPINION

In our opinion, subject to the effects of such adjustments, if any, that might have been determined to be necessary had the limitation referred to in the qualification paragraph not existed, the financial report presents fairly the statement of financial position and cash flows as at the date in accordance with the cash basis of accounting as described above and notes to the accounts.

SHEARER & ELLISS
CHARTERED ACCOUNTANTS



1 October 2009

AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION
A.C.N. 087 155 780

STATEMENT OF FINANCIAL PERFORMANCE
FOR THE YEAR ENDED 30 JUNE 2009

	LAST YEAR		THIS YEAR	
INCOME				
Interest Received	354.43		272.60	
Member Subscriptions	650.00		4,600.00	
Withholding Tax Refund (ATO)	139.00		154.00	
Refund ASIC fees			165.00	
		$1,143.43		**$5,191.60**
EXPENDITURE				
Audit Fees (2007 and 2008)	-		1,186.90	
Bank Charges	74.00		116.60	
Website Fees & Charges	605.00		605.00	
Fees & Charges (ASIC)	1,120.00		-	
Meeting Costs	-		270.62	
TFN Withholding Tax	252.00		-	
		$2,051.00		**$2,179.12**
NET SURPLUS (DEFICIT) FOR THE YEAR		**-$905.57**		**$3,012.48**
Accumulated Surpluses beginning of year		**12,876.03**		**11,968.46**
ACCUMULATED SURPLUS AS AT 30 JUNE 2009		**$11,968.46**		**$14,980.94**

The accompnaying notes form part of these financial statements

AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION
A.C.N. 087 155 780

STATEMENT OF FINANCIAL POSITION
FOR THE YEAR ENDED 30 Jun 2009

	LAST YEAR	THIS YEAR
ACCUMULATED SURPLUSES		
Accumulated Surpluses	**$11,968.46**	**$14,980.94**
Represented by:		
CASH AT BANK		
CBA Term Deposit	8,566.04	8,833.92
Commonwealth Bank - 2908 1034 0611	3,402.42	6,147.02
NET ASSETS	**$11,968.46**	**$14,980.94**

The accompnaying notes form part of these financial statements

AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION
A.C.N. 087 155 780

STATEMENT OF CASH FLOWS
FOR THE YEAR ENDED 30 June 2009

	LAST YEAR	THIS YEAR
CASH FLOWS FROM OPERATING ACTIVITIES		
Interest Received	354.43	272.60
Member Subscriptions	650.00	4,600.00
Audit Fees	-	1,186.90
Bank Charges	- 74.00	- 116.60
Filing Fees	- 1,120.00	- 165.00
Meeting Costs	-	- 270.62
Website Fees	- 605.00	- 605.00
TFN Withholding Tax	- 113.00	- 154.00
NET CASH PROVIDED BY/(USED IN) OPERATING ACTIVITIES	**-$907.57**	**$3,012.48**
NET INCREASE / (DECREASE) IN CASH HELD		3,012.48
Cash at beginning of financial year	12,876.03	11,968.46
Cash at end of financial year	**$12,876.03**	**$14,980.94**
RECONCILIATION OF CASH		
Cash at end of the financial year as shown in the Statement of Cash Flows is reconciled to the related items in the Balance Sheet as follows:		
CBA Term Deposit	8,566.04	8,833.92
Commonwealth Bank - 2908 1034 0611	3,402.42	6,147.02
	$11,968.46	**$14,980.94**

The accompnaying notes form part of these financial statements

AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION
A.C.N. 087 155 780

STATEMENT OF RECOGNISED INCOME AND EXPENSE
FOR THE YEAR ENDED 30 June 2009

	Retained Earnings
BALANCE AT 1 JULY 2007	**$12,876.03**
Profit Attributable to Members	-$907.57
Balance at 30 June 2008	**$11,968.46**
Profit Attributable to Members	$3,012.48
Balance at 30 June 2009	**$14,980.94**

The accompanying notes form part of these financial statements

AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

A.C.N. 087 155 780

NOTES TO AND FORMING PART OF THE ACCOUNTS
FOR THE YEAR ENDED 30 JUNE 2009

STATEMENT OF ACCOUNTING POLICIES

These financial statements are special purpose financial accounts of Australian & New Zealand Paediatric Nephrology Association, a company limited by guarantee. The accounts have been prepared in accordance with the requirements of the Associations Incorporation Act (Queensland) specifically for use by the members of the Association. The accounts are based on historical cost and do not take into account the changing value of money. The cash basis of accounting has been applied.

No regard has been paid to the application of Accounting Standards or other mandatory professional reporting requirements (Urgent Issues Group Consensus Views) issued by Australian professional accounting bodies except where specifically stated.

NOTES TO ACCOUNTS

Income Tax
It is believed the association is exempt from income tax.

Annual General Meeting of the Australian and New Zealand Paediatric Nephrology- Teleconference

Wednesday 28 October 2009
5.00 pm - 7.00 pm Australian eastern daylight saving time

Dial in number: 61 2 85246600
Conference code: 4129594675

ANZPNA members just need to dial in to phone number, and then enter conference code. The number should work for calls from New Zealand - - the back up number from New Zealand is 0800445473. Any problems- chair, Lil Johnstone mobile 0412 515 033

Apologies: Gad Kainer, Richard Kitching, Elisabeth Hodson, Josh Kausman,
Resignations

Minutes of 2008 meeting - Accepted ✓

New members: Proposal: Anne Durkin — moved from UK nephrologist

Nominations/re-elections of secretary, treasurer and chair — Lil Johnstone

Chair person's Report — Lil Johnstone ✓

Treasurer's report — Paul Henning ✓

IPNA report - Assistant Regional Secretary — William Wong ✓

Paediatric Transplantation standing committee — Stephen McTaggart ✓

SAC Nephrology — Amanda Walker ✓

Genetic trials report — Stephen Alexander ✓

SPEC report — Stephen Alexander ✓

ANZDATA Report — Steve McTaggart ✓

New Business Arising:
Accreditation — Amanda Walker *

Trainees - Amelia Le Page
Rebecca Spicer

MINUTES OF MEETING OF ANZPNA

Sunday, 10th August 2008
Darling Harbour Convention Centre, Sydney

Chair: Dr Lilian Johnstone
Minute taker: Dr Fiona Mackie

Present:
Tonya Kara, Paul Roy, Gad Kainer, Mandy Walker, Sam Crafter, Andrew R. Rosenberg, Sean Kennedy, Rowan Walker, William Wong, Steve McTaggart, Josh Kausman, Jeff Fletcher.

1. Apologies:
Paul Henning, Richard Kitching, John Knight, Elizabeth Hodson, Harley Powell, Ian Hewitt, Max Morris, Jonathon Craig.

Observers:
Emma Ball, Amelia LePage.

2. Minutes for Last meeting
Accepted and proposed by Andrew Rosenberg seconded by Tonya Kara.

3. New Members
Chanel Prestige (Associate) and Swasti Chaturvedi (Associate) accepted. Proposed by Gad Kainer, seconded by Andrew R. Rosenberg.

4. Chair Persons Report
This was tendered. There is a typographical error and sensipar should be changed to Sevelamer, otherwise accepted.

5. Treasurers report: FM for Paul Henning accepted without comment.

6. IPNA Report – William Wong.
A small profit was made from IPNA Hungary. The next growth symposium will be in Spain in May. In 2010 IPNA will be in New York. There has been further development on the IPNA website. There was general discussion about concern about eligibility of Australia for IPNA fellowships. IPNA is in the process of developing criteria for these 6 month fellowships. There was general support for the idea of applying for Australia to be considered as a training centre and William Wong will progress this further with IPNA

7. Paediatric Transplantation Standing Committee – Steve Alexander.
There will be national consideration of allocation processes. Scott Campbell is directing this process. There are plans for paediatric input however it is not sure exactly how this will be organised. Steve Alexander will clarify this with Scott Campbell.

8. SAC Nephrology – Mandy Walker.
There is an accreditation process occurring for sites in adult nephrology. Mandy Walker plans to email accreditation criteria being used for the adult sites to the ANZPNA group for review and comment. Some adaptation may be required for paediatric site accreditation.

There has been a new billing item for supervision of services by nephrologists. The item is 13104. There may be some who are registered as paediatricians,(particular older members) rather than nephrologists and they would need to be recognised as nephrologists by the HIC in order to use this billing. There have been some attempts to solve this problem through a grandfather clause at the SAC. This would not be a problem for newer trainees.

9. Genetics Trial for Report, tended by Steve Alexander.
NATA accreditation has not occurred yet. Currently only samples at Children's Hospital, Westmead are being analysed. It was planned that a teleconference will take place in the near future to further discuss.

10. ANZ data report – Steve McTaggert.
There are plans for modifications to the data collection sheet. Steve McTaggert will email these to the group. Gad Kainer suggested reporting paediatric data up to 19 years of age.

Sean Kennedy has joined the committee. Steve McTaggart is the Chair. Some suggestions for additional data to be collected were requested. Suggestions raised: Anaemia post transplant, echo results, growth, malignancy, peritonitis, calcium phosphate balance post transplant.

11. Spec report
Tendered by Steve Alexander.

12. KTN report – Steve McTaggart.
The group is very keen to include paediatric trials.

13. ANZPNA website
There have been some modifications to the website. Please email any changes to the Secretary of ANZPNA, Fiona Mackie who will forward them to Gad Kainer. Listings can be made public or private. There have been further discussions with the dieticians about adding their forum to the website. No objections were voiced concerning this.

13. New Business

13.1 Kidney Camps – Mandy Walker
There was discussion about the camps and the issue of provision of medical care, whether it ought to be 24 hours a day or not. The next one is to be held at Easter time on the Gold Coast. Dialysis will be done at a near by hospital. Steve McTaggert will be attending the camp.

13.2 Support for regional nephrologists
Already discussed in the IPNA report.

13.3 Gene Bank – Jeff Fletcher.
Currently only their own patients at Children's Hospital, Westmead are being banked. If it is expanded to national banking, then they would plan to form an oversight committee.

13.4 Paediatric Medical Advisory Group – Sean Kennedy
This is the group that mainly consists of pharmacists. Their terms of reference are prioritisation of medications currently not met by PBS listing. They have a priority list already of medications to deal with and would like paediatric input as to which particular medications are important for them. Sean Kennedy will circulate that current list to the group and canvas opinions on which medication should be on that priority list.

14. Multi Centre Trials
A teleconference occurred with Colin Jones and Paul Henning. There was discussion about the current protocol biopsies in transplantation. The units that are prepared to support and enrol in the trial are Brisbane, Monash, Royal Children's Hospital Melbourne and Adelaide. Children's Hospital, Westmead and Sydney Children's Hospital will not be proceeding with the trial at present, neither will New Zealand. It was not clarified today whether Perth would participate. The resolution was that those who agreed with proceeding with the trial will progress the study further. Mandy Walker proposed ANZPNA contributing towards the development of protocol with financial means such as towards an ethic applications. Seconded by Steve Alexander, the executive will further consider this.

15. Date of Next Meeting
To be confirmed.

Chairman's Report
Australia and New Zealand Paediatric Nephrology Association
Annual General Meeting

Wednesday 28 October 2009

I am pleased to present the Chairman's Report for 2008-2009.

ANZPNA has continued to work to increase its profile in the Nephrology community and within the paediatric community within Australia and New Zealand.
To that end, the membership has contributed to the development of the National Organ Matching Service kidney allocation guidelines, and has advocated successfully on behalf of children and teenagers to improve their likelihood of transplantation. This work needs to continue with the various State organ matching authorities. My thanks for the input and hard work of Steven McTaggart, Fiona Mackie and Steve Alexander in driving this forward.

ANZPNA has been invited by RACP to be involved in a conducting a seminar at the International Congress of Paediatrics in 2013. The membership were agreeable, and further development concerning the content and speakers needs to occur.

Many members continue to be active within a variety of groups, and on a number of committees. I would particularly like to acknowledge Steve Alexander who is completing his term on SPEC, ANZSN; and I thank him for his hard work and enthusiasm in this role, and for his efforts to support a paediatric focus at the Annual Scientific Meeting. I would like to thank all members who give so much of their time to represent paediatric nephrology in so many areas.

As you know there are significant changes in the training curricula for advanced trainees. I would like to acknowledge the 'curriculum committee' led by Mandy Walker, who will hopefully be completing their task with the ratification of the new curriculum for paediatric nephrology at this meeting.

I would like to congratulate Andrew Rosenberg for the award of the John Sands medal by the RACP.

I remain hopeful that the ANZPNA membership can develop closer links with respect to research and multi-centre trails, and hope that development of a consensus protocol for the management of atypical haemolytic uraemic syndrome may act as a starting point.

In completing my term, I sincerely thank Fiona Mackie, Paul Henning, Max Morris and William Wong for their support and wise counsel over the last three years. I would encourage younger members of ANZPNA to consider taking up one of the Executive roles.

Lilian Johnstone

Chair, ANZPNA

ANZPNA Treasurer's Report for 2008-2009 Financial Year

The Association's financial position remains stable and a surplus of just over $3,000 was recorded for the financial year 2008/09. In part, this favourable figure reflects receipt of some membership fees from 2008 as well as those from 2009. The former were due the previous financial year but were not received until the current reporting year due to a late posting of the notice in 2008. Expenditure was in keeping with that of previous years. It should be noted that the statements reflect payment of auditor's fees for 2008 and 2009.

I am pleased to record that this year we have complied with all regulatory requirements set by ASIC without incurring late fees. The financial statements and associated documentation have been submitted to our auditors but I do not yet have their report. I have therefore attached a provisional set of statements and will provide the audited documents to the Association's office bearers and company directors when they become available.

At the time of writing twenty-seven of a potential thirty-three members are up to date with subscription payments.

Paul Henning
Honorary Treasurer
ANZPNA

AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

STATEMENT OF FINANCIAL PERFORMANCE FOR THE YEAR ENDED 30TH JUNE 2009

Last Year			This Year
	INCOME		
354.43	Interest received	272.60	
650.00	Member subscriptions	4600.00	
139.00	Reimbursement of Tax (ATO)	154.00	
	ASIC Refund	165.00	
1143.43			5191.60
	EXPENDITURE		
-	Audit fees (2007 and 2008)	1186.90	
74.00	Bank charges	116.60	
605.00	Website fees and charges	605.00	
1120.00	Fees and charges (ASIC)	-	
-	Meeting costs	270.62	
252.00	TFN Withholding Tax	-	
2051.00			2179.12
(907.57)	**NET SURPLUS (DEFICIT) FOR THE YEAR**		3012.48
12876.03	Accumulated surpluses beginning of year		11968.46
11968.46	**ACCUMULATED SURPLUS AS AT 30TH JUNE 2009**		14980.94

NB. This statement reflects the financial position of the Association as assessed by the Honorary Treasurer and has not yet been audited (P Henning, 1st October 2009)

AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

STATEMENT OF FINANCIAL POSITION AS AT 30TH JUNE 2009

Last Year		This Year
	ACCUMULATED SURPLUSES	
11968.46	Accumulated surpluses	14980.94
	Represented by:	
	CASH AT BANK	
8566.04	CBA Term Deposit	8833.92
3402.42	Commonwealth Bank – 06 2908 10340611	6147.02
11968.46		**14980.94**
$ 11968.46	**NET ASSETS**	$ 14980.94

IPNA Council Report to ANZPNA Annual General Meeting

Financial Report:
Currently approx net of $900, 000 in account. 2010 Congress will be huge drain on funds.

Teaching course
2-4 course/yr at a cost of $50,000 each. All courses on website. Pierre Cochat will chair a committee comprising of members of regional societies who to plan teaching courses in a way to avoid conflicts and maximize participation

Relationship with ISN
Closer relationship with ISN sought. Discussions with John Feehally incoming President of ISN. Since September 09 Council meeting Isidro has met with John Feehally and he has offered to develop closer ties with IPNA. All are in support of closer collaboration with ISN in terms of teaching, training, Congresses.

The following are agreed projects for 2010-2012.

1. Society Communications

ISN and IPNA staff will exchange regularly information about forward planning and initiatives to ensure synergy and avoid duplication.
ISN and IPNA will exchange information on a regular basis about meetings, publications, and other activities for posting on both Society websites.

2. Council and Committee representation

ISN and IPNA will decide in further discussions whether cross-representation on the Councils or other Committees of the two societies will provide additional benefit over and beyond this partnership agreement.

3. World Kidney Day

World Kidney Day is a joint initiative of ISN and the International Federation of Kidney Foundations. ISN and IPNA will support public awareness about kidney disease and high blood pressure through mutual promotion of World Kidney Day. It is suggested that discussions about the potential for shared support should become a standard agenda item for the steering committee of WKD.

4. Shared Congress Symposia

ISN and IPNA will plan shared symposia at the next World Congress of Nephrology (Vancouver, April 2011) and at the next IPNA Congress (New York, August 2010). Planning committees with representatives from ISN and IPNA will make programme proposals for these symposia to the Scientific Programme Committees of each Congress.

5. Fellowships in Low & Middle Income Countries

The ISN Fellowship Programme funds competitive Fellowships for periods ranging from 3 to 24 months allowing nephrologists from emerging countries to obtain appropriate clinical and/or research training in a nephrology unit in the developed world, or in a suitable training centre within the fellow's own geographical region. The IPNA Fellowship Programme ranges from 6-12 months duration for pediatricians interested in pursuing further training in various aspects of pediatric nephrology. The underlying principle of this program is to provide pediatricians who work far from a

pediatric nephrology training center with training in order to disseminate knowledge of pediatric nephrology to different regions around the world..

ISN and IPNA commit to working over the next twelve months to develop a programme of joint Fellowships to be funded 50-50 by the two Societies. The focus of these Fellowships will be on training pediatric nephrologists and pediatric nephropathologists in clinical training and in research appropriate for the developing world home center. **(Issue to discuss)**

A separate detailed proposal about the promotion, application, and selection and evaluation process for these Fellowships will be prepared.

6. Education in Low & Middle Income Countries

ISN and IPNA both have long established Continuous Medical Education programme supporting local nephrology educational meetings in the emerging world by providing ISN or IPNA sponsored speakers. ISN and IPNA will collaborate to seek synergistic opportunities, supporting educational programmes which support nephrology training for both adults and children.
In addition to these continuing efforts, ISN and IPNA will also consider planning at least one major educational event in the developing world in 2011 or 2012.

Sponsorship

ISN and IPNA will together seek sponsorship from industry and other external sources to support these initiatives. Care will be taken to ensure that no such sponsorship compromises funding which would be anticipated to support the core activities of either Society. No single activity will be supported by a single sponsor; multiple sponsors will always be sought in order to defend against any external perception of inappropriate influence.

Website development
New IPNA website went live in early September. Members encourage to visit the site. There is now an electronic receipt facility available on the website.

Development strategies for IPNA's future
Barbara Fivush has been working on strategies to increase IPNA's financial support which has has been eroded since the beginning of the economic recession. A toolkit has been placed n website including mission statement of our society, aims of the society and applications for potential donors. She asked all assistant secretaries to engage with non government organizations, individuals for support of IPNA's goals.

IPNA awards
Sandy Watkins has surveyed IPNA membership about trainees awards and the eligibility criteria to attend IPNA Congress 2010. Agreed that there should age limit, trainee must have an abstract accepted for presentation and be able to show that he or she is in a bona fide training position. Travel award will be $500US, and registration $250US.
There will be 75 scholarships available for trainees. IPNA Secretary General will appoint a Scholarship committee who will decide on the recipients of the awards. Assistant Secretaries will act as gate keepers and prioritise the applicants from their regions. Applications forms will be available on the IPNA2010 website.

Report on IPNA 2010 – Rick Kaskel
Website –www.ipna2010.org
Opening date for online abstracts in 1st October and closing date is 15/3/2010
Encouragement for Regional Societies to sponsor trainees to attend if possible
A Renal Pathology course, day conference on Cystinosis, Alports and FSGS will be held just before the main Congress.
Hilton New York room rate of $221.00 + local taxes for Congress and 2 days on either side of meeting.
Linden Frosch Travel will be official travel agent

Journal Editor
Otto Mehls said that journal is running well, improved impact factor (2.6). Indicated that Council must form a committee to identify new editor to replace himself and renegotiate Springer contract by July 2010

Relationship with Textbook Pediatric Nephrology
Patrick Niaudet spoke to Council about the relationship between editors of the textbook, IPNA and Springer. Textbook now published by Springer. He indicated that there would benefits in linking the journal to the text, such a journal article could directly refer to the relevant section in the textbook. Council asked what obligation, if any would IPNA have in supporting the text. The textbook now has the IPNA logo on the front but this not an endorsement of this text over any other textbook of Paediatric Nephrology.

Fellowship program

Cost of programme $200,000 for 2008/9 and $250K for 2009/10. 10-12 fellowships supported every 6months. $15,000 considered to up upper limit for fellowships
All IPNA fellows will be invited to New York congress. Regional Secretaries asked to be more closely involved in determining level of funding for IPNA fellows that undertake study and training in their region. Regional Secretaries will ask for a list of former IPNA fellows which will be forwarded to Sandy Watkins (enclosed is IPNA Fellowship information by year, site, country of origin).

TSANZ Paediatric Standing Sub-Committee

ANZPNA Update October 2009

Meetings:

- TSANZ, 18 June 2009
- Teleconference 2 September, 2009.

Office Bearers:

- Steve McTaggart elected as Chair. Thanks to Steve Alexander for his contribution and guidance as Chair over the last few years.
- Secretarial support provided by TSANZ.

General Business:

1. **Paired Kidney Exchange**
   - Due to commence late 2009 – first run ~ March next year.
   - Details of donor/donor age difference still under discussion but aim is to match donors with approx same age (~within 10 years).
   - Patients can be listed for pre-emptive transplantation if desired.
   - Agreed that all Units were supportive of PKE for paediatric patients.

2. **Cadaveric Organ Allocation – Paediatric Prioritisation**
   - Changes to Paediatric allocation accepted by RTAC. Note these only apply at the National level and individual States encouraged to lobby for State-based priority allocation
   - Errors in the Transplant Authority Draft document on Organ Allocation have been fed back to Working Party

3. **Study on infectious complications following transplantation**
   - Steve McT to arrange survey of all Units to determine current practice for screening and management of prophylaxis.

Other business

IPTA 2003 – Auckland Bid

- Dr Helen Evans (Hepatologist, Auckland) has submitted a bid. Some resistance from Northern hemisphere – announcement pending.

Paediatric Nephrology training requirements

- There is a requirement from the college for all adult and paediatric nephrology training sites to be accredited to ensure adequate training opportunities and support.
- There are no current minimum standards for training centres in paediatric nephrology in Aus or NZ. Adult training criteria are not completely applicable to paediatrics thus there is a need to develop own minimum set.
- Current advanced training in paediatric nephrology is prospectively accredited
    - 24 months core training
    - 12 month elective
    - 6 months mandatory community/development or psych paediatrics (College stipulation: not negotiable for any subspecialties), may be counted as "non-core"
- All paediatric nephrology Units were surveyed regarding minimum requirements for core training (24 months)
    - 6 of 8 replies (chasing the remaining ones)
    - responses displayed graphically
- Discussion points highlighted in red in draft accreditation document

Specialist Advisory Committee in Nephrology

Criteria
for
Accreditation of Advanced Training Sites in Paediatric Nephrology

Background

Accreditation of advanced training sites was approved as an activity of the Royal Australasian College of Physicians (RACP) in September 1999.

Advanced training in nephrology is supervised by the Specialist Advisory Committee (SAC) in Nephrology of the RACP. Training is undertaken prospectively under guidance of supervisors who provide formative and summative assessments of the trainee's program content and performance. In order to facilitate approval of training programs submitted by trainees yearly, the SAC will accredit the training sites and then periodically review the accreditation of sites, in order to ensure that they are of acceptable quality and of an adequate standard.

Purpose of Accreditation of Sites

1. To facilitate approval of training programs
2. To determine:
   i. the appropriateness of supervision for advanced training;
   ii. the sufficiency of clinical experience;
   iii. opportunities for continuing education and research during advanced training;
   iv. the suitability of infrastructure for advanced training;
   v. recommendations for improving training at the sites.
3. To assist trainees to select the site suitable to their current training needs.

General Guidelines

1. Sites undertaking advanced training in nephrology must comply with the four general criteria outlined below.

2. Documentation of these standards may be based on data accessible from the ANZDATA Registry, historical data obtained from previous supervisor's report forms and data obtained from surveying heads of departments, supervisors and advanced trainees at individual sites. In instances where the SAC considers that further clarification of compliance with standards is required, a site visit may be undertaken.

3. Accredited sites must notify the SAC of any substantial change of circumstances within their site which may lead to their failing to meet the minimum criteria for accreditation. Notification should occur within one month of the changed circumstances.

In general, a site must be able to provide 6, 12 or 24 months of training *(Discussion point)* in order for it to be considered suitable for accreditation. Site accreditation will be considered in the context of the recommendation that all trainees rotate to different hospitals within the two core years of their advanced training *(Discussion point)*

4. . Thus if trainees have a limited exposure to a particular aspect of nephrology, e.g. transplantation, at one site they may be able to obtain this experience by rotating to an alternate site in the second year of their core training.

Suggested minimum benchmarks for nephrological procedures over the two core years of advanced training are:

- 100 urine microscopies *(interpretation of reports not reporting micros)*
- 50 renal biopsies *(interpretation of histology not performing bx, should be separately credentialed: How many should be performed under supervision?*
- placement of 50 acute vascular *accesses .Not applicable to paediatrics*

Suggested minimum benchmarks for exposure to clinical nephrology over the two core years of advanced training are:

- participation in 50 *(discussion point Graph 1t)* general nephrology (non-dialysis or transplantation) outpatient clinics
- supervision of 50*(discussion point graph 2)* patients with acute renal failure
- supervision of 50 *(discussion point graph 3)* CAPD patients in an inpatient or outpatient setting
- supervision of 50*(discussion point graph 4t)* haemodialysis patients in an inpatient or outpatient setting
- supervision of 24 *(discussion point Graph 5& 6)* acute renal transplants.

These benchmarks reflect current levels of clinical activity and exposure to procedures undertaken by advanced trainees in nephrology in Australia. They are not meant to be prescriptive but are provided to give trainees some framework with which to compare their own training activity and to plan the overall structure of their training.

Accreditation Criteria

The following criteria will be considered in accreditation of a site.

Criteria 1

The site shall have adequate staff to provide supervision of advanced training. (Generally agreed OK)

1.1 Usually this will mean that at least one nephrologist who is a Fellow of the RACP and a member of the ANZSN should be full-time on site.

1.2 Supervisors should be experienced in the supervision of advanced trainees in nephrology. Where supervisors do not have such experience, attendance at a supervisor's workshop is desirable. One or more nephrologists whose appointments combine to make a full-time appointment may be supervisors for the advanced trainee. Several supervisors may share this role.

1.3 The nephrologist nominated as supervisor must work directly with the advanced trainee and be present to observe direct patient care and to provide adequate training in and supervision of nephrological procedures.

1.4 After hours and ambulatory care assessments should be discussed with the supervisor on a regular basis.

Criteria 2

The site shall have sufficient patients for advanced training (generally agreed OK)
)

2.1 The workload of the site should encompass some or all of the range of patient contacts required for the advanced trainee to gain experience in all aspects of consultant nephrological practice. Trainees should have exposure to patients with general nephrological conditions, hypertension, acute renal failure, pre-dialysis chronic renal

failure and end-stage renal failure patients. They should be able to gain experience in haemodialysis, peritoneal dialysis and renal transplantation. Trainees must be provided

With the opportunity of assessing these patients in a variety of contexts including ambulatory care assessment, inpatient admissions and consultations to other units.

Criteria 3
The Department of Nephrology should provide formal training in nephrology (generally agreed OK)

3.1 The site shall provide formal training which may include some or all of the following: A lecture programme, journal club, grand rounds, seminars, case presentations, radiology meeting, histopathology meeting, grand rounds or research meetings.
3.2 The site should provide the advanced trainee with an opportunity to teach junior colleagues, undergraduates, nursing and allied health staff, and to be involved in quality assurance activities.
3.3 The site should provide the opportunity for the advanced trainee to attend at least one annual scientific meeting of the ANZSN or postgraduate course in nephrology during the two years of their core training.
3.4 The site should provide opportunities for the advanced trainee to develop research interests either on site or through affiliation with appropriate research institutions.

Criteria 4
The site should provide suitable infrastructure for advanced training. (Generally agreed OK)

4.1 There should be access to the infrastructure required to support a nephrology service including adequate chemical pathology, haematology and histopathology laboratories, radiology service, access to materials required for urine microscopy and access to appropriate dialysis facilities.
4.2 The site shall provide access to a medical library with current and relevant text books, journals and computer or Internet based education, retrieval and search facilities.
4.3 The site shall provide an environment where regular discussion and feedback between the advanced trainee and supervisor occurs.
4.4 The site should have an active quality assurance program.

Reporting Process

Supervisors and/or Department Heads will need to complete and return a survey report to the SAC for initial consideration of accreditation and for review of the accreditation status every five years. They are also required to report to the SAC on any changes during the five year cycle.

The report is considered by the SAC and the accreditation decision conveyed to the sites as soon as possible.

While accreditation of sites will predominantly be by survey, in exceptional circumstances a site visit may be undertaken if more information is required to confirm the adequacy of a site.

Provisional Accreditation

Provisional accreditation may be granted to sites that are waiting to be reviewed and accredited by the SAC through the normal accreditation process. This is to ensure that existing trainees at the site are not disadvantaged.

Accreditation Cycle

Sites are reviewed every five years. The SAC may also undertake to review a site at its discretion before the end of the cycle.

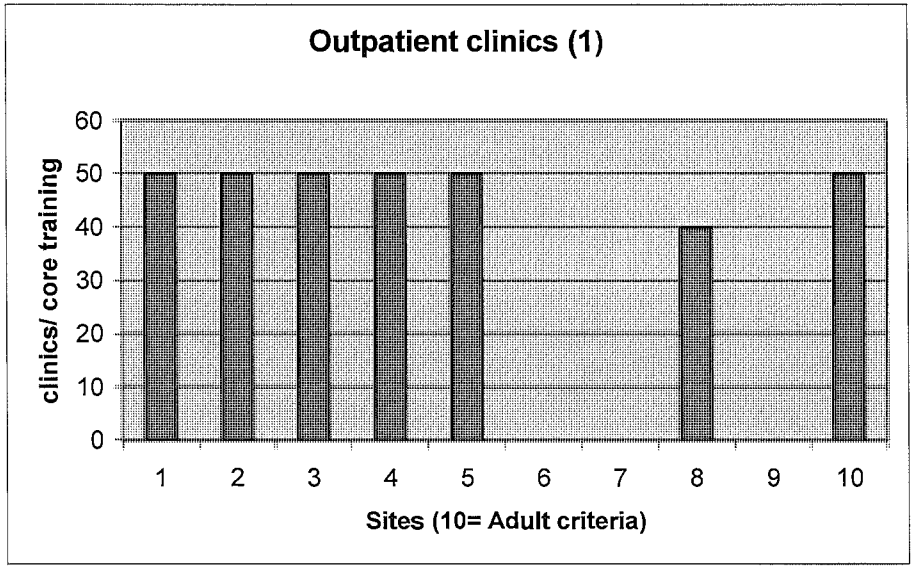
Accreditation of Overseas Advanced Training Sites

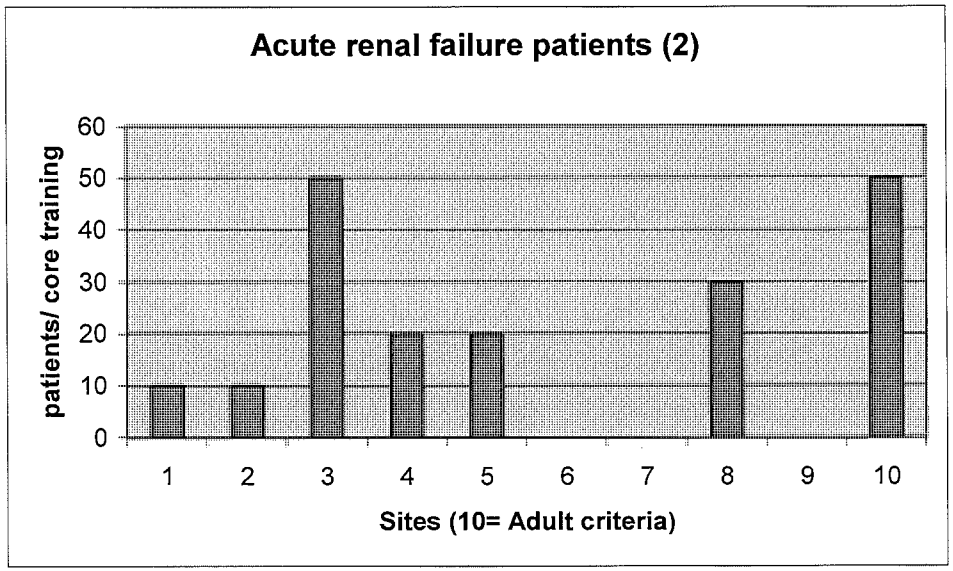
Training obtained overseas is acceptable, provided the proposed training site meets the accreditation criteria. Overseas training sites will be assessed and approved based on information provided by the trainee's supervisor/Head of Department in the form of a letter and completion of survey forms. The supervisor will also receive the RACP handbook *Requirements for Physician Training* which includes the requirements of advanced training in nephrology for information. If a local supervisor has recent knowledge of the facilities provided by an overseas training site, this will also be considered in the accreditation process. A site visit will not be considered.

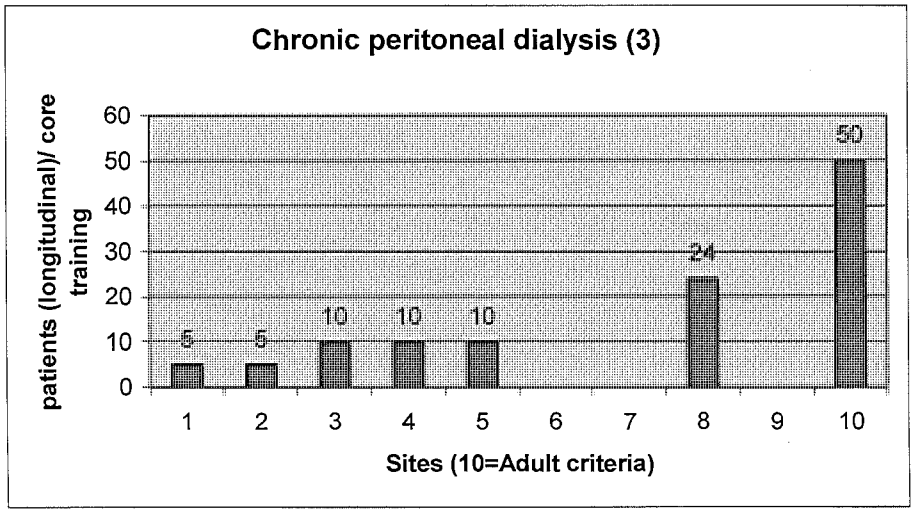
Appeals Process

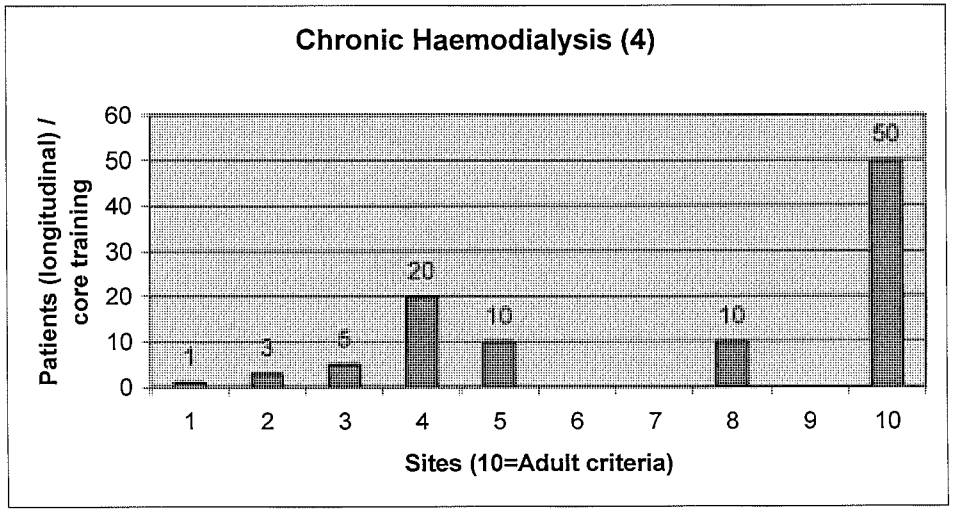
If a site does not gain accreditation or reaccreditation or is not satisfied with the decision or the accreditation process, then it has the right to request that the SAC reconsider its decision. If the SAC upholds its original decision, the applicants may request review of the decision which is conducted by the CPT/CPPT (whichever is appropriate). If the CPT/CPPT upholds the decision of the SAC, the applicants may appeal the decision to the RACP Appeals Committee. The decision of this committee will be forwarded to the applicants, the SAC and the CPT/CPPT.

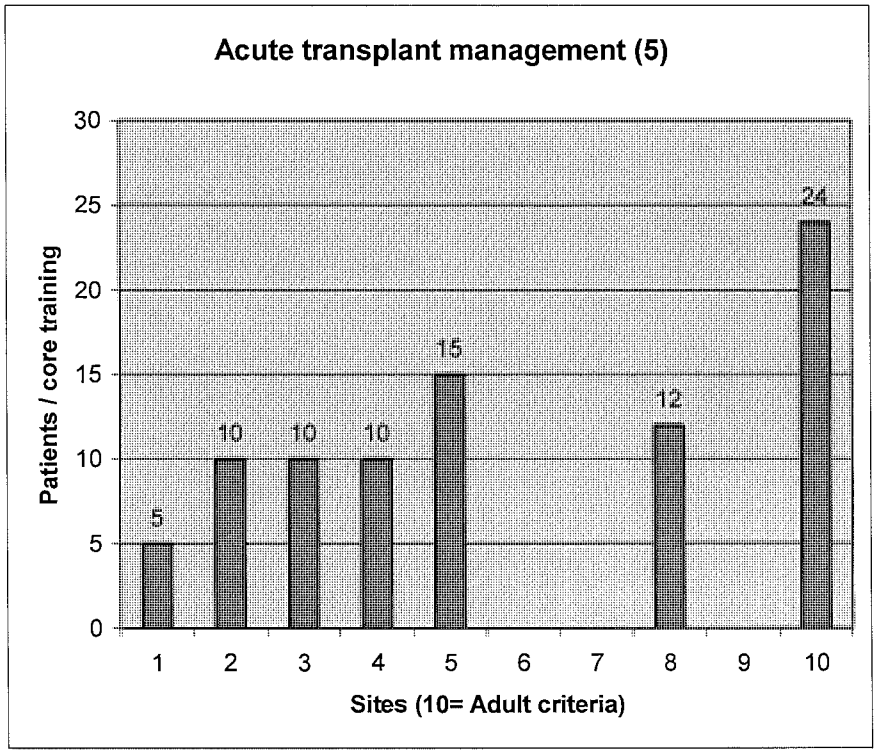
Oct 2009 ANZPNA AGM

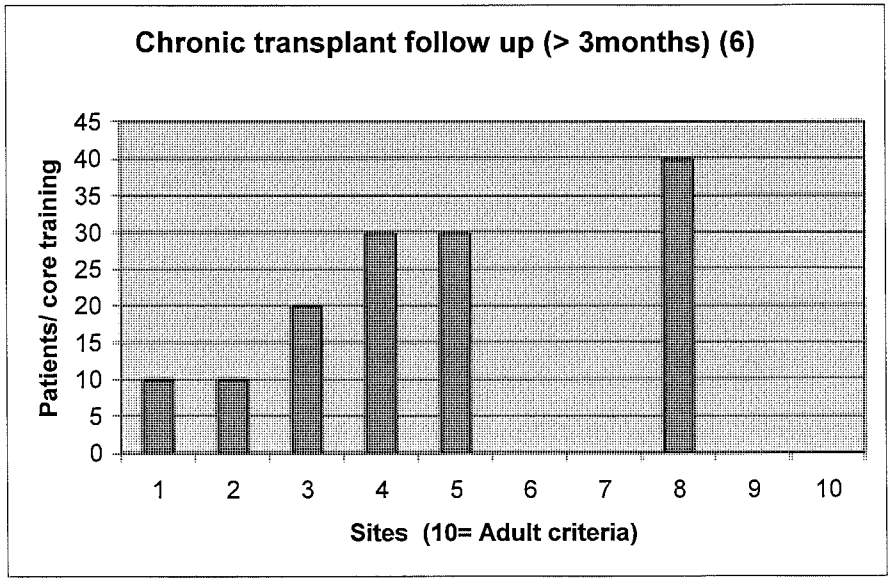

Outpatient clinics (1)
clinics/ core training
60
50
40
30
20
10
0
1 2 3 4 5 6 7 8 9 10
Sites (10= Adult criteria)


Acute renal failure patients (2)
patients/ core training
60
50
40
30
20
10
0
1 2 3 4 5 6 7 8 9 10
Sites (10= Adult criteria)


Chronic peritoneal dialysis (3)
patients (longitudinal)/ core training
60
50
40
30
20
10
0
5
5
10
10
10
24
50
1 2 3 4 5 6 7 8 9 10
Sites (10=Adult criteria)


Chronic Haemodialysis (4)
Patients (longitudinal) / core training
60
50
40
30
20
10
0
1
3
5
20
10
10
50
1 2 3 4 5 6 7 8 9 10
Sites (10=Adult criteria)


Acute transplant management (5)
Patients / core training
30
25
20
15
10
5
0
5
10
10
10
15
12
24
1
2
3
4
5
6
7
8
9
10
Sites (10= Adult criteria)


Chronic transplant follow up (> 3months) (6)
Patients/ core training
45
40
35
30
25
20
15
10
5
0
1
2
3
4
5
6
7
8
9
10
Sites (10= Adult criteria)

Renal Genetics Subcommittee 2009

Chair: Jeff Fletcher

Cystinosis:
4 monthly testing continuing: Mass Spectrometry now working and will be tested in parallel with standard technique over next 3 runs.
TSANZ review (Beccie Spicer)
Eye ointment: running over 12 months.
Possibly Sally Hulton to go to ANZSN 2010.

Gene Testing:
WT-1 established at Murdoch.
Nephrin and Podocin testing now established at CHW.
HNF-1 now available Queensland.

Kidney Gene Bank: continuing to acquire families.

Visitors:
Lisa Guay Woodford 2008 McCredie fellow
Harald Jueppner visiting 2009 Harvard Fellow
Likely visit LGW 2010 May 27th Thursday CHW Westmead.

Jeff Fletcher; Steve Alexander

I wish to nominate Sean Kennedy for SPEC.

Steve Alexander

Paediatric Report

Working Group

Dr Steven McTaggart – Project Manager
Dr Paul Henning
Dr Sean Kennedy

2009 Report

Basic epidemiological data
ESKD focus

Publications and Presentations

1. Orr NI, McDonald SP, McTaggart S, Henning P, Craig JC. Frequency, etiology and treatment of childhood end-stage kidney disease in Australia and New Zealand. Pediatr Nephrol. 2009 Sep;24(9):1719-26.

2. Malignancy following ESKD in Childhood. Steven McTaggart, ANZSN 2009.

Projects in Progress

1. Bordador E, Johnson DW, Henning P, Kennedy S, McDonald S, Burke JR, McTaggart SJ. Epidemiology and outcomes of peritonitis in children receiving peritoneal dialysis in Australia and New Zealand.
   Submitted Pediatric Nephrology

2. Sam Izzard, Stephen Alexander
   BMI effect on outcome in paediatric transplantation (lipid data to be included)

3. Rebecca Spicer, Steven Alexander
   Outcomes of patients with cystinosis post-transplant
   In progress – Data requested

4. Danielle Longmore, Steven McTaggart
   Growth hormone use and PTLD
   In progress

5. Gad Kainer, Sean Kennedy
   Outcomes of late referral of children with Stage 5 kidney disease
   (Single centre study)

6. Amelia Le Page, Fiona Mackie, Sean Kennedy, Steven McTaggart
   Role of EBV in transplant outcomes

7. Angela Webster, Steven McTaggart, Stephen McDonald
   Malignancy following ESKD in Childhood
   In progress

Other Issues

1. Post-transplant infections data-sheet
2. Genetic diagnosis sheet

ANZPNA

(Australian & New Zealand Paediatric Nephrology Association)

Minutes of
Annual General Meeting 2007
Sunday 2nd September 1300-1400 hours
Palace of Arts, Budapest, Hungary

Present: Andrew Rosenberg, Colin Jones, Max Morris, Steve Alexander, Steve McTaggart, Fiona Mackie, Lilian Johnstone, Harley Powell, David McCredie, Ken Jureidini, Elisabeth Hodson, Gad Kainer, Ian Hewitt, Josh Kausman, Peter Trinka (observer)

Apologies: Mandy Walker, Debbie Lewis, William Wong, John Burke, Jeff Fletcher, Jonathon Craig

Minutes of 2006 AGM: Minutes confirmed with 1 amendment (Paul Henning was present)
Proposer Steve Alexander
Seconded Colin Jones
Matters arising from minutes – None

Membership:
New members Emma Ball (associate), Sam Crafter (full)
Resignations: David Lines

Chairpersons report:
Lil Johnstone reported:

- There are still some problems with communication with the RACP and various subcommittees and recognition of ANZPNA as the peak national body of paediatric nephrologists in Australia and New Zealand. To address this formal correspondence has been sent to RACP, ANZSN, ANZDATA and Kidney Health Australia.
- A number of sub-committees within ANZPNA have been formally established including Multi-centre trials committee, Genetic testing group, Nephrology Curriculum group.
  ANZPNA executive would like to encourage use of the website as a means of communication for the group. Minutes of meetings will be posted there for member-only viewing. Address: www.anzpna.com.
  Username: surname
  Password : email address
- Mandy Walker has initiated some discussions with Kidney Australia regarding providing training for areas of needs. Colin Jones discussed the difficulties with this including necessary visa and funding requirements.
- The Executive proposes consideration of changing the articles of association at the next AGM. In particular they would like to change the definition of a quorum.

- Colin Jones was thanked for performing in the role of IPNA secretary so ably.
- Jonathon Craig has stepped down from the ANZDATA steering committee and was thanked in his absence for his contribution.
- LJ thanked the Executive of ANZPNA for their work.

Treasurer's report

FM presented PH's report in his absence. The financial position of the Association remains sound (accumulated surplus as at 30th June 2007 $15058.93). The Association has however recorded a small loss over the past year ($655.77) which in part reflects the decision at last year's AGM to reduce the annual membership to $50 from $100. There was considerable discussion regarding this. CJ suggested that we need to factor in increased operability of the Association in terms of costs. There were more teleconferences occurring and currently these costs were being covered by the various hospitals but may not continue to be so. **SMcT proposed that the membership fees be increased back to $100. Seconded: CJ Carried: unanimously Action: PH to increase subscription rates to $100 for 2008**

There was discussion about honorary membership- it was felt in general that a member may be considered for honorary membership when paid employment had ceased. A number of individuals have not paid subscription fees for several years and will be contacted individually to discuss whether they wish to continue membership.

Committees:

IPNA- Colin Jones tended his report. There was some discussion about the IPNA fellowship program. This continues to work well with approximately 20 fellowships given each year. Few are provided in 1st world countries because of the difficulties in providing hands on access to clinical work, immigration requirements and funding not meeting requirements in many 1st world countries. CJ cautioned that we need to consider these issues when discussing training positions in Australia. (need about $40 000 pa salary to meet Australian requirements).

SPEC of ANZSN — Steve Alexander reported. There will be a fellows retreat in May 2008. Please let Steve know of any trainees who would be eligible to attend. ANZSN has considerable funding for fellows to attend conferences and should be encouraged to apply. ANZSN 2008 will be held in Newcastle. Invited speakers include Lisa Guay-Woodford. There is suggestion of combining a renal genetic satellite meeting including Lisa Guay-Woodford
There has been some preliminary discussion about holding IPTA 2013 in New Zealand.
SA reported on the programme for WTC 2008 Sydney. The issue was raised of whether next year's AGM should be held prior to the paediatric symposium at WTC

Action: FM to canvas members availability for AGM held at WTC .

RENAL GENETICS GROUP:

The group is most interested in organising for podocin and nephrin mutation analysis to be performed locally because of the clinical applicability and for prognostic reasons. It is likely this will be established at CHW by next year and the NATA accreditation process would occur after that. It was indicated by the group that it would be a useful resource to have a list of laboratories performing genetic testing on our website. Action: **SA will send list to GK for posting on the website**

SAC Nephrology

LJ spoke to this in MW's absence. ANZPNA members have been invited to contribute to the FRACP paediatric curricula. There was discussion re accreditation criteria for training sites- we currently have no criteria and no formal process for this to occur. This has begun to occur formally at adult nephrology training sites. It was agreed we would probably have to develop criteria in the future.

MULTICENTRE TRIALS GROUP:

A protocol has been developed for the protocol biopsy study. **CJ asked that comments on the protocol be forwarded to the representative at each centre for the trials group. These should be forwarded in the next month so that Paul Henning can draft the ethics application.**

ANZDATA:

Steve McTaggart has been appointed as the paediatric representative. He pointed out that there is no mechanism for us to nominate ANZPNA members to the working party of ANZDATA. The decision is made by the members of the steering committee. Three people are required on the paediatric working group- S McT is the project manager now so that 1 more position is available. **Action: SMcT has requested interested parties express interest to him- the appointment would then be made after consideration by ANZDATA.** The major focus of the next paediatric ANZDATA report will be PD and peritonitis.

New business arising :

Paediatric representation on subcommittees- It was generally agreed that we could not insist on nominations from ANZPNA to various subcommittees. CJ made the point that rotation of these positions amongst members of ANZPNA was important.
WTC- discussed by SA above

Training in paediatric/adolescent nephrology for adult trainees- correspondence from SK to Paul Snelling noted. Agreed important to support this. Further discussion should occur with MW.
Paediatric renal dieticians and access of ANZPNA website: FM proposed motion that the paediatric renal dieticians be allowed access to our website for communication, sharing of protocols. Motion: carried unanimously. **Action: FM to notify Maggie Aitken, dietician of outcome and further discussions to take place with FM and GK as website manager.**

Action	Person to carry out action
Increase subscription rates to $100 for 2008	Paul Henning
Canvas members availability for AGM to be held at WTC, Sydney 2008 .	Fiona Mackie to email members
Post list of genetic tests and laboratories on ANZPNA website	Steve Alexander to send list to Gad Kainer for posting on website
Submit comments on protocol biopsy trial to trials representative and then Paul Henning	Trials representative at each centre to collate comments and forward to Paul Henning
Interested parties in ANZDATA working party to discuss with Steve McTaggart	Interested parties and Steve McTaggart
Renal dieticians to access ANZPNA website for communication and sharing of protocols	Fiona Mackie and Gad Kainer to have further discussions with renal dieticians and set up process.

Australian and New Zealand Paediatric Nephrology Association

Chairman's Report

Annual General Meeting, 10th August 2008, Sydney Convention Centre, Sydney.

ANZPNA members have continued to be active throughout 2007-8 in a variety of roles including those within Australian and New Zealand Society of Nephrology, Australian and New Zealand Dialysis and Transplant Registry, Transplantation Society of Australia and New Zealand and International Paediatric Nephrology Association.

The subcommittees established last year have progressed, particularly the Medical Education Subcommittee, which has developed a curriculum for paediatric nephrology training in collaboration with the nephrology curriculum of the Specialist Advisory Committee, Nephrology, Royal Australasian College of Physicians. The development of multi-centre trials within Australia and New Zealand has been supported by members however putting this into practice has highlighted some areas that need to be addressed. The work of both subcommittees will be discussed further today. Thanks to Mandy Walker and Colin Jones in their roles as Chairs.

The ANZPNA were pleased that the PBS listing of ~~sensipar~~ sevelamer (Renagel) has been changed to include children and were happy to support Genzyme with their application to the Pharmaceutical Benefits Advisory Committee. Thanks to Jonathan Craig and Fiona Mackie.

The ANZPNA remains solvent with adequate financial reserves. Shearer and Ellis have been appointed auditors following the resignation of Johnson and Greathead Pty Ltd.

The Executive is continuing to address the best way for the ANZPNA to exist as a legal entity, looking at the ANZPNA and its relationship with RACP and ANZSN, and the corporate compliance requirements of ASIC.

The DNT subcommittee of ANZSN have invited ANZPNA to hold a breakout meeting at the DNT meeting in Lorne, Victoria in March 2009.

I continue to be greatly supported by Fiona Mackie and Paul Henning, and thank them for their support. Max Morris and William Wong remain valuable members of the Executive, ANZPNA. I would remind members that the current Executive completes its term in 2009, and ask you to consider taking up an active role on the Executive.

Lilian Johnstone
Chair, ANZPNA

ANZPNA Treasurer's Report for 2007-2008 Financial Year

The Association's financial position continues to be sound although once again the account indicates a small "loss" for 2007/08. It should be noted, however, that membership fees received for 2008 do not appear in the accounts due to a late posting of the notice. Payments were not received until after June 30th and will therefore appear in the accounts for 2008/09. In August 2007 I was informed that our auditors (Johnson and Greathead) wished to resign chiefly because they are based in Brisbane and I was in Adelaide. The executive (also the company directors) accepted the resignation and appointed Shearer and Ellis as auditors for the Association.

Once again this year we incurred "fees" payable to ASIC for a number of matters of compliance over and above the standard annual review fee. To some degree these reflect my own inexperience in dealing with the minutiae of the large number of ASIC rules applying to the dealings of incorporated bodies. As a result, the time and effort involved in complying with ASIC standards is disproportionate to the modest financial activity of the Association. I have referred to this matter in last year's report and it is my view that it will continue to create problems in a recurring fashion especially for each newly elected treasurer. I intend at the end of my term to provide a short hand guide for future treasurers which may help. The guidelines for company officers on the ASIC website are substantial in length and I found some aspects difficult to understand.

The financial statements and associated documentation have been submitted to our auditors but I do not yet have their report. I have therefore attached a provisional set of statements and will provide the audited documents to the Association's office bearers and company directors when they become available.

At the time of writing twenty-two of a potential thirty-four members are up to date with subscription payments. I will not be able to attend the Annual General Meeting and have asked the secretary to present this report on my behalf. I am happy to receive questions by mail or email.

Paul Henning
Honorary Treasurer
ANZPNA

AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

STATEMENT OF FINANCIAL PERFORMANCE FOR THE YEAR ENDED 30TH JUNE 2008

Last Year			This Year
	INCOME		
347.23	Interest received	354.43	
1550.00	Member subscriptions	650.00	
	Reimbursement of Tax (ATO)	139.00	
1897.23			1143.43
	EXPENDITURE		
-	Audit fees	-	
83.00	Bank charges	74.00	
2055.00	Website fees and charges	605.00	
415.00	Fees and charges (ASIC)	1120.00	
-	Meeting costs		
2553.00			1799.00
(655.77)	**NET SURPLUS (DEFICIT) FOR THE YEAR**		(655.57)
13531.80	Accumulated surpluses beginning of year		12876.03
12876.03	**ACCUMULATED SURPLUS AS AT 30TH JUNE 2008**		12220.46

NB. This statement reflects the financial position of the Association as assessed by the Honorary Treasurer and has not yet been audited (P Henning, 1st August 2008)

AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

STATEMENT OF FINANCIAL POSITION AS AT 30TH JUNE 2008

Last Year		This Year
	ACCUMULATED SURPLUSES	
12876.03	Accumulated surpluses	12220.46
	Represented by:	
	CASH AT BANK	
8482.26	CBA Term Deposit	8818.04
4393.77	Commonwealth Bank – 06 2908 10340611	3402.42
12876.03		**12220.46**
$ 12876.03	**NET ASSETS**	$ 12220.46

IPNA Assistant Secretaries Meeting April 4-5 2008

Present:
I Salusky, F Kaskel, HW Schapner, HK Yap, G Reusz, N Orta Sibu, W. Wong, F Eke, C Holmberg, K Phadke, T Igarashi, A Portale, R Mak, M Baum, J Hunter(visitor)

1. Presentation by Dennis Koogod from Da Vita
"Bridge of Life" presentation. – developing paediatric dialysis programmes in developing countries, mainly in South America, India and central America. Helping local medical and nursing staff to gain clinical experience in dialysing children.
Website www.bridgeoflifemm.org

2.Minutes of Budapest Meeting
See attached

3. Financial Report –HK Yap
Dr Yap reported that financial state of IPNA is good health but pointed out the ongoing activities such as teaching course, fellowship programmes and website development will have significant effect on the account which presently stands at approximately $800, 000US

4. Final report for IPNA 2007- Budapest –G. Reusz
1015 registrants from over 70 countries with 88 travel grants awarded. Questions relating to the eligibility of the grants were asked – age limit, differing amounts to different regions and how they were to used – registration versus travel. G Reusz indicated that it was difficult to obtain high level sponsorship in Hungary with even from large biomedical companies. In the end just over € 200,000 was obtained through sponsors. The meeting made a modest profit of €15463.
A small booklet of people and events during the Budapest Congress was produced celebrating the 14th IPNA Congress.

5. Fellowship Programme – Portale
Committee consists of Mignon McCulloch, Aysin Bakkaloglu and Yong Choi
To date 84 applicants with 63 having being approved and 17 rejected. 47 have graduated from the programme. Most common reason for rejection was significant prior experience in nephrology. Two fellows left training early after 1 and 3 months. Most of the trainees are from India. IPNA encourages trainees to train at sites within their region.
On average there are 16 applicants per year with 12 per year being approved.
The stipend from IPNA covers travel to and from the training site. After completing the 12 month training, the graduating fellow receives a certificate from IPNA, a copy of the textbook *Pediatric Nephrology* and support to attend one regional paediatric nephrology meeting.

Further discussion included advertising the programme more widely, the application procedure, increasing enrolment, a standardised curriculum and training reports. The possibility fellowships to support advanced training and research was also discussed. It was acknowledged that these activities would require greater financial support of the organisation. .

6. Teaching courses –R Mak
Committee members- P Cochat, Felicia Eke, Michelle Lopez, Robert Mak, Alexey Tsugin and H Kim Yap.
Principles underpinning the courses – 1) facilitate global education, 2) encourage cross cultural exchange, 3)distribute evidenced based guidelines, 4)promote ethical standards of practice, 5)promote research principles 6) promote publication of clinical experience
So far course have been held in Beijing, Panama, Brazil, Vietnam.

Requirements for training centres and applications for teaching course can be found on the website

7. IPNA- Baxter Training Programme, Children's Medical Institute, National University Hospital of Singapore - HK Yap
IPNA and Baxter provide 50% each sponsorship. The programme is its 6th year. It is open to all doctors under age 40 years who are working in hospitals caring for children with kidney disease. 5 fellows have been through the programme.

8. Relationship with ISN.
I Salusky spoke of closer ties with ISN to ensure that meeting do not clash and objectives are similar.

9. Growth Symposium 2009, Spain
The next IPNA sponsored Growth Symposium will be Olivedio, Spain 27-30 May 2009
A council meeting will be held at the meeting

10. Website development
Jane Hunter of CMG publishing group spoke to council regarding how her company CMG could help with IPNA website development. Focal point of the website will be the society. Content of the website will include
Society News and information
important educational and teaching features ,
guidelines, research protocols
conference calender
Pediatric Nephrology textbook
The Journal

Some council members cautioned the ongoing cost of website maintenance to the society. A number of mock ups were presented to council. Ms Hunter was given a brief on what the council wanted for its website. She has undertaken to adopt the recommendations from council and represent them at the next council meeting in Bangkok 08/08

11. IPNA Congress 2010 _ New York, Aug 29- Sep 2, 2010
Frederick Kaskel 2010 Congress President reported to council on progress of the 2010 meeting. There will be a pre meeting symposium on hypertension on afternoon of 29 August followed by a reception. The meeting will commence on Monday 30 August and finish at lunch on Thursday Sep 2.

NEW YORK HILTON

12. History of IPNA
Aaron Friedman spoke to council of efforts to collect and collate historical information on the beginnings of IPNA. Prof Leon Fine who has been involved with the history of the ISN spoke of his experience in working to document the ISN history.

Minutes of 2006 Annual General Meeting of the ANZPNA

Melbourne Convention Centre, 15 August 2006

Present at meeting: Drs Max Morris, William Wong, Charlie Crompton, Steve Alexander, Steve McTaggart, David McCredie, Colin Jones, Harley Powell, Lillian Johnstone, Andrew Rosenberg, Fiona Mackie, Joshua Kausman, Jeff Fletcher, Sean Kennedy, PAUL HENNING.

Apologies received

Drs Tonya Kara, Gad Kainer, Elisabeth Hodson, Debbie Lewis, Jonathan Craig, Frank Willis, Ian Hewitt, Rowan Walker, Amanda Walker, John Burke, Ken Jureidini.

Minutes of 2005 AGM

The minutes of the 2005 were read and confirmed by the membership present.

Matters arising from 2005 minutes

No matters

Chair persons report

Max Morris presented his report. He thanked the outgoing executive committee for their support over the past 3 year term. He also thanked Monica Collins of Wyeth Pharmaceuticals for sponsorship of members to attend the meeting and the educational program that was to follow the AGM.

Treasurers report

Charlie Cromptom presented the financial report for 2006. He noted that the auditors have not been able to undertake the audit of the accounts because of the timing of the AGM this year and provisional statement is presented.. The association has accumulated a surplus of $13.531.80. The web site fee is not included as yet. Several members were not financial at the time of the writing of the report, but 100% of the membership had paid up by the 2006 AGM. He proposed that the annual subscription be reduced to $50.00 so as the accumulated surplus did not increase too rapidly without some dedicated purpose. Dr Crompton proposed that the annual subscription be dropped to $50.00.
Motion seconded by Steve Alexander.
Motion carried

Report of regional assistant secretary Colin Jones

IPNA council met in Beijing and Cape Town. IPNA is in a financially sound position. He reported that one of the core IPNA activities was to support training fellowships. Isidor Salusky will succeed Matthias Brandis as Secretary General at the Hungary 2007 meeting.
Colin Jones concluded that his 6 year term will come to an end at the 2007 IPNA meeting. The membership thank him for his efforts in representing the association

Dr Max Morris discussed the issue that there were no nominations from the membership to succeed Colin Jones. Dr Andrew Rosenberg proposed Dr William Wong. He will consider the nomination and will contact Colin Jones by October 2006

Chairman's Report – ANZPNA – Annual General Meeting, 3rd September 2007, Budapest, Hungary

In the last 12 months, the ANZPNA Executive has been working to increase the profile and activity of the ANZPNA within the Australasian Nephrology community. To this end, a number of sub-committees have been formally established, including subcommittees addressing multi-centre trials, genetic testing in renal disease and the nephrology curriculum within the new curriculum framework of the RACP. In addition, formal correspondence to highlight the existence of the ANZPNA has been sent to RACP, ANZSN, ANZDATA and Kidney Health Australia. I would like to thank all members who have contributed to the new sub-committees, who have remained active and busy on many other sub-committees, and who contribute to raising the profile of paediatric nephrology and the ANZPNA.

Future directions of the ANZPNA include developing the website further so it is used frequently and actively by the ANZPNA membership; working with KHA to try and develop a sponsorship program for paediatricians in areas of need to develop experience in paediatric nephrology; and establishing ANZPNA as a recognised Special Interest Group in RACP.

The Executive is also looking at amendments to the Articles of Association, particularly quorum definition, the role of ANZPNA in appointments of members to other bodies, and the best way for the ANZPNA to exist as a legal entity. Following input from members, changes to the Articles of Association will be brought to the AGM in 2008.

I would like to recognize Colin Jones in his role as IPNA Regional Secretary for the last 6 years. Colin has worked tirelessly in this role, and has contributed greatly to the profile of ANZPNA within the IPNA. He and Fred Jureidini successfully planned and hosted the 13th Congress of IPNA in Adelaide. Thank you Colin, and thank you to William Wong for taking over this role.

In the same vein I would also like to acknowledge Jonathon Craig's contribution to ANZDATA as Chair of the Paediatric Sub Committee. In the years that Jonathon has been involved with ANZDATA, the paediatric report has changed to reflect ANZPNA group interests. Steve McTaggart has been appointed to Chair of the Paediatric Sub-committee.

I have been greatly supported by Fiona Mackie and Paul Henning, Colin Jones and Max Morris as Executive, ANZPNA. Gad Kainer has been very helpful in developing the website further. I look forward to input from members in further developing the profile and activities of ANZPNA.

Lilian Johnstone
Chair, ANZPNA

Chairman's Report – ANZPNA – Annual General Meeting, 3rd September 2007, Budapest, Hungary

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Lilian Johnstone
Chair, ANZPNA

Australian & New Zealand Paediatric Nephrology Association

Multi-Centre Trial Report

Budapest – IPNA Scientific Congress

September 2007

Following the August 2006 ANZPNA Annual General meeting it was decided to test the membership with development of a multi-centre trials development process.

As Chair of this Committee, I was joined by representatives chosen from various centres around the country. These members of the committee were Fiona Mackie, Stephen Alexander, Amanda Walker, Paul Henning, Charlie Crompton, William Wong and Stephen McTaggart. The Chair was much delayed in organising himself and consequently teleconferences were held on 23rd March, 20th April, 1st June and 24th August 2007.

At each teleconference the discussion of how we could organise ourselves as a Committee, what topics would be suitable for a multi-centre approach and the methodology that could be used were discussed. Minutes from each meeting were completed by Ms Vicki Burns and distributed to each representative. The latest product of this consultative approach has been the development of a "pilot study of protocol biopsy in paediatric renal transplantation".

The most current draft of this pilot study is attached to this report for your information, and criticism. Please discuss your concerns with this draft study to your Committee representative so that we can further develop this study.

The next planned teleconference is due for November 2007.

I thank the members of the committee for their help in getting to this point.

COLIN JONES

Protocol Renal Transplant Biopsy - Pilot Study

AIMS

- To describe the pathological findings in renal biopsies at 6 and 18 months following transplantation in a cohort of children treated in paediatric renal units in Australia and New Zealand over 12 months.
- To establish the incidence of Chronic Allograft Nephropathy (CAN), sub-clinical acute rejection (SAR) and borderline SAR in this cohort, and to identify the presence of clinical or laboratory correlations if present
- To evaluate the potential for protocol biopsy in a clinical trial.

PATIENTS

All patients receiving a renal transplant performed in the participating centres regardless of donor source, matching or order of graft during a 12 month period of recruitment and 12 months follow up.

METHODS

a) Ethics approval will be required.
b) Standard local centre protocols for transplant immunosuppression including treatment of acute rejection and CNI toxicity.
c) Renal Biopsy:
   i. Timed within 4.5 to 7.5 months after renal transplant procedure
   ii. Method – 16G or 18G closed needle biopsy following Unit standard practice with the following provisions (subject to each centre conferring with their pathologist):
      - Tissue collected in 1% neutral buffered formalin; Alcoholic Dubrosqbrazil Bouins fixative; Glutaraldehyde; and RNA Later for RNA studies.
      - Short cycle used
      - Cut sections to 2 micron thickness
      - Stain tissue for H & E, C4d, Polyoma virus and Sirius Red (a better stain to assess extent of fibrosis and has been used in studies for quantitative evaluation)

   iii. Assessment:
      - Adequacy of biopsy
      - Usual hospital pathology
      - Transfer slides to centralised site for blind assessment according to Banff96 criteria and semi-quantitative analysis of tubular atrophy, interstitial fibrosis and associated inflammatory infiltrates

d) Other data collection
   - *Clinical* – donor source and characteristics; HLA mismatches; Immunosuppression used; ischaemia times (all from ANZDATA)
   - *Laboratory* – monthly serum creatinine + during the 2 weeks before protocol biopsy; Monthly Hb, WBC and platelet counts; Monthly CNI trough or C2 levels as appropriate.
   - The findings of other biopsies performed.

ANZPNA 2007 General Meeting Budapest
SPEC Report

ANZSN 2007 in Goldcoast
Fellows retreat in May

2008 ANZSN Newcastle
Invited speakers
Lisa Guay Woodford
Kam Kalantar-Zadeh

Dates: Pre-meeting 6th-7th September 2008
Meeting 8th-10th 2008

Suggestion of a renal genetic satellite
LGW
Melissa Little
Judy Savige
Elisabeth Algar
?Robyn Jamieson
? James Dean
Mike Eccles

Fellows Symposium 2008 either Goldcoast or Sydney

Please let me know about fellows or registrars with an interest.

Re ANZSN some debate re abstract scoring, clinical versus lab research.

Also re fellows: there is a lot of money for travel.

No-one within the guidelines has not been funded for a local or an overseas meeting.

Application forms from Aviva.

ANZPNA 2007 General Meeting Budapest
TSANZ subcommittee Report March 2007

Issues:

Governance, officers
Parent member

Trials:
Protocol biopsies

ANZDATA report

Transplant 2008 Aug 6-10th
2SOAs
Pre-meeting Symposia IPTA cobadged August

IPTA 2013? NZ

Other issues:
Relationship with TGA
Dying patient-dealt with by ANZPNA
National guidelines re allocation.
Paired organ requests.
Altruistic donors.

Report on the 2008 World Transplantation Congress Sydney Australia:
Dates: 10th-14th August 2008
Website: www.transplantation2008.org

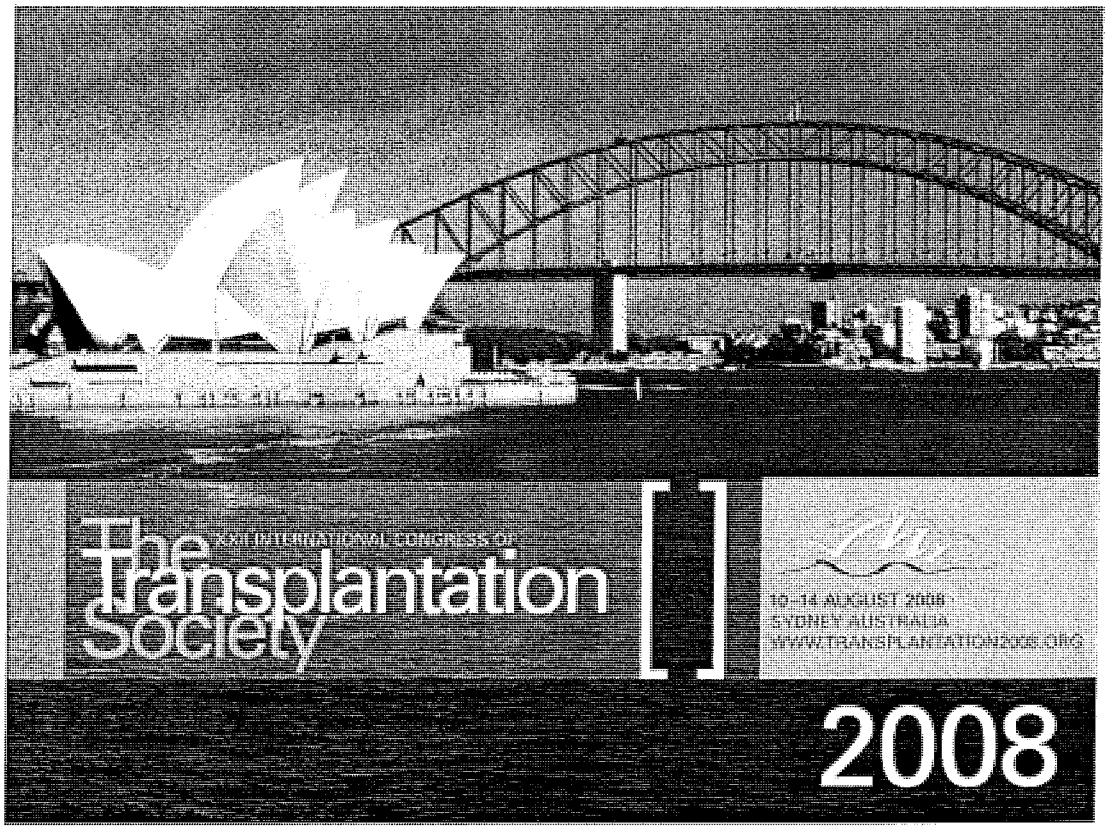
The paediatric program for this meeting is being organized by the paediatric subcommittee of the program committee. There is local and international representation on this committee including several members of IPTA.
We have met by phone conference throughout 2006 and have had input into the main program.
The key features for paediatricians are that there will be 2 (State of the Art) SOA sessions on the Monday and Tuesday.

The proposed program for these is outlined below.

Symposium 1. Long Term Care of The P(a)ediatric Transplant Patient	Cardiovascular Disease Risk Factors and Prevention
	Enhancing Bone Health
	Maximizing Growth
Symposium 2. Maximising Long-term graft survival	Hot New Regimes in trial New agents for immunosuppression and tolerance
	Prevention of chronic injury to the allograft
	Pharmacokinetics or Antibody therapies pre and post transplant

There are also a number of associated SOAs including infectious diseases that cover many issues of interest to "pediatric transplanters" on the Wednesday and Thursday. The main program will have a number of excellent basic and clinical speakers in the plenary sessions. There will also be a number of breakfast sessions including a series on imaging in transplantation.
The weekend symposia will run from 9-12:30
3 speakers on adolescent transition
3 speakers on the challenges of paediatric transplantation: Sensitised paediatric patient, the immunocompromised paediatric patient, future strategies in paediatric patients.

Steve Alexander (stephena@chw.edu.au)
Paediatric Committee Chair



Saturday August 9th, 2008	Sunday August 10, 2008	Monday August 11, 2008	Tuesday August 12, 2008	Wednesday August 13, 2008	Thursday August 14, 2008
07.00 - 18.00 Registration	07.00 - 18.00 Registration	07.15 - 08.15 Early Morning Courses	07.15 - 08.15 Early Morning Courses	07.15 - 08.15 Early Morning Courses	07.15 - 08.15 Early Morning Courses
09.00 - 15.00 Pre-Congress CME Program	09.00 - 12.30 Pre-Congress CME Program	08.30 - 10.00 Plenary Session I	08.30 - 10.00 Plenary Session II	08.30 - 10.00 Plenary Session III	08.30 - 10.00 Plenary Session IV
		10.00 - 10.30 Coffee Break	10.00 - 10.30 Coffee Break	10.15 - 10.30 Young Investigators Award	10.00 - 10.30 Coffee Break
		10.30 - 12.00 Oral Presentation 1-10 (10 parallel sessions)	10.30 - 12.00 Oral Presentation 21-30 (10 parallel sessions)	10.30 - 12.00 Presidential Address & Medawar Prize	10.30 - 12.00 Oral Presentation 51-60 (10 parallel sessions)
		12.15 - 13.15 Lunch Workshop	12.15 - 13.15 Lunch Workshop		12.00 - 13.00 Business Meeting
		12.00 - 13.30 Poster Session I	12.00 - 13.30 Poster Session II	12.00 - 13.30 Poster Session III	12.00 - 13.30 Poster Session IV
		12.00 - 13.30 Lunch Symposium	12.00 - 13.30 Lunch Symposium	12.00 - 13.30 Lunch Symposium	12.00 - 13.00 Lunch Symposium
		13.30 - 15.00 State-of-the-Art Symposium (10 parallel sessions)	13.30 - 15.00 State-of-the-Art Symposium (10 parallel sessions)	13.30 - 15.00 State-of-the-Art Symposium (10 parallel sessions)	13.00 - 14.30 State-of-the-Art Symposium (10 parallel sessions)
	13.30 - 17.00 Satellite Symposium	15.00 - 15.30 Coffee Break	15.00 - 15.30 Coffee Break	15.00 - 15.30 Coffee Break	14.30 - 16.00 Oral Presentation 61-70 (10 parallel sessions)
		15.30 - 17.00 Oral Presentation 11-20 (10 parallel sessions)	15.30 - 17.00 Oral Presentation 31-40 (10 parallel sessions)	15.30 - 17.00 Oral Presentation 41-50 (10 parallel sessions)	16.00 - 17.00 Plenary Session V
		17.30 - 19.00 Satellite Symposium	17.30 - 19.00 Satellite Symposium	17.30 - 19.00 Satellite Symposium	Close
Corporate Evening	18.00 Opening Ceremony & Reception	Presidents Dinner	Cultural Evening	19.30 Gala Evening	

ANZPNA renal genetics group: Friday 25th of May 2007 11:00

Andrew Rosenberg, Steve McTaggart, Lil Johnston, Jeff Fletcher, Steve Alexander

Topics:

Current practice:
Local Testing: Alports, WT-1
Overseas testing: Hildebrandt nephrotic genes

Diseases of interest:

Diagnostically: WT-1, Pax-2;
Prognostically: 20% frequency SR Nephrotic syndrome 8% recurrence vs 30%

Issues:

Cost:
Reliability:
Speed:
Centrality.

Research: KGB operating 3 years 200 DNA samples; 100 transplant recipients; 2 large pedigrees; cohort of children with CAKUT
Start collecting cystinosis DNA.
Survey of frequency of genetic conditions in ANZ (JF)
Funding: CCRE future round
Trials: PTC (?)

Future Needs:

Actions since meeting:

Fund setting up NATA accredited testing for nephrotic genes at CHW. (?cystinosis).
LGW visit
Renal Genetics Symposium
CCRE-genetics

Future:
Internet based
listing of laboratories for rarer conditions.
Cystinosis testing.

ANZDATA REPORT

ANZPNA Annual General Meeting, 3rd September 2007, Budapest, Hungary

1. **Committee Members and Structure**
   The roles of the ANZDATA Steering Committee, Executive and Working Groups have recently been clarified. In addition, the processes for selection of members and succession have also been discussed and the view of the Steering Committee is that nominations will be called for vacancies, and people will be selected by the Steering Committee according to a number of criteria that relate to their ability to fulfil the roles set out for the Working Groups. The role of ANZPNA in electing members to the Working Groups and Steering committee is currently limited to nominations of potential representatives, with the final decision resting with the ANZDATA Steering Committee.

   The current committee representatives are detailed in the attachments.

2. **Paediatric Working Group**
   Members of the Working Group are to be selected on the following criteria;
   - Leadership skills
   - Subspeciality expertise
   - Previous Registry data analysis and ability to work in a team.

   The aim is to create a team to lead ANZDATA-based research to maximise scientific output and continually review the scientific basis of data collection. The Working Group reports to the Steering Committee every 6 months and is responsible for the Annual Report.

   The current Paediatric Working Group is Steve McTaggart (Project Manager) and Paul Henning. Another member is required for the working party and following discussion at the AGM, there will be a call for nominations.

3. **Current Issues**
   a. Wed-based data entry
      All units are encouraged to utilise this as much as possible. Real-time reports are to be provided monthly. Website is currently being updated.
   b. Data collection
      Cholesterol data collection has improved but remains less than optimal. Decision needs to be made on the continued collection of this data.
   c. New data fields
      No new data fields can be added without the removal of a current field. If cholesterol data is scrapped, opportunity exists to replace this with an alternative.
   d. Annual Report
      Current format seems to be working well. Suggestions welcome.
   e. Publications
      Kennedy SE, Mackie FE, Rosenberg AR, McDonald SP. Waiting time and outcome of kidney transplants in adolescents. Transplantation 2006, 82; 1046-50.
      ? Fletcher J, Alexander S.

Steven McTaggart
26 August 2007.

ANZDATA Registry Working Groups 2007

Name	Position	Secretary	2002-03	2004	2005	2006	2007	2008	2009	2010
Cancer Working Group										
Dr Stephen McDonald—QEZB5	ANZDATA—Convenor		02+03	04	05	06	07	08	09	10
Prof Jeremy Chapman—WEST2	Project Manager	Lara Stretton	02+03	04	05	06	07			
Dr Germaine Wong—WEST2	Fellow in Cancer Epidemiology		-	-	-	06	07			
A/Prof Randall Faull—RADL5							07	08	09	
Dr Vicki Levidiotis—RPAH2							07	08	09	
Professor Adrian Hibberd—HUNT2							07	08	09	
Haemodialysis Working Group										
Dr Stephen McDonald—QEZB5	ANZDATA—Convenor		02+03	04	05	06	07	08	09	10
Dr Mark Marshall—MIDM8	Project Manager		03	04	05	06	07	08		
Dr John Agar—GLNG3			02+03	04	05	06	07			
Dr Kevan Polkinghorne—MMCA3			03	04	05	06	07	08		
Paediatric Working Group										
Dr Stephen McDonald—QEZB5	ANZDATA—Convenor		02+03	04	05	06	07	08	09	10
Dr Steven McTaggart—PSAH4	Project Manager						07	08	09	
Dr Paul Henning—WCHL5					05	06	07			
Peritoneal Dialysis Working Group										
Dr Stephen McDonald—QEZB5	ANZDATA—Convenor		02+03	04	05	06	07	08	09	10
Prof David Johnson—PSAH4	Project Manager		03	04	05	06	07	08		
A/Prof Johan Rosman—MIDM8				04	05	06	07	08	09	
Dr Fiona Brown—MMCA3					05	06	07			
Dr Kate Wiggins—SVIN3					05	06	07			
Dr Kym Bannister—RADL5						06	07	08		
Transplantation Working Group										
Dr Stephen McDonald—QEZB5	ANZDATA—Convenor		02+03	04	05	06	07	08	09	10
Dr Scott Campbell—PSAH4	Project Manager			04-06 Member Work Grp			07	08	09	
A/Prof Steven Chadban—RPAH2			2002-2006 Project Manager				07	08	09	

9 July 2007

Dr Paul Snelling
Chair, SAC in Nephrology
Royal Australasian College of Physicians

Dear Paul,

Earlier this year I was invited by the organising committee of the Asia-Pacific Forum in Nephrology to present a workshop on transitional care in nephrology. I presented the workshop entitled "Transitional Care of the Adolescent with Chronic Kidney Disease", twice in Sydney on May 26. The audience was fairly small but included a mixed group of adult and paediatric nephrologists and trainees. The adult nephrologists were from both large teaching hospitals and rural practices.

The workshop was designed to raise awareness of the difficulties that adolescent patients may encounter as they transition from paediatric to adult care and how these difficulties may manifest as non-adherence resulting in poor outcomes. The response to the workshop was generally positive with many participants expressing the sentiment that this was an important but often overlooked issue in nephrology.

Attention was drawn to the recently published RACP document 'Transition to Adult Health Services for Adolescents with Chronic Conditions'. In particular the statement contained within that "The core competencies required by health care providers to render developmentally appropriate health care and facilitate health care transition should be an integral component of basic and advanced training requirements for all physicians" was discussed. It was generally agreed that developing expertise in caring for adolescents is an important aspect of training in adult nephrology. One suggestion, which was met with some favour, was that adult nephrology trainees could benefit from exposure to paediatric outpatient clinics.

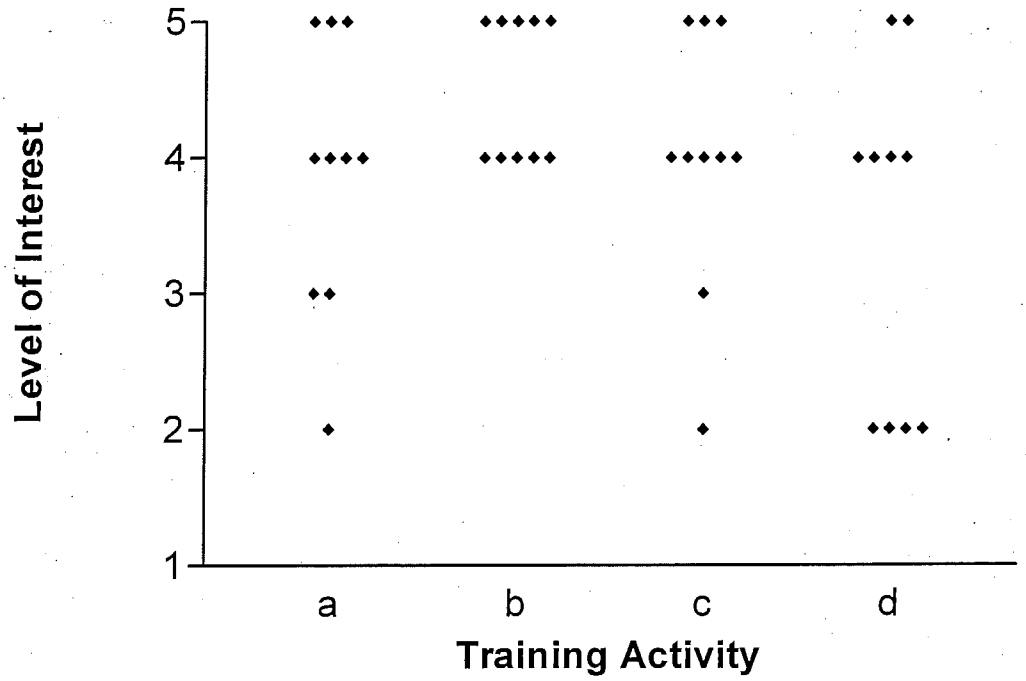
As you are aware, I also presented a talk on adolescent nephrology at the June session of the NSW Kidney School. This presentation was based on the APFN workshop and canvassed similar issues. I subsequently took the opportunity to survey nephrology trainees about their knowledge of and attitudes to adolescents with chronic kidney disease using a brief questionnaire. Ten trainees returned the questionnaires, eight were present at the presentation, the other two responded to an email sent by Fidye Westgarth. I suspect the responses were influenced by the presentations (given by Fiona Mackie and I), never the less, the results were a little surprising and I have summarised them below.

Demographics of respondents

- Average number of years experience in clinical nephrology: 3.7 (range 1 to 7)
- 4/10 were Australian graduates
- All are currently working in NSW, but some had previously worked in Victoria and WA.

Seven trainees had **no** postgraduate experience in paediatric medicine.
Only three recalled receiving any undergraduate teaching in adolescent medicine, while **no-one had received any formal training in adolescent medicine as a basic trainee.**

One trainee had read the RACP document 'Transition to Adult Health Services for Adolescents with Chronic Conditions'



a. Paediatric nephrology clinics
b. Adolescent nephrology clinics
c. A term in paediatric nephrology
d. An elective year in paediatric nephrology

SAC Nephrology Meeting 2007:
Teleconference Friday 18 May, 2007.
Next meeting : November 23rd 2007

A number of issues were raised. Most of these pertain to Adult trainees however I am informing ANPNA membership for interest and comment.

1. Advanced training Supervisors.
    a. Two supervisors for each training site and training period (even if 6 months, or less) are strongly recommended.
    b. Why? Not intended to create difficulty/unnecessary anxiety about supervision, but to protect trainees from personality conflicts and communication difficulties that may arise.
    c. The second supervisor does not have to be workshop approved
    d. Both supervisors have to be in ACTUAL contact with the trainee

2. Mid Year Progress Report Forms
    a. This form is a generic form, and at this stage looks the same for each SAC subspecialty. It is still designed to identify training difficulties/ trainees' difficulties, prior to the final meeting in November where the year is signed off. Feedback regarding the form invited from AT supervisors
3. Curriculum
    a. Will be further discussed in November 2007 meeting: re implementation of the Renal Curriculum, and supervisors' feedback.
    b. A curriculum will be rolled-out for some other (non-renal) AT programs in 2008.
    c. Currently: The renal curriculum needs Paeds, New Zealand, RACP reviews, I will distribute draft within next few weeks, for discussion
    d. Will have overall domains, then themes, then learning goals to frame training and learning requirements around.
    e. No examination process is planned for Renal Advanced Training.
4. Confidential Trainee Survey (all registered trainees surveyed)
    a. Sites are accredited for core and non-core advanced training. anonymous feedback in the January survey, and the comments generated are very useful to plan for up-coming site-accreditation.
    b. Comments from trainees in the immediate five-years prior to the site-visit are reviewed to tailor priorities at visits, to assess how many trainees can be supported in the rotations, re-credential/de-credential sites, and discuss trainees concerns.
5. Project Requirements (Adult trainees)
    a. Peer Reviewed Abstract Project " The Poster": In some circumstances, a reflective article will be requested by the SAC from the trainee clarifying learning objectives surrounding the poster and what has been learned from undertaking the project, poster and presentation. It

MINUTES OF MEETING OF ANZPNA

2nd March 2007

Meeting by teleconference

Present:
Max Morris, Paul Henning, Lilian Johnstone, Colin Jones and Fiona Mackie.

1. Report from Chair
LJ has spoken with Robyn Langham, Chair of ANZSN regarding the role of our organisation and the need to refer paediatric issues to us.

2. Report from Paul Henning Regarding Financial Matters
The correct names and office bearers are now lodged with ACIS. Because they were incorrect and the information was not submitted in a timely fashion, we received two fines. The current balance of the operating cheque account is $3800 and of the investment account is $8300. PH will send subscription notices out to members. The subscription rate is $50. FM raised the issue of whether all members were financial as she has noticed that last year's subscription cheque (FM) has not been cashed. PH will check against the list of current members. The website payments were discussed.

3. Discussed ANZ Data Working Party Membership
Steve McTaggert has been elected by ANZDATA to be the chair of the Paediatric Working Committee. It was pointed out by LJ that ANZDATA have traditionally in adult medicine selected the members of working groups rather than the actual members nominating themselves. There was discussion about this and the majority were in favour of ANZDATA consulting the chair of ANZPNA regarding nominations for the working group. LJ will write to the chair of ANZDATA to suggest this. FM will send an email to Steve McTaggert informing him that Mandy Walker has an expressed interest in being part of the working group. CJ suggested formalising how we decide on memberships in the terms of our constitution.

4. Discussion about this year's Annual General Meeting
FM had sent an email requesting preferences for 2007 AGM. There were 7 votes for a stand alone meeting, 3 votes for it to be combined with ANZSN and 3 were happy with either arrangement. After further discussion it turns out that 10 and possibly 11 members will be attending IPNA. It was decided that we will have our extended AGM and educational meeting every second year and that this year's AGM would be a working meeting, which if we have sufficient numbers to meet a quorum, we plan to have at IPNA. A room has already been set aside on Sunday, 2nd September 2007 between 1:00 pm and 2:30 pm at the IPNA Budapest Meeting. FM will circulate an email informing members about the meeting.

5. IPNA
CJ has reported on IPNA. He has a meeting of the regional secretaries in New York in March. There is a change of leadership of the IPNA planned and Isidro Salusky is taking over as chair. There were no major issues to discuss. William Wong will

6. Trials

CJ reported on this and he apologised for not progressing this issue further. He has received email input from Steve McTaggert and Fiona Mackie regarding design of possible trial. There was discussion of whether we need to establish the practice of protocol biopsies as a standard before being able to participate in a national trial. CJ will organise a teleconference between the nominated representatives from each unit who are happy to participate in the trial in the next few weeks.

Action List

- PH will send subscription notices out to members
- PH will check financial status of members on list
- LJ will write to the chair of ANZDATA requesting that the chair of ANZPNA is consulted regarding nominations for the paediatric working group
- FM will send an email to Steve McTaggert informing him that Mandy Walker has an expressed interest in being part of the working group
- FM will circulate and email informing members about the AGM to be held on Sunday, 2nd September 2007 between 1:00 pm and 2:30 pm at the IPNA Budapest Meeting
- CJ will organise a teleconference between the nominated representatives from each unit who are happy to participate in potential paediatric trials in the next few weeks.

ANZPNA

CHAIR PERSON'S REPORT - 2006

The year 2005/2006 has been shorter than usual, with our last AGM being in late November 2005, and this AGM being our first meeting together in 2006. The innovation of combining the AGM with a half-day scientific meeting will hopefully attract a high attendance, and may be worthy of further consideration in the future. Thank you to Wyeth and Monica Collins for sponsoring our lunch, dinner, room hire, and for travel expenses for 5 members to attend this meeting.

Colin Jones stands down from being Assistant Secretary for our region on IPNA Council, and to date no-one in our group has wished to offer their service. This matter will be discussed further at this AGM.

The new Chairperson and Secretary were elected by ballot of all members, and the election result will be announced at this AGM. The Honorary-Treasurer position is accepted by Paul Henning, who will be confirmed at this AGM. Congratulations to all 3 new office bearers.

Thank you to William and Charlie for assisting me with the administration of our business over the last 3 years.

Best wishes to all members for 2007.

Max Morris

ANZPNA Treasurer's Report for 2005-2006 Financial Year

The association's financial situation is sound, with a modest improvement in our financial position over the last 12 months, with the account indicating a 'profit' of A$ 2,188.20. The discontinuation of the directors' liability insurance has reduced the outgoings, with the only other significant costs being the website, AGM expenses, and ASIC compliance issues.

As our AGM is earlier than usual, the financial report has not yet been audited. A provisional statement of our position is attached.

There are several members who are not financial at the time of writing this report. I hope to report 100% paid up membership by the time of the AGM.

I once again ask the opinion of the membership about the annual subscription. Would members be happy to maintain the current fee, or consider reducing it to say A$50? If the fee was set at $50, and there were no unforeseen expenses, the association's accounts would still be in positive balance at the end of the next financial year.

C Crompton
Honorary Treasurer
ANZPNA

ANZPNA statement of financial performance for year ended 30th June 2006

Last year			This year
	INCOME		
56.05	interest received	178.65	
2540	member subscriptions	3100	
2596.05			3278.65
	EXPENDITURE		
495	audit fees	495	
64.75	bank charges	77.5	
605	website fees		
1684.2	insurance		
270	fees and charges	170	
	meeting costs	347.5	
3118.95			1090
-522.9	**NET SURPLUS FOR THE YEAR**		2188.65
11871.8	accumulated surplus beginning of year		11348.9
11348.9	**ACCUMULATED SURPLUS AS AT 30 JUNE 2006**		13531.8

6 Regional Secretaries - 1 full meeting / year Council
- 1 additional Assistant Secretaries meeting.
- committee tasks
- paid meetings
- ten 6 years.

Report from Regional Assistant Secretary – IPNA

During the last year IPNA Council met in Beijing in October 2005 and again in Cape Town in March 2006.

Status of IPNA

IPNA remains a stable and financially sound association. There were 1,582 members in October 2005. Sponsorships included 82 members with 37 dervived from individual IPNA members and 29 from the Japanese Society of Paediatric Nephrology.

Dr Isidro Salusky suggested appealing to founding members to compile of history of paediatric nephrology. Subsequently interviews and attempts at interviews have been made with Gavin Arneil as the 1st Secretary-General from the founding of the association in 1977 and Ira Griefer and other prominent European members.

The Australasian story will be overlooked unless someone volunteers to take it on. Dr David McCredie has written a short review of his recollections of the starting of IPNA internationally. I will pass this onto Isidro Salusky.

However, I think it would be worthwhile if the Australian story were written in a detailed manner from a state based perspective in each case and a New Zealand perspective in that instance.

Financial Standing of IPNA

Cash position January 31st, 2006: $591,419.42 (US)
Calendar Year 2005:

US expenses $428,677.64
US income $553,253.71

European Office
Expenses: $240,263.37
Income: $174,582.26

Outstanding expenses

Council meeting expenses Bejing:	$44,514.80
Pakistan Earthquake Donation:	$20,446.80
All Fellowships:	$61,160.69
Payments to Springer Heidelberg	$176,700.75
Office expenses – Dallas	$82,030.45
Katrina Donation	$20,000.00
Salary (Dr Otto Mehls)	$22,500.00

The financial perspective included an increased number of Fellowships of increased duration and increasing expenditure. This is seen as a core activity for IPNA.

Treasurer

Isidro Salusky succeeds Matthias Brandis as Chairman of IPNA at the Hungary meeting. A Search Committee of which I am a member is choosing a shortlist of candidates suitable for the position of Treasurer.

Adelaide Meeting.

The final report for the IPNA meeting was presented by Ken Jureidini and myself at the Beijing Council meeting. Dr Brandis thanked the ANZPNA membership and particularly the efforts of John Burke, Andrew Rosenberg and Hartley Management.

Training – Teaching Courses.

Robert Mak has been involved in trying to redevelop this aspect of IPNA. There are many suggestions but little has happened on the ground at this stage.

Paediatric Nephrology

As reported in my interim report in March, Springer won the contract for the Journal and this will see the Association receive around $500,000 per year for the next 5 years.

Otto Mehls and Michel Baum provided a report indicating an increased number of submissions that has accelerated more recently. Acceptance rate of the Journal is 53.4%, with the rate for original articles at 48.8% and for brief reports 35.9%. The impact factor is rising and is around 1.44. The average review time has dropped from 8 weeks to 23 days.

IPNA Council 2007

Tivadar Tulassay and Gyorgy Reusz have been developing the Budapest meeting. There is little involvement by IPNA in this meeting at this stage. I highlighted this fact to the membership earlier and received a couple of offers to submit work for presentation in the non-abstract part of the meeting.

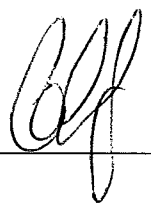
Pan Arabic Society of Paediatric Nephrology

The meetings have been becoming more concerned about whether this should be an affiliated Society. The argument for centers on the number of unaffiliated paediatric nephrologists, the opportunities for teaching and the help that this would ultimately give to children in that area of the world. The negatives to making the Society an affiliated one include the distinction from the AFPNA (which held an African meeting in Cape Town at the time of the Cape Town Regional Secretaries meeting). Also concerns of uncertain nature where raised regarding the status of women and non-Muslims in the Society. This is becoming a contentious issue.

Term of Regional Secretary

My term as Regional Secretary comes to an end at the Hungary meeting in September 2007. Methods have been put in place to choose my successor.

It has been a pleasure and honor to represent our Association at the Council.



Colin Jones

From: Colin Jones <colin.jones@rch.org.au>
To: <wwong@adhb.govt.nz>, <amanda.walker@southernhealth.org.au>, <A.Rosenberg@unsw.edu.au>, <Nicola.Prosser@health.wa.gov.au>, <charliec@cyllene.uwa.edu.au>, <colin.jones@rch.org.au>, <robin@drystate.com>, <David.mccredie@rch.org.au>, <deborahl@chw.edu.au>, <Elisah@chw.edu.au>, <f.mackie@unsw.edu.au>, <MackieFi@sesahs.nsw.GOV.AU>, <francis.willis@health.wa.gov.au>, <KainerG@sesahs.nsw.GOV.AU>, <Harley.powell@rch.org.au>, <hemant.kulkarni@health.wa.gov.au>, <Ian.Hewitt@health.wa.gov.au>, <JefferF2@chw.edu.au>, <jburke@gil.com.au>, <JKnight@prdgb.JNJ.com>, <jonc@health.usyd.edu.au>, <joshua.kausman@rch.org.au>, <jureidinik@wch.sa.gov.au>, <Lilian.Johnstone@southernhealth.org.au>, <Margot.McIVER@gwahs.health.nsw.gov.au>, <maxm@adhb.govt.nz>, <Michael.falk@act.gov.au>, <henningp@wch.sa.gov.au>, <lpaulroy@yahoo.com>, <richard.kitching@med.monash.edu.au>, <Rowan.Walker@mh.org.au>, <stephena@chw.edu.au>, <Steven_McTaggart@health.qld.gov.au>, <tonya1@xtra.co.nz>
Date: 21/03/06 4:37:52 pm
Subject: Assistant Secretaries Meeting, IPNA Council, March 15-16 2006

This abbreviated form of the IPNA Council met in Cape Town.

1. Financially the organisation remains in good health. Springer won the contract for the Journal and this will see the Association receive around $500,000 per annum for the next 5 years. I can provide a detailed financial report on request.

2. IPNA meeting Hungary. No member of our Association has been listed as a speaker at this stage. Of approximately 120 speakers, 15 were from either Japan, Asia, India and Australasia. I indicated that this was not satisfactory and have put forward some suggestions. Would anyone who thinks a member of our Association has a topic that should be presented at the meeting please contact me in the next week or so.

I have asked for a room for approximately 15 people at the meeting for our Association meeting.

3. History of IPNA. Isidro Salusky is chairing a small committee to attempt to write the beginnings of the history of the IPNA story while the pioneers of the Association are still alive. The Australasian story will be overlooked unless someone volunteers to take it on. The method suggested is that a younger colleague interview an older member and that the services of a paid journalist be used to produce a readable text, along with a collection of "memorabilia".

4. My term as Regional Assistant Secretary comes to an end at the Hungary meeting in September 2007. We need to inform IPNA Council of my successor at the Palermo meeting (October 2006). I will have discussions with the ANZPNA Executive about organising an election for this position.

With best wishes
Colin.

Dr Colin Jones
Director
Department of Nephrology
Associate Professor, University of Melbourne
Royal Children's Hospital

Minutes of Annual General Meeting Australian and New Zealand Paediatric Nephrology Association
29 November 2005, 1pm – 5pm Melbourne .

Present:
Elizabeth Hodson, Lillian Johnstone, Tonya Kara, Joshua Kausman, Steven McTaggart, Steve Alexander, Colin Jones, Harley Powell, David McCredie, Fiona Mackie, William Wong, Max Morris.

Apologies
Jonathan Craig, Hemant Kulkarni, John Knight, Richard Kitching, Frank Willis, Ken Jureidini, Paul Henning, Gad Kainer, Rowan Walker, Debbie Lewis, Margot McIvor, John Burke, Charles Crompton, Mandy Walker

Resignations: The secretary received correspondence from Dr Paul Tomlinson and Dr David Lines indicating their wish to resign from the association

Minutes of 2004 meeting.
David McCredie asked for the minutes of 2004 to be adjusted to reflect the visit of Dr Alison Eddy to Melbourne post IPNA. The minutes were duly amended and will be re-circulated to the membership.

Reports
Final Report of 13th IPNA Congress
Colin Jones thanked ANZPNA for the Adelaide Congress, indicating that it was a great success. Financial details were presented. Surplus from Congress returned to US account

Assistant secretary report
Foreign graduates wanting to undertake further medical training in Australia must now satisfy ILETS regulations and achieve score 7 in English proficiency Applicants must have $AUD40000 to satisfy occupational training requirements

Colin Jones reported that his term as Assistant Secretary expires following IPNA 2007. A new person will need to be nominated by the membership by 09/2006. The secretary will organise a ballot mid 2006. Council meetings (twice yearly) are normally linked to meetings

Chairperson's Report
Max Morris reported that it has been a quiet year. He thanked Colin Jones and Vicki Burns for organising the venue for the AGM and other members who representing ANZPNA on various committees.

Concerned was expressed on a recent report in "Nephrology " on the low number of paediatric nephrology trainees. A stock take shows that there currently 6

trainees. Colin Jones reported that RCH(Melbourne) has established a 12 month renewable paediatric nephrology fellowship funded externally.

Treasurers Report

The loss for ANZPNA for the last financial year (1st July 2005 to 30 June 2005) was $522.90. The independent auditors reported that the financial report was a true representation of the financial state of the Association
There is currently $11.348.90 in the account
At the time of this meeting, 3 of the membership had not paid their 2005 annual subscription.
The treasurer raised the issue of the need to remain an incorporated society. The membership discussed this and concluded that the association remain an incorporated society in the event of possible bequests or donations in the future

The 2006 subscription was discussed. The major outgoing is the annual auditor's report and maintenance of the ANZPNA website. It was decided that the 2006 subscription will remain at $AUD100.00

TSANZ Paediatric Standing Committee.

The committee reports to TSANZ and ANZPNA
Fiona Mackie reports the committee met in May 2005. Issues discussed included different waiting times for children on the deceased donor waiting list. There was no data available. Stephen Alexander was to write to NOMS to request data on time from dialysis to transplantation for paediatric kidney recipients in each state
Discussion of research projects using ANZDATA in conjunction with Stephen McDonald
The International Tranplant Congress will be in Sydney. Steve Alexander is the paediatric programme convenor and indicates that there will 2 state of the art paediatric sessions. Suggestions for the main programme are welcomed

SAC Nephrology Training requirements

SAC Nephrology in Australia has passed a ruling that adult nephrology trainee have a mandatory requirement for the trainee to change site of training every 12 months. This requirement has a significant adverse impact on paediatric nephrology trainees who do not have dedicated funding and in which funding is transferable between states. The membership asks that Ian Hewitt, the current paediatric representative on the SAC and Mandy Walker the incoming represnetative ask for an exclusionary clause for paediatric trainees. The executive will write to Dr Pauling Snelling chair of SAC Nephrology

Fiona Mackie proposed a motion that the executive write to SAC objecting the to new mandatory requirements of nephrology training
Seconder: David McCredie
Motion carried unanimously

Trials reports – Aranesp
Steve McTaggart reports that 3 hospitals are taking part. It is safety and efficacy trial. So far 20 patients enrolled with the aim of 30 patients. Publication of the results of the trial was discussed and the membership agreed that only those hospitals directly involved in the trial will have authorship of the final report'

Elisabeth Hodson proposed that S McTaggart be the lead author and others (including nurses) as contributors

Motion seconded by Lillian Johnstone

Motion carried unanimously

ANZDATA Report (Paul Henning, Stephen McTaggart, Jonathon Craig)
Steve McTaggart reports from ANZDATA about a new format for reports. There will be 2 sections, the lst will contain general information and the 2nd section will focus on a specific area. The area of interest will alternate between dialysis and transplantation, 2005 will be transplantation.

ANZPNA Affiliation with RACP Paediatrics Division
Max Morris has received corespondence from Neil Wigg, President of the Paediatric Division of the RACP concerning possible means of affiliation with the College. No further progress has been made on this issue.

RACP Written examinations committee member for Nephrology
William Wong reported that 2006 will be his last year on the Written Examinations Committee for Paediatrics. A new member must be nominated to attend the May 2006 committee meeting as an observer who then replace William in the 2007 meeting. William Wong will circulate a notice to all members asking for expressions of interest.

Other Business
Sirolimus
Andrew Rosenberg reported that Wyeth Pharmaaceticals was keen to support an educational meeting for paediatric nephrologists. The membership was keen to hear an update on sirolimus in paediatric renal transplantation. Andrew Rosenberg was asked by the membership to investigate further the possibility of having a symposium on sirolimus sponsored by Wyeth which would be conducted within the RACP guidelines of relationship with the pharmaceutical industry.

Gene bank/testing
Steve Alexander discussed the issue of the lack of a laboratory in Australia to conduct gene testing for genetic renal disease. Members are currently sending samples offshore for genetic analysis. He also indicated that a gene bank is

being established at Children's Hospital Westmead. The membership is to look into establishing a kidney gene bank in Australia. The executive is to write a letter of support to ???? in developing this service

Cystinosis –white cell cystine assays
Steve Alexander discussed the issue of standardised testing of white cystine by accredited laboratories.

Transplant protocols
William Wong discussed this on behalf of Paul Henning. Co-ordinating transplant protocols to enable clinical trials was suggested.

Common protocol for initial treatment of idiopathic nephrotic syndrome.
Discussion from membership about current treatments for first presentation of childhood nephrotic syndrome. Many paediatricians using RCH)Melbourne) website for treatment protocol. ANZPNA to draft a position statement for the treatment of initial episode and lst relapse of INS

Membership of ANZPNA by renal nurses
Elisabeth Hodson discussed the possibility of paediatric renal nurse becoming associate members of the society because they have are vital and integral part of our services. The current constitution states that only medical specialists can be full members of the association. Elisabeth will explore issue of associate membership of nurses further

Change of executive
Call for nominations of new executive after the 2006 AGM which will be in Melbourne during the ANZSN Annual Scientific meeting

The meeting closed at 5:07pm

ANZPNA

Annual General Meeting of the Australian and New Zealand Paediatric Nephrology Association 29 November 2005
Curzon Room, Rydges Hotel, North Melbourne, 1.00pm - 4pm

Apologies
Jonathan Craig, Hemant Kulkarni, John Knight, Richard Kitching, Frank Willis, Ken Jureidini, Paul Henning, Gad Kainer, Paul Roy, Rowan Walker, Debbie Lewis, Margot McIvor

Resignations Paul Tomlinson

Minutes of 2004 meeting → needed by September 2006

IPNA reports	1. Assistant Regional Secretary	Colin Jones
	2. Final Report of 13th IPNA Congress	Colin Jones
Chair person's Report		Max Morris
Treasurer's report	— subscriptions to stay same $100	Charlie Crompton
Paediatric Transplantation standing committee		~~Fiona Mackie~~ Steve Alexander
SAC Nephrology Training Requirements	— see correspondence	Fiona Mackie
Trials reports-Aranesp + AKT		Steve McTaggart
ANZDATA Report → recommend the ANZPNA appoint paid. representatives.		Steve McTaggart
ANZPNA & affiliation with RACP Paediatrics & Child Health Division — on hold.		Max Morris
RACP written examination committee		William Wong

Other Business → GEOFF SHANG (SYDNEY CHILDRENS)

Gene Bank/Cystinosis/Genetic testing	Steve Alexander
Sirolimus — MONICA COLLINS → ? link to ANZPNA meeting	Andrew Rosenberg
Transplant protocols + NEPHROTIC SYNDROME PROTOCOL.	William Wong

ANZPNA
TREASURER'S REPORT
YEAR ENDING 30 JUNE 2005

THE YEAR IN REVIEW

There has been little financial activity within the association over the last 12 months. The opening bank balance at 1/7/04 was $11871.80, and closing balance at 30/6/05 $11.348.90. As suggested at the 2004 AGM, the directors's liability insurance has not been renewed. The audited financial statements are attached.

SUBSCRIPTIONS

Once again extracting annual subscriptions from some members has been difficult, with the usual suspects proving recalcitrant. Nine members out of 28 remain non-financial. I have provided a list of these members to the chairman. A further request for payment has recently been sent.

BANKING

A term deposit account has been established with CBA. The $8000 deposit attracts 4.15% interest and is rolled over every 4 months.

FINANCIAL POSITION

The financial position of the association is sound, as there are few outgoings, now reduced further due to non-renewal of the director's liability insurance. The web-site and ASIC compliance costs are the only significant draw on funds at present, and unless this changes I suggest reducing membership fees to $50 per annum.

COMMENTS

I question the need for our association to be an incorporated company. The compliance issues with respect to ASIC are significant, as are the costs and potential penalties.

Charles Crompton
Honorary Treasurer
ANZPNA

Australian & New Zealand Paediatric Nephrology Association

Financial Statements for the Year Ended 30th June 2005

AUSTRALIAN & NEW ZEALAND
PAEDIATRIC NEPHROLOGY ASSOCIATION

DIRECTORS DECLARATION

The Directors have determined that the company is not a reporting entity and that this special purpose financial report should be prepared in accordance with the accounting policies outlines in Note 1 to the financial statements.

The Directors of the company declare that:

1. The financial statements and notes, presents fairly the company's financial position as at 30th June 2005and its performance for the year ended on that date in accordance with the accounting policies described in Note 1 to the financial statements;

2. In the Directors opinion there are reasonable grounds to believe that the company will be able to pay its debts as and when they become due and payable.

This declaration is made in accordance with a resolution of the Directors.

Dr Charles Crompton
Director
Treasurer ANZPNA

12 / 11 / 2005

AUSTRALIAN & NEW ZEALAND
PAEDIATRIC NEPHROLOGY ASSOCIATION

DIRECTORS REPORT

The Directors present their report on the society for the financial year ended 30th June 2005.

The Directors in office during this period were as follows;
Dr Max Morris (Chairman), Dr William Wong (Honorary Secretary), and Dr Charles Crompton (Honorary Treasurer). The directors have been in office since the 31st August 2004 to the date of this report.

The principal activity of the Association during the financial year was to foster and develop the study of paediatric nephrology in Australia and New Zealand. No significant change in the nature of these activities occurred during the year.

The figures in the financial statements are for the twelve-month period ending 30th June 2005. The loss of the company for the financial year was $ 522.90.

Nil dividends were paid or declared since the start of the financial year. No options over issued shares or interests in the company were granted during or since the end of the financial year and there were no outstanding options at the date of this report.

No indemnities have been given or insurance premiums paid, during or since the end of the financial year, for any person who is or has been an officer or auditor of the company.

The Association's operations are not regulated by any significant environmental regulation under a law of the Commonwealth or of a State or Territory. At this time the Directors are not aware of any other developments likely to have a significant effect on the Association's operations.

Signed in accordance with the resolution of the Directors.

Dr Charles Crompton
Director
Treasurer ANZPNA

12/11/2005

AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

INDEPENDENT AUDITOR'S REPORT

SCOPE

We have audited the financial report of **AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION** for the year ended 30th June 2005. The elected committee of the Association is responsible for the presentation of the financial report and the information contained therein, and have determined that the cash basis of accounting used is appropriate for the needs of the members. We have conducted an independent audit of the financial report in order to express an opinion to the members of the Association on its preparation and presentation. No opinion is expressed as to whether the basis of accounting used is appropriate to the needs of the members.

Our audit has been conducted in accordance with Australian Auditing Standards to provide reasonable assurance as to whether the financial report is free of material misstatement. Our procedures included examination on a test basis, of evidence supporting the amounts and other disclosures in the financial report and the evaluation of accounting policies and significant accounting estimates. These procedures have been undertaken to form an opinion as to whether, in all material respects, the financial report is presented fairly in accordance with the cash basis of accounting so as to present a view which is consistent with our understanding of the financial position of the Association and the results of its operations. Statements of Accounting Concepts and Accounting Standards are not applicable to the cash basis of accounting adopted by the Association.

The audit opinion expressed in this report has been formed on the above basis.

QUALIFICATION

As is common for organisations of this type, it is not practicable for the Association to maintain an effective system of internal control over registrations subscriptions and other fund raising activities until their initial entry in the accounting records. Accordingly, our audit in relation to income was limited to amounts recorded.

QUALIFIED AUDIT OPINION

In our opinion, subject to the effects of such adjustments, if any, that might have been determined to be necessary had the limitation referred to in the qualification paragraph not existed, the financial report presents fairly the statement of financial performance of the Association for the year ended 30th June 2005, and its financial position and cash flows as at that date in accordance with the cash basis of accounting as described above and notes to the accounts.

JOHNSON & GREATHEAD
ACCOUNTANTS & AUDITORS

Greathead

... ...
Dennis Greathead

Date: 21 / 11 / 2005

AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

STATEMENT OF FINANCIAL PERFORMANCE
FOR THE YEAR ENDED 30TH JUNE 2005

Last Year			This Year
	INCOME		
48.80	Refund, Overpaid liability insurance	-	
39.75	Interest Received	56.05	
5,020.00	Member Subscriptions	2,540.00	
5,108.55			2,596.05
	EXPENDITURE		
423.50	Audit Fees	495.00	
70.40	Bank Charges	64.75	
-	Website Fees	605.00	
1,666.60	Insurance	1,684.20	
89.00	Fees & Charges	270.00	
353.10	Stationery (Letterhead)	-	
557.68	Meeting Costs	-	
3,160.18			3,118.95
1,948.37	**NET SURPLUS FOR THE YEAR**		(522.90)
9,923.43	Accumulated Surpluses Beginning of year		11,871.80
	ACCUMULATED SURPLUS		
11,871.80	**AS AT 30 JUNE 2005**		11,348.90

The accompanying notes form part of these financial statements.

AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

STATEMENT OF FINANCIAL POSITION
AS AT 30TH JUNE 2005

Last Year		This Year
	ACCUMULATED SURPLUSES	
11,871.80	Accumulated Surpluses	11,348.90
	Represented by:	
11,871.80	Commonwealth Bank - 2908 1034 0611	11,348.90
11,871.80		11,348.90
$ 11,871.80	**NET ASSETS**	$ 11,348.90

The accompanying notes form part of these financial statements.

AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

STATEMENT OF CASH FLOWS
FOR THE YEAR ENDED 30 JUNE 2005

Last Year		This Year
	Cash Flows From Operating Activities	
39.75	Interest Received	56.05
5,020.00	Member Subscriptions	2,540.00
48.80	Miscellaneous	-
(423.50)	Audit Fees	(495.00)
(70.40)	Bank Charges	(64.75)
(1,666.50)	Insurance	(1,684.20)
(89.00)	Filing Fees	(270.00)
(353.00)	Meeting Costs	-
-	Website Maintenance Fees	(605.00)
(557.68)	Stationery	-
1,948.47	**Net Cash Provided by / (Used in) Operating Activities**	(522.90)
1,948.47	**Net Increase / (Decrease) in Cash Held**	(522.90)
9,923.43	Cash at Beginning of Financial Year	11,871.80
11,871.90	Cash at End of Financial Year	11,348.90

Reconciliation of Cash

Cash at end of the financial year as shown in the Statement of Cash Flows is reconciled to the related items in the Balance Sheet as follows:

11,871.80	Commonwealth Bank - 2908 1034 0611	11,348.90
11,871.80		11,348.90

• single Council meeting each year
+ Centric meeting for Assistant Secretaries.

ANZPNA

Report from the Assistant Secretary, IPNA

Following the Adelaide 13th Congress, there has been a meeting of the Assistant Secretaries in March 2005 in Freiburg and an IPNA Council meeting in Beijing in September.

1. 13th Congress of the IPNA, Adelaide Convention Centre, 29th August – 3rd September 2004

The Adelaide meeting has received high praise from all members of Council and I have been asked to pass on the compliments and congratulations the Council members to the ANZPNA.

The report of the Conference Manager summarizes the Congress from a financial and scientific viewpoint.

2. Financial state of the Association

The finances of the organization remain strong. The 2005, September 30 cash position was $793,562.19 (US). Accounts are kept in Germany and the United States. I can provide details of the account to interested members on request.

The surplus of the 13th Congress was sent to the United States account.

3. Fellowship Programs

IPNA supported fellowships have been developed successfully with more than 10 fellowships being completed. The fellowship program is based around regional areas and most fellowship have been performed in Singapore and India and Cape Town. One fellowship has been completed in Brisbane.

The program is aimed at teaching basic nephrology and not at giving 3rd World Nephrologists more skills or research training. Funding is limited to around $12,000 -$18,000 per year. Most fellows are unable to apply to get into first world countries. In Australia's case, the IELTS English exam requirement (of a score of 7 or better in all 4 areas) excludes many and the additional requirement of $40,000 AUD per annum imposed by Immigration for occupational visa precludes many fellows coming here.

not allowed to examine patients

→ OCCUPATIONAL TRAINEE VISA.

4. Paediatric Nephrology

All the Editors are Otto Mehls and Michelle Baum. The contract for the journal is being renegotiated. At least 3 companies are bidding to have the journal and the monies being offered to the Society will see the Society earn $100,000 to $200,000 per year. At the current time of the subscription fee of $150 (US) for IPNA membership, $130 goes to the Journal.

The impact factor of the journal has increased from levels around 1.1 (late 1990s) to around 1.4.

The number of journal articles published by Australian authors remains low.

5. Expiry of the Assistant Secretary's Term

The current Assistant Secretary's term ends with the conference in Hungary in 2007. Arrangements need to be made to choose a new Assistant Secretary for IPNA.

Colin Jones
Assistant Secretary – IPNA.

The Royal Australasian
College *of* Physicians

Paediatrics & Child Health Division

13 December 2004

File No. 00/202

COPY

Professor Rowan Walker
President – ANZPNA
Department of Nephrology
Grattan Street
Royal Melbourne Hospital VIC 3050

Dear Dr Walker

Re: Paediatric Special Interest Groups and Affiliation with the Paediatrics & Child Health Division, RACP.

The possibility of affiliation of Paediatric Special Interest Groups' (SIGs) with the Paediatrics & Child Health Division has been an issue for some time. Over the past years there has been considerable discussion at the RACP on how best to establish a workable relationship between the SIGs and the Division, particularly when there is significant variation among the SIGs. Issues of indemnity, responsibility and resources also have required consideration.

After extensive discussions with the secretariat of the RACP during the last two years, the CEO has now suggested mechanisms for affiliation of paediatric SIGs with the Division.

The Division proposes options for two forms of affiliation

Category 1. A SIG within the Paediatrics & Child Health Division, RACP

Category 2: Alliance of SIG with the Paediatrics & Child Health Division, RACP.

These categories are detailed in the attached documentation.

The Division is committed to providing an ongoing relationship which is useful for individual SIGs, but which does not prevent their linkages with other special societies, research groups etc. The relationship between the Special Interest Groups and the Division would be beneficial when advice is required by each on a range of policy or professional matters.

From a legal and indemnity viewpoint, the Division is not able to establish a formal affiliation with a paediatric SIG that involves financial liability or administrative support and expenses. It can, however, provide the following:

support for professional and educational advice and advocacy, particularly as these relate to specialty issues of child health and welfare;

- encouragement and facilitation of participation in components of the RACP's business. This includes areas such as curriculum development, advice on training and continuing professional development matters, and involvement in the paediatric program at the Annual Scientific Meetings;

- links on the RACP webpage to your SIG website.

In addition, the Division would seek your advice and expertise on policy issues with regard to the area of paediatric specialty of your paediatric SIG, which may also involve the development of policies.

I would be grateful if your group could look carefully at these models to see how they might be relevant for your needs, knowing that our ultimate aim is to work closely together for the benefit of children and our profession. If your SIG wishes to develop an affiliation with the Paediatrics & Child Health Division, I would be grateful if you could indicate which of the two options your SIG would prefer.

The Division looks forward to receiving your advice in due course.

With best wishes

Yours sincerely

Don Roberton

Professor Don Roberton
President
Paediatrics & Child Health Division

Enc. 1. Objectives of Affiliation.
2. Guide for Category 1 affiliation.
3. Guide for Category 2 affiliation.

The Royal Australasian
College *of* Physicians

Paediatrics & Child Health Division

25 May 2005

Professor Rowan Walker
President – ANZPNA
Department of Nephrology
Grattan Street
Royal Melbourne Hospital VIC 3050

Dear Professor Walker

Re: Paediatric Special Interest Groups and Affiliation with the Paediatrics & Child Health Division, RACP

I refer to correspondence forwarded to you on 13 December 2004 relating to the possibility of affiliation of the Paediatric Special Interest Groups' (SIGs) with the Paediatrics & Child Health Division. A copy of the correspondence is enclosed.

The Division would appreciate receiving your response by 8 July 2005.

Yours sincerely

A/Professor Neil Wigg
President
Paediatrics & Child Health Division

145 Macquarie Street, Sydney NSW 2000, Australia Tel: (61 2) 9256 5409 Fax: (61 2) 9256 5465 E-mail: paed@racp.edu.au Web: www.racp.edu.au
ACN 000 039 047 ABN 90 270 343 737

The Royal Australasian
College *of* Physicians

Paediatrics & Child Health Division

OBJECTIVES OF AFFILIATION OF PAEDIATRIC SPECIAL INTEREST GROUPS WITH THE PAEDIATRICS & CHILD HEALTH DIVISION

Paediatric Special Interest Groups are important in providing for the educational, research and professional needs of paediatricians and those working in child health in a variety of disciplines. These groups also often have significant interests in common with physicians practising in similar areas in adult medicine; with scientists; allied health, nursing and other health practitioners; and with national and international research programs. Some of the paediatric SIGs are part of the appropriate Special Society, and others operate quite independently.

It is the wish of the Paediatrics & Child Health Division (PCHD) to provide forms of affiliation which are useful for individual Paediatric Special Interest Groups, but which do not prevent their linkages with other special societies, research groups, etc. The affiliations will be of benefit to the Division, by providing a source of expert advice where needed on a range of matters. The affiliations would also be of benefit to the Special Interest Groups in relation to professional matters for the practice of paediatrics and its sub-specialities, and as a formal avenue for input when advice is required by the Division on a range of policy or professional matters.

Objectives

1. Provide a structure and process for obtaining advice on relevant issues from Paediatric Special Interest Groups.

2. Assist with educational objectives for paediatricians and trainees.

3. Encourage and facilitate participation in components of the Paediatric Annual Scientific Meetings.

4. Assist with the development of health policy issues relevant to specialty areas of paediatric practice.

November 2004

The Royal Australasian
College *of* Physicians

Paediatrics & Child Health Division

Category 1:

Special Interest Group within the Paediatrics & Child Health Division

Definition
A group of Fellows of the RACP with a specific interest relating to issues of child health and welfare, consistent with the aims and objectives of the Paediatrics & Child Health Division (PCHD) of the RACP.

Proposed Regulations
Relevant issues relating to activities undertaken by the Special Interest Group will be referred to the Special Interest Group (SIG) for opinion. This will include public statements.

The PCHD will acknowledge the SIG when a joint statement is used by the PCHD, and vice versa.

2. Committee Representation: the SIGs will be requested to nominate members to appropriate positions on various sub Committees of the Division appropriate to the areas and expertise of the SIG. Ultimately, this representation would be decided by the full Divisional Committee.

3. Prior to admission as a SIG, the group will submit to the Divisional Committee its Terms of Reference, including core business, criteria for membership, management structure, resource base and projected activities.

4. Minutes of all SIG meetings would be presented to the Division.

5. An Annual Report will be prepared by each SIG with a summary of projected activities.

6 Each SIG will have a register of its membership that will be documented in its Annual Report.

7. Each SIG will be expected to levy a membership and other fees to cover its own administrative costs and additional activities such as a separate scientific meeting of the Special Interest Group.

8. The SIG would use 'joint' letterhead, i.e. PCHD/SIG.

9. The SIG would be listed on the College website as an integral part of the PCHD, and linked to the SIG website.

The Royal Australasian
College of Physicians

Paediatrics & Child Health Division

Category 2:

Alliance of Special Interest Group with the Paediatrics & Child Health Division

Definition
A group of members, not exclusively holding FRACP, with a specific interest relating to issues of child health and welfare, consistent with the aims and objectives of the Paediatrics & Child Health Division (PCHD) of the RACP.

Proposed Regulations

1. The alliance to work in collaboration with the PCHD to form an authoritative opinion on specialty issues of child health and welfare.
2. PCHD will refer to the alliance to advise on issues relating to its specialty area.
3. PCHD will acknowledge specialty groups when their opinion forms part of a public statement made by the PCHD.
4. The alliance may ask PCHD to support it on issues. PCHD will have the right to decide which issues it will support.
5. Public statements by the alliance shall not include reference to PCHD unless endorsement has been sought and given by the Divisional Committee.
6. An alliance has no right of representation on any PCHD Committee.
7. An alliance may have shared educational activities with the PCHD but will not qualify for RACP educational funding.
8. The alliance must have a designated membership and structure to achieve alliance status.
9. The PCHD will decide on a particular body's eligibility for an alliance.
10. The RACP Members from within the alliance may form a separate Special Interest Group..
11. An annual report of membership and activities is required to be presented to PCHD.

Fiona Mackie MB BS, PhD, FRACP
Paediatric Nephrologist
Director of Physician Training
Provider No: 2063783H

PHONE: *02 - 9382 1646*
FAX: *02 - 9382 1580*
Email: F.Mackie@UNSW.edu.au

FM:CT

Monday, 16 May 2005

Dr Ian Hewitt
Paediatric Nephrologist
Princess Margaret Hospital for Children
GPO Box D184
Perth GPO Private Boxes WA 6001

Dear Ian,

I was reviewing the November 2004 minutes of the SAC in Nephrology as part of my new role as the CPPT representative on this SAC. I noticed that in minute 3.1.2 that there was a resolution passed that it would be mandatory from 2006 for advanced trainees in nephrology to train at different sites for each clinical year. There is no exclusionary clause there for paediatrics. I think that it would be extremely difficult to enforce such a rule in paediatrics. Certainly in NSW at least advanced training in nephrology has to be done as a fellowship and individual funding for a 1-2 year period for each trainee has to be sought. There is no dedicated recurrent funding for training of advanced trainees in nephrology. As a consequence this funding is not transferable to other institutions. I would be interested to hear your opinion on whether this arrangement would work for paediatric trainees in nephrology in other states, but if it is a similar situation then perhaps you could ask the SAC to state that paediatrics is exempt from this requirement.

Kind regards

Yours sincerely,

F. Mackie

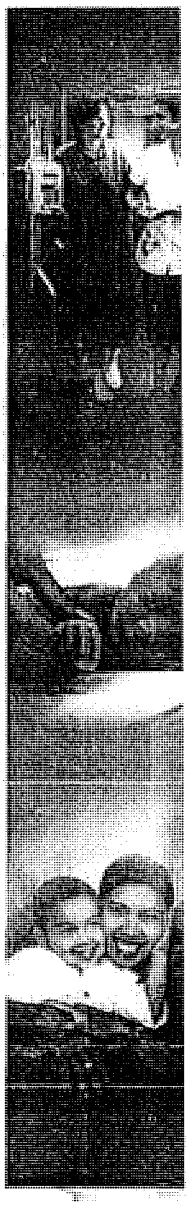
Fiona Mackie
Paediatric Nephrologist

Department of Health
Government of Western Australia

Women's & Children's Health Service

Dr Ian Hewitt
M.B.B.S., F.R.A.C.P
Renal Physician
Princess Margaret Hospital

Telephone +61 8 9340 8354
Facsimile +61 8 9340 8301
Email: ian.hewitt@health.wa.gov.au



27 May 2005

Dr Fiona Mackie
Paediatric Nephrologist
Sydney Children's Hospital
High Street
RANWICK NSW 2031

Dear Fiona

In reply to your letter of the 16 May 2005 regarding the resolution passed that advanced trainees in nephrology should try different sites for each clinical year.

This was introduced as at a number of hospitals, trainees who graduated from medical school became interns, residents and registrars, concluding their training without exposure to other institutions with different approaches to management of patients. There has been an approach by the College to ensure that training requirements are as uniform as possible with similar guidelines across paediatrics and adult medicine. There have been small variations to this such that Adult Nephrology trainees have to keep a record of procedures done such as biopsies, fistula needling by placement of a central line etc. Prescribing a large number of procedures to be performed for Paediatric Nephrologist's may prove difficult.

I note from your correspondence that in NSW that advanced training in Nephrology has been done as a fellowship with individual funding for a 1-2 year period. I would envisage that any fellowship grant for 2 years would entail one or possibly two years of research such that the trainee could undertake a clinical year and research year or possibly two research years with a clinical year funded as a registrar in the same institution, with a further clinical year taken elsewhere, possibly in conjunction with a research year. Of interest, the individuals within the College who promoted the resolutions were from New South Wales with concern expressed that certain Melbourne institutions conducted all training within the one hospital.

In the past, Princess Margaret Hospital had two trainees who are now Paediatric Nephrologist's in Australia, commenced with a clinical year in the department, followed by a research year with further clinical and research training overseas, one at the hospital for sick children in Toronto, the other at the Boston Children's hospital. With 2-5 kidney transplants per annum at our hospital and a small number of patients on dialysis at any one time, I do not feel that there is sufficient exposure to warrant all clinical training to be performed here. Possibly at your hospital there are significant numbers, however I have endeavoured to ensure trainees spend a year in a facility with at least 30 transplants per annum.

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PO Box 134
Subiaco WA 6904
Tel: (08) 9340 2222
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Princess Margaret Hospi for Children
Roberts Road
Subiaco WA 6008
GPO Box D184
Perth WA 6840
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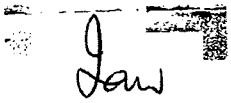
Fax: (08) 9340 8111

To maintain skills, I have taken study leave in large overseas facilities at intervals and am currently endeavouring to spend 6 months at a regional transplant facility in Padua where 30-40 kidney transplants are performed per annum.

In conclusion, I would argue that an individual state health departments should be approached in the event that a trainee has difficulty complying with the College of Physician guidelines if they wish to have appropriately experienced and well qualified trainees to fill future positions within the sub specialty of Paediatric Nephrology.

With kind regards

Yours sincerely



DR IAN HEWITT
RENAL PHYSICIAN

MASTER

ANZDATA Update – ANZPNA AGM 29 November 2005.

ANZDATA Paediatric Subcomittee (ANZDATA-PS)
There has been a recent reorganisation of the Paediatric Subcommittee. Jonathan Craig will continue as Coordinator; Steve McTaggart and Paul Henning have joined while ~~Amanda Walker~~ and Fiona Mackie have stepped down. Liz Johnstone

Annual ANZDATA Report 2005 (See Appendix 1)
As part of the general review of the ANZDATA Paediatric Annual Report, we have adopted a new strategy that we hope will be both interesting and informative. The report will now be formatted in two distinct sections, as follows;

Section 1
- Standard stock and flow data on incident/prevalent patients, presented as brief text with relevant tables/graphs
- Aim is to provide data for assessment of activity across individual units and to facilitate benchmarking.

Section 2
- This section will alternate each year, between a Dialysis Report and a Transplant Report.
- Within these reports, specific analyses will be performed and presented as brief text with relevant tables/graphs.
- The nature of each analysis will be open to discussion, with input from all members of ANZPNA. The analysis will be facilitated by ANZDATA-PS members or ANZDATA central staff.

Paediatric Lipid Data Collection
Reporting of cholesterol data remains poor. Information from ANZDATA is as follows;

From 1 October 2003 to 31 Dec 2004 there were 567 paediatric assessments reported to us. That is 279 from October 2003 to March 2004 and 288 from April 2204 to December 2004.

- *Cholesterol data was missing in 63% cases overall (66% Oct03-Mar04; 60% Apr04-Dec04)*
- *LDL data was missing in 76% cases overall (80% Oct03-Mar04; 73% Apr04-Dec04)*
- *HDL data was missing in 74% cases overall (76% Oct03-Mar04; 71% Apr04-Dec04)*
- *Triglycerides data was missing in 65% cases overall (67% Oct03-Mar04; 67% Apr04-Dec04)*
- *Statin data was missing in 6% cases overall (9% Oct03-Mar04; 3% Apr04-Dec04)*

The ANZDATA-PS considers the collection of this data to be a **major priority** for all members of ANZPNA in order to demonstrate our commitment as a group to utilising the considerable resources provided by the ANZDATA staff. We strongly feel that a significant effort should be undertaken by all members to improve the collection of data and bring this project to fruition. Failure to do this will reflect poorly on ANZPNA and severely limit our ability to influence data collection in the future.

Some of the strategies that are being considered to improve data collection include;
- Establishing finite collection periods for data collection for individual projects.
- Defining clear outcomes of data collection, prior to commencement of any project eg proposed publication strategy.
- Regular e-mail reminders, especially prior to data collection periods. at end 3/12. - 2yr.
- Reminders also to be sent to staff responsible for data collection/input.
- Possibility of more regular meetings via teleconferencing.

Additional Projects
It has been decided that the clear focus at present should be on ensuring the success of the current Lipid project. However, we would also like to encourage all members to contribute new ideas for potential projects. Any body that would like to discuss potentially new data collection or other projects utilising ANZDATA data should contact one of the members of the subcommittee.

Papers in Progress
Outcomes after Paediatric Transplantation – J Craig, S McDonald

APPENDIX 1 - Draft ANZDATA Paediatric Report 2005

This year the paediatric report will include three focused sections –

- an overview of frequency, causes and treatment modalities for children with ESKD
- peritonitis
- anaemia

Part 1: General overview

1. Incidence and prevalence of ESKD in children and adolescents 1980-2004

As shown in figure 1 the incidence of children and adolescents developing ESKD and being treated with renal replacement therapy has remained consistent at around 8-10 per million in the past 25 years. This reflects a stable incidence of disease and threshold for treatment during this time period.

Figure 1: Incidence of RRT per million population in the 0 to 19 year age group

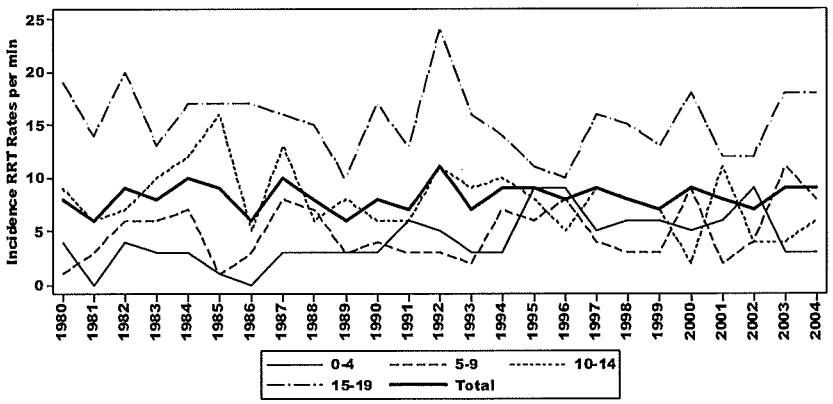
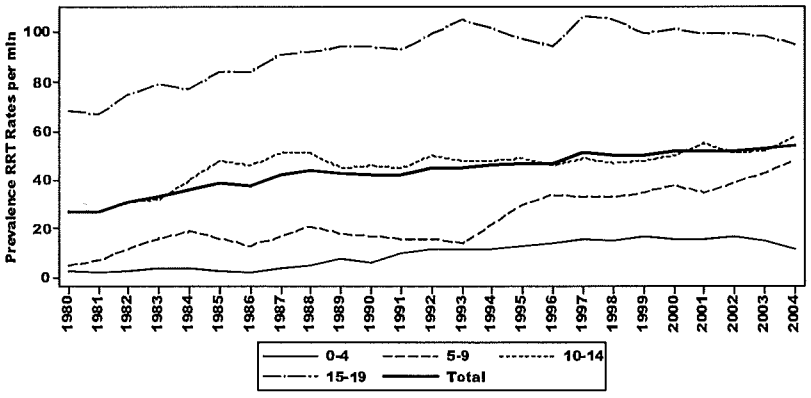


Figure 2: Prevalence of RRT per million population in the 0 to 19 year age group



In comparison, the prevalence of treated ESKD has steadily increased since 1980, from about 25 to 50 per million population 0-19 years old. Given the stable incidence this is due to the increased duration that children and adolescents have ESKD, and demonstrates improved survival. This appears to be the case for all age groups.

2. Causes of ESKD in children and adolescents 1999-2004

Figure 3: Causes of ESKD by age 1999-2004

PRD	Age Group 0-4	5-9	10-14	15-19	Total
Glomerulonephritis	6	42	50	266	364
	1.65	11.54	13.74	73.08	100.00
	4.69	27.27	34.97	59.64	41.79
Reflux Nephropathy	4	13	11	61	89
	4.49	14.61	12.36	68.54	100.00
	3.13	8.44	7.69	13.68	10.22
Cystic Disease	3	11	25	21	60
	5.00	18.33	41.67	35.00	100.00
	2.34	7.14	17.48	4.71	6.89
Posterior Urethral Va	20	7	8	11	46
	43.48	15.22	17.39	23.91	100.00
	15.63	4.55	5.59	2.47	5.28
HUS	0	4	0	18	22
	0.00	18.18	0.00	81.82	100.00
	0.00	2.60	0.00	4.04	2.53
Hypoplasia/Dysplasia	37	23	19	2	81
	45.68	28.40	23.46	2.47	100.00
	28.91	14.94	13.29	0.45	9.30
Uncertain	3	0	9	8	20
	15.00	0.00	45.00	40.00	100.00
	2.34	0.00	6.29	1.79	2.30
Miscellaneous	55	54	21	59	189
	29.10	28.57	11.11	31.22	100.00
	42.97	35.06	14.69	13.23	21.70
Total	128	154	143	446	871
	14.70	17.68	16.42	51.21	100.00
	100.00	100.00	100.00	100.00	100.00

? category of miscellaneous

Overall, glomerulonephritis remains the most common cause of ESKD in children and adolescents (42%) but causes vary significantly with age. In young children hypoplasia/dysplasia is the most common cause.

3. Modality of treatment 1999-2004

Figure 4: Proportion of children and adolescents treated by haemodialysis 1999-2004 by age and year of treatment

Age	Year of treatment											
	1999 (n = 192)		2000 (n = 198)		2001 (n=198)		2002 (n=204)		2003(n=182)		2004(n=100)	
	N	%*	N	%	N	%	N	%	N	%	N	%
0-4	17	45	4	17	5	13	13	36	2	11	0	0
5-9	1	5	5	10	5	26	4	16	18	45	9	41
10-14	21	41	3	23	26	65	17	40	5	20	13	59
15-19	58	69	83	73	54	69	60	60	74	75	42	75
total	97	51	95	48	90	51	94	46	99	54	64	58

*** denotes the proportion of patients in that age strata treated with hemodialysis (compared with peritoneal dialysis)**

Overall around half of children and adolescents are treated by haemodialysis with peritoneal dialysis more commonly used in younger children and haemodialysis used in older children. No clear change in choice of modality is evident during the past 5 years.

Part 2: Peritonitis (to be completed)

Part 3: Paediatric Anaemia Management

A cross-sectional survey of anaemia management was undertaken on all patients treated within Australian and New Zealand Paediatric Units at the ANZDATA census date of 30 December, 2004. On that date, 252 patients were receiving care in Paediatric Units, with 39 (15%) being treated with either peritoneal dialysis or haemodialysis and 213 (85%) having received a kidney transplant. Data on anaemia management in the transplant population are not included in this report.

The distribution of haemoglobin according to dialysis modality is shown in Figure 1. Fourteen percent of haemodialysis patients and 33% of peritoneal dialysis patients were below the currently recommended target haemoglobin concentration of 10 g/dl (p=0.20). There was no significant relationship between age and haemoglobin level (Figure 2).

Figure 1. Haemoglobin level according to dialysis modality

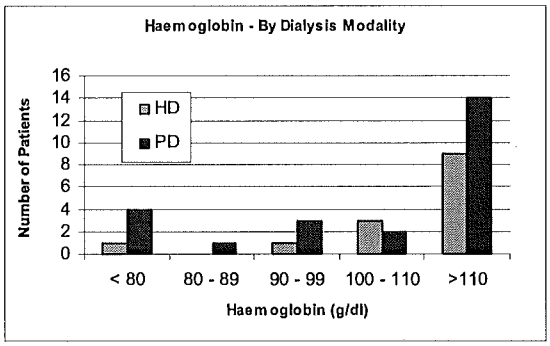
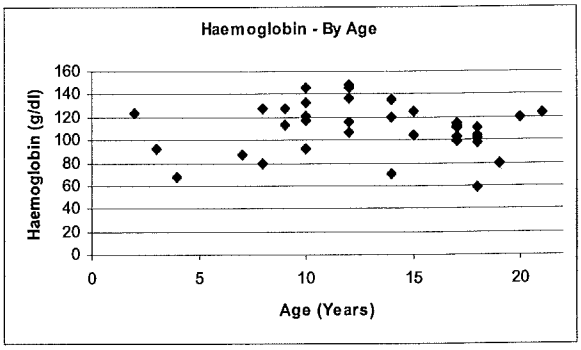


Figure 2. Age distribution of haemoglobin level



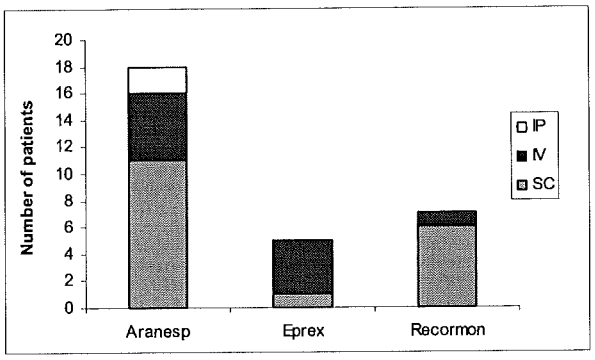
The transferrin and ferritin levels were not significantly different between haemodialysis and peritoneal dialysis groups (Table 1). Five children had ferritin levels <100 µg/l, 9 had transferrin saturation levels <20% and 3 children had both.

Figure 1. Iron parameters for dialysis patients. Data are means and ranges.

	HD n=14	PD n=24	p-value
Ferritin (µg/l)	331 (60 – 584)	533 (55 – 2115)	p = 0.18
Transferrin Saturation (%)	26 (7 – 46)	33 (11 – 86)	p = 0.20

Thirty eight (97%) of the dialysis patients were currently being treated with some form of recombinant erythropoietin. Method of administration varied with most children on Aranesp treated subcutaneously, and all but one patient on Eprex treated intravenously (Figure 3).

Figure 3. Type and mode of administration of erythropoietin.



In summary, this data provides a brief snapshot of anaemia management of paediatric dialysis patients within Australian and New Zealand. Further studies in paediatric populations are required to assess the impact of haemoglobin level on important clinical outcomes such as cardiovascular disease.

ANZPNA

(Australian & New Zealand Paediatric Nephrology Association)

Minutes of
Annual General Meeting 2004
Wednesday 1st September 1245-1345hours
Adelaide Convention Centre

Present: Andrew Rosenberg, Colin Jones, Max Morris, Charlie Crompton, John Burke, Steve Alexander, Steve McTaggart, Fiona Mackie, Lillian Johnstone, Harley Powell, David McCredie, Paul Henning, Ken Jureidini, Mandy Walker, Elisabeth Hodson, Jonathan Craig, Debbie Lewis, Gad Kainer, Frank Willis, Helmut Kalkarnie, Tonya Kara, Leigh Haysom, Jeff Fletcher, Paul Tomlinson.

Apologies: Ian Hewitt

Minutes of 2003 AGM: Minutes confirmed

Proposer Max Morris
Seconded Mandy Walker

Matters arising from minutes – None

Chairpersons report:
Max Morris reports that there has been little activity apart from the preparation for the 13th Congress of IPNA in Adelaide. The chair conveyed his congratulations to Colin Jones and Ken Jureidini for their hard work in hosting IPNA in Australia.
Steve McTaggart proposed a motion of thanks to Colin Jones, Ken Jureidini, Andrew Rosenberg and John Burke for their work.

Proposal seconded by Max Morris
Motion carried unanimously

Treasurer's report
The honorary treasurer reports that accounts are in a healthy state. All subscriptions for 2004 are current. The website will cost $150 pa for upkeep. This would increase to $500-1000 if the site needed upgrading.
After allowing for the one of payment $1600 for insurance of the society, there is a modest amount of funds left over. Investment of some this money was discussed.
Treasurer reported that here was no need for a special subscription in 2005

Proposer: Charlie Crompton
Seconded: Mandy Walker

Executive for 2005
The executive(M Morris, W.Wong, C. Crompton, R Walker, C Jones) was reconfirmed

Proposer: Max Morris
Seconder: William Wong
Carried unanimously

Membership:

New members Helmut Kalkarni – full
Leigh Haysom – associate
Jeff Fletcher – associate

Andrew Rosenberg proposed that Sean Kennedy be offered associate membership- seconded by Fiona Mackie
It was unanimously agreed that associate membership is to be free of charge
There was discussion about the different types of membership
Colin Jones suggested that the executive review membership based on the current constitution.

Subscription fee for 2005 calendar year: This will remain at $AUD100.00

Committees:
SAC-RACP
Ian Hewitt is current Paediatric representative on SAC Nephrology in Australia. His current term is up for renewal in 2005. Need to discuss with him as to whether he wishes to continue.

SPEC of ANZSN — Colin Jones has indicated he will stand down from SPEC at the end of his present term. He nominated Steve Alexander as his replacement
Seconded: Steve McTaggert,
Nomination affirmed by the membership present.

ANZDATA: — Jonathan Craig is appointed paediatric representative. Lillian Johnstone and Fiona Mackie have been on a working party to represent paediatric issues to ANZDATA. Fiona Mackie reported that the working party has not been active and should be disbanded. It was agreed that individual members can approach ANZDATA after appropriate discussion on the website. Sub reports analysis should be directed to Jonathan Craig.

TSANZ — Steve Alexander is on the working group for sirolimus

ANZPNA website: Gad Kainer was thanked for his work on setting up the website
GK reports that the website is under-utilised at present. More content is needed, eg., protocols
Address: www.anzpna.com.
Username: surname
Password : email address

Cochrane Report:
Jonathan Craig has indicated that funding for the Cochrane collaboration is becoming an issue with no pharmaceutical sponsorship being allowed. He encourages advanced

trainees in paediatric nephrology to undertake a systematic review. Support for this is available.

Publications:
Charlie Cromptom reported that *"Nephrology"* is scheduled to publish the Growth Hormone paper
Jonathan Craig was congratulated on the recent publication of children with ESRD in the New England Journal of Medicine

Studies: Aranesp study
Steve McTaggart reported that Melbourne, Adelaide is still awaiting TGA approval Brisbane has recruited 4 patients, Sydney Childrens's and Perth still awaiting ethics approval and Westmead has recruited 4 patients
John Burke suggested there is a needfor more meetings with study collaborators

Other business: David McCredie informed the membership the Dr Allison Eddy will be visiting Melbourne to give a talk on the mechanism of renal disease.

ANZPNA

(Australian & New Zealand Paediatric Nephrology Association)

2003 Annual General Meeting Minutes

The 2003 Annual General Meeting of the ANZPNA was held on Sunday, 31st August 2003 at 10.30am in the Boardroom (Level 8 – Administration Building), Princess Margaret Hospital for Children, Roberts Road, Subiaco, Western Australia.

PRESENT

Drs. Steve McTaggart, Charles Crompton, Elisabeth Hodson, Andrew Rosenberg, Rowan Walker, Amanda Walker, Frank Willis, Fred Juredini, Colin Jones, Richard Kitching, Ian Hewitt,

APOLOGIES

Drs. Paul Tomlinson, Fiona Mackie, Lil Johnstone Michael Falk, Harley Powell, David McCredie, Gad Kainer, John Knight, Jonathon Craig, Paul Roy, Paul Henning, William Wong, Deborah Lewis, Steve Alexander, John Burke, Max Morris

MINUTES OF PREVIOUS MEETING HELD 1ST SEPTEMBER 2002

Moved: Dr. Elisabeth Hodson, Seconded: Dr Ken Juredini. Passed: unanimously

BUSINESS ARISING

Liability insurance of executive

This was discussed in the Treasurer's report

REPORTS

Chairman's report — Attachment 1

A/Prof Rowan Walker talked to this report. He noted that IPNA activities had occupied executive throughout the last 12 months. Many other issues were to be covered by Treasurer's report. Privacy issues have been addressed. Tenure for office bearers and Guidelines for Office Bearers (*attachment 1a in agenda*) have been completed. ANZPNA Website is now underway with thanks to Dr. Gad Kainer for his work in this area. Joint clinical projects are underway – thanks to all involved.

A/Prof Walker noted that there is increasing recognition of ANZPNA as key representative body in many arenas.

He thanked the other members of current Executive and also secretarial staff at RCH, Melbourne.
Moved: Dr. Andrew Rosenberg, Seconded: Dr. Elisabeth Hodson Passed: Unanimously
(Outline of Duties – *Tabled in Agenda as attachment 1a)*

Treasurer's report — Attachment 2

Dr. Steve McTaggart spoke to his report. This has been a year of consolidation and improvement in smooth running of financial aspect of the Association. Currently approx $10,000 in single account. (Refer financial statements). Much of the profit related to collection of previous subscriptions,
Expenses include corporate affairs ASIC and auditors, general paperwork, secretarial ($100's). Costs associated with AGM ($1700 for room hire for 2002 AGM). Costs are usually approx $1000/yr not including liability insurance (approx ? $500/yr) Decisions need to be made regarding use of profit and financial management of this. Importance of ongoing external funding for Website was highlighted. Taxation position - Aust Tax Office advice is self assessed decision. Guidelines are available – ANZPNA does meet the tax exempt criteria; may request ruling from Taxation Dept (will attract a fee). ANZSN received a private ruling that indicated they are tax exempt.

Subscriptions now most paid few outstanding. Note that Articles of Association indicate the process for handling recurrent defaulting members. The executive agreed to be liberal in interpretation of Articles due to delay in collection of the 3 years' subscription during 2002. Members who default on payment after 2 years are no longer members. If

reapply then discussed at next AGM. Ian Hewitt raised issues relating to collection of previous payments prior to readmission to ANZPNA. Articles of association indicate defaulting members remain liable to pay previous owed monies prior to readmission.

Level of subscription suggested to remain at $100/year.

Corporate accounting and accountability ASIC monitors activities regularly and annual returns lodged each year.

Attention: Charles Crompton

IPNA finances

Ken Juredini outlined profit from Meeting goes to IPNA, and losses covered by IPNA. There may be some opportunity for educational grant if large profits generated. ANZPNA is not running meeting and not being paid for the service ie not undertaking service. $3,300 IPNA funds in Cheque account is still active. This account should be closed and money moved to Hartley account

Attention Ken Jureidini

Outline of duties of Treasurer

(Tabled as Attachment 1b in Agenda)

Steve McTaggart outlined duties of Treasurer including lodgement of financial statements and reports. No reminders are sent by ASIC. Bank statements are reviewed by auditor with Director's statement and Director's report (proforma available to ANZPNA Treasurer). Current Auditor to be retained and bank account to be retained but need change of co-signatories with change of Executive and Registered Business address.

Attention: Charlie Crompton and Steve McTaggart

There was discussion relating to challenges that may be encountered if executive is located within New Zealand. Other members, past president may be nominated to be additional co-signatory. ASIC rules may change from time to time – ASIC website has a useful guide to recent changes.

Attention: Charlie Crompton

Liability insurance - Willis Insurance Brokers, Sydney.

Steve McTaggart had discussions regarding liability insurance; cost has increased substantially over last 12 months ($500 - $1000/policy) which covers all directors against "corporate misadventure". The insurance brokers calculate level of risk after careful review of financial records and activities. Rowan Walker questioned the level of exposure of risk. Steve McTaggart highlighted that ASIC Website outlines financial responsibility of the directors. Director's personal assets may be vulnerable if ANZPNA sued.

Rowan Walker raised role of ANZPNA association RACP whether this covered this liability. Steve McTaggart highlighted that this relates more to corporate rather than medical issues. Examples include slander by Executive, errors in taxation/financial reporting. More details to be obtained but the members agreed that this should be pursued.

Attention: Charles Crompton and Steve McTaggart

Moved Rowan Walker Seconded Charles Crompton Passed by all

Rowan Walker thanked Steve McTaggart for his efforts

Secretary's report **Attachment 3**

Amanda Walker spoke to this report.

Geography of secretarial office

There was considerable discussion about where past corporate and other records pertaining to ANZPNA should be held. They are currently housed in Dept Nephrology, Royal Children's Hospital, Melbourne. The volume of records will become quite substantial in the near future. There was discussions regarding the need for a more permanent office especially in view of ASIC requirements.

Outline of duties of Secretary

(Tabled as Attachment in Agenda 2)

Vote of thanks to Vicki Burns for assistance with secretarial support

Issue of secretarial resources remains a problem with increasing Association activities. Approx 8 – 10 hours/month of secretarial support required (Approximately $3000 per year).

Centralised secretarial and document storage discussed – options could include linking with ANZSN or paying at one hospital. Proposal to incorporate ANZPNA membership as component of ANZSN membership. Further discussions by incoming Executive with consultation within other paediatric sub-speciality groups

Attention: Executive

ANZPNA Website

Secretary and Gad Kainer to ensure continuity of information for the ANZPNA Website
Need to consider ANZPNA e-mail address to centralise enquires
Website content could include member details.

Attention: William Wong

NOMINATIONS FOR EXECUTIVE

Nominations were Max Morris (Chair)
William Wong (Secretary)
Charlie Crompton (Treasurer)
All agreed that the term would be for 3 years duration

ANZPNA MEMBERSHIP

Membership of ANZPNA

H Kulkani (associate member) Advanced Trainee Yr 1	Monash Medical Centre, Melbourne
J Fletcher (associate member) Advanced Trainee Yr 1,	The Children's Hospital at Westmead, NSW
L Haysom (associate member) Post FRACP trainee	Sydney Children's Hospital, Randwick, NSW

Members agreed that these applicants should be admitted to ANZPNA as associate members

Attention: Secretary

Current ANZPNA membership **(Attachment 4: also available electronically)**

Liability insurance of ANZPNA Executive **Steve McTaggart**

Discussed in treasurer's report

Paediatric Nephrology Workforce **Amanda Walker**

27 nephrologists, 8 current trainees currently in Australia and New Zealand. Workforce implications of this were discussed. To be distributed to the full members.

TRAINING IN PAEDIATRIC NEPHROLOGY

SAC Nephrology **Ian Hewitt**

Annual meeting in November, telephone conference in April. Nomination required for 2005.

ANZPNA membership – Trainee perspective

Letter from Josh Kausman was noted and suggestions of "trainee corner" for ANZPNA and database of overseas Nephrology contacts were discussed. It was agreed for Executive to pursue these further.

Attention: William Wong

There was discussion re possibility of reintroducing educational component to the ANZPNA AGM. No decision was undertaken and it was agreed for this to be discussed by the incoming Executive.

Attention: Executive

There was discussion about the educational opportunities for Paediatric Nephrology trainees via ANZSN SPEC (Colin Jones is current Paed rep on SPEC). Steve McTaggart suggested that there may be a need to formalise the position of paediatric representative on SPEC

Attention: Colin Jones

Paediatric position on ANZSN Council was revisited as outlined in minutes of 2002 AGM – no action to date

Attention: Amanda Walker/ William Wong

List of current trainees - Privacy implications **Amanda Walker**

Details of current Associate members are included in membership list however often trainee details cannot be listed without their specific consent.

ANZPNA WEBSITE

Progress report **Gad Kainer/Amanda Walker**

Quote relating to development of Website was tabled and discussed. $6,000 funds for ANZPNA Website have been generously provided by by Roche. This would cover development but not maintenance and updating. Ongoing sponsorship will need to be established. There was considerable discussion about role of Website and need for maintenance of this site. Role is as representing ANZPNA in the broader medical community. Gad Kainer to be asked to clarify ongoing projected costs.

Attention: Amanda Walker/ Gad Kainer

Website content **Gad Kainer/Amanda Walker**

PUBLICATIONS & STUDIES

Guidelines for publications

(Tabled as Attachment 5 in Agenda)

Date of last modification - 1st Sept 2002. To be reviewed 2005.

COLLABORATIVE STUDIES

Growth hormone **Charles Crompton**

OzGrow data analysis - difficulties encountered with completion of report. May be suitable for gen paed publication. Data included growth data, puberty, complication and final height data in children with CRF/ Tx/ dialysis and growth hormone supplementation. Difficulties included statistical analysis (not widely understood in the broader medical community). Outcomes indicated benefit for individual patients and as group slowing of loss of growth potential less than reported in the clinical trial data. This study with all its difficulties is an appropriate review of growth of children with chronic renal failure in real of in clinical practice. Many hours of work already undertaken and would require substantial additional work to bring to publication standards.

Colin Jones reported that much of the data was useful & suggested that the group review the current submission for discussion with reviewers comments and then submit to Nephrology.

Attention: Charlie Crompton

Juvenile diabetes & ACEI **Gad Kainer**

Andrew Rosenberg reported that discussion with endocrine college was underway

HMGCoA reductase study **Fiona Mackie**

Andrew Rosenberg reported that patient number would limit the study. Colin Jones commented that adult studies haven't demonstrated significant improvement in adult nephrotic patients. Rowan Walker commented that study of HMGCoA reductase efficacy in adult ESRF patients was underway.

Aranesp study **Steve McTaggart**

(Tabled as Attachment 6 in Agenda)

Steve McTaggart outlined that Amgen did not assist in development of protocol based on John Burke's EPO study in 1995. Amgen did not impact on protocol or limits, they did request extension of study to patients stable on fortnightly Aranesp be changed to Monthly dosing. May be given IV or SC

Funding $600/pt x 50 patients ($30,000 total) payable at completion of study. Elisabeth Hodson raised queries re early part payment to assist in data collection. Steve McTaggart agreed this would be appropriate. Patient numbers based on ANZDATA current number <18 yrs entering ESRF program.

Other outcome measures such as CVS outcome, LV mass were discussed. It was felt it would be worthwhile looking at CVS risk eg echo pre/at 12 months? Sub population or all patients. ? Larger centres only? AMGEN agreed to look at extra funding for inclusion of echo in these studies.

Colin Jones commented that adding extra tests then increases complexity and workload of the study – he suggested keep it simple. Ethics submission would require amendments – thus further delay in commencing the study.

Richard Kitching raised the issue of central assessment of echo data ?intercentre variation may skew results.

Colin Jones reported that Amer Soc Echo standards were used with his study. Some patients echoed at RMH & RCH to check concordance. He noted that Echo results are very dependent on operator and site of taking measurements. He attempted to get echo at time of transplant with variable echo results (due variable operators).

He highlighted that Echo measurements need to be defined. Colin Jones & Lil Johnstone would be appropriate resource people. Expect majority Echos to be normal.

Attention: Steve McTaggart (to e-mail scanned ethics approval to members)

Multicentre US study (69 patients) **Elisabeth Hodson & Steve McTaggart**

Progress uncertain Steve McTaggart to check with AMGEN

Steve McTaggart thanked involved members – phase 4 investigator driven studies – raised concerns relating to medical indemnity.

Attention: All members

Renal disease and Low Birth Weight **Steve McTaggart**

(Tabled as Attachment 6 in Agenda)

Steve McTaggart reported that this study has some difficulties. He highlighted the amount of work involved in this study and has discussed many limitations of trial protocol with primary investigators. Primary question is: Is there difference in birth weight in patients with any renal disease?

Difficulties in access of primary data (eg accuracy of birth weight data) raise concerns regarding the validity of the results and conclusions. Retrospective data collection ie not prospective study. Limited value to ANZPNA membership. Participants to be decided by individual paed Nephrology units.

Attention: All members

Ian Hewitt mentioned other similar WA local studies underway collected prospectively over many years.

Steve McTaggart to discuss with investigators further

Attention: Steve McTaggart

International Multicentre trial of use of MMF in childhood Nephrotic Syndrome **Ken Juredini**

Nothing further yet

MMF IgA and Fish oil **(Chief Investigator: Ron Hogg US)**

Rowan Walker reported limited progress. Desire in ANZSN to set up trial centre. Rowan Walker directed members to Website. Fish oil not available in Australia – Ron Hogg will review an amendment to address this. Contact him directly

Attention: All members

Association with other international collaborative group (eg NAPRTCS) **Rowan Walker**

Bill Harmon contacted. NAPRTCS. No significant discussion

Attention: Rowan Walker

QUALITY ASSURANCE ACTIVITIES

Benchmarking **Lil Johnstone**

Nothing further to report at moment.

Attention: Lil Johnstone

ANZDATA Subcommittee Report **Jonathan Craig**

(Tabled as Attachment 7 in Agenda)

Rowan Walker commented that Jonathon Craig nominated to head subcommittee to report to ANZDATA. Report provisionally accepted by N Eng J Med.

New data forms for 30/09/03 – report will be descriptive and presentation at ANZSN. Incidence of cancer in children with ESRF data will be collected. Improvement of type of publication from ANZDATA . Jonathan Craig is head of working party of that group. Suggested that he continue in current position for next few years. Other paediatric involvement in working party appears uncertain – take on more people to working party.

Attention: Jonathan Craig

Rowan Walker reported that purpose of working group is to define content of report and focus of data collection. Working party to meet by teleconference 2-3/yr to discuss progress. Subgroup of ANZDATA advisory committee – appointment is by ANZPNA at AGM.

Steve McTaggart highlighted the need for comprehensive paediatric report in ANZDATA. Previous reports included "stock and flow" which was useful for members.

Rowan Walker to discuss further with Jonathon Craig. Members to indicate interest in joining working party and identify areas of interest. ?All working group members be named on publications.

Attention: Rowan Walker and Jonathan Craig

RACP annual scientific meeting May 2003 Report — Paul Roy

(Tabled as Attachment 8 in Agenda)

CARI guidelines report — Rowan Walker

Rowan Walker reported that there has been appointment of a new CARI project officer (Denise Campbell) with assistance from Lesley Edwards. New guidelines developed: . Peritonitis, Proteinuria as diagnostic test, CMV disease in transplant population now on CARI Website.
Elisabeth Hodson commented that paediatric aspects are in amongst adult guidelines, and at times difficult to find.
Rowan Walker reported that there is adequate paediatric representation on CARI working groups. Searching is now undertaken by CARI office and they will also complete some of editing.
Global guidelines group – to examine commonality in international guidelines also underway.

Cochrane Renal Group report — Jonathon Craig

(Tabled as Attachment 9 in Agenda)

Elisabeth Hodson highlighted the ample opportunities for participation in these activities.

Attention: All members

PATIENT RELATED ISSUES

Access to health care cards for renal patients — Elisabeth Hodson

Elisabeth Hodson highlighted the review of carer's allowances – many patients may lose entitlements. Centrelink will not clarify HCC status if no carer's or other allowances. May lead to pharmacy bills of $100's. It is unclear whether patients can apply for Health Care Card. Centrelink is not forthcoming with clarification.

Attention: ANZPNA Executive

Pharmaceutical group in ANZSN – may be another venue to pursue this issue

Attention: Charles Crompton & Elisabeth Hodson

Patient education resources — Amanda Walker (Attachment 5)

(Tabled as Attachment 10 in Agenda)

Amanda Walker highlighted the benefit of collecting patient education resources available across Australia & New Zealand. List of titles could be maintained via the website.
Attachment 10 has list of brochures available from Renal Resource Centre.
Monash Medical Centre is developing some patient booklets about UTI's aimed at 7-10 year olds which will be available in late 2004.

Attention: Amanda Walker and William Wong

INTERNATIONAL PEDIATRIC NEPHROLOGY ASSOCIATION

IPNA 2004 Meeting Progress reports — Ken Juredini/Colin Jones (Attachment 6)

Ken Jureidini reported on May 2003 council meeting. IPNA $1,000,000 currently in reserve. Work is underway in obtaining support for nephrologists in developing countries. ?IPNA Fellowships.
Springer has retained journal publishers. Time to publication 4-5 months, electronic 2-3 months, increased impact factor to1.391 Fellowship program set up in coordination with ISN. Council charter is to improve support further for developing countries.
Registration brochure and call for papers tabled for discussion.

Congress program

Colin Jones reported that Justice Michael Kirby accepted invitation to be opening keynote speaker.

Andrew Rosenberg reported that International Workshop on Hypertension – focussing on essential hypertension in children.
Keynote speakers and plenary lecturers have been confirmed. CME activities well developed not yet finalised. 16 –22 /22 symposia completed. Elisabeth Hodson congratulated everyone on their efforts to date. Free communications will generate a lot of work once abstracts have been submitted, will be distributed to the theme groups for review. Criteria yet to be determined.
In all free communication sessions, 1/2 hour update talks – almost finalised.

Rowan Walker raised concerns of Recent advances in Paediatric Dialysis. Andrew Rosenberg will review concerns and liase further with Rowan Walker.

Deadline for abstracts Feb 6th, 2004. Key dates need to be highlighted on brochure ?front page.

Attention: Ken Jureidini

Page 5 highlight associated workshops and conferences with Renal Developmental Workshop (Barossa). Laparoscopic Urology Workshop (Adelaide WCH) International Paediatric Urology Meeting (Barossa). Hypertension Workshop on Sunday. International Federation of Kidney Foundations ?Sat/Sun.
ANZSN commence on Tuesday p.m., concurrent ANZSN/IPNA day is Wednesday Topics for the session include transitional issues, nephrotic syndrome, infection, transplantation, (symposia No 13 – 18). Adult Nephrology participants will be offered reduced registration for IPNA. Reduced rates for registrants of IPNA and ANZSN.

Ken Juredini discussed sponsors
Premium Sponsors: AMGEN, Fresenius Medical Care, Janssen-Cilag,
Major Sponsors: Pharmacia, Baxter, Coopers, Speaker sponsors: Gambro, Mayne Pharmacy, Women's & Children's Hospital, SA Tourist Comission
Concert Sponsor: Adelaide Concert Hall,
Opportunities for further sponsors
International Federation of Kidney Foundation supported by AMGEN

IPNA budget — Ken Jureidini — (Attachment 7)

Breakeven costs for 500 delegates (column D). Initial estimate $850 Aus (US $ 500)
Registration Fees does not take into account for "shop on" site monies. IPNA agreed for registration to be Aus $800 (maybe in US$500) still to be determined. Student fee may be available on individual basis. IPNA will subsidise registration for physicians from developing countries.

Website is preferred method of registration.

Social program – concert will be specified. Reduced fees for Symphony Orchestra Dinner scheduled on Thursday night. Reduced rate not available for non-attendence.

Registration – visiting speakers' registration costs covered if not members of IPNA.

All travel booked through Bunnik Travel via Website to ensure ease of bookings for registrants.
Cheaper airfares available when booked in Australia in contrast to booking in own country has been demonstrated to apply in Japan ?applicability to Europe. – will be outlined clearly on IPNA Website. Malaysian Airlines have major advantages – will allow book through Aus offices c/f Qantas. Preferred airline status will allow discounts from many destinations and fly directly to Adelaide. Qantas & Air New Zealand negotiations underway. South African Air negotiations underway. IPNA support likely to involve subsidised travel (to go via preferred airline).

Abstract submission to be electronic. May also be available via hardcopy. No charge for handling abstracts.

Onsite shopping will be available and discount vouchers at specific Adelaide shops.

Rowan Walker thanked Ken Juredini, for his efforts

Financial implications — Steve McTaggart

Covered in Treasurer's report

INTERNATIONAL PEDIATRIC TRANSPLANT ASSOCIATION

International Congress of Transplantation - Sydney 2008
(Tabled as Attachment 11 in Agenda)

Satellite IPTA meeting **Steve Alexander/Rowan Walker**

Rowan Walker - ITS meeting in Sydney 2008, IPTA meeting as satellite/concurrent meeting floated as possibility. No reply from Bill Harmon. IPTA second yearly meeting, last occurred April 2003.

Attention: Steve Alexander

OTHER BUSINESS

Ken Juredini reported on informal discussions about undertaking a comparative study Tacrolimus vs Cyclosporin in Aus in paed transplant. No trials comparing t2 hour monitoring. European trial of 3 year follow up has been completed – trough levels, high acute rejection rate. Elisabeth Hodson outlined that meta-analyses suggest evidence of Tacrlolimus superior to Cyclosporin but some limitations in these studies. Need to be prepared to randomise patients this may be difficult to ensure widespread multicentre involvement, concerns raised relating to adequacy of powering of this study due to low rejection rates and low patient numbers. Safety, efficacy study may be of use. Elisabeth Hodson raised concerns that if international study was commenced then ANZPNA should participate in that.

May be option of combined paediatric and adult patient multicentre study. Limitations in obtaining funding. Disucssion to continue

Attention: Ken Jureidini

The meeting closed at 5.30 p.m.

ATTACHMENT 1

ANZPNA MEETING 31/08/2003: Princess Margaret Hospital Perth WA

Chairman's Report

2003 has again seen the ANZPNA executive and membership preoccupied with the development and organisation of the IPNA 22004 (Adelaide) Program. I am grateful to every member of ANZPNA for his or her willingness to be involved in this process. I would like to offer a special vote of thanks to key players such as 'Fred' Jureidini, Colin Jones, Andy Rosenberg and John Burke (and others no doubt) for their persistence and drive towards make the Meeting a memorable one. It is hard to see the Meeting being anything other than an overwhelming success.

On more mundane matters the Executive has continued to work on the following. I believe we have achieved substantial progress on nearly all of these matters

- Stabilisation of our financial status. The timing of Annual Subscriptions is now back in the correct and logical sequence. Our affairs with ASCIS are essentially seen as being in order.
- Resolution of Privacy issues
- Rationalisation of terms of tenure and definition of responsibilities for office bearers. This is an important advance given our small constituency and the need to combine some corporate memory, a fair and reasonable distribution of work-load, and to progress the organisation
- Development of an ANZPNA web-site.
- Further development of possible joint Clinical projects.

I am very confident in saying that I believe the ANZPNA has continued to enhance its credentials as the key medical body providing comment, advice and resource in the area of paediatric Nephrology. I am also proud of the involvement of ANZPNA members in a number of key nephrological areas in Australia and New Zealand including ANZDATA Registry, Cochrane, CARI, DNT Committee, AKF & TSANZ.

My special thanks to outgoing Executive members; Amanda Walker (Secretary), Steve McTaggert (Treasurer) and Paul Roy for their willing support over the past 2 years. They have all been individuals with a generous disposition and have all been keen to see the organisation progress. I am confident that the ANZPNA remains a cohesive group with laudable aspirations and will continue to grow in stature over the years ahead.

Thank you again to Vicki Burns and Kerrie Scott at RCH for bearing the burden of secretarial support for the ANZPNA Executive. Their job has not been easy given the additional demands of IPNA. Vicki's previous experience with ANZPNA has certainly made life much better for the Chairman and Secretary that might have otherwise been the case.

Rowan Walker

ATTACHMENT 2

AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

Treasurer's Report

Year Ending 30 June 2003

GENERAL COMMENTS

The financial statements of the Association for the past two financial years are attached at the end of this document. The Association is currently in a reasonably strong financial position, with assets of $9,923.43, all of which is cash on deposit with the Commonwealth Bank. Profit for the year ending 30 June 2002 was $4045.38 and largely resulted from the back-payment of 3 years of ANZPNA subscription fees from each member. Profit from the year ending 30 June 2003 was $487.64 and this figure more closely represents the actual income of the Association on a year-to-year basis. Given this, for the forseeable future any major undertakings by the Association are likely to have a significant impact on the currently available capital.

ANZPNA TAXATION POSITION

An inquiry was sent to the Australian Taxation Office (ATO) asking for clarification of the Association's taxation position. The ATO reply indicated that a process of self-assessment is used to determine taxation status, although a specific ruling can be applied for if there is any ambiguity. ANZSN has been granted tax-exempt status via a direct ruling. As the aims and nature of ANZPNA are felt to be congruent with ANZSN, by the process of self-assessment ANZPNA is considered to be tax exempt.

SUBSCRIPTIONS

Subscriptions for 2003 were sent in early February and the majority of members are financial. Those members who are not financial have been sent reminders. Note that under the Articles of Association, those members who fail to pay their subscription for two years in a row may be removed from the membership list, after suitable notification.

CORPORATE ACCOUNTING AND ACCOUNTABILITY

ANZPNA has significant corporate responsibilities for financial record keeping and reporting. These requirements are somewhat onerous for a small association such as ours, but failure to comply has resulted in significant fines. A good relationship has been developed with the Association's auditor and this has been helpful in ensuring compliance with these regulations.

The Treasurer's role in meeting the statutes set by the Australian Securities and Investment Commission (ASIC) is detailed in the recently completed 'Treasurer's Duties' document that is to be tabled at the 2003 AGM.

DIRECTORS LIABILITY

Initial enquiries regarding insurance cover for each of the ANZPNA Directors (for costs and expenses incurred by them in defending any legal proceedings arising out of their conduct while acting in their capacity as a Director) have been made. Final quotes are awaited but are expected to be of the order of $500-$1000 per annum.

IPNA 2004

The last remaining separate Commonwealth Bank account that was opened to deal with the running of IPNA 2004 has been closed, with the balances transferred to the National Bank Account held in the name of Hartley Management Group. This account is operated jointly by Hartley and ANZPNA members on the organising committee for IPNA. Under the terms of the IPNA Memorandum of Understanding, this account is to be administered separately from bank accounts associated with ANZPNA's activities. Thus, ANZPNA at present has no direct financial connection to IPNA, and this is the currently desired fiscal position. The situation post-IPNA is unknown and will need to be addressed at that time.

Steven McTaggart
Honorary Treasurer
August 2003

ATTACHMENT 3

ANZPNA

Annual General Meeting 2003
Honorary Secretary Report

Much of the secretarial time this year has been spent ensuring the smooth running of the ANZPNA executive with fewer pressing issues during the last 12 months.

There has been representation of ANZPNA on many fronts. These will be discussed within the text of the agenda.

The key duties of the secretary are listed on attachment 3. Many of these duties are time consuming and are often delegated to Dept staff. It has been estimated by Ms Vicki Burns, Admin Assistant, RCH Nephrology Dept that ANZPNA related duties consume approximately 8 - 10 working hours per month. This has included maintaining, filing and retrieval of paper documentation, handling queries from the executive (Vicki has been a fantastic resource person during this time) and being the direct contact point for ANZPNA executive and members.

This has been surprisingly challenging with Vicki and I working in different institutions. As much as is possible has been handled via email but often paper documents have been located at one site when needed at the other. This would be more of a challenge if geographic separation was greater.

If ANZPNA is to expand its activities further then there will become a need for more centralized storage of documentation. Currently most are transferred to the new secretary with movement of documents interstate. ANZPNA needs to determine if this is appropriate to also involve transferring documents to New Zealand (ASIC requires the Registered Office to be located in Australia).

ANZPNA will need to determine which documents should be held at the registered office, in addition to those required by ASIC. Should the registered office hold copies of multicentre trials protocols and patient education resources for example?

The development of ANZPNA website will begin to bring together many of the activities of the organization to one location. It will also create other opportunities for the membership. Clearly the secretary will play a key role in liaising with the nominated Webmaster to ensure accuracy of the information held on this site. An ANZPNA email address may also need to be considered.

Finally I would like to thank the other members of the Executive for their cooperation and enthusiasm during this term of office. I would particularly like to acknowledge Ms Vicki Burns' for her efforts and support of ANZPNA and its' Executive. I would like to offer my good wishes to the incoming Executive as it meets the challenges of IPNA, completion of Website and further expansion of ANZPNA.

Amanda M Walker, 28th August, 2003

ATTACHMENT 4

ANZPNA ADDRESS & CONTACT DETAILS
Updated JULY 2003

Member	Phone	Fax	E-mail
Dr Stephen Alexander Department of Nephrology Children's Hospital at Westmead Locked Bag 1 Westmead NSW 2145	02 9845 3430	02 9845 3432	stephena@chw.edu.au
Dr John Burke Alexandra House 201 Wickham Terrace Brisbane QLD 4000	07 3832 5421	07 3831 8250	jburke@gil.com.au
Dr Jonathon Craig Children's Hospital at Westmead Locked Bag 4001 Westmead NSW 2145	02 9845 3431	02 9845 3432	jonc@health.usyd.edu.au
Dr Charles Crompton Department of Nephrology Princess Margaret Hospital for Children PO Box D184 Perth WA 6840	08 9340 8354 08 9340 8222 0418 917 733 08 9366.1927 private practice	08 9340 3801 08 9366 1947 private practice	Nicola.Prosser@health.wa.gov.au charliec@cyllene.uwa.edu.au
Dr Michael Falk Canberra Hospital PO Box 11 Woden ACT 2606	02 6244 2046 0419 641 449	02 6244 3281	Michael.falk@act.gov.au
Dr Paul Henning Department of Nephrology Adelaide Women's & Children's Hospital King William Road North Adelaide SA 5006	08 8161 7000 08 8161 7303 0401 125 657	08 8161 6048	henningp@wch.sa.gov.au
Dr Ian Hewitt Princess Margaret Hospital for Children GPO Box D184 Perth WA 6840	08 9340 8354 08 9340 8222 0418 928 983	03 9340 3801	Ian.Hewitt@health.wa.gov.au
Dr Elisabeth Hodson Children's Hospital at Westmead Locked Bag 1 Westmead NSW 2145	02 9845 3431	02 9845 3432	Elisah@chw.edu.au
Dr Lilian Johnstone Renal Unit Monash Medical Centre Clayton 3168	03 9594 6395 Pager – 9387 1000	03 9594 4262	johnstonel@optusnet.com.au l.johnstone@southernhealth.org.au
Dr Colin Jones Nephrology Royal Children's Hospital Flemington Road Parkville 3058	03 9345 5054 0418 385 951	03 9345 5611	colin.jones@rch.org.au
Dr Ken (Fred) Jureidini Department of Nephrology Adelaide Women's & Children's Hospital King William Road North Adelaide SA 5006	08 8161 7000 08 8161 7303	08 8161 6048	jureidinik@wch.sa.gov.au
Dr T. Kara Renal Services Starship Children's Hospital Park Road AUCKLAND NZ	0064 9 5758 135	0064 9 307 4913	tonyak@aohb.govt.nz
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Who We Are
What We Do
Where We Are
Newsletters
Brochures and Fact Sheets
Kidney Links
Fundraising Links
Grants and Scholarships
The CARI Guidelines
The Kidney Quicklinks
The Australian Kidney
National Renal Resources
Kidney Awareness Week

Contact Us
Mailing List

Coins for Kidney Cure

Donate Now

National Renal Resource Centre

RRC

Centre for Chronic Kidney Disease

What Is It

The Centre provides renal patients with information and educational material to assist them in coping better with the effects of renal disease on their lifestyle.
The Renal Resource Centre is a community health service of Northern Sydney Health.

Who Can Use It?

The Centre and its resources are available for use by ALL renal units and staff, patient associations and individual patients inside and outside Australia.

What It Does

Resource Library

Videotapes, audiocassettes, books, booklets, community and government resource material relevant to renal patients and professionals.

Telephone counselling and referral

Information and counselling are available on renal disease and its treatment and community and professional resources.

AUSTRALIAN KIDNEY FOUNDATION

Australian Kidney Foundation Fact Sheets and Brochures

Understanding and preventing renal bone disease

- Alport's syndrome
- An introduction to peritoneal dialysis
- Blood in the urine
  Arabic Italian Greek Chinese Vietnamese
- Blood Pressure and Kidney Disease
- Calcium and Phosphate Management
- Dehydration
- Diabetes and your kidneys
- Diabetes and Kidney Disease
- Diagnostic Testing
- Facts about sexuality for renal patients and their partners
- Finding kidney problems before your baby is born
- Kidney Stones
- Glomerulonephritis
- IgA Nephropathy (AKF)
- IgA Nephropathy (RRC)
- Kidney Cancer
- Kidney and Urinary Tract Health for Women and Men
- Kidney Health
- Kidney Transplants

ATTACHMENT 5

SYMPOSIA - Tuesday (not included in conjoint arrangements)

7	Chronic allograft nephropathy	Lorraine Racusen, Annette Meik, Patrick Mauriat
8	Nutrition in acute and chronic renal failure	Robert Mak, Tidaver Tulsaay, Alberto Edelford
9	Genetics and Renal Disease	Lisa Guay-Woodford, Norm Rosenblum, Friedhelm Hildebrandt
10	Advances in management of ARF	Tim Bunchman, Barry Williams Patrick Brophy, Mgon McCulloch

SYMPOSIA – Wednesday

11	Management of post-renal transplant infections	Richard Fine, Marie Degreabiac Michael Green, Lorraine Racusen, Helen Pilmore
12	Bone and Mineral Metabolism	Isidro Salusky
13	Nephrotic Syndrome	Phillippe Cochat
14	Mechanisms and management of renal disease progression	Allison Eddy
15	Vasculitis	Mike Dillon
16	Adolescent issues in chronic renal disease	Sharon Adrenoli

SYMPOSIA - Thursday

17	D+ Hemolytic uremic syndrome	Phil Tarr, Marta Rivas
18	Recent advances in pediatric dialysis	Dennis Geary, Franz Schaefer, Brad Warady, Stuart Goldstein, Lesley Rees
19	Regulation and dysfunction of renal tubular function	Matthias Brandis
20	Management of ESRF in the infant	M.G. Coulthard, Sandra Watkins, Felicia Eke

CME Program

Monday (not included in conjoint arrangements)

1	KEYPAD SESSION :Haematuria &Proteinuria	
2	EVIDENCE BASED MEDICINE	
3	Neglect, Abuse & Munchausen By Proxy In Renal Practice	S Roy Meadows
4	Obstructive Nephropathy	Robert Chevalier

Tuesday (not included in conjoint arrangements)

5	KEYPAD SESSION: Nephrocalcinosis And Mx Inborn Errors Of Metabolism With High Serum Ammonia Concentrations	
6	EVIDENCE BASED MEDICINE	
7	Renal Cystic Disease	Ellis Avner
8	IFKF Cybernephrology	

CME Program

Thursday

9	KEYPAD SESSION : Investigation of hypertension Treatment of severe hypertension	
10	EVIDENCE BASED MEDICINE	
11	Cystinuria: Clinico-Genetic Correlations	Paul Goodyer
12	Oxalosis: Lessons From The Genetic Frontier	Aaron Freidman

IPNA Congress 2004

IPNA ANZSN CONJOINT MEETING ARRANGEMENTS

Wednesday designated conjoint day

Thursday- no cost to either IPNA or ANZSN members attending other meeting.

IPNA deal for Sunday Monday and Tuesday

$200 International Workshop on Hypertension
(Childhood Essential Hypertension: Origins of Adult Disease)
Monday and Tuesday IPNA program
Opening address ? High Court Justice Michael Kirby

Concert South Australia's Symphony Orchestra

IPNA Congress 2004, Adelaide South Australia

28th August to 2nd September 2004

ATTACHMENT 7

	A	C	D	E	F	G	H
1	**FIXED COSTS**	**Forecast**	**Budget**	**All figures in AU$**			
2							
3	**Administrative Costs**						
4	Postage, freight & couriers	15,000	15,000				
5	Telephone & Facsimile	4,000	4,000				
6	Email and web hosting	4,000	4,000				
7	Organising Committee	10,000	10,000				
8	Professional Conference Organiser - Management Fee	45,250	45,250				
9	Legal expenses	7,500	7,500				
10	Bank/Govt/Credit Card Charges	9,000	9,000	Based on govt taxes + 85% of income on credit card @ 2.5%			
11	Insurance	10,000	5,000	Premium approx 1% of total registration income			
12	Audit Fee	2,000	2,000				
13	**Administrative Costs Sub-Total**	**106,750**	**101,750**				
14							
15	**Social Functions**						
16	Welcome Reception - venue hire, entertainment, staging	4,000	4,000	ACC			
17	Concert - venue hire, entertainment, staging	2,000	2,000	Festival Theatre			
18	Congress Dinner - venue hire, entertainment, staging	10,000	10,000	ACC			
19	Farewell BBQ - venue hire, entertainment, staging	2,000	2,000	Venue TBC			
20	**Social Functions Sub-Total**	**18,000**	**18,000**				
21							
22	**Speakers and Guests**						
23	Invited Speaker registration costs - 40 @ variable cost	19,800	19,800				
24	Invited Speaker travel & accom - 40 @ $4000	120,000	160,000	Changed 27 Aug 03 ref KJ			
25	Committee hospitality	5,000	5,000				
26	Bursaries - 80 @ 50% Reg Fee	0	36,000	Removed Feb 03 - being covered by IPNA funding			
27	Council/Speakers Dinner	0	3,500	Increased Jul 03 - 70 @ $120; covered by IPNA (removed 27 Aug)			
28	Prizes/Gifts	2,000	2,000				
29	**Speakers and Guests Sub-Total**	**146,800**	**226,300**				
30							
31	**Facilities**						
32	Venue Hire for conference	62,595	62,595	See 'Venue Hire' sheet			
33	Poster Boards	3,000	3,000	Based on 160 poster sites			
34	Audio-visual hire	75,000	75,000	Includes allowance for responder units			
35	Ground Transport	10,000	10,000	Allows for 1 off-site function			
36	Trade expenses	51,020	51,020	See 'Trade' sheet			
37	Sponsorship expenses	99,300	99,300	See 'Sponsorship' sheet			
38	Signage	10,000	10,000				
39	**Facilities Sub-Total**	**310,915**	**310,915**				
40							
41	**Marketing/Advertising**						
42	Delegate boosting	25,000	25,000				
43	Journals, newsletters etc	10,000	10,000				
44	Web site establishment and updates	20,000	20,000				
45	**Advertising Sub-Total**	**55,000**	**55,000**				
46							
47	**Printing & copying**						
48	Logo and stationery design	555	750				
49	Stationery	2,000	2,000				
50	Calendars	1,484	1,484				
51	Initial Flyer	3,000	3,000	2 flyers			
52	Call for Papers	5,000	5,000				
53	Registration Brochure	10,000	10,000				
54	Final program	4,000	4,000				
55	Pocket program	1,000	1,000				
56	Book of Abstracts	20,000	20,000	Who pays? IPNA or Congress??			
57	Delegate List	2,000	2,000				
58	Tickets to functions	1,000	1,000				
59	General Copying	3,000	3,000				
60	**Printing & Copying Sub-Total**	**53,039**	**53,234**				
61							
62	**TOTAL FIXED COSTS**	**690,504**	**765,199**				
63							

IPNA Budget in AU$ as at 29/08/2003

	A	C	D	E	F	G	H
64	**VARIABLE COSTS**			**NUMBER OF DELEGATES**			
65				**500**	**750**	**1000**	
66	**Administrative Costs**						
67	Professional Conference Organiser - Per Head Fee	24,500	49	24,500	36,750	49,000	
68	Accommodation deposits						
69	**Administrative Costs Sub-Total**	**24,500**	**49**	**24,500**	**36,750**	**49,000**	
70							
71	**Catering**						
72	4 morning & 4 afternoon teas	24,000	48	24,000	36,000	48,000	
73	4 lunches	60,000	120	60,000	90,000	120,000	
74	Happy Hour	7,500	15	7,500	11,250	15,000	
75	**Catering Sub-Total**	**91,500**	**168**	**91,500**	**137,250**	**183,000**	
76							
77	**Social Functions**						
78	Welcome Function	25,000	50	25,000	37,500	50,000	
79	Concert	25,000	50	25,000	37,500	50,000	
80	Congress Dinner	50,000	100	50,000	75,000	100,000	
81	Farewell BBQ	25,000	50	25,000	37,500	50,000	Removed from Reg fee Jul 03
82	**Social Functions Sub-Total**	**125,000**	**250**	**125,000**	**187,500**	**250,000**	
83							
84	**Delegates' Handouts**						
85	Satchels	12,500	25	12,500	18,750	25,000	
86	Paper/pens	500	1	500	750	1,000	
87	Namebadges	1,000	2	1,000	1,500	2,000	
88	**Delegates Handouts Sub-Total**	**14,000**	**28**	**14,000**	**21,000**	**28,000**	
89							
90	**Contingency**	**10,000**		**10,000**	**10,000**	**10,000**	
91							
92	**TOTAL VARIABLE COSTS**	**265,000**	**495**	**265,000**	**392,500**	**520,000**	
93							
94	**TOTAL COSTS (FIXED + VARIABLE COSTS)**	**$955,504**		**$1,030,199**	**$1,157,699**	**$1,285,199**	
95							
96	**INCOME**			**NUMBER OF DELEGATES**			
97				**500**	**750**	**1000**	
98							
99	Earlybird IPNA Member Registration Fee (60% total registrants)		$850.00	255,000	382,500	510,000	Reg fees set to break-even at 500 delegates
100	Standard IPNA Member Registration Fee (20% total registrants)		$950.00	95,000	142,500	190,000	
101	Earlybird Non-Member Registration Fee (20% total registrants)		$950.00	95,000	142,500	190,000	
102	Standard Non-Member Registration Fee (0% total registrants)		$1,050.00				
103							
104	Total Registration Fees	445000		445000	667500	890000	
105	Sponsorship	423000		423000	423000	423000	See Sponsorship sheet
106	Trade exhibition	125000		125000	125000	125000	See Trade sheet
107	Travel agent commissions	5750		5750	5750	5750	Assumes 200 bookings for 5 nights @ $150 per night, 2% comm + 10
108	Accommodation deposits						
109	Additional Welcome Reception Tickets						
110	Additional Concert Tickets						
111	Additional Dinner Tickets						
112	BBQ Tickets	25000					Excluded from reg fee Jul 03
113	Bank Interest	2000		2000	2000	2000	
114	Other						
115							
116	**TOTAL INCOME**	**$1,025,750**		**$1,000,750**	**$1,223,250**	**$1,445,750**	
117							
118							
119	**EXCESS OF INCOME OVER EXPENDITURE**	**$70,246**		**($29,449)**	**$65,551**	**$160,551**	
120							
121							
122	PROFIT AS % OF EXPENDITURE			-3%	6%	12%	
123							
124							
125							

ANZPNA

(Australian & New Zealand Paediatric Nephrology Association)

Annual General Meeting – Minutes 2002

The Annual General Meeting of the ANZPNA was held on Sunday, 1st September, Sydney Convention Centre, Room - Promenade 3, Darling Harbour, Sydney at 10.00 am

Present:

R. Walker (Chair), A. Walker, S. McTaggart, P. Henning, P. Roy, S. Alexander, G. Kainer, J. Craig, D. McCredie, M. McIver, F. Juredini, E. Hodson, J. Burke

Apologies:

A Rosenberg, L Johnstone, F Willis, J. Knight, M. Morris, W. Wong, C. Crompton, I. Hewitt,

Minutes of previous meeting: **Appendix 1**

Minutes of 3rd Annual General Meeting held at Sydney Convention Centre, Sydney, 13th May 2001 were accepted as true and accurate.

Proposed P. Roy
Seconded: E. Hodson

Accepted unanimously

BUSINESS ARISING from minutes

Australian medical Workforce Advisory Council report and implications for Paediatric Nephrology.
There was considerable discussion about the need to ensure adequate numbers of trainees to address needs of paediatric nephrology in the future. There is a need for ANZPNA to act as an advocate for suitable training opportunities and positions on an Australia wide and state base.

Current workforce information requires updating and this should occur on a 5 yearly cycle

Action
Workforce data to be collected
Attention: A. Walker

Use of Mycophenolate Mofetil in childhood nephrotic syndrome
K. Juredini reported that there have been informal discussions with Stan Jordan, Roche regarding implementation of formal trial of efficacy of MMF in childhood nephrotic syndrome. There are currently no formal multicentre trials underway. It was suggested that if a suitable international multicentre trial could be identified then it may be appropriate for Paediatric Nephrology Units to participate

Action
Further discussions re international multicentre trial of use of MMF in Childhood nephrotic syndrome
Attention K. Juredini

Chairman's report **Appendix 2**
R. Walker spoke to his report, highlighting the increasing role of ANZPNA in representing paediatric nephrology across Australia & New Zealand.
Accepted unanimously

Proposed: S. McTaggart
Seconded: K. Jureidini

Treasurer's report **Appendix 3**
S. McTaggart spoke to his report.
Subscriptions – there has been difficulty in direct debit payment of subscriptions with poor identification of payees. This appears to be a system error with bank

Action
Ensure clear identification when payment is made by direct debit
Attention: S. McTaggart

Corporate accounting & accountability – Considerable discussion followed highlighting the difficulties poor accounting practices have created and the need to avoid this in the future. The corporate accounts have been audited and are ready for submission to ASIC. There will be a late fee associated with this lodgement; this will need to be drawn from subscriptions.

Action
Submission of accounts to ASIC with payment of late fine
Attention: S. McTaggart

Accounts year ended: 2002 are yet to be audited

Action
Completion of accounts with auditing & timely submission to ASIC
Attention: S. McTaggart

IPNA 2004
K. Juredini indicated that the two previous Commonwealth Bant accounts that were opened to deal with the running of IPNA 2004 have not been closed. Currently F. Juredini, M. Falk, P. Henning and C. Jones are signatories. It was agreed that the term deposit account should be closed and monies moved to IPNA2004/Hartely Management Group account

Action
Attention S. McTaggart & K. Juredini

It was highlighted that ANZPNA is responsible for money handled by Harley Management Group and as such, the interest on this money is income that will have taxation implications. There needs to be close communication between ANZPNA accountant and Hartley Management Group including clarification of tax liabilities and clarification of ANZPNA's registration as Non Profit organization

Action
Attention S. McTaggart & K. Juredini

Liability insurance for ANZPNA Councillors was discussed. It was agreed that this should be investigated further with the view of ensuring adequate insurance for the Executive of ANZPNA.

Action
Attention S. McTaggart

Terms of Appointment of Executive
Current term - 2 years without the capacity to extend.
It was agreed many of the current difficulties experience by the Executive could be overcome with the structure of definite duties and responsibilities.
The appointment of an "Assistant Treasurer" was raised as a mechanism for ensuring adequate "corporate financial memory".

Benefits of the Chair and Secretary in the same city were highlighted.
The need for good geographic representation was also discussed.

It was resolved that:
The Executive to re-examine the terms of appointment of Officeholders
Proposed D. McCredie
Seconded P. Roy
Passed unanimously

Action
Attention: ANZPNA Executive

Treasurer's report was accepted
Proposed E. Hodson
Seconded C. Jones
Passed unanimously

Secretary's Report Appendix 4
A. Walker spoke to this report.
The need for definition of roles and responsibilities was highlighted.

Action

Draft Outline of role of executive positions
Attention: A. walker

The Secretary's report was accepted
Proposed E. Hodson
Seconded P. Roy

Membership of ANZPNA
Membership description – Full, Associate

Associate Membership
It was proposed that

"Associate member of ANZPNA is a trainee in Paediatric Nephrology who will receive notices and circulars but will be ineligible to vote and will not be levied fees"

Proposed E. Hodson, Seconded J. Burke
Voted - Passed by majority,
Voted against - 1

Full membership
G. Kainer raised the role of ANZPNA as a credentialing body for paediatric nephrology. After considerable discussion, it was agreed that credentialing is the role of RACP rather than ANZPNA.
It was highlighted by C. Jones that the ANZPNA is a political body representing the interests of children with renal disease, and the practitioners caring for these children.

The Articles of Association were reviewed and discussed. There were several interpretations of "substantial involvement in Paediatric Nephrology" (Articles of Association clause 4). It was felt this represented an inclusive rather than exclusive statement. S. Alexander suggested members who move into another, but related field, retaining primary qualifications, should retain membership. This might apply to research or corporate sector.

Practitioners in other disciplines such as Radiology and Urology could apply for full membership to ANZPNA. They would be proposed and seconded and their application would be reviewed by the Executive and discussed at the AGM.

Honorary Membership
J. Burke suggested that eminent Paediatric Nephrologists may be proposed as honorary members. D. McCredie suggested they should have made a significant contribution to Australian paediatric nephrology. Their application should be reviewed at the Annual General Meeting.

Action
Complete process for amendment of Articles of Association to incorporate changes
Application forms for categories of Associated Member and Honorary Member
Copy of Articles of Association to all members
Attention: A. Walker

Nominations for membership

Name	Hospital	Full/Associated	Nominated by
Dr. R Kitching	Monash Medical Centre	Full	Dr Lilian Johnstone
Dr T. Kara	Starship – New Zealand	Associate	Dr Amanda Walker Dr Max Morris
Dr J. Kausman	Royal Children's Hospital	Associate	Dr William Wong Dr Colin Jones Dr Harley Powell

The above applicants were successful in obtaining membership in category listed.

Action
Notification and amend membership list
Attention: A Walker

Corporate associations & membership
Refer above discussions
Membership directory – privacy implications
Most data collected

Action
Distribute membership list
Attention: A Walker

Training in Paediatric Nephrology
SAC Nephrology
As I. Hewitt was an apology, A Walker spoke to this.
The minor changes to components of training were highlighted as outlined in **Appendix 5**
Discussion arose in relation to the need to gain experience in placement of acute vascular and peritoneal access. It was felt that paediatric nephrologists no longer commonly perform this.
E. Hodson suggested change of wording to "encourage experience in acute vascular and peritoneal access".
Other changes outlined were felt appropriate.

Action
Further discussion with SAC Nephrology
Attention A Walker & I Hewitt

Current trainees
A Walker suggested it would be desirable for ANZPNA to be aware of names of current trainees in Paediatric Nephrology as training and other opportunities may be available from time to time.

Action
ANZPNA maintain an up to date list of trainees
Attention: A. walker & I. Hewitt

Guidelines for publications –document
Guidelines for publication on behalf of Australia and New Zealand Paediatric Nephrology Association (ANZPNA) drafted by G. Kainer, C Jones and J Burke was discussed.

Number 8, last paragraph should now read "The final draft should be sent to the chairperson prior to submission"
Number 9 lines 2 "be circulated to the Executive".
Add 10. This Guideline to be reviewed in 3 years.

It was resolved that with the changes and agreement for review of the guidelines in 3 years, that the Guidelines for publication on behalf of Australia and New Zealand Paediatric Nephrology Association (ANZPNA) be accepted.

Proposed S. McTaggart
Seconded S. Alexander

Passed unanimously.

ANZDATA perspective - Rowan Walker
R. Walker reported on discussions relating to ensuring adequate acknowledgement of individuals and institutions that contribute to ANZDATA publications. ANZDATA will be drafting publication guidelines in the near future. Similarly publications generated from work by ANZPNA need to ensure adequate acknowledgement of all contributors

Growth hormone
It was agreed that this paper requires completion and submission.

Action
Attention: C Jones & C Crompton

Growth hormone subcommittee report by C Crompton, C Jones
No longer required – disbanded - E Hodson

Benchmarking: L Johnstone
A Walker reported for L Johnstone that data collection was completed on 30th September 2001. Clarification of data in consultation with contributing units was undertaken earlier this year and data entry is complete. Analysis in underway with plans of publication to be completed towards the end of 2002.

Report of APSU Study of Nephrotic syndrome: E. Hodson Appendix 6
E. Hodson reported that the data had been collated and there were few differenced between the states with regard to management or outcome, however there was a notable difference in the incidence in nephrotic syndrome across the states. This was thought to be a reflection of ascertainment difficulties rather than a true difference in incidence.
Other possibilities may be differences in the racial make up across the states. A full report was presented at ANZSN.

ANZDATA Paediatric subcommittee report: J Craig Appendix 7
J Craig summarized the key points as outlined in appendix 7. There was then general discussion regarding publication of the data and journal of choice.
He also reported that following Teleconference in March, 2002 with paediatric subcommittee, information regarding Cholesterol, LDL and Triglyceride would be collected annually, Statin use would be collected 6 monthly as should height, weight and functional status. Bone age would be deleted, as the quality of data was poor.

If members feel other data should be collected this should be directed to the working party for consideration.

Collaborative studies
Juvenile diabetes & ACEI :G. Kainer **- Appendix 7(a)**
G. Kainer outlined a general proposal for long term prospective study over 20 years assessing the role of ACEI in prevention of nephropathy in patients with juvenile diabetes. This would require substantial funding and collaboration between paediatric and adult endocrinologists and paediatric nephrologists. There may be two patients groups – newly diagnosed type 1 & II diabetics and patients with known diabetes without proteinuria. Recruitment would be from diabetic clinics across Australia & New Zealand. End points might be time to micro Alb, time to CRF/ESRF. Gad was commended on his efforts and encouraged to develop his ideas further.

Action
Attention: G. Kainer

HMGCoA reductase study: F Mackie **- Appendix 8**
G. Kainer spoke about the tabled proposal. Comments to be forwarded to F. Mackie

Pharmaceutical multi-centre trials : R. Walker
R. Walker highlighted that there may be multicentre trials that as a group ANZPNA may be able to participate in, particularly phase 4 studies. Similarly studies undertaken by NAPRTCS may be suitable.

Action
Bill Harmon (NAPRTCS) to be approached
Attention: R. Walker

RACP Annual scientific meeting Hobart 2003
Tuesday 27th May, 2003, Breakfast session 7.45 – 9 am:
Meet the expert – Antenatal hydronephrosis Paul Roy

Symposium suggested were Nephrotic syndrome, including APSU data which may be of considerable interest to paediatric nephrologists but may be of more limited interest to general paediatricians.
Other suggestions were "Office Management of Haematuria & Proteinuria" and "Simple Electrolyte Problems"

Action
Confirm speakers for latter 2 topics
Attention: A. Walker

ANZPNA A. Walker
ANZPNA web site A. Walker
A. Walker discussed the advantages of an ANZPNA website which could serve to represent aims and objectives of ANZPNA well. It could help establish/maintain links for trainees, overseas graduates and

members. Issues related to establishment such as site (?RACP site) and sponsorship (.com rather than .com.au) will need to be explored further.

It was proposed that G. Kainer and A. Walker work on development of web site and report at AGM 2003.
Proposed C Jones, Seconded K Juredinin
Passed unanimously

Action
Prepare website
Attention: G. Kainer and A. Walker

CARI guidelines
Report of CARI steering committee. R Walker
R. Walker reported that new CARI guidelines are being developed. Areas are

i. measurement of proteinuria
ii CMV prophylaxis in renal transplantation
iii treatment of peritonitis in peritoneal dialysis

Cochrane collaboration
J Craig spoke to this report. He highlighted that the Cochrane collaboration would be keen to assist advanced trainees in developing suitable projects.
J Craig was congratulated for his role in the Cochrane collaboration
Cochrane collaboration has agreed to assist with data searching and a full time officer may be appointed to further facilitate the projects. Cochrane collaboration J. Craig

ANZSN
S McTaggart noted that ANZSN may not at all times have a paediatric representative on council to represent the needs of children with renal disease. There was general discussion as to whether there should be a coopted member or corresponding member in that situation.

It was proposed that ANZPNA executive write to ANZSN council to ascertain when there is no Paediatric Nephrologist on Council whether Council would consider a coopted or corresponding member.
Proposed . Roy, Seconded R Walker
Passed unanimously

Action
Write to ANZSN for comment
Attention: A. Walker

IPNA Report from Executive - C. Jones
IPNA resolutions were discussed and agreed these should be promulgated strongly within the medical and general community.
It was resolved that "IPNA resolutions be endorsed and the Executive distribute these to Executive ANZSN, RACP and Australian Urology Association"

Proposed J Burke, Seconded S. McTaggart
Passed unanimously

Mechanisms to develop ANZPNA further were discussed. It was suggested by K Juredini that ANZPNA resolutions, constitution and guidelines for publication be widely distributed and placed on the website, once developed. He proposed that ANZPNA continue to explore mechanisms for promulgating our commitment to children with renal disease"

Proposed R Walker, seconded S McTaggart
Passed unanimously

P Henning also suggested that ANZPNA explore means of expressing advocacy for childhood renal health

IPNA 2004 (Sunday 29th August – Thursday 2nd September)
An overview of the organisation was provided by K Juredini. Hartley Management have coordinated travel agents and recommended tours and accommodation, including promotion of major tourist destinations.

There will be shops on the conference site marketing jewellery, Australiana, clothing etc with some 10% of turnover being passed to conference.

It has been agreed that registrations should be below $500 US with breakeven point being 500 registrants ($430US registration) and $250,000 sponsorship.
Costs will include invited speakers (?22)
IPNA members – no travel expenses covered
Non IPNA members registration, travel and accommodation
ANZSN travel costs , accommodation and honorarium

The Developmental Nephrology Workshop is planned for Barossa Valley prior to IPNA meeting.
ANZSN will run parallel sessions Wed 1st, Thursday 2nd and Friday 3rd September.
Paediatric Urology workshop will be run Sunday 29th - Monday 30th August 2004
(coordinated by Hok Tan). Approx 150 people, held at Women's and Children's Hospital, Adelaide
Paediatric Hypertension workshop Sunday 29th August
International Kidney Foundation have also planned to run a day meeting during this time
RSA conjoint meeting is no longer likely.

Scientific program
Developmental Nephrology Workshop - L Guay-Woodford
Hypertension workshop - E Brewer
Paediatric Urology - H. Tan

ANZSN conjoint sessions might include
Renal development – genetics (keynote/plenary)
Aquaporins
Ca, Mg, Phosphate handling
Acquired electrolyte abnormalities
Genetics FSGS/Podocyte abnormal
Steroid withdrawal post transplant – debate

Possible program may include

Monday - Urology/continence
Tuesday- Gen Paed Nephrol
Wed conjoint with ANZSN
Thursday - Paed Nephrol

IPNA program
Anticipate 22 invited speakers,
Publicity
In conjunction with Hartley Management this will be undertaken by J Burke, A Rosenberg & A Walker to complete booklets.

Action
Attention: A Rosenberg, A Walker

Overview

Organisation	Ken Jureidini
Scientific Program	Colin Jones

Theme group reports

Developmental	E Hodson, L. Johnstone
Dialysis and Transplantation	F Mackie, R Walker
Acute renal failure	S McTaggart, H Powell, C Crompton
Clinical Nephrology	G Kainer, M Walker
Urology & renal radiology	P Roy, W Wong

Content Groups

EBM	J Craig
Ethics & Law	P Henning
Poor Children & Children of 3rd world	M McIver, M Morris, D McCredie
Paediatric Nephrology for General Paediatrician	P Tomlinson, F Willis
Basic Science	C Jones, K Jureidini, A Rosenberg

ANZPNA – IPNA agreement Appendix 9

IPNA – Other business: Sponsorship of journal for developing world paediatric nephrologists

OTHER BUSINESS

Nicardipine for severe hypertension
K Jureidini raised the need to have this medication available for treatment of severe hypertension in childhood.

Action
Approach Roche regarding access within Australia
Attention: K Jureidini

Meetings
Dialysis & Transplant meeting 5 – 7th March 2003, Barossa Valley
TSANZ 9 – 11th April Canberra
ANZSN – check details

Next AGM ANZPNA
? Saturday 8th March, 2003 Barossa Valley

Minutes of the 3rd Annual General Meeting
Sunday May 13, 2001
Sydney Convention and Exhibition Centre, Sydney
Commencing at 11 am

1. Present: Paul Roy (Chairman), John Knight, Elisabeth Hodson, Colin Jones, Harley Powell, Gad Kainer, Andrew Rosenberg, John Burke, Lilian Johnstone, Fiona Mackie, William Wong, Stephen McTaggart, David McCredie, Margot McIver, Paul Tomlinson, Ken Jureidini and Michael Falk.

2. Apologies: Jonathan Craig, Deborah Lewis, Stephen Alexander, Max Morris, Mandy Walker, David Lines, Paul Henning, Frank Willis, Charlie Crompton, Ian Hewitt, Rowan Walker.

3. Presentation by Graham Teague, Managing Director, Hartley Management Group Pty Ltd.
Hartley Management Group have been appointed as the conference organisers for the IPNA 2004 congress in Adelaide. Amanda Pearson will be the conference manager and will be responsible for the day to day organisation. To date a committee structure has been established, a draft budget developed and a time line created. Stationery, a flyer and a calendar have been produced. The flyer is available to any member of ANZPNA, who is attending a conference at which the flyers could be distributed. A sponsorship proposal has been developed and copies were circulated at the meeting. The website is operational. It will be used for on-line registration and abstract submission. It could be used to allow reviewing of abstracts on-line. Graham reported that it was essential to get a handle soon on the marketing plan. This needs to be directed to the areas most likely to have access to large numbers of potential delegates such as the IPNA Seattle meeting to prevent budget blow out. There soon needs to be a contract between Hartley Management and the congress organisers. This was discussed further later in the meeting. John Knight asked Graham how Hartley Management's work over the next 4 years would be financed. Graham said that there will be a clause to allow delayed payment from the organisers to Hartley Management included in the contract. Currently the organisers had received a loan of $15,000 from the Adelaide Convention and Tourist Authority and about $12,000 from IPNA. In addition AKF will provide $8000 at the rate of $2000 per annum.

4. Confirmation of the Minutes of the 2nd Annual General Meeting held at the Hotel Sofitel. Melbourne on March 17, 2000.

   Proposed: Andrew Rosenberg
   Seconded: Colin Jones
   Accepted unanimously

5. Report of the Chairman: Paul Roy spoke to his report (Appendix 1). Paul reported that a workforce survey had been conducted and the analysis was tabled. The results suggested that the workforce was relatively young, that women were under represented and that a significant proportion of children with renal disease in Australia and New Zealand were cared for by nephrologists, whose primary training was in adult medicine.
   Acceptance of the Chairman's Report was proposed by Lilian Johnstone, seconded by John Burke and accepted unanimously.

6. Report of the Honorary Treasurer: Michael Falk presented the report (Appendix 2). He reported that the ANZPNA had minimal reserves though enough for day to day issues. The auditor's report was not available. It was agreed that the report could be accepted provisionally on the understanding that the auditors' report would be received shortly. Provisional acceptance of the Treasurer's Report was proposed by David McCredie, seconded by Andrew Rosenberg and accepted unanimously.

7. Report of the Honorary Secretary: Elisabeth Hodson spoke to her report (Appendix 3). Acceptance of the Secretary's report was proposed by Andrew Rosenberg, seconded by Gad Kainer and accepted unanimously.

8. Election of new members: No applications had been received for membership. Lilian Johnstone asked that Dr Richard Kitching, who is both an adult and paediatric nephrologist and is working with the Monash paediatric renal service, should be considered for membership. It was agreed that a formal application should be made at the next AGM in 2002.

9. Presentation by Professor John Horvath, Chairman of Australian Medical Workforce Advisory Council. Professor Horvath was invited to the meeting by Paul Roy to tell the meeting about the AMWAC process for assessing workforce needs. The process in any specialty involves describing the existing workforce, assessing it, making projections about future workforce based on availability of specialists (trainees, expected retirements, participation), making recommendations, monitoring the effects and finally reviewing the results. He said that paediatric nephrology is one of a number of small specialties, where there would always be difficulties in balancing the workforce with workload. AMWAC had agreed that there were too many training positions in paediatrics at present but to date no attempt had been made to reduce trainee positions. He suggested that individual hospitals and then state health departments be approached to transfer some of the surplus paediatric training positions to paediatric subspecialties.

   It was agreed that the information be obtained from each state on the age of current workforce, projections on retirement and trainees and that a model for training new paediatric nephrologists be developed. This model should include rural and outreach issues, training of overseas graduates and national training schemes. Currently we are aware of three trainees, who are interested in nephrology (one at Royal Children's Hospital and two at Sydney Children's Hospital). In addition there is one fully trained UK paediatric nephrologist resident in Australia. **ACTION: UNIT HEADS TO PROVIDE ABOVE INFORMATION TO ELISABETH HODSON**

10. Council of IPNA: John Burke is to complete his term as Assistant Secretary to IPNA after the IPNA congress in September in Seattle. Nominations were called for his successor and three nominations were received. A postal ballot was held and Colin Jones was elected as the next Assistant Secretary for a term of six years. Affirmation of the ballot process and the result was proposed by Andrew Rosenberg, seconded by Ken Jureidini and carried unanimously.

11. Report of the Growth Hormone Subcommittee: The report (Appendix 4) from Charlie Crompton was presented by Elisabeth Hodson. Charlie had also circulated to ANZPNA members a copy of the paper, which reported the data on rhGH use in children with renal failure in Australia. This paper had already been submitted to Pediatric Nephrology without including the Australian members of ANZPNA as co-authors. Andrew Rosenberg felt that the paper should be withdrawn. John Knight agreed since multicentre studies are very important and all contributors must be confident that their work would be

acknowledged. Andrew Rosenberg proposed the motion – "that, since the paper had not been reviewed by the contributors and the authorship had not been listed as previously agreed, the paper should be withdrawn until these matters had been attended to". The motion was seconded by John Knight and passed unanimously.

It was agreed that John Burke, Gad Kainer and Colin Jones should develop a policy for research under the auspices of ANZPNA. Areas to be covered would include how a research protocol would be dealt with, who would review the final version of the manuscript before submission and how authorship would be dealt with. ACTION: JOHN BURKE, GAD KAINER, COLIN JONES TO DEVELOP POLICY.

12. Benchmarking: Lilian Johnstone presented the results of the benchmarking project to date. The project involved data collection on arterio-venous access and central venous access for haemodialysis, peritoneal dialysis and renal biopsies (Appendix 5). Data collection commenced in September 1999 and will finish in September 2001. The data will then be collated and prepared for publication. It was agreed that the data would be presented as the mean and 95% confidence intervals for each parameter. The data collected so far would be circulated to the individual centres, who would be informed which part of the data belonged to their centre. Lillian asked that each centre check the data and also send any outstanding data forms to her by September.
ACTION: ALL UNIT HEADS TO ENSURE THAT DATA FORMS ARE FORWARDED TO LILIAN BEFORE SEPTEMBER 2001

13. Reports of clinical studies:
    Multicentre double-blind placebo controlled trial of chemoprophylaxis in children with isolated vesicoureteric reflux. (Appendix 6).
    Elisabeth Hodson presented the report from Jonathan Craig. Patient recruitment has been completed and final follow up will be completed in October 2001.
    Epidemiology of childhood nephrotic syndrome. (Appendix 7).
    Elisabeth Hodson presented the report. Patient ascertainment will be completed in June 2001. It was requested that all efforts be made to notify new cases and to remind paediatric colleagues to notify patients.
    Randomised controlled trial of cyclophosphamide in the treatment of focal and segmental glomerulosclerosis. (Appendix 8).
    Stephen McTaggart presented the report. No patients had been recruited so the trial was terminated.

14. ANZDATA registry: Rowan Walker has completed his term as Project Manager for Paediatrics on the ANZDATA registry. Jonathan Craig has taken over. It was agreed that Jonathan should convene a subcommittee to make suggestions on the paediatric data to be collected and that these should be circulated to members for comment.
ACTION: JONATHAN CRAIG TO CONVENE A SUBCOMMITEE OF ANZPNA AS ABOVE.

15. Relationship of Assistant Secretary to IPNA to the ANZPNA executive: It was agreed that the Assistant Secretary should be co-opted to the executive during their term. Proposed John Burke, seconded Ken Jureidini and carried unanimously.

16. New Executive for ANZPNA: Nominations for the new Executive to take over in September/October 2001 will be sent in August 2001.

17. Future meetings of ANZPNA: It was proposed by Elisabeth Hodson and seconded by Ken Jureidini that the Annual General Meeting of ANZPNA should be held in conjunction with the Annual Scientific Meeting of ANZSN and in general should follow the ANZSN meeting. The motion was passed unanimously. It was also decided that ANZSN should be approached to include a symposium on a paediatric nephrology topic and organised by members of ANZPNA on the last day of the ANZSN meeting. In addition ANZPNA would offer to organise future symposiums at the RACP meeting. In 2002 the ANZSN meeting will take place in Sydney from August 26 to August 30. These dates include the Postgraduate Meeting and do not clash with the ESPN meeting, which starts on September 20.

18. CARI guidelines: John Knight reported that there would be some changes in the way these have been set out following the Dialysis and Transplant Workshop in April 2001. In particular only those interventions with appropriate levels of evidence will be called guidelines. The ANZDATA form should be used to audit the implementation of the guidelines. John reported that it was decided at the Workshop to endorse the concepts of living donor to cadaveric pool donation and of swaps of kidneys between families, where for example potential donors were blood group incompatible with their potential recipients but was blood group compatible with the potential recipient of the other family. It was suggested that the guidelines written by members of ANZPNA be circulated to ANZPNA members for comments. Elisabeth Hodson pointed out that the guidelines were available to all ANZPNA members through the CARI website, which can be accessed on www.CARI.kidney.org.au.

19. Other guidelines for children with renal failure: This item was withdrawn.

20. Trial of mycophenolate (MMF) in childhood nephrotic syndrome: Ken Jureidini presented a proposal to perform a randomised controlled trial of MMF in frequently relapsing steroid responsive nephrotic syndrome (Appendix 9). John Knight and Andrew Rosenberg raised doubts about whether MMF was a suitable medication to trial. It was agreed that Ken should contact Dr Stan Jordan, who is thought to be running a trial on MMF, to find out more about the trial. Ken will then discuss the trial further with Steve Alexander and Steve McTaggart before reporting back to the Executive. **ACTION: KEN JUREIDINI TO CONTACT STAN JORDAN**

21. Kidney Kids Camp: Lilian Johnstone reported that South Australia and Victoria would hold a Kidney Kids camp every 18 months in alternate states. This is supported by the AKF. Elisabeth Hodson reported that New South Wales would continue to hold a camp annually in April. This also supported by the AKF.

22. IPNA Congress 2004 (Appendix 10):

    Sponsorship: AKF and Gambro have contributed $23,000. Since the AGM, Ken Jureidini has learnt that Fresenius will be a Premium Sponsor ($50,000)

    Contract with Hartley Management Group: There was considerable discussion as to whether the contract with Hartley Management group should be between ANZPNA and Hartley Management Group or between IPNA and Hartley Management Group. If the former was to occur, ANZPNA would require a letter from IPNA stating that IPNA would underwrite the 2004 congress. Since the AGM, John Burke has talked with Mattias Brandis, Treasurer of IPNA, who felt that the contract should be between ANZPNA and Hartley Management Group. John Burke, Colin Jones and Ken Jureidini are to discuss this at the IPNA Council meeting in New York in June 2001. A draft contract is now available. It was suggested that a legal opinion be obtained on this contract.

    Bank account for IPNA Congress 2004: There was discussion on whether ANZPNA

should set up a bank account for IPNA Congress in 2004 because of the potential conflict of interest if Hartley Management Group set up this account. However ANZPNA would then need an ABN number and would have to complete GST paperwork. At the subsequent executive meeting following a letter from Hartley Management, it was decided that Hartley Management Group should set up the account with its Director (Graham Teague) as one signatory with two other signatories. The four people authorised to provide the two ANZPNA signatures will be Colin Jones, Ken Jureidini, John Knight and Michael Falk.

Distribution of profits from IPNA Congress 2004: In response to John Knight's argument that IPNA should state in their memorandum that ANZPNA should be entitled to keep 50% of any profits of the congress, Ken Jureidini stated that IPNA had stated that any profits should be returned to IPNA and that ANZPNA could then negotiate with IPNA for a portion of the profits.

Florence McCredie Lecture: David McCredie reported that this lecture, in honour of his mother, was usually given at the Royal Children's Hospital. In 2004, it would be organised as part of the IPNA Congress in 2004. He invited other members of ANZPNA to investigate whether their hospitals had similar lectureships, which could be used for the IPNA Congress in 2004.

Developmental Nephrology Workshop: This is scheduled to take place in the Barossa Valley before the IPNA Congress in 2004 and will be organised by Dr Robert Chevalier directly with Hartley Management Group.

Committee structure: Ken Jureidini will provide a list of the IPNA 2004 committees and the members for the ANZPNA Executive.

ACTION: KEN JUREIDINI TO PROVIDE A LIST OF COMMITTEES AND THE MEMBERSHIP TO ELISABETH HODSON.

Scientific Programme: Colin Jones reported on this. The timeline involves a review of the actions of the Seattle Scientific Programme Committee and of the IPNA 2001 Congress by March 2002, decision on scientific themes by June 2002, development of the themes by September 2002, first round of invitations to speakers by January 2003, second round of invitations by July 2003, call for abstracts in September 2003 and abstracts to be received in early 2004. The aim would be to introduce new themes and new speakers. Colin has co-opted a wider committee to review the Seattle meeting by asking members of ANZPNA and some paediatric nephrologists from Japan and other Asian countries to complete a questionnaire on individual sessions.

Marketing and publicity: All ANZPNA members should act as ambassadors for the 2004 meeting.

ACTION: ALL MEMBERS, WHO ARE ATTENDING MEETINGS, SHOULD TAKE BROCHURES ABOUT THE IPNA CONGRESS IN 2004 TO THESE MEETINGS. THE BROCHURES ARE AVAILABLE FROM KEN JUREIDINI.

The meeting closed at 5 pm.

CHAIRMAN'S REPORT

ANZPNA MEETING 1/9/2002 : DARLING HARBOUR, SYDNEY

This is my first report, albeit brief, but I particularly wanted to express the view that the ANZPNA can be justly proud of its evolution and current status. In the local Nephrology community, especially the ANZSN, the DNT Committee, the AKF and the ANZDATA Registry convince me that here is increasing recognition of the Association being the key resource for referring issues relating to renal disease in children. It is also a source of some pride that ANZPNA personnel have served in key roles on nearly all CARI Guideline Working Parties. I am of the belief that this enhanced role on ANZPNA has come about by a continued willingness of Association members to not only serve on key Nephrology Committees but to be outgoing and communicative and not isolationist. I also believe that Jonathon Craig's influence and excellent leadership in the Cochrane organisation should help place Paediatric Nephrologists at the forefront of education and promotion of the importance of evidenced based medicine.

Our attention not surprisingly for the immediate future will be on our international status and our relationship with IPNA and the IPNA Scientific Meting scheduled for Adelaide in 2004. The Executive of ANZPNA are not only indebted to 'Fred' Jureidini and Colin Jones and all the members of the local organising Committee but to all the ANZPNA members who have shown a willingness to support the local organising Committee and especially during this difficult phase of developing the Scientific Content. It is hard to imagine that the Meeting will be anything but a great success.

Apart from the IPNA Meeting, the New Executive has been grappling with a number of issues - most of which form Agenda items at this Meeting. Thus the list below is by no means exhaustive but represents perhaps the 3 most time consuming items over the past 6 months

- Privacy Legislation
- Finances including obtaining an Auditor's Report
- Membership

As the Chairman, I would like to express my thanks to the others on the Executive; Amanda Walker, Steve McTaggert and Paul Roy for their work ethic, attention to detail and excellent advice. I think we are moving forward with considerable confidence. I also thank the outgoing Executive members, Elisabeth Hodson, Colin Jones and Michael Falk for providing a smooth transition for the new regime and Colin Jones additionally for providing support through the Renal Unit at the RCH in Melbourne. Perhaps the most important person to thank is Vicki Burns, the long-suffering secretary of the RCH Renal unit who willingly provides not only much needed secretarial skills but also takes on may managerial responsibilities on behalf of the ANZPNA.

Financial Report

Australian and New Zealand Paediatric Nephrology Association
ACN 087 155 780

The following report continues on from the interim Treasurer's Report that was circulated to all members in February 2002 (Appendix 3A).

Subscriptions
The call for back-payment of the annual subscription fee was regrettable and it is hoped that a similar situation does not occur again in the future. To date, 19 of the 28 members have paid the outstanding balance. Those who have not paid will shortly receive a further reminder notice.

Corporate Accounting and Accountability
All members need to be aware that as an incorporated company, ANZPNA has significant corporate responsibilities for financial record keeping and reporting. These requirements have not been fully met in the past, resulting in the Association having to pay significant fines to the Australian Securities and Investment Commission. The appointment of an Auditor (see below) should prevent a recurrence of this situation.

Members may also have noted in the AZNSN 2002 Councillor's Report that ANZSN pays premiums to insure each of the ANZSN Councillors against liabilities for costs and expenses incurred by them in defending any legal proceedings arising out of their conduct while acting in the capacity of Councillor of the Society. No such cover exists for the Executive of ANZPNA, leaving them exposed to significant personal liability.

Auditor
As detailed in the Interim Report, Mr Colin Marr (auditor and accountant for ANZSN and TSANZ) was approached to handle the financial affairs of the society. Mr Marr declined our offer to also act as accountant for ANZPNA. Due to impending legal action by the Australian Securities and Investment Commission, Mr Denis Greathead was appointed as the Association's auditor. His report for the financial year ending 30 June 2001 is enclosed (Appendix 3B). A Directors Statement is to be submitted with the audited accounts (Appendix 3C).

Accounts for Y/E 2002
The accounts for the last financial year are incomplete due to delays in supply of necessary information. The Association's Balance Sheet and Profit and Loss Statement for the first 6 months of the last financial year (1/7/01 – 31/12/01) are included as Appendix 3D. The accounts for the full financial year are yet to be audited and therefore the financial details of the presnted report should only be considered as preliminary.

IPNA 2004
Two previous Commonwealth Bank accounts that were opened to deal with the running of IPNA 2004 have been closed, with the balances transferred to a new National Bank Account held in the name of Hartley Management Group. This account is operated jointly by Hartley and ANZPNA. The day-to-day expenses for conference management are met by Hartley, who are then reimbursed by ANZPNA from money in this account. This arrangement was instigated to simplify GST and Tax reporting for the Society. However, ANZPNA is still primarily responsible for these funds and therefore is likely to have a liability with regard to the interest earned on this money. There are outstanding issues regarding the taxation position of the Association (see Interim Report, Appendix T1) that still need to be clarified.

Steven McTaggart, Honorary Treasurer
August 2002

AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2001

CONTENTS

AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

INDEPENDENT AUDITOR'S REPORT

SCOPE

We have audited the financial report of **AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION** for the year ended 30th June 2001. The elected committee of the Association is responsible for the presentation of the financial report and the information contained therein, and have determined that the cash cash basis of accounting used is appropriate for the needs of the members. We have conducted an independent audit of the financial report in order to express an opinion to the members of the Association on its preparation and presentation. No opinion is expressed as to whether the basis of accounting used is appropriate to the needs of the members.

Our audit has been conducted in accordance with Australian Auditing Standards to provide reasonable assurance as to whether the financial report is free of material misstatement. Our procedures included examination on a test basis, of evidence supporting the amounts and other disclosures in the financial report and the evaluation of accounting policies and significant accounting estimates. These procedures have been undertaken to form an as to whether, in all material respects, the financial report is presented fairly in accordance with the cash basis of accounting so as to present a view which is consistent with my understanding of the financial position of the Association and the results of its operations. Statements of Accounting Concepts and Accounting Standards are not applicable to the cash basis of accounting adopted by the Association.

The audit opinion expressed in this report has been formed on the above basis.

QUALIFICATION

As is common for organisations of this type, it is not practicable for the Association to maintain an effective system of internal control over registrations subscriptions and other fund raising activities until their initial entry in the accounting records. Accordingly, our audit in relation to income was limited to amounts recorded.

QUALIFIED AUDIT OPINION

In our opinion, subject to the effects of such adjustments, if any, that might have been determined to be necessary had the limitation referred to in the qualification paragraph not existed, the financial report presents fairly the income and expenditure statement of the Association for the year ended 30th June 2001, and its cash and bank balances as at that date in accordance with the cash basis of accounting as described above and notes to the accounts.

JOHNSON & GREATHEAD
Accountants & Auditors

Greathead
.....
DENNIS G GREATHEAD
Dated: 27 / 8 / 2002

AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

INCOME AND EXPENDITURE STATEMENT
FOR THE YEAR ENDED 30TH JUNE 2001

		This Year
INCOME		
Interest Received		932.20
EXPENDITURE		
Bank Charges	137.87	
Filing Fees	200.00	
Office Expenses	110.60	
		448.47
NET SURPLUS FOR THE YEAR		483.73
Accumulated Surpluses Beginning of Year		33,985.80
ACCUMULATED SURPLUS AT 30 JUNE 2001		34,469.53

The accompanying notes form part of these financial statements.

AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

BALANCE SHEET
AS AT 30TH JUNE 2001

	This Year
ACCUMULATED SURPLUSES	
Accumulated Surpluses	34,469.53
Represented by:	
CURRENT ASSETS	
Commonwealth Bank - 5114 1015 5800	3,352.60
Commonwealth Bank Term Deposit - 5114 5007 4378	25,726.52
Commonwealth Bank - 2908 1034 0611	5,390.41
	34,469.53
NET ASSETS	$ 34,469.53

The accompanying notes form part of these financial statements.

AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION
NOTES TO AND FORMING PART OF THE ACCOUNTS
FOR THE YEAR ENDED 30TH JUNE 2001

STATEMENT OF ACCOUNTING POLICIES

These financial statements are special purpose financial accounts of **Australian & New Zealand Paediatric Nephrology Association,** a company limited by guarantee.The accounts have been prepared in accordance with the requirements of the Associations Incorporation Act (Queensland) specifically for use by the members of the Association. The accounts are based on historical cost and do not take into account the changing value of money. The cash basis of accounting has been applied

No regard has been paid to the application of Accounting Standards or other mandatory professional reporting requirements (Urgent Issues Group Consensus Views) issued by Australian professional accounting bodies except where specifically stated.

Income Tax

It is believed the association is exempt from income tax.

AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

STATEMENT BY OFFICE BEARERS

We hereby state that, in our opinion, the accompanying statement of Income and Expenditure is drawn up so as to give a true and fair view of the results of the activities of **Australian & New Zealand Paediatric Nephrology Association** for the year ended 30 June 2001 and the accompanying Balance Sheet presents a true and fair view of the state of affairs of the Association as at 30 June, 2001.

Signed ..... Secretary / /2002

Signed ..... Treasurer / /2002

Australian & New Zealand Paediatric Nephrology Association
ACN 087 155 780
AU Balance Sheet
As of December 31, 2001

	Dec 31, 01
ASSETS	
Current Assets	
Current/Savings	
ANZPNA	5,379.97
HMG IPNA 2004 Congress	65,955.04
IPNA XIII Congress - CBA	3,354.28
Total Current/Savings	74,689.29
Other Current Assets	
Term Deposit	25,726.52
Total Other Current Assets	25,726.52
Total Current Assets	100,415.81
TOTAL ASSETS	100,415.81
LIABILITIES	0.00
NET ASSETS	100,415.81
EQUITY	
Opening Bal Equity	32,215.80
Retained Earnings	1,527.21
Net Income	66,672.80
TOTAL EQUITY	100,415.81

Australian & New Zealand Paediatric Nephrology Association

ACN 087 155 780

29/08/02

Accrual Basis

Profit & Loss

July through December 2001

	Jul - Dec 01
Ordinary Income/Expense	
Expense	
Bank Service Charges	12.00
CHQ Book Stamp Duty	3.00
Congress Management Expenses	3,751.44
State Govt Duty - FID	16.26
State Govt Tax - GDT	1.80
Total Expense	3,784.50
Net Ordinary Income	-3,784.50
Other Income/Expense	
Other Income	
Interest Income	757.30
Other Income	69,700.00
Total Other Income	70,457.30
Net Other Income	70,457.30
Net Income	**66,672.80**

Interim Treasurer's Report

The following report has been drafted to clarify some issues regarding the financial status of the Australian and New Zealand Paediatric Nephrology Association (ACN 087 155 780). The full financial report will be presented at the AGM in September.

Company Obligations

As a registered company, ANZPNA has a number of legal obligations that it must meet, including having our 'books' audited and lodging an annual return each year. This has not occurred yet for the 2000-2001 financial year but it is hoped will be completed within the next month. In order to streamline this process for future years, the Executive has made the decision to appoint Mr Colin Marr as the ANZPNA accountant. Mr Marr is based in Sydney and currently handles the accounts of both the ANZSN and TSANZ and thus is experienced in dealing with organisations such as ANZPNA. The use of a central auditor should ensure continuity of financial accounting despite the regular changes in the Executive.

If any member objects to having Mr Marr appointed as the ANZPNA accountant, could you please notify me as soon as possible.

Australian Tax Office and GST

As a non-profit organization, ANZPNA does not have to lodge a tax return unless our earnings are above $416 per annum. Subscriptions are not considered as income and therefore the Association's only taxable income is derived from bank interest. To date, interest has not been above this threshold and as such, the Association does not have a Tax File Number and has not yet lodged a tax return. This is likely to change in the near future due to the effect of IPNA 2004 seeding money that is being held in ANZPNA accounts.

As a non-profit organization with a turnover of less than $100,000, ANZPNA is not required (and is not) registered for the GST. As such, we are **not** required to include the 10% GST on supplies and therefore subscriptions are GST-free. GST accounting for supplies made as part of IPNA 2004 are currently (and will continue to be) met by Hartley Management Group.

Subscriptions

According to ANZPNA records, subscriptions may not have been called for in 1999 and have not been called for in 2000, 2001 and 2002. Because of the uncertainty regarding subscriptions for 1999, the Executive have elected to forgo payment for 1999. An invoice for the other years (3 x $100 [no GST]) is being posted and should reach all members within the next 2 weeks. Please note the following payment options:

1. Direct deposit at any branch of the Commonwealth Bank (Account details are included on the invoice). Please send me an e-mail (steven_mctaggart@health.qld.gov.au) to let me know that you have made the payment. This is the preferred method of payment.
2. Posting a cheque to Dr S McTaggart, Queensland Child and Adolescent Renal Service, Royal Children's Hospital, Herston Rd, Herston, QLD 4029. Cheques should be made payable to ANZPNA and crossed *Not negotiable*.

In keeping with FRACP practice, the invoice forms your receipt ie. a further receipt for payment will **not** be issued.

The Executive wishes to sincerely apologise to all members for the oversight in subscriptions that has led to the need for back-payments. New accounting procedures that have been put in place should ensure that this does not occur again.

Steven McTaggart, Honorary Treasurer
February 2002

ANZPNA

AUSTRALIAN & NEW ZEALAND
PAEDIATRIC NEPHROLOGY ASSOCIATION

C/- PAEDIATRIC RENAL & CONTINENCE SERVICE
DEPARTMENT OF PAEDIATRICS
MONASH MEDICAL CENTRE
232-247 CLAYTON ROAD
CLAYTON. VIC 3168

PHONE: 61 3 9345 5054 • FAX: 61 3 9345 5611
E-MAIL. RENAL@CRYPTIC.RCH.UNIMELB.EDU.AU

DIRECTOR'S REPORT

The directors present their report on the society for the financial year ended 30th June 2001.

The figures in the financial statements are for the twelve month period ending 30th June 2001.

The Directors in office during this period were as follows;
Paul Roy MBBS FRACP - Chairman
Elisabeth Hodson MBBS FRACP - Honorary Secretary
Michael Falk MBBS FRACP - Honorary Treasurer
Colin Jones MBBS FRACP

The principal activity of the Association during the financial year was the promotion of the study of Paediatric Nephrology. No significant change in the nature of these activities occurred during the year.

The net surplus for the year was $483.47.

Since the end of the financial year, the Association has successfully bid for the right to hold an International Paediatric Nephrology Conference in Adelaide in 2004. This conference is underwritten by the International Paediatric Nephrology Association (IPNA), who are responsible for any profit or loss arising from this Conference. Therefore, while ANZPNA are acting as hosts, it is not expected that this will significantly change the state of affairs of the society in future financial years.

At this time, the Directors are not aware of any other developments likely to have a significant effect upon the Association's operations.

The Association's operations are not regulated by any significant environmental regulation under a law of the Commonwealth or of a State or Territory.

Signed in accordance with the resolution of the Directors.

Dr Paul Roy
Chairman ANZPNA 1/7/00 – 30/6/01

1 September 2002

Australian New Zealand Paediatric Nephrology Association
Secretary's Report
Annual General Meeting, 1st September, 2002

i. The registered office of ANZPNA has been transferred to
Paediatric Renal & Continence Service,
Monash Medical Centre,
246 Clayton Rd, Clayton, Vic., 3168.
Ph 03 9594 4497, fax 03 9594 6259

Vicki Burns, RCH Nephrology and Lia Bretag, MMC Paediatrics are providing secretarial support. This has created some difficulties that have generally been overcome by extensive use of e-mail. Preferred e-mail address for all ANZPNA is amanda.walker@southernhealth.org.au

All appropriate documentation relating to change of office and office bearers was lodged appropriately with ASIC, thanks to Elisabeth Hodson. There were some difficulties with lodgement of annual return and financial statements with ASIC, this will be outlined further by Treasurer.

A comprehensive outline of duties of Chair, Secretary & Treasurer may have been helpful when commencing this position. These shall be drafted prior to next AGM.

ii. Many of the activities have related to IPNA 2004, specifically the agreement between ANZPNA & IPNA and assistance in development of "themes".

iii. There have been several approaches regarding training opportunities in Paediatric Nephrology in Australia. I have forwarded these to the appropriate Units.

iv. There has been a small amount of consultation by other organisations relating to issues involving paediatric nephrology handled by Rowan Walker.

Amanda M. Walker.
31st August, 2002

Nephrology

Supervising Committee

Specialist Advisory Committee (SAC) in Nephrology.

Definition of Specialty

Nephrology encompasses the physiology of normal and abnormal renal function; the science, clinical expression, investigation and management of diseases of the kidney and urinary tract, including specialised management of hypertension; the pathophysiology of renal failure; the management of acute and chronic renal failure, and of end stage renal disease by dialysis and renal transplantation.

General Principles

1. Advanced Training in paediatric nephrology must provide broad experience in all aspects of nephrology in inpatient and ambulatory care settings.
2. This experience should involve trainees in the clinical management of children with a wide variety of renal diseases. You are expected to have an understanding of physiology, pathology, pharmacology and immunology in so far as each applies to the kidney.
3. The training should include experience in all forms of dialysis and renal transplantation.
4. It is important that you undertake a period of research during Advanced Training.
5. It is recommended that the period of training be spent in more than one hospital or medical centre.
6. Mandatory requirements must be fulfilled (page 24).

Components of Training

Core Training

A minimum of two years must be spent in clinical paediatric nephrology positions with responsibility for patient care.

Posts devoted to dialysis without other significant medical components will not be accepted for more than six months of core training.

The following areas of experience should be included in this training:

- diagnosis of renal disease, including urine microscopy, assessment of renal function, renal biopsy and its interpretation

- organ imaging and other specialised investigations
- specialised knowledge of the management of hypertension
- fluid and electrolyte balance
- management of acute and chronic renal failure
- techniques of haemodialysis, haemofiltration and peritoneal dialysis
- renal transplantation;
- urolithiasis
- urinary tract infection
- cooperative management of urological problems.

Procedural Skills

You are expected to gain expertise in renal biopsy techniques.

Elective Training

Normally the SAC may approve a maximum of one year elective training which may be undertaken in any field which has relevance to the management of patients with renal disease.

Assessment

In each year of Advanced Training in nephrology, you are required to submit three copies of a project report to the College by *15 September*. The report normally should not exceed 2000 words excluding tables and references. It should be of a similar style and format to that which would be considered for submission to a refereed journal.

The project report could result from one of the following areas:

- a clinical or laboratory research project
- a case report which is acceptable as one of the three projects to be submitted during Advanced Training
- a progress report of substantial original work in progress for a senior degree.

Each project should be accompanied by a statement by the project supervisor confirming that you have performed the major part of the work. Presentation of a research project at a scientific meeting of the Australian and New Zealand Society of Nephrology or the Transplantation Society of Australia and New Zealand or other accepted national or international meeting, is considered a sufficient alternative to the submission of a written report. In the case of presentations, a copy of the abstract (you as the first author), should be submitted to the College accompanied by a statement from the supervisor that you have performed a major part of the work and presented it personally.

It is preferable for one project to be submitted during each year of training by the *15 September* deadline. However, at least one project *must* be submitted by the end of the second year of training in order for further Advanced Training to be approved prospectively.

ANZPNA Annual General Meeting September 1, 2002

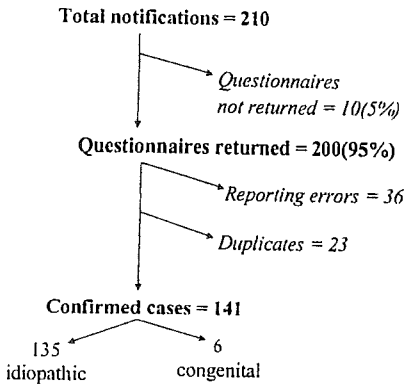
Report on APSU study
Elisabeth Hodson, Narelle Willis, Jonathan Craig

Objectives
Idiopathic nephrotic syndrome
- To estimate the incidence of idiopathic nephrotic syndrome
- To describe its distribution in relation to age, sex, socio-economic status, geography and ethnicity
- To describe the steroid regimes and other treatments used in the first episode of idiopathic nephrotic syndrome
- To describe disease relapse rates amongst steroid responsive children
- To describe the frequency and type of infective and thrombotic complications

Congenital nephrotic syndrome
- To estimate the incidence of congenital nephrotic syndrome in Australia
- To describe its distribution in relation to age, sex, socio-economic status, geography and ethnicity

Methods
Paediatricians, who reported a new case of childhood nephrotic syndrome to APSU, were sent initial and one year follow up questionnaires requesting clinical details

Results
Nephrotic syndrome notifications Jul 1998 – June 2001



State	Number	Incidence
NSW/ACT	56	1.35 (0.81-2.12)
VIC	41	1.44 (0.78-2.43)
QLD	18	0.81 (0.30-1.74)
SA	4	0.45 (0.02-1.91)
WA	12	1.01 (0.28-2.39)
TAS	3	0.98 (0.02-4.38)
NT	1	0.66 (0.00-5.92)
Australia	**135**	**1.15 (0.84-1.53)**

Incidence per 100 000 (95% CI) children aged <15 years

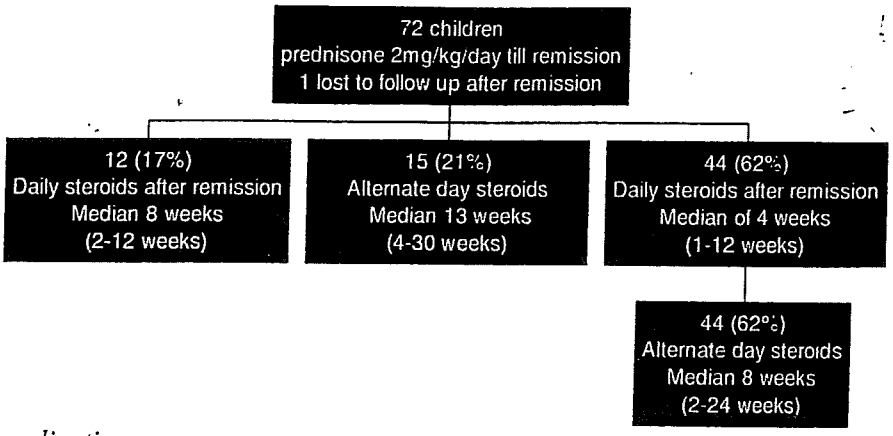
Idiopathic nephrotic syndrome
Initial questionnaire

The national reported incidence was 1.15 (95%CI 0.84-1.53) per 100 000 children aged <15 years. There was no significant difference between states (c^2 = 3.42, p = 0.75). There were 74 boys and 61 girls giving an incidence of 1.23 (95% CI 0.81-1.76) for boys and 1.06 (95% CI 0.66-1.59) for girls- a difference which is not significant (c^2 = 0.11, p = 0.74). The incidence decreases significantly with age (c^2_{trend} = 19.33, p < 0.0001).

Follow up questionnaires
To date 93 1-year follow up questionnaires have been analysed and the results will be reported in a poster at the ANZSN meeting. Twenty-one children had steroid resistant

nephrotic syndrome (SRNS); FSGS was the most common biopsy diagnosis (11 patients). Seventy two children had steroid sensitive nephrotic syndrome (SSNS). The median time to remission was 10 days and 91% of those who responded to steroids had responded by 4 weeks. At one year follow up 21% had no relapse, 40% were infrequent relapsers, 22% were frequent relapsers and 17% were considered to be steroid dependent.

Steroid regimens



Complications

During follow up, 6 children with SSNS developed infections (pneumonia 3, peritonitis 3) and no child developed a thrombotic episode. At 1 year follow-up all children were alive and well, 7 (11%) of 63 children had haematuria, 4 (6%) of 64 had SBP ≥ 120 and no child had elevation of serum creatinine levels. During follow up, 2 children with SRNS suffered 3 infections, one of which required admission to intensive care. No child suffered a thrombotic episode. At 1 year follow-up 5 of 15 children had haematuria, 3 of 19 had systolic blood pressure (SBP) above 120. All children were alive at 1 year but 3 children had chronic renal failure.

Congenital Nephrotic Syndrome

Of 6 children with congenital nephrotic syndrome (CNS), 2 children had Denys-Drash Syndrome and I had Galloway-Mowat Syndrome – all died within 6 months of birth. Of the remaining 3 children, 2 had CNS of the Finnish type and information is awaited on the final child. Both children with Finnish type CNS were alive at one year but both had suffered bacterial infections and were developmentally delayed.

Further analyses

Further analyses of the demographic data are required particularly in relation to ethnicity. Detailed analysis of the initial and follow up clinical data remains to be carried out. Initial analysis of the clinical data indicates similar patterns of disease to other reported studies. The considerable variability in treatment identified from the initial questionnaire is confirmed in the 1 year questionnaire.

The reported incidence of idiopathic nephrotic syndrome in Australia is 1.15 per 100 000 children aged 15 years and below. This is approximately half the incidence reported from a population-based study in the USA in the 1950s and from a recent population-based study in Yorkshire, UK reported in 2001. There are no significant differences in incidence between Australian states. However the small number of cases reported from South Australia is disturbing and the possibility of incomplete ascertainment of patients requires further investigation.

1. Paediatric report for 2002
This will take the form of a paper submitted to a suitable journal and published (in modified form) in the annual registry report.

The objective is to look at the long-term outcome (mortality) of children who develop ESRD since the inception of the registry (1970).
The following are proposed explanatory variables
- age (continuous for the final analysis, but at first pass 0-4, 5-9 etc up to 19 years)
- year of ESRD development (continous for the final analysis, but initially in blocks of 5 years)
- cause of ESRD (6 categories)
- gender
- treatment modality (Tx, dialysis (hemo/pd) with adjustment for times on each

In the first instance these would be plotted as time to death analysis graphically (KM plots).
We also would need tables cross classifying cause of death with age at ESRD and age at death.

Timeline: End of April for a protocol and unadjusted survival data

2. Changes to the paediatric data
It was decided that height, weight, bone age and functional status would remain, and head circ, pubertal status, ROD status and growth hormone use would be deleted. Rationale for this decision were that these data were not collected anyway (missing data), not as clinically relevant as they were once (eg ALP level), and had not been used or they had been used and were unlikely to be used again (eg GH).

It is proposed that cholesterol/LDL/HDL/triglycerides (annual fasting measurements) be added to the list because they were often done routinely anyway, were likely to be important for long term patient outcome, and are usually done as "suite" of tests rather than total cholesterol alone. It is also proposed that another category - statin use (yes/no) - also be added, obtained 6 monthly, for 1 year only be added to paediatric report, to simply describe and compare statin use across centres.

Regards

Jonathan
--

Gad Kainer

RESEARCH PROPOSAL

A double blind placebo controlled trial of ACE inhibitor, AIIb antagonist, or combination therapy in prevention of diabetic renal and microvascular disease

HYPOTHESIS:

The use of ACEI, AII inhibitors or combination is superior to placebo in delaying the onset of renal and microvascular disease in diabetes and reduction the long-term adverse outcomes of diabetes can be reduced when these agents are used before onset of overt renal and microvascular disease occurs.

AIMS

1. The primary aim of this prospective study is:

To determine whether use of Angiotensin Converting Enzyme inhibitors **(ACEI),** Angiotensin-2 blocking drugs **(AIIb) or a combination of these two agents** could delay the onset of renal and microvascular disease in diabetics.

2. Secondary aims of this study are to evaluate:

a. Whether treating patients from the time of diagnosis of diabetes with these drugs, either delays the onset, or reduces the incidence of other co-morbid conditions that afflict many diabetics in the long-term[①].

b. The safety of these medications given long-term to children[②].

RATIONALE FOR STUDY

It has been observed that renal involvement in all types of diabetes is heralded by onset of microalbuminuria **(references).** Microalbuminuria heralds the onset of not only renal disease, but microvascular disease in general. Meticulous control of blood sugar delays the onset of renal and microvascular disease as well as other complications **[references].** However, despite good glycaemic control, renal, microvascular disease and other complications of diabetes are common. The number of patients suffering from these "co-morbid" conditions increases with time from diagnosis of diabetes **[references].** Studies in diabetics and albuminuria indicate that treatment with ACE inhibitors **(ACEI)** and angiotensin 2 receptor blocking **(AIIb)** drugs can reduce the rate of deterioration in renal function [references]. There have not been any prospective studies in diabetic patients, adults or children, using either ACE inhibitors or angiotensin 2 blocking drugs **prior** to onset of albuminuria.

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① These conditions include: Diabetic retinopathy, peripheral vascular disease, peripheral neuropathy, coronary heart disease, cerebral vascular disease.

② "Long acting" ACEI drugs and Allb drugs are currently "off label" prescription for children in Australia

Summary of proposal for multicentre study of the effects on renal function of HMG Co A reductase inhibitors in paediatric renal transplant recipients with graft dysfunction at all cholesterol levels.

Fiona Mackie MB BS, PhD, FRACP,

Sydney Children's Hospital

Background/Rationale

Most patients with renal transplants have mild-moderate chronic renal insufficiency. Hyperlipidaemia may contribute to renal dysfunction in renal disease. Foam cells are frequently found in segments of glomeruli undergoing sclerosis and oxidized LDL has been shown to stimulate inflammatory and fibrogenic cytokine production [1]. HMG Co A reductase inhibitors exert antiinflammatory and antiproliferative actions independent of cholesterol lowering [2]. Statin treatment in animal models of vascular disease is associated with reduced cellular proliferation, increased apoptosis and decreased leucocyte accumulation [2,3]. Renal injury typically initiates inflammatory cascades involving similar cellular events as seen in vascular tissue. In an Ang II dependant animal model of hypertension and renal disease statin use decreased blood pressure, albuminuria and cortical necrosis and this was associated with reduced infiltration of inflammatory cells, adhesion molecules and levels of transcription factor Nf kappa B [4].

In human trials, a study of 676 renal transplant recipients found that serum cholesterol at 1 year was an independent covariate influencing graft and patient survival [5]. This effect was log linear suggesting the lower the cholesterol the greater the effect. Recently it was demonstrated in a large randomised trial of 20536 individuals that statin

use over a 5 year period, regardless of cholesterol levels significantly reduced mortality from all causes in high risk patients for cardiovascular disease [6]. A recent meta analysis examining the effect of HMG CoA reductase inhibition on renal function in proteinuric renal disease found a lower rate of decline in glomerular filtration rate with treatment vs controls. There was also a tendency to reduction in protein/ albumin excretion [7].

Aims

To carry out an Australian and New Zealand multicentre randomised blinded placebo controlled trial using atorvastatin, an HMG CoA reductase inhibitor, in paediatric renal transplant recipients with graft dysfunction (GFR<80 ml/min/1.73 m^2/day) at all cholesterol levels:

To determine whether lipid lowering with HMG CoA reductase inhibitors slows the decline of renal function post transplantation over a 5 year observation period.

Endpoints

Primary endpoint: Change in renal function as determined by glomerular filtration rate over a 5 year period

Secondary endpoints: Protein excretion and blood pressure

Patient eligibility

1. Functioning graft of greater than 1 year.
2. GFR < 80ml/min/1.73 m^2/day
3. No history of lipid lowering medications.
4. Less than 18 years and greater than 1 year.
4. No laboratory evidence of liver dysfunction

Power/Feasibility

For the primary endpoint of preservation of GFR, it is calculated by power analysis that 58 subjects are required per group in order to achieve a 95% chance of avoiding a type I error (power 80%). This would detect a 30% difference in GFR of 15 ml/min/1.73 m^2 between the 2 groups. The most recent ANZDATA report with data until December 1999 indicated that there were 212 paediatric renal transplant recipients with functioning grafts (age less than 19 years) and it is estimated that approximately 20 patients per year for 2000-2002 could be added to this.

Safety

HMG CoA reductase inhibitors have been shown in a number of studies to be safe and effective in adult renal transplant recipients [8,9,10,11,12,13]. In a pilot study performed at Sydney Children's Hospital, we have treated 8 paediatric renal transplant recipients with hyperlipidaemia with Atorvastatin for a mean time of 18 months. Treatment to date has been efficacious (mean % reduction of cholesterol of 41 ± 10%, LDL 57 ± 7%) and safe. There have been no significant changes in creatinine or cyclosporin levels. No patients have experienced myalgia or rises in CK or transaminase levels. Similar findings of efficacy have recently been reported in another small study of paediatric renal transplant recipients [14].

Funding

If there is agreement in principle from an adequate number of centres for the study to be feasible then application will be made for NHMRC funding.

Comments:

Any comments or questions would be gladly received via email f.mackie@unsw.edu.au or phone 02-93821646. A more detailed proposal will be forwarded to interested participants after further discussion.

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3 Blanco-Colio LM, Villa A, Ortego M et al: 3-HMG CoA reductase inhibitors, atorvastatin and simvastatin induce apoptosis of vascular smooth nmuscle cells by downregulation of Bcl-2 expression and Rho A prenylation. Atherosclerosis 161:17-26, 2002

4 Park JK, Muller DN, Mervaala EM: Cerivstatin prevents angiotensin II-indeuced renal injury independent of blood pressure and cholesterol lowering effects Kidney Int 58:1420-1430, 2000

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12 Locsey L. Asztalos L. Kincses Z. Balazs G. Fluvastatin (Lescol) treatment of hyperlipidaemia in patients with renal transplants. *International Urology & Nephrology.* 29:95-106, 1997

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14 Krmar RT, Ferraris JR, Ramirez JA: Use of atorvastatin in hyperlipidemic hypertensive renal transplant recipients Pediatric Nephrology 17:540-543, 2002

AGREEMENT – CONGRESS 2004

AGREEMENT made the day of 2002

BETWEEN: **INTERNATIONAL PEDIATRIC NEPHROLOGY ASSOCIATION INC** (a not-for-profit corporation established in the County of Albany in the State of New York, United States of America) of C/- Professor Matthias Brandis, University Children's Hospital, Department of Pediatric and Adolescent Medicine, Mathilden Strasse 1, D-79106 Freiburg Germany ("IPNA")

AND: **THE AUSTRALIAN & NEW ZEALAND PAEDRIATRIC NEPHROLOGY ASSOCIATION** ACN 087 155 780 (a company limited by guarantee incorporated in Australia) of C/- Paediatric Renal Office, Monash Medical Centre, 246 Clayton Road, Clayton Victoria 3168 ("ANZPNA")

AND: **COLIN LINDSAY JONES** of C/- Department of Nephrology, Royal Children's Hospital, Flemington Road, Parkville Victoria 3052 and **KENNETH FARID JUREIDINI** of C/- Renal Unit, Women's and Children's Hospital, 72 King William Road, North Adelaide SA 5006 (together called "**Organising Committee**")

BACKGROUND

A. IPNA and ANZPNA share many common objectives associated with promoting the study and dissemination of information relating to paediatric nephrology.

B. IPNA conducts international conferences every three years and has agreed with ANZPNA and the Organising Committee to convene the 2004 Congress in Adelaide, South Australia.

C. ANZPNA has agreed to assist IPNA in the organisation and administration of the 2004 Congress and to appoint the Organising Committee to act on behalf of ANZPNA for the purposes of this Agreement, subject to the terms of this Agreement.

OPERATIVE PROVISIONS

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1. DEFINITIONS AND INTERPRETATION

1.1 Definitions

In this Agreement unless the context otherwise requires:

"*Accountant*" means Mr John Gamble of CSM Horwath, Level 1, 99 Frome Street, Adelaide SA 5000; or

(a) such other person as nominated in substitution for that person or firm of accountants from time to time by IPNA and approved by the Organising Committee on behalf of ANZPNA; or

(b) if the Organising Committee and IPNA cannot reach agreement, for the purposes of paragraph (a), then such other person as nominated by a representative of the International Chamber of Commerce.

"*Accounts*" means those separate bank accounts operated by Hartley in respect of the 2004 Congress as contemplated by clause 6.2 of this Agreement;

"*Approved Budget*" means the most recently approved (in accordance with clause 4.3) Revised Budget;

"*Business Day*" means days upon which trading banks in South Australia are open for business;

"*Consultants*" means any accountant, lawyer, company or other consultant (including Hartley) whose services may assist in the efficient organisation and implementation of the 2004 Congress;

"*Delegates*" means those medical practitioners and allied healthcare professionals having an interest in paediatric nephrology who are invited to, and pay to attend (or are otherwise sponsored to attend) the 2004 Congress;

"*Educational Program*" means those lectures, presentations and demonstrations to be presented at the 2004 Congress to Delegates in relation to matters associated with paediatric nephrology or related research and the practice of medicine in related areas;

"*Final Statement*" means the final statement of account for the 2004 Congress and by which the Net Profit/Net Loss can be determined and which will be prepared in accordance with clause 4.3;

"*Gross Receipts*" means all those amounts payable to, and received by, any or all of IPNA, ANZPNA, the Organising Committee or Hartley in connection with the 2004 Congress, including Subscriptions, sponsorship payments and other interest earned on funds deposited from time to time in the Accounts;

"*Hartley*" means Hartley Management Group Pty Ltd ACN 050 294 614 which carries on the business of organising and facilitating conferences;

"*Legitimate Expenses*" means those amounts properly incurred and expended by any or all of IPNA, ANZPNA or the Organising Committee in accordance with the Approved Budget and in connection with the 2004 Congress, including payments to Consultants, costs associated with the Venue, catering costs, provision of entertainment, meals and included benefits for Delegates and associated expenses associated with the 2004 Congress;

"*Net Profit/Net Loss*" means the amount calculated by deducting from the Gross Receipts the Legitimate Expenses;

"*Payment Approval Form*" means a form completed in a format substantially as appears in the Annexure to this Agreement;

"*Records*" means those papers, documents, accounts, invoices, contracts and other documents associated with recording Gross Receipts and Legitimate Expenses;

"*Revised Budget*" means a draft budget outlining the Organising Committee's best reasonable estimates from time to time of:

(a) the anticipated Gross Receipts and the anticipated Legitimate Expenses; and

(b) the cash flow projections for the 2004 Congress;

"*Subscriptions*" means the subscription fee payable by each Delegate in order to attend the 2004 Congress;

"*2004 Congress*" means the conference to be convened by IPNA in Adelaide during August and September 2004 to promote the study of, and disseminate information in relation to, paediatric nephrology;

"*Venue*" means the Adelaide Convention Centre, North Terrace, Adelaide, South Australia and any other location from which events or entertainment associated with the 2004 Congress will be convened.

1.2 Interpretation

In this Agreement, unless the context otherwise requires:

(a) words denoting the singular number shall include the plural and vice versa;

(b) words denoting any gender shall include all genders;

(c) where a word or phrase is defined, other parts of speech and grammatical forms of that word or phrase shall have corresponding meanings;

(d) words denoting natural persons shall include bodies corporate and vice versa;

(e) references to clauses are to clauses of this Agreement;

(f) headings are for convenience only and shall not affect interpretation.

(g) a reference to any part of this Agreement or any other agreement or instrument shall include that party's executors, administrators, successors and permitted assigns (as the case may be); and

(h) references to any agreement or instrument shall include references to such agreement or instrument as amended, novated, supplemented, varied or replaced from time to time;

(i) references to any legislation or to any provision of any legislation shall include any modification or re-enactment of that legislation or legislative provision or any legislation or legislative provision substituted for, and all regulations and instruments issued under, such legislation or provision;

(j) reference to dollars and $ are to amounts in Australian currency;

(k) all Schedules and Annexures to this Agreement form part of this Agreement; and

(l) where under this Agreement an obligation is expressly or impliedly imposed on more than one person, those persons are jointly and severally liable for the due observance of that obligation.

2. APPOINTMENT OF ANZPNA AND ORGANISING COMMITTEE

The parties acknowledge that:

2.1 the 2004 Congress will be promoted to Delegates as IPNA's conference;

2.2 subject to clause 3, the 2004 Congress will be arranged, organised and co-ordinated on behalf of ANZPNA by the Organising Committee;

2.3 subject to clause 3, ANZPNA agrees to enter into all necessary contractual arrangements associated with, or incidental to, the 2004 Congress (including those relating to the Venue and the Consultant); and

2.4 the 2004 Congress will be funded by, and shall in all respects be at the commercial risk/benefit (as to losses and profits of the 2004 Congress) of IPNA.

3. DELEGATION AND INDEMNITY

3.1 Subject to clause 3.2 and without limiting clause 3.5, IPNA authorises ANZPNA to undertake all necessary contractual and other arrangements associated with the 2004 Congress including:

(a) negotiating sponsorships of the 2004 Congress;

(b) booking the Venue;

(c) engaging the Consultants;

(d) arranging the accommodation packages for Delegates;

(e) selecting and booking speakers for the Educational Program;

(f) selecting and arranging entertainment packages (for intervals in the formal components of the 2004 Congress, Delegate functions and for Delegates' free time);

(g) accepting registrations from Delegates (including payments of deposits and Subscriptions); and

(h) any similar or otherwise related activities that may facilitate the effective presentation of the 2004 Congress.

3.2 For the purposes of this Agreement:

(a) ANZPNA authorises and appoints the Organising Committee to act exclusively on ANZPNA's behalf as ANZPNA's attorneys in all things that arise as a consequence of ANZPNA's obligations under this Agreement and that are associated with, or incidental to, the 2004 Congress provided that the Organising Committee acts in accordance with the Approved Budget; and

(b) IPNA consents to ANZPNA's appointment of the Organising Committee under paragraph (a).

3.3 Further to clause 3.2(a), ANZPNA agrees:

(a) to ratify any undertaking or arrangement given or made by the Organising Committee through the proper exercise of their powers under clause 3.2(a); and

(b) to indemnify the Organising Committee against any cost, liability or damages incurred by the Organising Committee in the proper exercise of their powers under clause 3.2(a);

3.4 Further to clauses 2.4 and 3.1, IPNA agrees to indemnify ANZPNA against any cost, liability or damages incurred by ANZPNA in respect of:

(a) ANZPNA's proper performance of its duties under this Agreement; and

(b) the contractual and other liabilities incurred by ANZPNA as a consequence of the activities and actions of the Organising Committee under this Agreement.

3.5 The Organising Committee shall enter into all relevant contractual relationships for the 2004 Congress on behalf of ANZPNA and:

(a) ANZPNA will not be obliged, or entitled, to enter into any contractual relationship in connection with the 2004 Congress except as contemplated by clause 3.2(a); and

(b) IPNA will not be obliged, or entitled, to enter into any contractual relationship in connection with the 2004 Congress with the exception of this Agreement.

4. APPOINTMENT OF HARTLEY

4.1 The Organising Committee will appoint Hartley to assist with the planning, administration, accounting, record-keeping, organisation and co-ordination of 2004 Congress.

7.3 Unless IPNA disputes the Final Statement in accordance with clause 6.4, then within 20 Business Days after IPNA's receipt of the Final Statement, either:

(a) the Organising Committee shall pay to IPNA from the Accounts an amount equal to the Net Profit; or

(b) IPNA shall pay as directed by the Organising Committee an amount equal to the Net Loss,

as the case may be.

7.4 If IPNA disputes the Final Statement:

(a) IPNA shall advise the Organising Committee within 10 Business Days after IPNA's receipt of the Final Statement of IPNA's basis of such dispute (by identifying the discrepancy in either the Gross Receipts or the Legitimate Expenses, the miscalculation or other factor in the Final Statement that IPNA believes renders the Organising Committee calculation of the Net Profit/Net Loss incorrect);

(b) IPNA, ANZPNA and the Organising Committee shall negotiate with each other in good faith in order to resolve such dispute as quickly as practicable;

(c) unless resolved beforehand, either the Organising Committee or IPNA may engage the Accountant on behalf of the parties jointly at any time within 40 Business Days after IPNA's receipt of the Final Statement in order to audit the Final Statement;

(d) The Accountant's calculation of the Net Profit/Net Loss shall be final and binding upon the parties and clause 6.3 shall apply as if the Accountant's decision constitutes the Final Statement; and

(e) the Accountant shall act in this regard as an expert and not as an arbitrator and the Accountant's costs shall be borne by IPNA.

8. TERMINATION

8.1 Any party may terminate this Agreement:

(a) if another party breaches any term of this Agreement and fails to remedy such breach within thirty days of notice in writing requiring it to do so; or

(b) another party enters into or is placed under any form of insolvency administration pursuant to chapter five of the *Corporations Act 2001*.

8.2 Upon the expiration or termination of this Agreement, IPNA will pay ANZPNA within 14 days all fees and other moneys due to the ANZPNA under this Agreement.

8.3 The expiration or termination of this Agreement will not affect any rights any party has against another party as a consequence of what occurred prior to the date of expiration or termination.

9. NOTICES

Any notices required to be given under this Agreement by any party to another shall be:

9.1 in writing addressed to the address of the intended recipient shown in this Agreement below or to such other address as has been most recently notified by the intended recipient to the party giving the notice:

(a) in the case of IPNA:

Address: C/- Professor Matthias Brandis
University Children's Hospital
Department of Pediatric and Adolescent Medicine
Mathilden Strasse 1
D-79106 Freiburg
Germany

Facsimile: +49 0761 270 4481
Attention: Professor Mathias Brandis

(b) in the case of ANZPNA:

Address: C/- Paediatric Renal Office
Monash Medical Centre
246 Clayton Road
Clayton Victoria 3168

Facsimile: +61 3 9594 6259
Attention: Dr Rowan Walker

(c) in the case of Colin Lindsay Jones:

Address: C/- Department of Nephrology
Royal Children's Hospital
Flemington Road
Parkville Victoria 3052

Facsimile: +61 3 9345 5611
Attention: Dr Colin Jones

(d) in the case of Kenneth Farid Jureidini:

Address: C/- Women's and Children's Hospital – Renal Unit
72 King William Road
North Adelaide SA 5006

Facsimile: +61 8 8161 6048
Attention: Dr Ken Jureidini

Agreement – Congress 2004

DATE _____

ANZPNA

(Australian & New Zealand Paediatric Nephrology Association)

Executive Teleconference – Minutes
23rd December 2002

Attended: **Steve McTaggart, Rowan Walker and Mandy Walker**

Payments for membership
3 direct deposit can't be identified - need to apply to bank for ID. 6 others haven't paid. Steve will bill $400 rather than $100 to send out Jan, return by 2nd last week of Feb. Continue to bill per calendar year. If non payment for 2 years then drop off membership - need to discuss further if this occurs.

IPNA funds
Steve to continue to follow up as Commonwealth Bank IPNA Account not yet closed. Need copies of all statements for Association's financial reports.

Liability insurance
Contact identified via ANZSN, costs incurred depend on funds in control. Insurance broker identified, application then get quote. Specific information required prior to accurate quote can be given. Further advice to be sought from ?Executive of ANZSN (HEO - John Kelly. Steve to follow up also with the insurance brokers (QBE).

Tax liabilities
Still a little unclear - non profit organisation - letter to be sent to Tax Commissioner requesting ruling.

Annual return
To be finalized by next week.

AGM timing
Previously discussed to have AGM after CARI meeting in March, however there may be relatively little to report. Alternative times may be May in Horbart with RACP ASM, September in Perth with ANZSN or with APFN in Sanctuary Cove in May.

After considerable discussion May was considered most appropriate. ?Thursday 15th May, 2003. Sanctuary Cove. Details to be confirmed.

Articles of Association/ Assistant Treasurer
The executive have re-examined the need for an assistant Treasurer. It was felt that now the financial records are in order, that the need for this position is diminished. It was suggested however that the Executive should have the power to co-opt individuals for specific tasks, from time to time.

The issue of duration of terms was also discussed. It was felt that 2-year terms are short creating difficulty with "corporate memory". It was suggested that 3 year terms be considered and put to the membership.

Duties of executive
Comprehensive web site: ASIC - www.asic.gov.au
Nominations for election of office bearers - distribute March, 03

Web site
Refer to Gad Kainer's correspondence. It was agreed that Gad should pursue further independent industry quotes and this then be discussed further with the membership. ?at AGM ?via email prior?

Publications
Colin Jones & Charles Crompton have discussed Growth hormone paper The paper was reviewed by the International journal: One reviewer liked it and two panned it. Charlie felt there was a massive amount of work to do to have it accepted. He doesn't feel the data would be good enough to merit publication in an international journal at this stage because better data is being generated by overseas. However, he feels it may be able to be resurrected in a form for a local journal (Nephrology for instance).

Colin felt that if, indeed, better work is coming out from overseas that there would not be a lot to be gained by publishing it.

Workforce
Refer attached survey. Please return by 28th Feb, 2003
Current Nephrology trainees
Refer attached, please encourage application to join ANZPNA

Collaborative studies
Juvenile diabetes & ACEI Gad Kainer
HMGCoA reductase study Comments to F Mackie please Pharmaceutical multicentre trials
(R Walker to follow up

WORKFORCE SURVEY DOCUMENT

Name	**Current work practice**	**Projected 5 yrs**	**Projected 10 yrs**
Full time/ part time?			
% paediatric nephrology/week			
Hospital clinical (paed neph) hrs/week			
Private clinical (paed neph) hrs/week			
Research (paed neph) hrs/month			
Teaching (paed neph) hrs/month			
Admin (paed neph) hrs/month			
Committee/IPNA/ANZPNA/CARI work hrs/month			
% adult nephrology/week			
% General paediatrics/week			
% Other			
Is there enough work for more clinicians (if assume adequate funding)? If so, what % of 1 full time position?			
What % would be Hospital work?			
What % would be Private practice?			
Is there funding available for more paediatric nephrologists within your unit, currently?			
What are the training opportunities within your Unit?			
Do you have any Advanced Trainees? Please include name and year of training. Are they Associate members of ANZPNA?			

NEPHROLOGY TRAINEES

Paediatric Nephrology trainees known to ANZPNA

Trainee		Year 2002	Hospital	Membership ANZPNA
Samuel	Crafter	Ad 1	Adelaide	No
Jeff	Fletcher	B3	Westmead	No
Leigh	Haysom	Ad 1	Sydney Children's	No
Tonya	Kara	Ad1	Starship	Assoc
Joshua	Kausmann	Ad 1	RCH/MMC	Assoc
Hemant	Kulkarni	Ad 1+	MMC 2003	No

IPNA 2002 – Council Meeting Report

Bilbao Spain

The IPNA Council met in conjunction with the ESPN in Bilbao Spain, September 19-20, 2002.

The report of the Secretary-General, Mathias Brandis, highlighted the 3 goals of the organization at this stage:

1. Development of paediatric nephrology for services for poor children in the world.
2. Education of doctors in poor countries
3. Support of poor paediatricians practicing nephrology primarily through journal subscription.

The financial statements represented by the Treasurer (Bruce Stapleton). The net balance of accounts at the end of this year is expected to be $380,000 and the net balance for year 2003 is expected to show $480,000. I can provide details of the financial statements if members require.

A progress report was made by Dr Ken Jureidini regarding the organization development of the meeting in Adelaide, 2004. Dr Jones gave a report of the scientific program development. The principal financial aspect discussed was the plan to increase the number of invited overseas speakers to 40. The progress report is appended to this report.

Reports of the various regional paediatric nephrology associations were given. The discrepancy in numbers of paediatric nephrologist represented by different members of Council was highlighted by Mathias Brandis by asking how many members each group had. A copy of the report delivered by Dr Jones is amended to this report.

Dr Robert Chevalier reported on the Developmental Workshop in 2004. The venue of the Barossa Valley has facilities for 100-150 participants. The registration for non-members to attend the IPNA 2004 congress will be reduced to an estimated $250 US if they also register for the workshop. There is currently a shortfall of funding for the conference. Local scientists who have been contacted for helping developing the workshop include a number of Australian and New Zealand people (Dane Alcorn, Marelyn Wintour, John Bertram, Melissa Little, and Jenny Stow as well as Grant Sutherland and Eric Haan).

There were a number of discussions regarding journal sponsorship for poor members and non-members. The development of a regional training program is in progress. The organization may fund around $50,000 US for 2003 for some Fellows to start training. The regional basis of training was favoured. A unit would be given money to train a Fellow for a set period of time, which would not be extendable. A substantial contribution by the local unit would be required as well as a report. A sub-committee is further developing this.

A presentation for a Growth Hormone workshop in April 2004 in Heidelberg was made Burkhard Tonshoff and Rick Kaskel.

The selection of the site of Budapest, Hungary for the IPNA Congress 2007 was made. The competition was from Cairo.

Rodriguez Soriano was made an Honorary Member of the society.

A committee of Avind Bagga, Paul Goodyear and Druck Garcia addressed constitution and election issues with regard to the IPNA Council. This was discussed extensively. It is likely that the rules will change at the next IPNA meeting.

The next meeting of the IPNA Council will be held on Thursday, 1st May and 2nd May 2003 in Seattle, preceding the meeting from May 3-6 of the ASPN.

Colin Jones
Regional Secretary
IPNA Council

Australian and New Zealand Paediatric Nephrology Association Report

The Annual Meeting of the ANZPNA was held in Sydney in August. The meeting occurred in conjunction with the Scientific meeting of the Australian New Zealand Society of Nephrology. Continuing the practice of the last 3 years a post graduate nephrology education training course was held in the two days prior to the meeting. Paediatric Nephrology trainees have the opportunity of receiving 20 hours of lectures and seminars from a variety of experienced nephrologist.

The Association has recently completed a multi center study examining the 3 year outcome of infants with antenatal hydronephrosis due to vesicoureteric reflux who were treated with either antibiotic or placebo from birth. The Association is preparing for publication a report on risk factors and the epidemiology of mortality in paediatric renal transplant recipients from 1964 to 2000. This study was done in collaboration with the Cockran group using the Australian and New Zealand dialysis and Transplantation registry. This registry contains information regarding every patient who has been on chronic dialysis or has had a transplant since transplantation started in Australia in 1964. A prospective study on the epidemiology of childhood nephrotic syndrome was completed and the incidence of nephrotic syndrome was 1.15 per 100,000 children per year. A number of new studies were presented for consideration as multi center trails across the 2 nations.

Various members of this Association have been involved in the planning for the INPA 2004 meeting in Adelaide. This is subject to a separate report.

International Paediatric Nephrology Association resolutions reported in Paediatric Nephrology (2000) 15:1 were endorsed by the Association and passed on to National Medical bodies having advisory roles to government.

The Executive Committee of the Australian and New Zealand Paediatric Nephrology Association is Associate Professor Rowan Walker C/O Department of Nephrology, Royal Children's Hospital, Melbourne Australia. Facsimile No: +61 3 9345-5611, Email address: cjones@cryptic.rch.unimelb.edu.au

Progress Report

to the
IPNA Council Meeting
Bilbao – September 2002

Finances
The latest conference budget: attached
Highlights:
Registration: still aim to keep at or below $US500
Accommodation: $US10 – 135
Australian dollar – about $US0.55

Sponsorship
Sponsorship has already been secured with:
Premium - $50,000:
Fresenius Medical Care, Janssen Cilag, Amgen

Major - $25,000:
Pharmacia, Coopers Brewery

Speaker - $15,000:
Gambro, SA DHS

Other:
AKF - $8,000, WCH – $7,000, Florence McCredie - $5,000, Baxter - $10,000

Running total $260,000
Under review:
Novartis, SHS, Abbott, Schering, SANOFI, Genzyme, Bresagen, Roche, Solvay, Tekmed, Teraklin, Pfizer
IPNA's responsibility in seeking sponsorship.
Tourism SA facilitating meeting between Minister, local industry, IPNA Council representatives and Regional Organising Committee.

On site shopping at Exhibition
Opals and other jewellery, Aboriginal art and artefacts, Australian clothing and souvenirs, Jurlique Perfume, Bookshop, Haigh's Chocolate, Food items – 10% discount voucher for these and specialty shops in downtown area. Up to 10% takings to IPNA2004

IPNA Council role
Council members are requested to use contacts in industry to assist with sponsorship

Visits and promotion from Local Organising Committee:

JSPN – John Burke & Colin Jones
PhilippinesSPN – Ken Jureidini
South AmSPN – John Burke
AsSPN – Ken Jureidini
South AfSPN – Charlie Crompton
ESPN – Colin Jones, Ken Jureidini, Andrew Rosenberg
ChineseSPN – Ken Jureidini
ASPN – Colin Jones or Ken Jureidini, Andrew Rosenberg
IndianSPN – Ken Jureidini

Developmental Workshop:

Confirmed for Barossa Valley – probably Wed–Fri 25-27 August.
Sponsorship:
$US 9,000 confirmed
?further $10,000 from JSPN
Opportunities for further sponsorship
Website? and link and management?

International Federation of Kidney Foundations

International Pediatric Urology Workshop:

Likely workshop WCH - 28-29 August, participate IPNA2004 at least Monday 30. Hock Tan, Professor Surgery WCH. Likely 150 participants. At worst, revenue neutral. No impingement on naming.

Promotional Material

A new promotional flier is now in circulation. Members of Council are requested to promote IPNA2004. Promotional materials can be sent by the Adelaide Convention Tourism Authority.

IPNA 2004 Website

The conference website has been significantly upgraded, with Gad Kainer's input. The web site address is http//:ipna2004.com. All registration, submission and review of abstracts, bookings will be performed, where possible, via the web. Attached

email addresses

We need these and postal addresses for as many as possible

IPNA parent website

Links to ipna-online.org

Evening Program

Sunday: Opening ceremony and cocktail party (? Michael Kirby)
Monday: Concert: State Opera + Adelaide Symphony Orchestra in Adelaide Festival Centre
Tuesday: Optional Australian Wine Centre
Wednesday: Banquet
Thursday: Optional Great Aussie Barbecue and Ethnic night

Contracts

The legal contract between IPNA, ANZPNA and the Co-Chairmen of IPNA2004 and the PCO has been signed.

Organising committee executive

Co Chairmen:
Colin Jones: Scientific Program
Ken Jureidini: Operational Committee

Members:
Rowan Walker, John Burke, Graham Teague (Hartley Management)

Regional Organising Committee:

Ken Jureidini: Chair
John Burke
Colin Jones
Hui Kim Yap
Norishige Yoshikawa

Travel and Accommodation:

Bunnik Travel (www.bunniktravel.com.au), a dual Australian award-winning travel agent, has been appointed the official travel agent for the IPNA Congress.
You will have access to special airfares, hotel rates and tours, and you will be able to book on-line.
International delegates should consider utilizing this service, as booking airfares from Australia is often considerably cheaper, and the staff at Bunnik Travel are able to offer expert advice on touring options while in Australia.
They are also able to arrange special group airfares from any major city – if you can co-ordinate 10 or more passengers departing on the same flight, you will qualify for the discounts.

Return flights to Adelaide – September 2003:

Kuala Lumpar	$810	Seoul	$880	LA	$1,100
Beijing/Shanghai	$935	Hong Kong	$1,000	London	$1,100
Singapore	$865	Manila	$750	Frankfurt	$1,100
Delhi	$1,200	Tokyo	$750	Jo/burg	$970

Pre and post tours:

A large variety of these will be offered on IPNA and Bunniks' web sites, either separate or incorporate into a package of international flights and/or accommodation. Included will be:
Kangaroo Island, South Australia
Flinders Ranges, South Australia
Barossa Valley and /or other winery tours
Great Barrier Reef
Central Australia and Northern Australia, including Uluru and Kakadoo
Sydney
New Zealand +/- skiing
Asian holidays

Partners program:

Walking tours
Adelaide Hills
Wineries – Barossa Valley, Southern Vales
Australian Wine Centre
Aboriginal Art

SCIENTIFIC PROGRAM

On line:

- Congress program
- On-line registration
- Abstract submission

Key dates:

- Sept 2003 — Registration brochure/call for abstracts
- Feb 2004 — Closing date
- May 2004 — Authors notification
- June 2004 — Early bird registration closes
- August 2004 — Renal Development Workshop
- August 29, 2004 — IPNA congress commences

Papers - Call for Abstracts

You are encouraged to submit an abstract to be considered for inclusion in the Congress program. Abstract submission closes in February 2004, and authors will be advised of the status of their abstract in May 2004.

Abstracts may be submitted electronically using this form. Please download the abstract submisssion template and instructions here (both in Microsoft Word format), complete the details as per the instructions, and forward the document using this form.

Please name your completed document simply yet clearly, such as john_smith_renal_imaging.doc without any spaces in the document name.

Abstract Submission Form

Title of the abstract: [ ]

Please indicate the theme which best fits your abstract:

- ○ Developmental / genetic nephrology
- ○ Dialysis
- ○ Transplantation
- ○ General nephrology
- ○ Imaging and urological nephrology

Please indicate your preferred method of presentation:

- ○ Oral
- ○ Poster
- ○ Oral poster

Personal Details

Title: [ ]
First Name: [ ]
Last Name: [ ]
Institution: [ ]
Street Addess: [ ]
City / Suburb: [ ]
State / Province: [ ]
Country: [ ]
Postcode / Zipcode: [ ]
Phone: (country code, area code & number) [ ]
Fax: (country code, area code & number) [ ]
Email: [ ]

Conflict of Interest Declaration

I have read the 'Conflict of Interest Declaration' section of the Abstract Submission Guidelines and:

I have nothing to declare: ☐

I have an interest to declare: ☐

If you have an interest to declare, please describe it here:

Attach your abstract here

Select abstract to upload:

Send Information and Abstract Now

IPNA Budget in AU$ as at 16/09/02

	A	B	C	D	E	F	G	H
1	FIXED COSTS	Actual	Forecast	Budget	All figures in AU$			
2								
3	Administrative Costs							
4	**Postage, freight & couriers**	**$251.72**	**15,000**	**15,000**				
5	**Telephone & Facsimile**	**$576.89**	**4,000**	**4,000**				
6	**Email and web hosting**	**$461.23**	**4,000**	**4,000**				
7	**Organising Committee**	**$645.15**	**10,000**	**10,000**				
8	**Professional Conference Organiser - Management Fee**	**$13,783.00**	**45,250**	**45,250**				
9	**Legal expenses**	**$6,345.81**	**7,500**	**7,500**				
10	**Bank/Govt/Credit Card Charges**	**$14.00**	**9,000**	**9,000**	**Based on govt taxes + 85% of income on credit card @ 2.5%**			
11	**Insurance**	**$0.00**	**5,000**	**5,000**	**Premium approx 1% of total registration income**			
12	**Audit Fee**	**$0.00**	**2,000**	**2,000**				
13	Administrative Costs Sub-Total	$22,077.80	101,750	101,750				
14								
15	Social Functions							
16	**Welcome Reception - venue hire, entertainment, staging**	**$0.00**	**4,000**	**4,000**	**ACC**			
17	**Concert - venue hire, entertainment, staging**	**$0.00**	**2,000**	**2,000**	**Festival Theatre**			
18	**Congress Dinner - venue hire, entertainment, staging**	**$0.00**	**10,000**	**10,000**	**ACC; Adelaide Oval?**			
19	**Farewell BBQ - venue hire, entertainment, staging**	**$0.00**	**2,000**	**2,000**	**Venue TBC**			
20	Social Functions Sub-Total	$0.00	18,000	18,000				
21								
22	Speakers and Guests							
23	**Invited Speaker registration costs - 40 @ variable cost**	**$0.00**	**19,800**	**19,800**				
24	**Invited Speaker travel & accom - 40 @ $4000**	**$0.00**	160,000	**160,000**				
25	**Committee hospitality**	**$0.00**	**5,000**	**5,000**				
26	**Bursaries - 80 @ 50% Reg Fee**	**$0.00**	36,000	**36,000**				
27	**Council/Speakers Dinner**	**$0.00**	**3,500**	**3,500**				
28	**Prizes/Gifts**	**$0.00**	**2,000**	**2,000**				
29	Speakers and Guests Sub-Total	$0.00	226,300	226,300				
30								
31	Facilities							
32	**Venue Hire for conference**	**$909.09**	**62,595**	**62,595**	**See 'Venue Hire' sheet**			
33	**Poster Boards**	**$0.00**	**3,000**	**3,000**	**Based on 160 poster sites**			
34	**Audio-visual hire**	**$0.00**	**75,000**	**75,000**	**Includes allowance for responder units**			
35	**Ground Transport**	**$0.00**	**10,000**	**10,000**	**Allows for 1 off-site function**			
36	**Trade expenses**	**$1,897.50**	**51,020**	**51,020**	**See 'Trade' sheet**			
37	**Sponsorship expenses**	**$0.00**	**89,300**	**89,300**	**See 'Sponsorship' sheet**			
38	**Signage**	**$0.00**	**10,000**	**10,000**				
39	Facilities Sub-Total	$2,806.59	300,915	300,915				
40								
41	Marketing/Advertising							
42	**Delegate boosting**	**$10,713.82**	**25,000**	**25,000**				
43	**Journals, newsletters etc**	**$0.00**	**10,000**	**10,000**				
44	**Web site establishment and updates**	**$2,555.00**	**20,000**	**20,000**				
45	Advertising Sub-Total	$13,268.82	55,000	55,000				
46								
47	Printing & copying							
48	**Logo and stationery design**	**$555.00**	**750**	**750**				
49	**Stationery**	**$1,805.74**	**2,000**	**2,000**				
50	**Calendars**	**$1,484.00**	**1,484**	**1,484**				
51	**Initial Flyer**	**$635.00**	**3,000**	**3,000**	**2 flyers**			
52	**Call for Papers**	**$0.00**	**5,000**	**5,000**				
53	**Registration Brochure**	**$0.00**	**10,000**	**10,000**				
54	**Final program**	**$0.00**	**4,000**	**4,000**				
55	**Pocket program**	**$0.00**	**1,000**	**1,000**				
56	**Book of Abstracts**	**$0.00**	**20,000**	**20,000**				
57	**Delegate List**	**$0.00**	**2,000**	**2,000**				
58	**Tickets to functions**	**$0.00**	**1,000**	**1,000**				
59	**General Copying**	**$225.62**	**3,000**	**3,000**				
60	Printing & Copying Sub-Total	$4,705.36	53,234	53,234				
61								
62	TOTAL FIXED COSTS	42,858.57	755,199	755,199				

IPNA Budget in AU$ as at 16/09/02

	A	B	C	D	E	F	G	H
63								
64	VARIABLE COSTS				NUMBER OF DELEGATES			
65					500	750	1000	
66	Administrative Costs							
67	**Professional Conference Organiser - Per Head Fee**	**$0.00**	**24,500**	**49**	**24,500**	**36,750**	**49,000**	
68	**Accommodation deposits**	**$0.00**						
69	Administrative Costs Sub-Total	$0.00	24,500	49	24,500	36,750	49,000	
70								
71	Catering							
72	**4 morning & 4 afternoon teas**	**$0.00**	**24,000**	**48**	**24,000**	**36,000**	**48,000**	
73	**4 lunches**	**$0.00**	**60,000**	**120**	**60,000**	**90,000**	**120,000**	
74	**Happy Hour**	**$0.00**	**7,500**	**15**	**7,500**	**11,250**	**15,000**	
75	Catering Sub-Total	$0.00	91,500	168	91,500	137,250	183,000	
76								
77	Social Functions							
78	**Welcome Function**	**$0.00**	**25,000**	**50**	**25,000**	**37,500**	**50,000**	
79	**Concert**	**$0.00**	**25,000**	**50**	**25,000**	**37,500**	**50,000**	
80	**Congress Dinner**	**$0.00**	**50,000**	**100**	**50,000**	**75,000**	**100,000**	
81	**Farewell BBQ**	**$0.00**	25,000	**50**	**25,000**	**37,500**	**50,000**	
82	Social Functions Sub-Total	$0.00	125,000	250	125,000	187,500	250,000	
83								
84	Delegates' Handouts							
85	**Satchels**	**$0.00**	**12,500**	**25**	**12,500**	**18,750**	**25,000**	
86	**Paper/pens**	**$0.00**	**500**	**1**	**500**	**750**	**1,000**	
87	**Namebadges**	**$0.00**	**1,000**	**2**	**1,000**	**1,500**	**2,000**	
88	Delegates Handouts Sub-Total	$0.00	14,000	28	14,000	21,000	28,000	
89								
90	Contingency	$0.00	10,000		10,000	10,000	10,000	
91								
92	TOTAL VARIABLE COSTS	0	265,000	495	265,000	392,500	520,000	
93								
94								
95	TOTAL COSTS (FIXED + VARIABLE COSTS)	$42,859	$1,020,199		$1,020,199	$1,147,699	$1,275,199	
96								
97								
98								
99	INCOME				NUMBER OF DELEGATES			
100					500	750	1000	
101								
102	**Earlybird IPNA Member Registration Fee (60% total registrants)**			**$900.00**	**270,000**	**405,000**	**540,000**	**Reg fees set to break-even at 500 delegates**
103	**Standard IPNA Member Registration Fee (20% total registrants)**			**$1,000.00**	**100,000**	**150,000**	**200,000**	
104	**Earlybird Non-Member Registration Fee (20% total registrants)**			**$1,000.00**	**100,000**	**150,000**	**200,000**	
105	**Standard Non-Member Registration Fee (0% total registrants)**			**$1,100.00**				
106								
107	**Total Registration Fees**		**470000**		**470000**	**705000**	**940000**	
108	**Sponsorship**	**$119,360.96**	**423000**		**423000**	**423000**	**423000**	**See Sponsorship sheet**
109	**Trade exhibition**		**125000**		**125000**	**125000**	**125000**	**See Trade sheet**
110	**Travel agent commissions**		**5750**		**5750**	**5750**	**5750**	**Assumes 200 bookings for 5 nights @ $150 per nig**
111	**Accommodation deposits**							
112	**Additional Social Function Tickets**							
113	**Bank Interest**		**2000**		**2000**	**2000**	**2000**	
114	**Other**							
115								
116	TOTAL INCOME	$119,361	$1,025,750		$1,025,750	$1,260,750	$1,495,750	
117								
118								
119	EXCESS OF INCOME OVER EXPENDITURE	$76,502	$5,551		$5,551	$113,051	$220,551	
120								
121								
122	**PROFIT AS % OF EXPENDITURE**				**1%**	**10%**	**17%**	
123								

IPNA Venue Hire Sub-buget as at 16/09/02

Adelaide Convention Centre												
Sunday 29 Aug	IPNA			ANZSN			Expo				Catering
	These figures included in main budget - line 32			These figures not in main budget - ANZSN to cover			These figures in Trade Sponsorship worksheet - line 7				
	Registration	Foyer G	$0.00								
	Opening Ceremony	Hall E	$4,334.00								
	Allowance for additional meeting	MR 1,2,3	$2,557.50								
	Welcome Reception	TBC	$0.00								
	Speakers' Preparation	MR 10/11	$0.00								
			$6,891.50			*$0.00*			*$0.00*		
Monday 30 Aug	Plenary Hall	Hall E	$4,334.00	Post-grad Training Course 1	MR 1	$775.00	Set up	Halls F,G	$7,161.00		TBC
	Breakout 1	Hall A	$2,596.00	Post-grad Training Course 2	MR 2	$775.00					
	Breakout 2	Hall C	$2,596.00								
	Breakout 3	Hall D	$2,596.00								
	Breakout 4	Hall E	$0.00								
	Allowance for additional meeting	MR 1,2,3	$2,557.50								
	Speakers' Preparation	MR 10/11	$0.00								
			########			*$1,550.00*			*$7,161.00*		
Tuesday 31 Augu	Plenary Hall	Hall E	$4,334.00	Post-grad Training Course 1	MR 1	$775.00	Exhibition	Halls F,G	$7,161.00		In exhibition
	Breakout 1	Hall A	$2,596.00	Post-grad Training Course 2	MR 2	$775.00					
	Breakout 2	Hall C	$2,596.00	Registration	Foyer H	$0.00					
	Breakout 3	Hall D	$2,596.00								
	Breakout 4	Hall E	$0.00								
	Allowance for additional meeting	MR 1,2,3	$2,557.50								
	Speakers' Preparation	MR 10/11	$0.00								
			########			*$1,550.00*			*$7,161.00*		
Wednesday 1 Sep	Plenary Hall	Halls A,D,	$9,526.00	Plenary - conjoint with IPNA		$0.00	Exhibition	Halls F,G	$7,161.00		In exhibition
	Breakout 1	Hall A	$0.00	Cocktail Party		$0.00					
	Breakout 2	Hall B	$2,920.50								
	Breakout 3	Hall C	$2,920.50								
	Breakout 4	Hall D	$0.00								
	Breakout 5	Hall E	$0.00								
	Allowance for additional meeting	MR 1,2,3	$2,557.50								
	Speakers' Preparation	MR 10/11	$0.00								
	Congress Dinner	Hall H	$0.00								
			########			*$0.00*			*$7,161.00*		
Thursday 2 Sep	Plenary Hall	Hall E	$4,334.00	Plenary Hall	Hall B	$2,920.50	Exhibition	Halls F,G	$7,161.00		In exhibition
	Breakout 1	Hall A	$2,596.00	Breakout 1	MR 1/2	$1,705.00					
	Breakout 2	Hall C	$2,596.00	Conference Dinner							
	Breakout 3	Hall D	$2,596.00								
	Breakout 4	Hall E	$0.00								
	Allowance for additional meeting	MR 1,2,3	$2,557.50								
	Speakers' Preparation	MR 10/11	$0.00								
			########			*$4,625.50*			*$7,161.00*		
Friday 3 Sep				Plenary Hall	Hall B	$2,920.50					TBC
				Breakout 1	MR 1/2	$1,705.00					
			$0.00			*$4,625.50*			*$0.00*		
	Total price including GST		$68,854.50			$12,351.00			$28,644.00		
	Total price excluding GST		$62,59			$11,228.18			$26,040.00		

IPNA Sponsorship Sub-budget as at 16/09/02

Expenditure	Budget	Notes
Fixed costs		
Prospectuses	$2,000.00	
Administration (phone, fax, postage, printing etc)	$5,000.00	
Sponsor benefits	$40,000.00	To be confirmed (comp reg, social functions, exhibition etc)
Total fixed costs	**$47,000.00**	
Variable costs		
Sponsorship Management	$42,300.00	$50 per hour to a maximum of 10% of Trade & Sponsorship income
Total variable costs	**$42,300.00**	
Total expenditure	**$89,300.00**	**This figure appears in AU$ Budget sheet - line 37**
Income	**Budget**	Notes
Premium Sponsor	$158,000.00	Janssen Cilag, Amgen, Fresenius, AKF
Major Sponsor	$25,000.00	Pharmacia
Plenary Speaker Sponsor	$30,000.00	DHS, Gambro
Congress Dinner Sponsor		
Satchel Sponsor		
Welcome Reception Sponsor		
Pocket Program Sponsor		
Name Badge Sponsor		
Morning/Afternoon Tea and Lunch Sponsors		
Happy Hour Sponsor		
Satchel Insert		
Advertising		
Other	$210,000.00	IPNA $25,000, Baxter $10k, W&CH $5k, Clipsal $5k, McCredie $5k, Coopers $10k; Other to come $150000
Total Sponsorship Income	**$423,000.00**	**This figure appears in AU$ Budget sheet - line 108**
Income less expenditure	**$333,700.00**	

IPNA Trade Sub-budget as at 16/09/02

Expenditure		Budget		**Notes**
Fixed costs				
Venue hire		$26,040.00		Halls F and G
Prospectuses, manuals		$2,000.00		
Administration (phone, fax, postage, printing etc)		$5,000.00		
Total fixed costs		**$33,040.00**		
Variable costs				
Booth hire 3m x 3m booths @ $400 each		$20,000.00		Based on 50 booths; room for posters and catering
Catering		$20,000.00		Estimate for catering (4 days @ $50 per day for 2 people per booth; excludes social functions)
Power consumption		$4,000.00		$20 per booth per day
Trade Exhibition Management		$25,000.00		$50 per hour to a maximum of 10% of Trade & Sponsorship income
Total variable costs		**$69,000.00**		
Total trade exhibition expenditure		**$102,040.00**		**50% of this figure appears in AU$ Budget sheet - line 36 (balance to ANZSN)**
Income		**Budget**		
3m x 3m booths @ $5,000	50	$250,000.00		Based on selling 50 booths
Total Trade Exhibition Income		**$250,000.00**		**50% of this figure appears in AU$ Budget sheet - line 109 (balance to ANZSN)**
Income less expenditure		**$147,960.00**		

Minutes of ANZPNA meeting

Friday, 22nd February, 2002

Present: Rowan Walker, Amanda Walker and Steve McTaggart (phone link-up)

Bank Account

The Association's bank account is Commonwealth Account 290810340611 currently operated from Woden, ACT. The process of change of signatories is underway. Documentation has been sent to Dr Paul Roy who will then forward to Professor Rowan Walker. After signatories of Rowan and Mandy will be lodged at the Commonweath Bank. New cheque books will also be requested.

Assessing current account records was discussed with Dr Michael Falk who has indicated that these will be mailed within the next 48 hours.

There is a second account with co-signatories of Ken Jureidini, Paul Henning and Michael Falk. This account operated from Adelaide contains seeding money from IPNA and AKF for IPNA 2004 conference. Statements will be forwarded to Steve McTaggart and the account will be closed with the monies being transferred to the IPNA 2004 account.

1. Accounting Issues

Dr Falk indicated that auditing for the last financial year (2000-2001) has not been completed. It may be more appropriate to appoint the current ANZSN accountant (Mr Colin Marr) as the ANZPNA accountant and auditor as the ASIC annual return is still outstanding.

Tax Issues

The Tax Office has no record of our association thus implying that there is no Tax File Number. A tax return is not required to be lodged unless taxable income is above $416.00 per annum. This is exclusive of subscriptions which are known as mutual receipts and are not accessible and do not attract GST.

Currently there are no GST obligations as ANZPNA is a non-profit organization with a turn-over of less than $100,000. There may come a need to register for generation of Tax Invoices and this needs to be discussed further with the Accountant.

Subscriptions

Subscriptions have not been called for 1999, 2000, 2001 and 2002. It was agreed that subscription notices would request payment for 2000, 2001 and 2002. Steve McTaggart will send a covering letter explaining reason for back-payment and also asking for opinions regarding how the money should be spent. Ideas might include support of trainees, generation of multi-centre projects.

2. Annual General Meeting

This has been planned for Sunday September 1st immediately prior to ANZSN meeting in Sydney. There was discussion whether the meeting should include a scientific component to which associates may be invited. Mandy will call for opinions.

Membership of ANZPNA

There was some discussion about whether the category of Associate Member should be broadened to include clinicians practicing in areas related to paediatric nephrology such as paediatric urology. It was noted that there is no clear indication regarding fee structure for associate members.

3. ANZPNA/IPNA Conference Agreement

Legal review of this document is pending.

NEXT MEETING 22nd March 2002 at 11.30am.

Minutes of the 3rd Annual General Meeting
Sunday May 13, 2001
Sydney Convention and Exhibition Centre, Sydney
Commencing at 11 am

1. Present: Paul Roy (Chairman), John Knight, Elisabeth Hodson, Colin Jones, Harley Powell, Gad Kainer, Andrew Rosenberg, John Burke, Lilian Johnstone, Fiona Mackie, William Wong, Stephen McTaggart, David McCredie, Margot McIver, Paul Tomlinson, Ken Jureidini and Michael Falk.

2. Apologies: Jonathan Craig, Deborah Lewis, Stephen Alexander, Max Morris, Mandy Walker, David Lines, Paul Henning, Frank Willis, Charlie Crompton, Ian Hewitt, Rowan Walker.

3. Presentation by Graham Teague, Managing Director, Hartley Management Group Pty Ltd.
Hartley Management Group have been appointed as the conference organisers for the IPNA 2004 congress in Adelaide. Amanda Pearson will be the conference manager and will be responsible for the day to day organisation. To date a committee structure has been established, a draft budget developed and a time line created. Stationery, a flyer and a calendar have been produced. The flyer is available to any member of ANZPNA, who is attending a conference at which the flyers could be distributed. A sponsorship proposal has been developed and copies were circulated at the meeting. The website is operational. It will be used for on-line registration and abstract submission. It could be used to allow reviewing of abstracts on-line. Graham reported that it was essential to get a handle soon on the marketing plan. This needs to be directed to the areas most likely to have access to large numbers of potential delegates such as the IPNA Seattle meeting to prevent budget blow out. There soon needs to be a contract between Hartley Management and the congress organisers. This was discussed further later in the meeting. John Knight asked Graham how Hartley Management's work over the next 4 years would be financed. Graham said that there will be a clause to allow delayed payment from the organisers to Hartley Management included in the contract. Currently the organisers had received a loan of $15,000 from the Adelaide Convention and Tourist Authority and about $12,000 from IPNA. In addition AKF will provide $8000 at the rate of $2000 per annum.

4. Confirmation of the Minutes of the 2nd Annual General Meeting held at the Hotel Sofitel, Melbourne on March 17, 2000.

   Proposed: Andrew Rosenberg
   Seconded: Colin Jones
   Accepted unanimously

5. Report of the Chairman: Paul Roy spoke to his report (Appendix 1). Paul reported that a workforce survey had been conducted and the analysis was tabled. The results suggested that the workforce was relatively young, that women were under represented and that a significant proportion of children with renal disease in Australia and New Zealand were cared for by nephrologists, whose primary training was in adult medicine.
   Acceptance of the Chairman's Report was proposed by Lilian Johnstone, seconded by John Burke and accepted unanimously.

acknowledged. Andrew Rosenberg proposed the motion – "that, since the paper had not been reviewed by the contributors and the authorship had not been listed as previously agreed, the paper should be withdrawn until these matters had been attended to". The motion was seconded by John Knight and passed unanimously.

It was agreed that John Burke, Gad Kainer and Colin Jones should develop a policy for research under the auspices of ANZPNA. Areas to be covered would include how a research protocol would be dealt with, who would review the final version of the manuscript before submission and how authorship would be dealt with. **ACTION: JOHN BURKE, GAD KAINER, COLIN JONES TO DEVELOP POLICY**

12. Benchmarking: Lilian Johnstone presented the results of the benchmarking project to date. The project involved data collection on arterio-venous access and central venous access for haemodialysis, peritoneal dialysis and renal biopsies (Appendix 5). Data collection commenced in September 1999 and will finish in September 2001. The data will then be collated and prepared for publication. It was agreed that the data would be presented as the mean and 95% confidence intervals for each parameter. The data collected so far would be circulated to the individual centres, who would be informed which part of the data belonged to their centre. Lillian asked that each centre check the data and also send any outstanding data forms to her by September.
ACTION: ALL UNIT HEADS TO ENSURE THAT DATA FORMS ARE FORWARDED TO LILIAN BEFORE SEPTEMBER 2001

13. Reports of clinical studies:

    Multicentre double-blind placebo controlled trial of chemoprophylaxis in children with isolated vesicoureteric reflux. (Appendix 6).
    Elisabeth Hodson presented the report from Jonathan Craig. Patient recruitment has been completed and final follow up will be completed in October 2001.
    Epidemiology of childhood nephrotic syndrome. (Appendix 7).
    Elisabeth Hodson presented the report. Patient ascertainment will be completed in June 2001. It was requested that all efforts be made to notify new cases and to remind paediatric colleagues to notify patients.
    Randomised controlled trial of cyclophosphamide in the treatment of focal and segmental glomerulosclerosis. (Appendix 8).
    Stephen McTaggart presented the report. No patients had been recruited so the trial was terminated.

14. ANZDATA registry: Rowan Walker has completed his term as Project Manager for Paediatrics on the ANZDATA registry. Jonathan Craig has taken over. It was agreed that Jonathan should convene a subcommittee to make suggestions on the paediatric data to be collected and that these should be circulated to members for comment.
ACTION: JONATHAN CRAIG TO CONVENE A SUBCOMMITEE OF ANZPNA AS ABOVE

15. Relationship of Assistant Secretary to IPNA to the ANZPNA executive: It was agreed that the Assistant Secretary should be co-opted to the executive during their term. Proposed John Burke, seconded Ken Jurcidini and carried unanimously.

16. New Executive for ANZPNA: Nominations for the new Executive to take over in September/October 2001 will be sent in August 2001.

should set up a bank account for IPNA Congress in 2004 because of the potential conflict of interest if Hartley Management Group set up this account. However ANZPNA would then need an ABN number and would have to complete GST paperwork. At the subsequent executive meeting following a letter from Hartley Management, it was decided that Hartley Management Group should set up the account with its Director (Graham Teague) as one signatory with two other signatories. The four people authorised to provide the two ANZPNA signatures will be Colin Jones, Ken Jureidini, John Knight and Michael Falk.

Distribution of profits from IPNA Congress 2004: In response to John Knight's argument that IPNA should state in their memorandum that ANZPNA should be entitled to keep 50% of any profits of the congress, Ken Jureidini stated that IPNA had stated that any profits should be returned to IPNA and that ANZPNA could then negotiate with IPNA for a portion of the profits.

Florence McCredie Lecture: David McCredie reported that this lecture, in honour of his mother, was usually given at the Royal Children's Hospital. In 2004, it would be organised as part of the IPNA Congress in 2004. He invited other members of ANZPNA to investigate whether their hospitals had similar lectureships, which could be used for the IPNA Congress in 2004.

Developmental Nephrology Workshop: This is scheduled to take place in the Barossa Valley before the IPNA Congress in 2004 and will be organised by Dr Robert Chevalier directly with Hartley Management Group.

Committee structure: Ken Jureidini will provide a list of the IPNA 2004 committees and the members for the ANZPNA Executive.

ACTION: KEN JUREIDINI TO PROVIDE A LIST OF COMMITTEES AND THE MEMBERSHIP TO ELISABETH HODSON.

Scientific Programme: Colin Jones reported on this. The timeline involves a review of the actions of the Seattle Scientific Programme Committee and of the IPNA 2001 Congress by March 2002, decision on scientific themes by June 2002, development of the themes by September 2002, first round of invitations to speakers by January 2003, second round of invitations by July 2003, call for abstracts in September 2003 and abstracts to be received in early 2004. The aim would be to introduce new themes and new speakers. Colin has co-opted a wider committee to review the Seattle meeting by asking members of ANZPNA and some paediatric nephrologists from Japan and other Asian countries to complete a questionnaire on individual sessions.

Marketing and publicity: All ANZPNA members should act as ambassadors for the 2004 meeting.

ACTION: ALL MEMBERS, WHO ARE ATTENDING MEETINGS, SHOULD TAKE BROCHURES ABOUT THE IPNA CONGRESS IN 2004 TO THESE MEETINGS. THE BROCHURES ARE AVAILABLE FROM KEN JUREIDINI.

The meeting closed at 5 pm.

Department of Nephrology
The Children's Hospital at Westmead
Locked Bag 4001
Westmead NSW 2145

Dr Elisabeth Hodson MBBS FRACP
Consultant Physician - Paediatric Nephrology
Telephone: 61 2 9845.3430
Fax: 61 2 9845.3432
Email: elisah@chw.edu.au
Provider no 29665AH

26th September 2001

All Members of ANZPNA

Dear Colleague,

Elections are now due for Chairman, Honorary Secretary and Honorary Treasurer of ANZPNA. The term of office for each position is 2 years. The Executive of ANZPNA also includes the immediate Past Chairman and the Assistant Secretary from ANZPNA to the IPNA. For the next 2 years Paul Roy, as immediate Past Chairman and Colin Jones as Assistant Secretary to IPNA, will remain on the Executive of ANZPNA.

I enclose a nomination form for these positions. I would be grateful if you could forward your nominations for these positions to me by 26th October 2001.

Yours sincerely,

Elisabeth

Dr Elisabeth Hodson
Secretary
ANZPNA

Dr E Hodson
Dept of Nephrology
The Children's Hospital at Westmead
Locked Bag 4001
Westmead NSW 2145

Australia and New Zealand Paediatric Nephrology Association

Nomination form for Chairman, Secretary and Treasurer of the Australian and New Zealand Paediatric Nephrology Association for 2001-2003

I (insert name of nominator) ..... nominate (insert name of nominee) ..... ,being a member of the Australian and New Zealand Society of Nephrology Association, to be:-

Chairman ☐

Honorary Secretary ☐

Honorary Treasurer ☐

(Please tick box for relevant position)

Proposed: Name: Signature:
Date:

Seconded: Name: Signature:
Date:

I (insert name of nominee) ..... ,being a member of the Australian and New Zealand Paediatric Nephrology Association, agree to be nominated to the position of:-

Chairman ☐

Honorary Secretary ☐

Honorary Treasurer ☐

(Please tick box for relevant position)

Name: Signature:
Date:

Please return completed nomination form to Dr Elisabeth Hodson at Department of Nephrology, The Children's Hospital at Westmead, Locked Bag No. 4001, Westmead, NSW 2145. Fax Number 61.2.9845.3432 by Friday October 26, 2001.

Workforce for Paediatric Nephrology
September 2001

NSW

Name	Sessions	Age range	Expected retirement age
Andrew Rosenberg	F/T	55-60	65
Elisabeth Hodson	F/T	55-60	62-65
Gad Kainer	F/T	50-55	P/T in 2 yrs; 65
Deborah Lewis	F/T	45-50	65
Jonathan Craig	0.5	35-40	65
Stephen Alexander	F/T	35-40	65
Fiona Mackie	0.6	35-40	65

Trainees: 2 (Sean Kennedy started 2001, Lee Hassam to start 2002)
Other: 1 UK trained nephrologist ? available part time in 2003. (Corinne Nevard)

Victoria

Name	Sessions	Age range	Expected retirement age
Colin L. Jones	F/T	46	65
Amanda Walker	F/T	41	65
Lilian Johnstone	0.4	40	65
Harley Powell	F/T	59	65
Rowan Walker	0.2	52	65
Richard Kitching	0.2	37	65

Trainee: 1 (Joshua Kausman. Aged 29. Completes clinical training in 12/2003. PhD studies for 3 years. Overseas 1 year. Commence as consultant in 2008)

West Australia

Name	Sessions	Age range	Expected retirement age
Ian Hewitt	F/T	53	65
Charles Crompton	3.5	45	65
Frank Willis	0	39	65

(Frank Willis is an associate in nephrology attending 1 outpatient session a fortnight, otherwise he is employed 8 sessions in emergency and general paediatrics)

South Australia

Name	Sessions	Age range	Expected retirement age
Paul Henning	F/T	48	63
Fred Jureidini	F/T	57	Part time at 60; retire 65

28th September 2001

Dear All

Just to bring up to date with ANZDATA matters.

As was decided at the last meeting of ANZPNA I have formed a working party with Lil Johnstone and Fiona Mackie. It's our job to come up with ideas for

1. change to paediatric form
2. the annual registry report
3. research

which we will then circulate to you all for consultation before any firm decisions are made. These are then "ratified" by the ANZDATA Advisory Committee (which met on 21/9/01).

Lil, Fiona and myself have discussed 1 and 2 in particular.

Re. the registry report we propose that we look at the long-term survival) outcomes for children treated for ESRD from the Registry's inception ie up to 30 years. We think this would be novel, informative and publishable. We plan to analyse for the effect of age, gender, year, treatment modality (RTx, dialysis). The question is relatively simple, but the analysis will be a bit complex.

Re. changes to the paediatric report form. We suggest stopping recording head circumference, and ROD status on the basis that it is often not filled in, never been used and very unlikely to be used. We are thinking more about what (if anything) might replace these and will let you know before any decisions are made.

Re. the outcomes of the Registry Advisory Committee, there was little of general interest, other than it will go to web-based in the next 1-2 years.

Let me know if you have any suggestions for the forms, reports, etc.

Regards

Jonathan, Lil, Fiona
(Paediatric Working Party)

Elizabeth Hodson

From: Fiona Godlee [info@biomedcentral.com]
Sent: Friday, 28 September 2001 1:12
To: Dr Hodson
Subject: BMC Nephrology Call for Papers

Dear Dr Hodson
I am writing to introduce a new peer-reviewed online journal of nephrology and to invite you to submit your next paper to it.

BMC Nephrology covers all aspects of the prevention, diagnosis, and management of kidney and related disorders. The journal is one of the 60 or so journals published by BioMed Central (http://www.biomedcentral.com/), a recently established online publishing house that is committed to making original research articles in biological and medical science freely available to all. Although we have identified you as working in the field of nephrology, if you primarily work in a different area, you will almost certainly find an appropriate BMC journal in our full list.

We believe that communication of original research is the single most important part of the scientific process and that the current publishing model is often more of a hindrance than a help to this critical activity because of the limited circulation and high costs of many journals.

BioMed Central overcomes this by making papers available online to anyone for no charge, while also having them listed in PubMed.

When you publish with BMC Nephrology (or with any of the other BMC journals) your article will be:

+ made freely available to anyone with Internet access - more people than ever will have the ability to read the results of your work

+ peer reviewed in the normal way but using the speed of the Internet to expedite the process - BMC's average time from submission to publication is currently 6.5 weeks and we aim to reduce this further

+ cited in PubMed and archived in PubMed Central, the NIH's central research repository - this will make your article easily accessible and securely archived

+ drawn to the attention of the readers of the two other BioMed Central journals that you deem to be most appropriate, by including it in their tables of contents as "related papers"

Moreover, once your article is published you will be able to see exactly how many people have accessed it.

We have started, but far from finished, putting together a world class editorial board for BMC Nephrology that includes some of the most respected researchers in the field. If you would like to suggest additional names we would certainly consider them.

Subject advisers
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Guy Neild
David Wheeler

Core reviewers

Qais-Al-Awqati

Keshwar Baboolal
Paul Cockwell
Meguid El-Nahas
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* Mitsuhiro Yanagida - Kyoto University, Japan

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Fiona Godlee
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JOURNAL OF AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

VOLUME 4, No 1. JANZPNA 2001

4th July 2001

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All Members
ANZPNA

Dear Colleague,

6th February 2001

New Assistant Secretary for IPNA

As you all know, John Burke is coming to the end of his term as Assistant Secretary representing the Australia and New Zealand Paediatric Nephrology Association on the Council of the International Paediatric Nephrology Association. His term will finish after the IPNA meeting in Seattle in September. We are now looking for nominations for a new Assistant Secretary.

I would be grateful if you would make the nominations on the nomination form enclosed with this letter. Also enclosed with this letter is a job description for the Assistant Secretary which John Burke has provided. In addition to the listed jobs, I would like to add that the Assistant Secretary provides a report to ANZPNA members following each council meeting.

Annual Meeting of ANZPNA – Sunday May 13

The Annual meeting of ANZPNA will be held on Sunday May 13, immediately before the RACP Annual Scientific Meeting in Sydney. As previously, we plan to start the Business Meeting around noon, finish it in the late afternoon and then go out to dinner somewhere. On 14th May, there will be a symposium as part of the RACP meeting on antenatal diagnosis. I understand from Louise Baur that quite a number of renally related abstracts have been received for the meeting and she will endeavour to include renal papers in the free paper sessions also on Monday 14th May. I would be grateful if you could indicate on the enclosed sheet whether you are or not likely to be coming to Sydney so that I can consider arrangements for the dinner.

CARI Guidelines

Charlie Crompton and I were invited to provide draft guidelines on the management on growth and nutrition in children for the current round of CARI Guidelines. These will be discussed at the next Dialysis and Transplant Workshop which will be held at the Crackenback Resort near Jindabyne between March 31 and April 3. Our draft guidelines will shortly be placed on the CARI web site which is at WWW.CARI.KIDNEY.ORG.AU. Charlie and I hope that you will take the opportunity to look at the draft guidelines before the workshop.

With best wishes,
Yours sincerely,

Dr Elisabeth Hodson
Secretary - ANZPNA

FILE COPY

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5th April 2001

Members of ANZPNA

Dear Member,

A ballot has been held for the position of Assistant Secretary representing the Australian and New Zealand Paediatric Nephrology Association on Council of the International Paediatric Nephrology Association. Votes were received from 26 of the 27 members of ANZPNA. Dr Colin Jones received 16 votes and therefore has been elected as the next Assistant Secretary by the majority of the members of ANZPNA

I enclose a copy of the Agenda of the Annual General Meeting on May 13th 2001. Professor John Horvath will attend the meeting at 1pm to discuss Workforce issues as they relate to paediatric nephrology.

The meeting will commence with lunch at noon and should finish by 6.30pm. Please note that there will be an overhead projector available at the meeting, but there will be no slide projector or data projector.

With best wishes,
Yours sincerely,

Elisabeth Hodson

Dr Elisabeth Hodson
Secretary
ANZPNA

2

AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

Annual General Meeting 2001

The Annual General Meeting of the Australian and New Zealand Paediatric Nephrology Association will be held on Sunday May 13, 2001 in the Harbourside Meeting Room 3, at the Sydney Convention Centre, Darling Harbour, Sydney at 12 noon.

AGENDA

1. Apologies
2. Confirmation of the Minutes from the Annual General Meeting held at Hotel Sofitel, Melbourne on March 17, 2000
3. Paediatric Nephrology Workforce issues: Discussion by Professor John Horvath
4. Report of the Chairman
5. Report of the Honorary Treasurer
6. Report of the Honorary Secretary
7. Election of new members
8. Other business
   - IPNA Council - Election of Assistant Secretary
   - IPNA Congress – Adelaide 2004
   - Report of Growth Hormone Subcommittee
   - Benchmarking
   - Report of clinical studies
     - VUR study
     - APSU nephrotic syndrome study
     - FSGS study
   - ANZ Data Registry
9. New Business
   - Relationship of Assistant Secretary to IPNA to the Executive of ANZPNA
   - New Executive for 2001 – 2003
   - Future meetings of ANZPNA
   - CARI guidelines
   - Other guidelines for children with renal failure
   - Trial of mycophenolate in childhood nephrotic syndrome
10. Any other business

Elisabeth Hodson
Honorary Secretary

May 10, 2001

Minutes of the 3rd Annual General Meeting
Sunday May 13, 2001
Sydney Convention and Exhibition Centre, Sydney
Commencing at 11 am

1. Present: Paul Roy (Chairman), John Knight, Elisabeth Hodson, Colin Jones, Harley Powell, Gad Kainer, Andrew Rosenberg, John Burke, Lilian Johnstone, Fiona Mackie, William Wong, Stephen McTaggart, David McCredie, Margot McIver, Paul Tomlinson, Ken Jureidini and Michael Falk.

2. Apologies: Jonathan Craig, Deborah Lewis, Stephen Alexander, Max Morris, Mandy Walker, David Lines, Paul Henning, Frank Willis, Charlie Crompton, Ian Hewitt, Rowan Walker.

3. Presentation by Graham Teague, Managing Director, Hartley Management Group Pty Ltd.
Hartley Management Group have been appointed as the conference organisers for the IPNA 2004 congress in Adelaide. Amanda Pearson will be the conference manager and will be responsible for the day to day organisation. To date a committee structure has been established, a draft budget developed and a time line created. Stationery, a flyer and a calendar have been produced. The flyer is available to any member of ANZPNA, who is attending a conference at which the flyers could be distributed. A sponsorship proposal has been developed and copies were circulated at the meeting. The website is operational. It will be used for on-line registration and abstract submission. It could be used to allow reviewing of abstracts on-line. Graham reported that it was essential to get a handle soon on the marketing plan. This needs to be directed to the areas most likely to have access to large numbers of potential delegates such as the IPNA Seattle meeting to prevent budget blow out. There soon needs to be a contract between Hartley Management and the congress organisers. This was discussed further later in the meeting. John Knight asked Graham how Hartley Management's work over the next 4 years would be financed. Graham said that there will be a clause to allow delayed payment from the organisers to Hartley Management included in the contract. Currently the organisers had received a loan of $15,000 from the Adelaide Convention and Tourist Authority and about $12,000 from IPNA. In addition AKF will provide $8000 at the rate of $2000 per annum.

4. Confirmation of the Minutes of the 2nd Annual General Meeting held at the Hotel Sofitel, Melbourne on March 17, 2000.

   Proposed: Andrew Rosenberg
   Seconded: Colin Jones
   Accepted unanimously

5. Report of the Chairman: Paul Roy spoke to his report (Appendix 1). Paul reported that a workforce survey had been conducted and the analysis was tabled. The results suggested that the workforce was relatively young, that women were under represented and that a significant proportion of children with renal disease in Australia and New Zealand were cared for by nephrologists, whose primary training was in adult medicine.
   Acceptance of the Chairman's Report was proposed by Lilian Johnstone, seconded by John Burke and accepted unanimously.

6. Report of the Honorary Treasurer: Michael Falk presented the report (Appendix 2). He reported that the ANZPNA had minimal reserves though enough for day to day issues. The auditor's report was not available. It was agreed that the report could be accepted provisionally on the understanding that the auditors' report would be received shortly. Provisional acceptance of the Treasurer's Report was proposed by David McCredie, seconded by Andrew Rosenberg and accepted unanimously.

7. Report of the Honorary Secretary: Elisabeth Hodson spoke to her report (Appendix 3). Acceptance of the Secretary's report was proposed by Andrew Rosenberg, seconded by Gad Kainer and accepted unanimously.

8. Election of new members: No applications had been received for membership. Lilian Johnstone asked that Dr Richard Kitching, who is both an adult and paediatric nephrologist and is working with the Monash paediatric renal service, should be considered for membership. It was agreed that a formal application should be made at the next AGM in 2002.

9. Presentation by Professor John Horvath, Chairman of Australian Medical Workforce Advisory Council. Professor Horvath was invited to the meeting by Paul Roy to tell the meeting about the AMWAC process for assessing workforce needs. The process in any specialty involves describing the existing workforce, assessing it, making projections about future workforce based on availability of specialists (trainees, expected retirements, participation), making recommendations, monitoring the effects and finally reviewing the results. He said that paediatric nephrology is one of a number of small specialties, where there would always be difficulties in balancing the workforce with workload. AMWAC had agreed that there were too many training positions in paediatrics at present but to date no attempt had been made to reduce trainee positions. He suggested that individual hospitals and then state health departments be approached to transfer some of the surplus paediatric training positions to paediatric subspecialties.

   It was agreed that the information be obtained from each state on the age of current workforce, projections on retirement and trainees and that a model for training new paediatric nephrologists be developed. This model should include rural and outreach issues, training of overseas graduates and national training schemes. Currently we are aware of three trainees, who are interested in nephrology (one at Royal Children's Hospital and two at Sydney Children's Hospital). In addition there is one fully trained UK paediatric nephrologist resident in Australia. **ACTION: UNIT HEADS TO PROVIDE ABOVE INFORMATION TO ELISABETH HODSON**

10. Council of IPNA: John Burke is to complete his term as Assistant Secretary to IPNA after the IPNA congress in September in Seattle. Nominations were called for his successor and three nominations were received. A postal ballot was held and Colin Jones was elected as the next Assistant Secretary for a term of six years. Affirmation of the ballot process and the result was proposed by Andrew Rosenberg, seconded by Ken Jureidini and carried unanimously.

11. Report of the Growth Hormone Subcommittee: The report (Appendix 4) from Charlie Crompton was presented by Elisabeth Hodson. Charlie had also circulated to ANZPNA members a copy of the paper, which reported the data on rhGH use in children with renal failure in Australia. This paper had already been submitted to Pediatric Nephrology without including the Australian members of ANZPNA as co-authors. Andrew Rosenberg felt that the paper should be withdrawn. John Knight agreed since multicentre studies are very important and all contributors must be confident that their work would be

acknowledged. Andrew Rosenberg proposed the motion – "that, since the paper had not been reviewed by the contributors and the authorship had not been listed as previously agreed, the paper should be withdrawn until these matters had been attended to". The motion was seconded by John Knight and passed unanimously.

It was agreed that John Burke, Gad Kainer and Colin Jones should develop a policy for research under the auspices of ANZPNA. Areas to be covered would include how a research protocol would be dealt with, who would review the final version of the manuscript before submission and how authorship would be dealt with. **ACTION: JOHN BURKE, GAD KAINER, COLIN JONES TO DEVELOP POLICY**

12. Benchmarking: Lilian Johnstone presented the results of the benchmarking project to date. The project involved data collection on arterio-venous access and central venous access for haemodialysis, peritoneal dialysis and renal biopsies (Appendix 5). Data collection commenced in September 1999 and will finish in September 2001. The data will then be collated and prepared for publication. It was agreed that the data would be presented as the mean and 95% confidence intervals for each parameter. The data collected so far would be circulated to the individual centres, who would be informed which part of the data belonged to their centre. Lillian asked that each centre check the data and also send any outstanding data forms to her by September.
ACTION: ALL UNIT HEADS TO ENSURE THAT DATA FORMS ARE FORWARDED TO LILIAN BEFORE SEPTEMBER 2001

13. Reports of clinical studies:
    Multicentre double-blind placebo controlled trial of chemoprophylaxis in children with isolated vesicoureteric reflux. (Appendix 6).
    Elisabeth Hodson presented the report from Jonathan Craig. Patient recruitment has been completed and final follow up will be completed in October 2001.
    Epidemiology of childhood nephrotic syndrome. (Appendix 7).
    Elisabeth Hodson presented the report. Patient ascertainment will be completed in June 2001. It was requested that all efforts be made to notify new cases and to remind paediatric colleagues to notify patients.
    Randomised controlled trial of cyclophosphamide in the treatment of focal and segmental glomerulosclerosis. (Appendix 8).
    Stephen McTaggart presented the report. No patients had been recruited so the trial was terminated.

14. ANZDATA registry: Rowan Walker has completed his term as Project Manager for Paediatrics on the ANZDATA registry. Jonathan Craig has taken over. It was agreed that Jonathan should convene a subcommittee to make suggestions on the paediatric data to be collected and that these should be circulated to members for comment.
ACTION: JONATHAN CRAIG TO CONVENE A SUBCOMMITEE OF ANZPNA AS ABOVE

15. Relationship of Assistant Secretary to IPNA to the ANZPNA executive: It was agreed that the Assistant Secretary should be co-opted to the executive during their term. Proposed John Burke, seconded Ken Jureidini and carried unanimously.

16. New Executive for ANZPNA: Nominations for the new Executive to take over in September/October 2001 will be sent in August 2001.

17. Future meetings of ANZPNA: It was proposed by Elisabeth Hodson and seconded by Ken Jureidini that the Annual General Meeting of ANZPNA should be held in conjunction with the Annual Scientific Meeting of ANZSN and in general should follow the ANZSN meeting. The motion was passed unanimously. It was also decided that ANZSN should be approached to include a symposium on a paediatric nephrology topic and organised by members of ANZPNA on the last day of the ANZSN meeting. In addition ANZPNA would offer to organise future symposiums at the RACP meeting. In 2002 the ANZSN meeting will take place in Sydney from August 26 to August 30. These dates include the Postgraduate Meeting and do not clash with the ESPN meeting, which starts on September 20.

18. CARI guidelines: John Knight reported that there would be some changes in the way these have been set out following the Dialysis and Transplant Workshop in April 2001. In particular only those interventions with appropriate levels of evidence will be called guidelines. The ANZDATA form should be used to audit the implementation of the guidelines. John reported that it was decided at the Workshop to endorse the concepts of living donor to cadaveric pool donation and of swaps of kidneys between families, where for example potential donors were blood group incompatible with their potential recipients but was blood group compatible with the potential recipient of the other family. It was suggested that the guidelines written by members of ANZPNA be circulated to ANZPNA members for comments. Elisabeth Hodson pointed out that the guidelines were available to all ANZPNA members through the CARI website, which can be accessed on www.CARI.kidney.org.au.

19. Other guidelines for children with renal failure: This item was withdrawn.

20. Trial of mycophenolate (MMF) in childhood nephrotic syndrome: Ken Jureidini presented a proposal to perform a randomised controlled trial of MMF in frequently relapsing steroid responsive nephrotic syndrome (Appendix 9). John Knight and Andrew Rosenberg raised doubts about whether MMF was a suitable medication to trial. It was agreed that Ken should contact Dr Stan Jordan, who is thought to be running a trial on MMF, to find out more about the trial. Ken will then discuss the trial further with Steve Alexander and Steve McTaggart before reporting back to the Executive. **ACTION: KEN JUREIDINI TO CONTACT STAN JORDAN**

21. Kidney Kids Camp: Lilian Johnstone reported that South Australia and Victoria would hold a Kidney Kids camp every 18 months in alternate states. This is supported by the AKF. Elisabeth Hodson reported that New South Wales would continue to hold a camp annually in April. This also supported by the AKF.

22. IPNA Congress 2004 (Appendix 10):
    Sponsorship: AKF and Gambro have contributed $23,000. Since the AGM, Ken Jureidini has learnt that Fresenius will be a Premium Sponsor ($50,000)
    Contract with Hartley Management Group: There was considerable discussion as to whether the contract with Hartley Management group should be between ANZPNA and Hartley Management Group or between IPNA and Hartley Management Group. If the former was to occur, ANZPNA would require a letter from IPNA stating that IPNA would underwrite the 2004 congress. Since the AGM, John Burke has talked with Mattias Brandis, Treasurer of IPNA, who felt that the contract should be between ANZPNA and Hartley Management Group. John Burke, Colin Jones and Ken Jureidini are to discuss this at the IPNA Council meeting in New York in June 2001. A draft contract is now available. It was suggested that a legal opinion be obtained on this contract.
    Bank account for IPNA Congress 2004: There was discussion on whether ANZPNA

should set up a bank account for IPNA Congress in 2004 because of the potential conflict of interest if Hartley Management Group set up this account. However ANZPNA would then need an ABN number and would have to complete GST paperwork. At the subsequent executive meeting following a letter from Hartley Management, it was decided that Hartley Management Group should set up the account with its Director (Graham Teague) as one signatory with two other signatories. The four people authorised to provide the two ANZPNA signatures will be Colin Jones, Ken Jureidini, John Knight and Michael Falk.

Distribution of profits from IPNA Congress 2004: In response to John Knight's argument that IPNA should state in their memorandum that ANZPNA should be entitled to keep 50% of any profits of the congress, Ken Jureidini stated that IPNA had stated that any profits should be returned to IPNA and that ANZPNA could then negotiate with IPNA for a portion of the profits.

Florence McCredie Lecture: David McCredie reported that this lecture, in honour of his mother, was usually given at the Royal Children's Hospital. In 2004, it would be organised as part of the IPNA Congress in 2004. He invited other members of ANZPNA to investigate whether their hospitals had similar lectureships, which could be used for the IPNA Congress in 2004.

Developmental Nephrology Workshop: This is scheduled to take place in the Barossa Valley before the IPNA Congress in 2004 and will be organised by Dr Robert Chevalier directly with Hartley Management Group.

Committee structure: Ken Jureidini will provide a list of the IPNA 2004 committees and the members for the ANZPNA Executive.

ACTION: KEN JUREIDINI TO PROVIDE A LIST OF COMMITTEES AND THE MEMBERSHIP TO ELISABETH HODSON.

Scientific Programme: Colin Jones reported on this. The timeline involves a review of the actions of the Seattle Scientific Programme Committee and of the IPNA 2001 Congress by March 2002, decision on scientific themes by June 2002, development of the themes by September 2002, first round of invitations to speakers by January 2003, second round of invitations by July 2003, call for abstracts in September 2003 and abstracts to be received in early 2004. The aim would be to introduce new themes and new speakers. Colin has co-opted a wider committee to review the Seattle meeting by asking members of ANZPNA and some paediatric nephrologists from Japan and other Asian countries to complete a questionnaire on individual sessions.

Marketing and publicity: All ANZPNA members should act as ambassadors for the 2004 meeting.

ACTION: ALL MEMBERS, WHO ARE ATTENDING MEETINGS, SHOULD TAKE BROCHURES ABOUT THE IPNA CONGRESS IN 2004 TO THESE MEETINGS. THE BROCHURES ARE AVAILABLE FROM KEN JUREIDINI.

The meeting closed at 5 pm.

Australian and New Zealand Paediatric Nephrology Association
Report of the Chair
May 13 2001

The past year has seen considerable progress in the planning for the 2004 IPNA Scientific Meeting in Adelaide. Details will be presented by Dr Ken Jureidini during the Annual General Meeting and in a separate meeting on the same day. I was able to promote the Meeting during the 23rd Paediatric Nephrology Seminar organised by Dr Jose Strauss , University of Miami in February this year.

Dr Colin Jones submitted an Interim report on benchmarking compiled by Dr Lillian Johnstone and Vicki Burns. A further report was anticipated for the current AGM.

An initial Workforce Survey was conducted. The analysis is tabled. From the results it appeared that the membership was relatively young but women appeared under represented. A significant proportion of children with renal disease in Australia and New Zealand continue to be cared for by nephrologists whose primary training and clinical activity is adult medicine. Professor John Horvath AO, Chairman AMWAC has agreed to attend the AGM and discuss matters related to workforce and the calculation of future workforce requirements.

The issue of continued PBS support for supply of Growth Hormone to children with chronic renal failure seems to be resolved favourably.

The Association was invited by Dr Jill Sewell, President, Paediatrics and Child Health Division, RACP to submit a report to RACP News and this was done.

Dr Jonathan Craig has been appointed Project Manager, Paediatrics, to ANZDATA Registry to succeed Dr Rowan walker.

Following a ballot, the Association has nominated Dr Colin Jones as Assistant Secretary to IPNA to succeed Dr John Burke.

A Seminar supported by the Association on "Management of Antenatally Diagnosed Renal Disorders" will be presented at the Annual Scientific Meeting RACP this week.

A meeting of the Executive was held by Teleconference on 25 October 2000.

The term of the members of the current Executive expires in October 2001. It would seem more efficient if the members of the new Executive, with the exception of the Chair who becomes immediate past Chair for two years, were elected at the second AGM of each current Executive and assume office at the conclusion of that meeting. I propose to move that this procedure be adopted except for unusual circumstances.

L Paul Roy, Chair, ANZPNA

Analysis of workforce questionnaire
Australian and New Zealand Paediatric Nephrology Association

Membership at the time of questionnaire 28

Forms returned 23 (all completed)

Sex		Age	
Female	6	30-40	5
Male	16	40-50	8
		50-60	7
		60-70	3

Nature of Paediatric Nephrology Practice

Hospital Salaried	Full Time 18	Part time 5
Private Practice	Full Time 0	Part time 0

Full time Paediatric Nephrology

Number 13

Hours worked

40	2
50	3
60	6
70	1
80	0

Greater than 50% time spent in patient care 11

Part time Paediatric nephrology

Number 10

Hours worked

10	3
15	1
20	3
25	1
30	2

Greater than 50% time spent in patient care 7

Work Content

Greater than 50% time spent in

Paediatric Nephrology	2
General Nephrology	5
General Paediatrics	1
General Medicine	
Other	1

Extramural activities

Regular outreach clinics 9

ANZPNA Annual General Meeting

2001

Treasurers Report

Overview
The funds of the society are adequate for day to day issues.

There are minimal reserves.

At present no strategic plan for changing that is in place

There is no clear relationship between the IPNA Meeting and ANZPNA funds.

Financials

Subscription 2001	($105)	
Subscription 2001	(due)	
Assets 2000	$2,923.40	Commonwealth Bank Ac # 1034 0611 BSB 2908
Assets 2001	$5,498.14	

Auditor's Report

Mr Keith Austin's report was not available for this meeting

Michael Falk
Honorary Treasurer

Appendix 3

Australian and New Zealand Paediatric Nephrology Association
Honorary Secretary's report for Annual General meeting on May 13, 2001

Professor Rowan Walker stood down during the year as Project Manager for Paediatrics on ANZDATA Registry Advisory Committee. On the advice of ANZPNA, Dr Jonathan Craig was offered the position of Project Manager for three years (2001 – 2003 inclusive) by the Dialysis and Transplant Subcommittee. Dr Craig has accepted the position.

Dr John Burke will complete his term as Assistant Secretary representing the Australian and New Zealand Paediatric Nephrology Association on the Council of the International Paediatric Nephrology Association after the IPNA congress in Seattle in September 2001. Nominations for this position were sort from members of ANZPNA. Since three nominations were received, a postal ballot was held and Dr Colin Jones was elected as the new Assistant Secretary and will serve a term of 6 years.

ANZPNA has organised and sponsored a symposium on pre- and postnatal management of antenatally detected urinary tract abnormalities at the ASM of the RACP. The speakers will be Professor David Ellwood, Dr Gad Kainer and Dr Peter Borzi. Professor Paul Roy will chair the symposium. I would like to thank Associate Professor Louise Baur and Maureen Pang from The Meeting Planners for their help in organising this symposium. ANZPNA needs to consider at this AGM whether it wishes to continue to hold its business meeting to coincide with RACP and ANZSN annual scientific meetings on alternate years and whether it wishes to sponsor symposia at future meetings of either RACP or ANZSN.

The current executive will complete its term of office in October 2001. Nominations will be sort in August for the positions of Chairman, Honorary Secretary and Honorary Treasurer.

Elisabeth Hodson

Appendix 4

The 2000-2001 report from the Growth Hormone Subcommittee of ANZPNA

Dr Charlie Crompton

All members will have received the updated rhGH guidelines from the Commonwealth Growth Hormone Program, indicating the addition of marketing approval for Norditropin and Humatrope for the treatment of growth failure in children with CRF.

The report of rhGH use in Australian children with chronic renal disease has been completed (!) and sent to Chris Cowell to be included in the next OZGROW Annual Report, and has also been submitted to 'Paediatric Nephrology". (attached)

The Subcommittee has not met in the last 12 months, and as the rhGH PBS issue has been resolved, I would suggest that the subcommittee no longer needs to exist.

Appendix 5

BENCHMARKING – INTERIM REPORT MAY 2001

Arteriovenous Access

5 centres contributed

1. Number of interventions

Total number of interventions: 49
Total number of children having interventions: 25

	A	B	C	D	E
Number of interventions	7	6	9	2	25
Number of children	2	5	8	2	8
Age (μ) (yr)	19.1	15.4	11.4	17.5	15.9
Weight (μ) (kg)	34.3	39.9	40.1	67	48.1

Number of interventions per child

	A	B	C	D	E
1		4	7	2	1
2	1	1	1		2
3					4
4					1
5	1				
Mean	3.5	1.2	1.1	1	3.1

Type of intervention

	A	B	C	D	E
Total	7	6	9	2	25
Creation	5	5	8	2	13
AVF	3	4	6	2	1
Graft	2	1	2		12
Removal/manipulation	2	1	1		12

Reason for removal/manipulation

	A	B	C	D	E
Infection	2				2
Stenosis		1			3
Clotted			1		8

Aneurysm 1

NB. One patient at centre A had AVF created with immediate thrombosis but no subsequent intervention. Patient at Centre C also recorded transplant on data sheet - ? concurrent.

AV Fistula - Site

	A	B	C	D	E
n	3	4	6	2	1
R/L	0/3	2/2	2/4	1/1	0/1
Radial	1	3	5	2	
Brachial	2	1	1		
Other					1 (basilic V)

AV Graft - Site

	A	B	C	D	E
n	2	1	2	0	12
PTFE	2	1			12
Thoratec			2		
R/L	0/2	1/0			1/11
Arm/Leg	0/2	1/0	0/2		6/6

Previous AV access

	A	B	C	D	E
Patients (n)	2	5	8	2	8
Patients with previous access (n)	2	2	1	0	5

Access creation

All AV access is created by a vascular surgeon. One centre reports access created by vascular surgeon and transplant surgeon ? one and the same.

Use of aspirin and warfarin

Warfarin was not used in any centre.

Aspirin was used as shown below

	A	B	C	D	E
Aspirin use (n)	0	5	0	0	0

Appendix 5

BENCHMARKING – INTERIM REPORT MAY 2001

Central venous Catheters

6 centres contributed data.
Total number of interventions: 73
Total number of children: 21

	A	B	C	D	E	F
Intervention (n)	16	28	13	3	6	7
Patients (n)	5	7	3	2	2	2
Age (μ) (yr)	6.9	9.7	16	3.75	12.3	10.5
Weight (μ) (kg)	20.4	28.3	46.9	13.7	38.2	22

Number of interventions per child

	A	B	C	D	E	F
1	2		1			
2		1	1	1	1	
3	1	2		1		1
4		1			1	1
5		2	1			
6		1				
7	1					

Type of intervention

	A	B	C	D	E	F
N	16	28	13	3	6	7
Insertion (n)	11	16	7	2	3	4
Removal (n)	5	12	6	1	3	3

Catheter type

	A	B	C	D	E	F
n	11	16	7	2	3	4
Cuffed (n)	10	9	0	2	3	4
Straight (n)	9	10	4	*	3	3

Double lumen (n)	9	11	7	1	3	3
Side (R/L)	5/6	8/8	3/4	2/0	1/2	2/2

Average time to first use

	A	B	C	D	E	F
Same day	1	7	3	1	2	
Next day	8	7	2	1	1	4
> 2 days	2	2	1			
Not used			1			

Insertion of CVC

	A	B	C	D *	E	F
Vascular surgeon					1	
General surgeon	2			1		
Transplant surgeon		5			2	
Paed Urologist	4					
Gen Paed Surgeon	8	5				4
Anaesthetist	1	6	7			

NB. Centre A indicated that general paediatric surgeon and paediatric urologist inserted CVC on 4 occasion.

External suture

	A	B	C	D	E	F
Yes (n)	9	5	0	2	1	4

Radiological confirmation prior to use

	A (n=11)	B (n=16)	C (n=7)	D (n=2)	E (n=3)	F (n=4)
Yes (n)	10	9	6	2	3	4

Testing for Staph. aureus

	A	B	C	D	E	F
Tested (n)	0	2	0	1	0	0
Present (n)		2		0		

Treated (n)	0	

Previous CVC

	A	B	C	D	E	F
Yes (n)	2	1	3	2	2	1

N=number of children

Heparin lock

	A	B	C	D	E	F
1000 U/ml	3	5		2		
2500 U/ml		11				
5000U/ml	8		6		3	4

Removal of CVC

	A	B	C	D	E	F
n	5	12	6	1	3	3
Infection		4				1
Transplantation	1		1		1	
Malposition	2	4			2	
Permanent HD access		1	1			1
Peritoneal dialysis				1		
Other	2 Temp CVC, split	3 fell out, split, poor flow	4 inadequate flows			1 thrombosis

Appendix 5

BENCHMARKING – INTERIM REPORT MAY 2001

Peritoneal Dialysis

6 centres contributed data
Total number of interventions: 74
Total number of children: 37

	A	B	C	D	E	F
Intervention (n)	21	4	19	12	5	13
Patients (n)	9	2	14	6	3	3
Age (μ) (yr)	6.25	4	9.9	8	0.9	8.2
Weight (μ) (kg)	21.3	13.8	31.2	31.8	9.32	19.7

Number of interventions per child

	A	B	C	D	E	F
1	5	1	9	1	1	
2		1	5	4	2	1
3	1			1		
4	3					
5						1
6						1

Type of intervention

	A	B	C	D	E	F
n	21	4	19	12	5	13
Insertion (n)	12	2	14	6	3	7
Removal/Manipulation (n)	9	2	5	6	2	6

Catheter and omentectomy

	A	B	C	D	E	F
Straight (n)	12	*	8*	6	2*	7
Double cuff (n)	12	2	13 *	0	3	7
Omentectomy (n)	3	1	4	5	2	4

Timing of dialysis

	A	B	C	D	E	F
Flushed to clear	12	1	3	6	3	6
Rested	4	1	12	3	2	2
Immediate dialysis	8		1	3	1	5

Catheter site

	A	B	C	D	E	F
Pre op determination	1	1	2	0	1	0
Direction						
Superior	4	1	2			
Inferior				6	2	1
Medial			1			
Lateral	6	1	10	6	1	5

Staph aureus testing

	A	B	C	D	E	F
tested	0	1	3	0	3	2
positive		0	1		1	1
treated			0		1	0

Mode of dialysis

	A	B	C	D	E	F
APD	12	2	8	2	*	4
CAPD			2	2	1	3
Didn't start			1			

Removal of catheter

	A	B	C	D	E	F
N	9	2	5	6	2	6
Peritonitis	1		3	1		
Catheter track infection		1				
Exit site						

infection						
Hernia						
Cuff extrusion				1		
Malposition	2					1
Change modality				1		
Transplant	3		3	1		
Other	3, poor flow (2), bladder augmentation	1 pleural leak		2 return of function	2 return of function, death	4 blocked (2), stitch hole, abdo prolapse of prox cuff

A multicentre double-blind placebo controlled trial of chemoprophylaxis in children with isolated vesicoureteric reflux

Progress Report
May 2001

Background

The term 'Reflux Nephropathy' refers to the long held belief that vesicoureteric reflux (VUR) leads to urinary tract infection and then to renal damage. Clinicians have therefore attempted to prevent the onset and development of this damage by early identification of those with asymptomatic VUR and treatment of these individuals with chemoprophylaxis and /or surgery. As outlined in the protocol, this theory is not always supported by the clinical data observed. VUR and renal parenchymal damage may not be causally related and appear to exist separately, as well as together. Randomised trials to date have not evaluated a control arm of placebo treatment compared to chemoprophylaxis or surgery. This trial will compare the outcome of children with and without conventional treatment (chemoprophylaxis).

Hypothesis and Aims

The investigators postulate that the renal parenchymal abnormality associated with VUR is congenital and is therefore not altered by postnatal events such as persistent VUR or urinary tract infection.

The study aims to ascertain:

1. if the outcomes are altered by chemoprophylaxis.

2. the prevalence of renal parenchymal damage in newborn children with VUR prior to the onset of symptomatic infection.

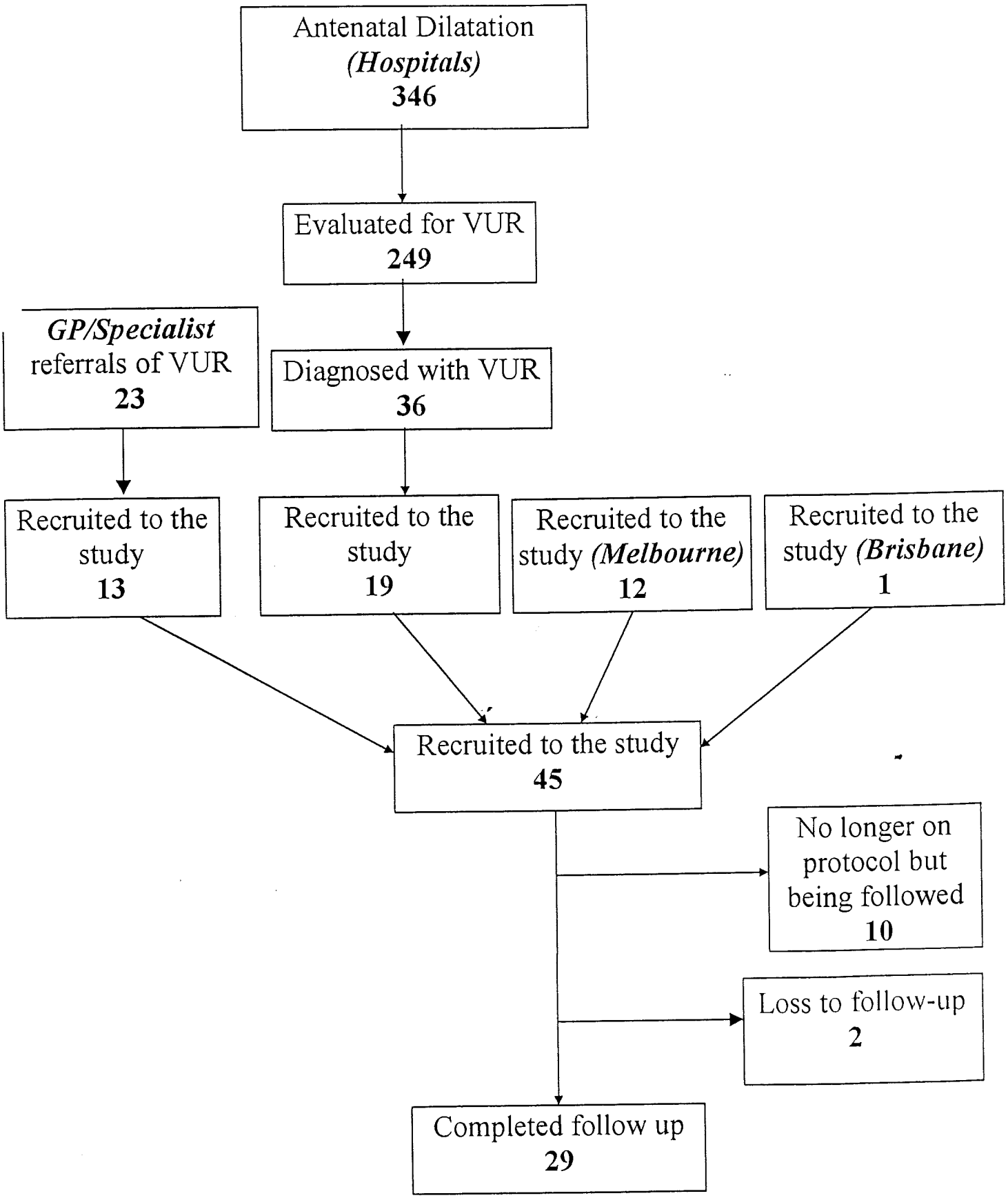
3. the natural history and clinical outcomes of VUR as measured by the incidence of urinary tract infection, the development of the glomerular filtration rate, blood pressure, renal growth and the onset of renal damage.

Progress to date

Since its commencement in 1995, this study has screened 346 children with a diagnosis of antenatal renal pelvicalyceal dilatation or a family history of VUR. Of these children, 249 have undergone postnatal evaluation of VUR. The prevalence of VUR in this sample is 14% (36/249). Of the children diagnosed with VUR, 17 were either ineligible for the study or declined participation. Nineteen (14 males, 5 females) children enrolled in the study.

A further 26 children have been recruited to the study through both private referrals (13), and the Melbourne (12) and Brisbane (1) Centres. To date, twenty-nine children have completed follow up, ten are no longer on the protocol but are being followed, and 2 children have been lost to follow up. No child with renal damage at entry has demonstrated progression of damage, nor has new damage been demonstrated in previously normal kidneys. Three children have been diagnosed with a urinary tract infection.

Figure 1: Recruitment to date



Appendix 7

Report on the progress of the study on the epidemiology of childhood nephrotic syndrome through the APSU.

Elisabeth Hodson, Narelle Willis and Jonathan Craig

Childhood nephrotic syndrome has been listed on the APSU card since July1, 1998 and will continue to be listed till June 30, 2001. The last follow up questionnaires will be sent out in July 2002. We should be able to consider writing up the incidence data and the initial management data by the end of 2001.

Between July 1, 1998 and December 31, 2000, 186 notifications of nephrotic syndrome were received. Of these 104 were confirmed cases of idiopathic nephrotic syndrome and 4 had congenital nephrotic syndrome. Twenty-three were duplicate reports, 48 notification errors and 11 questionnaires were not returned. A 94% return rate of initial questionnaires has been achieved.

The incidence of idiopathic nephrotic syndrome in Australia and in individual states is shown in the table below. There are no significant differences between states though incidence varies in the bigger states between 1.24 per 100,000 in NSW to 0.68 per 100,000 in South Australia. There is no significant difference in incidence between sexes. As expected the incidence decreases significantly with age.

Table x Geographic incidence of idiopathic nephrotic syndrome in Australia

State	Number	Incidence
NSW/ACT	42	1.24 (0.92-1.67)
VIC	26	1.09 (0.73-1.56)
QLD	16	0.86 (0.50-1.35)
SA	5	0.68 (0.22-2.11)
WA	12	1.21 (0.63-2.11)
TAS	3	1.18 (0.24-3.40)
NT	0	no reported cases
Australia	**104**	**1.07 (0.88-1.28)**

Incidence per 100,000 (95% CI) children aged below 15 years 1998 ABS figures

The responses to questions on initial management have been analysed and will be presented at the RACP meeting. The majority of children (92%) with idiopathic nephrotic syndrome were treated initially with prednisolone or prednisone at a dose of 2 mg/kg/day or 60 mg/m^2/day, given as a single daily dose (69%). Forty-two percent children received daily steroids for 4 weeks. Thirty nine percent children received daily steroids till they achieved remission (34) or for 2-3 weeks (6). The remainder received longer periods (6-12 weeks) of daily steroids.

We continue to worry about the completeness of case ascertainment and the number of notifications where the notifying physician fails to complete the initial questionnaire. In addition many questionnaires are incomplete. Please could you all remember to notify new cases and complete the questionnaires. Also please could you encourage your general paediatric colleagues to notify new cases and complete the questionnaires.

ROYAL CHILDREN'S HOSPITAL
ETHICS IN HUMAN RESEARCH COMMITTEE
MONITORING OF APPROVED PROJECTS
FINAL REPORT

THIS FORM MUST BE TYPEWRITTEN

It is a Commonwealth requirement that all investigators undertaking research approved by an Institutional Ethics Committee submit a final report once the research has been completed. Please complete this report carefully, as this information will be used to provide research summary reports.

EHRC REFERENCE NUMBER: **EHRC 99019A**

PROJECT TITLE: Randomised controlled trial of cyclophosphamide in the treatmentof focal segmental glomerulosclerosis

INVESTIGATOR(S)	DEPARTMENT	EXTENSION
Dr Steven McTaggart	Department of Nephrology	5054
DR Colin Jones	Department of Nephrology	5054

Please provide the following information :

1) Date of project completion

30/8/00

2) Was the number of subjects enrolled over the duration of the study the same as that originally approved?
   - If not, indicate why.

See below – Section (4)

3) Please outline any unforeseen events since the last annual report (or since the commencement of the project if less that 12 months in duration).

Nil

4) Please outline any delays in the progress of the research that were not anticipated at the time of ethical approval.

The aim of the project was to assess the efficacy of cyclophosphamide in the treatment of focal segmental glomerulosclerosis, after induction of remission using cyclosporin. As patients treated with cyclosporin relapse almost immediately after being taken off the drug, only a small number of patients (9 patients) were required to

show a statistically and clinically significant difference in the treatments. Our preliminary discussions amongst the nephrologists involved in the trial (all paediatric nephrologists throughout Australia participated) suggested that this would be an attainable goal.

However, during the year over which the study has been in progress there have been **no** patients recruited. Neither of the Chief Investigators has been informed of a single patient with this condition. The reasons for this lack of patients appears to be multifactorial but includes;

(1) The heterogenous nature of FSGS. A 'standard patient' that we wished to recruit for the study is unusual. In practice, there are often subtle clinical issues surrounding the treatment and care of these patients which requires an individualised approach, rather than the restrictions imposed by a formal trial regimen.

(2) A shift in treatment for this condition, with longer courses of steroid being used before considering the patient for alternative therapies.

(3) Lack of Referral. This is a potential problem in all large multicentre trials. The trial was well advertised throughout the year, at meetings and by way of a newsletter, and we believe that everything possible was done to ensure adequate knowledge of the trial by all participants.

We cannot identify any systematic problem that may have led to poor recruitment and is thus amenable to change. Therefore, given the lack of recruitment over the first year of the trial, and the likely inability to reach our required sample size over the next year of the trial, we have elected to cease the trial. As no patients have been recruited, no patients need to be notified of the outcome and there are no patient records to be kept.

5) What were the major outcomes of the project ? Did they prove your theory/hypothesis?

N/A

6) Will these outcomes have a cross-disciplinary impact ?

N/A

7) Has or will this study lead to changes in practice, and/or, further research ?

No

8) Do you anticipate writing up your research in a journal ? Please provide details for submitted and published articles. If you do not intend to write up the research, please indicate why.

No. No results

9) Do you intend to apply for a grant to undertake related or further research in this field ?

No

I affirm that the information I have provided is to the best of my knowledge true and accurate:

Chief Investigator.....

Steven McTaggart Colin Jones

Date.....30/8/00.....

Women's and Children's Hospital
ADELAIDE

Appendix 9

72 King William Road
North Adelaide
South Australia 5006
Telephone: (08) 8204 7000
Facsimile: (08) 8204 7459
Web: http://www.wch.sa.gov.au

MYCOPHENYLATE MOFETIL IN THE MANAGEMENT OF NEPHROTIC SYNDROME

Management of frequently relapsing Nephrotic Syndrome can often pose quite a therapeutic challenge. Various modalities of treatment are available for maintaining remission but response can be variable with potentially serious side effects. Mycophenylate mofetil is the 2 morpholino-ethyl ester of mycophenolic acid. It acts by selective, uncompetitive and reversible inhibition of guanosine nucleotide synthesis. It has a more potent cytostatic effect on lymphocytes than to other cells. It has been widely used as an immunosuppressant post transplantation(1,2) and in various diseases considered to have an autoimmune component (lupus erythematosis, scleroderma, dermatomyositis, chronic severe polyarthritis, chronic active hepatitis, myasthenia gravis, thrombocytopenic porpura) (3). It has recently been reported to result in improvement in proteinuria in patients with adult onset immune-mediated glomerular disease (4,5). Its use in the management of children with Nephrotic Syndrome is promising and needs further evaluation.

AIM: Randomly selected Contolled trial to study the efficacy of mycophenylate mofetil as against Cyclosporin A in children with frequently relapsing Nephrotic Syndrome.

METHODOLOGY: (For Discussion)

1. **Selection of patients**:
   - ?All children with Steroid Dependent or Resistant Nephrotic Syndrome with at least 3 or more relapses on steroids or other forms of therapy in the last 2 years.
   - ?Previous treatment with Cyclophosphamide a necessity.
2. **By random allocation:**
   - mycophenylate using a dosage of 600mg/m2 bd
   - alternatively Cyclosporin A 2.5-6 mg/kg/day.
   - Those patients who had already received Cyclosporin
     - ?to be excluded?
     - ?continue same treatment
     - ? half change to mycophenylate.
3. **Dose of steroids at time of initiation of study**:
   - ?1 mg/kg/day or alternate day therapy
   - ? for how long.
4. **Baseline tests** to include full blood count, electrolytes, urea, creatinine, LFT and lipid profile. Early morning urine to be be tested for ACR.
5. ? **Biopsy** a prerequisite at beginning of study
6. ? **Biopsy** at completion of treatment.

7. ? **Multicentric trial using patients from Hospital in Southern India**:
   - Need Novartis to sponsor Cyclosporin A
   - ? Do without CyA if not available and use only Mycophenylate as a related study.

8. **Monitor the patient's progress** clinically as well as biochemically. Acute adverse reactions include diarrhoea, vomiting and sepsis. Certain infections like tuberculosis and atypical mycobacterial infections and meningitis and infective endocarditis have been reported.

9. **Complete blood count** to be performed weekly during the first month, twice monthly for the 2nd & 3rd months and then montly throughout the first year. If neutropenia develops, (ANC < 1.3 x 10^9/l) the dose to be interrupted and the patient to be carefully observed. Serum creatinine, urea, LFT and cholesterol also to be monitored as well as early morning urine testing for ACR - once in 2 months.

10. ?**Therapeutic efficacy** to be reassessed at the end of 2 years.

REFERENCES:

1.Schwarz A (2001) New aspects in the treatment of nephrotic syndrome. J Am Soc Nephrol Feb12: (Suppl 17) S44-47.

2.Miller G, ZimmermanR 3rd, Radhakrishnan J, Appel G (2000) Use of mycophenylate mofetil in resistent membraneous nephropathy. Am J Kidney Dis Aug; 36 (2): 250-256

3.MartinacA,ZorcB(1999)Immunosuppressants.FarmaceutskiGlasnik;55(12):445-453

4.ChandraM,Susin M, Abitbol C Remission of relapsing childhood nephrotic syndrome with mycophenylate mofetil. Pediatr Nephrol Mar;14 (3): 224-226

5.Lazarov V ,Rapondjievava A, Shipkova M, Michailova A, Naumova E,Tishkov I, Nikolov D,Oellerich M (1999) Treatment with mycophenylate mofetil of patients with immune nephropathies.Nephrol Dial Transplant 5(1): 18-21

IPNA Council Meeting New York:

- June 8-10. To be attended by John, Colin & Ken

Website:

- www.ipna2004.com
- ?SA Tourism Minister support

Pamphlet:

- This has been circulated and printed copy circulated at meeting. It has been through several drafts and finished off by our graphic artist.

Prospectus:

- Also circulated by email and hard copy circulated at meeting.

Sponsorship:

- AKF – Premium Sponsor Status: $8,000
- Gambro – Major Speaker $15,000
- Fresenius
- Baxter
- NEC
- Amgen
- Bayer
- UMP

Finance:

- Michael Falk to report

Airlines:

- Potentially attractive deal being negotiated with Qantas

Contract with Hartley Management Group

IPNA Calendar:

- To be updated to leave out 2000 and Easter Sunday

Convention Centre:

- Enlargement on time

Developmental Nephrology Workshop

Committee Structure:

- Each of the committees will meet before the ANZPNA on Sunday (timetable to be advised)

ANZSN:

- Kym Bannister and Randall Faull to act as local representatives

Scientific Program:

AUSTRALIA AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

The teleconference for the Executive of the ANZPNA will be held on Wednesday May 30, 2001 at 4 pm.

AGENDA

1. Confirmation of the Minutes from the meeting of the executive on October 18, 2000
2. Business arising from the Minutes:-
   IPNA Congress in 2004
   Memorandum of understanding/contract with IPNA/Hartley Management
3. New business:-
   Request by Dr Chevalier re ANZPNA sponsorship for two Australian trainees to attend Developmental Workshop in Victoria, Canada at US$1000 each.

   Alliance of Paediatric Special Interest Groups with Paediatrics and Child Health Division of RACP.

   Office Bearers Liability Insurance for ANZPNA
4. Any other business

Elisabeth Hodson
Secretary
ANZPNA

Australia and New Zealand Paediatric Nephrology Association

Minutes of the meeting of the Executive of ANZPNA held on Wednesday May 30, 2001 at 4 pm by teleconference.

1. Present: Paul Roy (Chair), John Burke, Colin Jones, Ken Jureidini

2. Minutes of the previous meeting of the Executive held on October 18, 2000: These were confirmed as a correct record.

3. Business arising from the Minutes:-

   3.1 IPNA Congress for 2004: Information on a possible contract between ANZPNA and Hartley Management and on a formal quotation on the costs of the conference management service were provided for the meeting by Graham Teague of Hartley Management Group Pty. Ltd. It was agreed that IPNA would be asked to support the Contract between ANZPNA and Hartley Management and to provide a letter to ANZPNA stating that they would underwrite the Congress. John Burke, Colin Jones and Ken Jureidini would take this request to the IPNA Council meeting in New York in June 2001.

   3.2 Financial arrangements for IPNA 2004: In the event that the proposed financial arrangements between IPNA and ANZPNA for IPNA 2004 were approved by IPNA, it was agreed that the Hartley Management Group would set up a bank account for ANZPNA with the Director of Hartley Management Group as signatory and two of four members of ANZPNA as second and third signatories. In this way Hartley Management Group would be responsible for GST reporting. Payment of accounts for IPNA 2004 would be through a formal process of one signatory approving the invoice for payment and two others signing the cheque. It was agreed that the signatories would be Colin Jones, Ken Jureidini, Michael Falk and John Knight.

   3.3 ANZPNA internal mechanisms: It was agreed that the ANZPNA would formalise the IPNA Committee (or Committees) as sub-committee(s) of the main body and give it authority to manage the Conference, including allowing that (those) Committee(s) to enter into contracts as required.

   3.4 Other issues for IPNA 2004: Ken Jureidini reported that he was hoping to get a special deal on flights to Adelaide through Qantas. Fresenius are to be Premium Sponsors of IPNA 2004 so will provide $50,000.

4. New business:-

4.1 Request by Dr Chevalier for ANZPNA sponsorship for two Australian trainees to attend the Developmental Workshop in Victoria, Canada in September 2001: Colin Jones had received an email from Dr Chevalier requesting US$1000 each for two trainees from Monash University. Since this amount represented about 80% of ANZPNA's resources, it was agreed that Colin Jones should reply that ANZPNA was not able to provide this sponsorship.

4.2 Special Interest Affiliation with Paediatrics and Child Health Division of the Royal Australian College of Physicians: Paul Roy had received a letter from Jill Sewell, President of the Division, concerning models for closer cooperation between paediatric special interest groups and the College. Paul had replied asking for clarification of some articles. It was decided to wait for further correspondence from Dr Sewell before investigating this further.

4.3 Office Bearers' insurance: It was decided that the Office Bearers should have such insurance and that the RACP should be contacted about the company that they use for this.

5. Any other business: Since there was no other business, the meeting closed at 4.30 pm.

IPNA COUNCIL MEETING NEW YORK 9-10 JUNE 2001
(MAJOR ADGENDA ITEMS)

Financial Report – Estimated reserve at January 2002-$150,000. Estimated income for 2002-$262,000 and estimated expenditure-$246,000.

New Expenditures- Administrative secretary for M Brandis (Secretary General) $30,000. Secretarial services for B Stapleton (Treasurer) $15,000.

Regional Training Programs eg South East Asia, Africa - $30,000.

Support of regional meetings - $20,000.

Journal – Publication rate 65%, rejection rate 35%. Decision is made in 50% under 8 weeks.

Major Competitor for original articles – K I, JASN.

M Broyer is retiring as Co-editor. The Publications Committee (Chairman M Barratt) recommended O Mehls for 6 years from 2002-2007. He will be co editor for the first three years and then editor. R. Chesney continues as editor for next three years.

Journal is now published by Springer and contract finishes end 2001. Negotiations are now with Blackwell as well as Springer. Royalties may be higher with Blackwell. K I is published by Blackwell.

Cochrane Renal Group – Council passed the following resolution – "IPNA endorses the organisation of renal systematic reviews and metaanalysis as performed by the Cochrane Renal Group. IPNA recognises the potential of this form of research for the formulation of guidelines for clinical management".

IPNA Congress 2001 Seattle – 598 abstracts received (London 700). Acceptance rate 99%.

Early registrants (367) is lower than expected. The early registration date has been extended to 25 June.

Corporate funding $400,000.

IPNA Congress 2004 – K Juredini and C Jones reported satisfactory progress. C Jones and IPNA to obtain legal advice concerning IPNA bank account in Australia.

2nd African Paediatric Nephrology Conference – Port Harcourt, Nigeria 26th February – 1st March 2002.

ESPN 2002 – BILBAO, Spain, September 20th –23rd.

Assisted Regisration 2001 IPN Congress – Budget of $50,000. 50% reduction in registration and preference to under developed countries with consideration to good scientific abstracts for Western Countries. Advice to be obtained from regional secretaries on the financial needs of applicants.

Continuing Medical Education – Report by P Niaudet. Courses held in Russia, South East Asia, Middle East.

Improved liaison with regional secretaries is required. (ANZPNA should review needs in surrounding areas eg. New Guinea, Fiji and make application for a grant. This money could be spent in bringing a doctor to an Australian unit for a short period or sending one of our members to teach in a certain region.

IPNA website when established may include a section on medical management.

2nd International Paediatric Continuous Renal Replacement Therapy Conference – Orlando Florida 20th –22nd June 2002. The organiser is seeking an endorsement from IPNA. Further communication is required.

Emeritus Membership – retired or semi – retired from practice; receive journal at cost; non voter.

Honorary Membership – Awarded by council for outstanding contribution to Paediatric Nephrology in their region; receive journal at cost; non voter.

New Council Members -

K Yap (Singapore)
J Ding (China)
Y Choi (Korea)
D Espinosa (Cuba)
C Garcia (Brazil)
M Lopez (South America)

New members from Europe and North America have not been finalised, as further advice is required from their regional executives.

J BURKE

Elizabeth Hodson

From: Colin Jones <cjones@cryptic.rch.unimelb.edu.au> [RAHC.INET."cjones@cryptic.rch.unimelb.edu.au"] on behalf of RAHC.INET."cjones@cryptic.rch.unimelb.edu.au"
Sent: Thursday, 14 June 2001 11:17
To: Elizabeth Hodson
Subject: Re-sending the IPNA Report - New York June

Header

Elisabeth,

I have an undelivered e-mail address from your mail box. Can you please let me know whether you get this message and attached file.

Regards,

Vicki.

Dear ANZPNA Member,

The attached report was presented to the IPNA Council and accepted without significant comment.

I have not attached appendices (I), (II) and (III). These can be obtained from Ken Jureidini or myself.

Contractual Relationships
The contractual relationships were discussed in a separate meeting between Ira Greifer (President), Mathias Brandis (In-coming President) and current treasurer and Bruder Stapleton (IPNA 2001 Co-chair and incoming IPNA treasurer), Ken Jureidini, John Burke and myself.

The contractual relationships discussed between Hartley Management Group and ANZPNA both at the recent ANZPNA Annual General Meeting and in a separate Executive of ANZPNA conference call envisaged ANZPNA contracting with Australian providers of services (including Adelaide Convention and Tourism Association and Hartley Management Group, conference organisers) and then ANZPNA having a Memorandum of Understanding with IPNA. As foreshadowed by John Burke, the representatives of IPNA were not willing to enter such an arrangement. In the London and Seattle meetings IPNA (President and Treasurer) and the Chairman of those congresses signed contracts with the Conference Management companies. They were unwilling to change this procedure. Consequently contracts would be signed by the Congress Chairman (Ken and myself), IPNA President and Treasurer (Mathias Brandis and Bruder Stapleton) with Hartley Management Group and so forth. This leaves ANZPNA free of contractual obligations.

Ken and I will engage the appropriate legal services to draw up satisfactory documents and IPNA will do the same from their end.

Regards,

Colin Jones
Conference Co-Chairman

Ken Jureidini
Conference Co-Chairman

Dr Colin Jones
Director
Department of Nephrology
Royal Children's Hospital
Flemington Road
Parkville, Victoria 3052

JOURNAL OF AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

VOLUME 3, No 3 JANZPNA 2000

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PROGRESS REPORT on IPNA 2004

To the IPNA Council Meeting
Helsinki, Finland

16-17 June 2000

Ken Jureidini
Colin Jones

The report presented to the IPNA Council meeting is summarised below.

SEED FUNDING

Our cash flow estimates indicate we will require of the order of AUD$30,000 in seed-funding for IPNA 2004. The funds will be used to pay deposits on hotel and the convention centre, to allow for the production of appropriate marketing materials (stationery, calendars, advertisements, Website development, delegate boosting activities at relevant conferences), and to all0ow the sponsorship raising to be undertaken in a professional manner.

An application has been made to the Adelaide Convention & Tourism Authority (ACTA) for their maximum loan of AUD$15,000. This money is provided free of interest and fees. We are hopeful that the money will be forwarded shortly.

In addition to the ACTA funding, we understand that IPNA will provide US$15,000. We are grateful for the US$3,000 already received, however, early provision of the balance of these funds will allow planning to proceed in a timely fashion.

STATIONERY

Letterhead has been designed and approved by the Local Organising Committee. A colour photocopy was displayed.

A small initial print-run will allow for sponsorship raising to begin. Once a major sponsor is confirmed we plan to incorporate their logo into the letterhead.

ADELAIDE CONVENTION CENTRE

The Adelaide Convention Centre has been booked as the conference venue and exhibition site. An initial deposit has been paid to secure the space required.

ADELAIDE CONVENTION CENTRE

The Adelaide Convention Centre has been booked as the conference venue and exhibition site. An initial deposit has been paid to secure the space required.

COMMITTEE STRUCTURE

A committee structure has been decided upon and membership confirmed. A copy is attached.

AUSTRALIAN and NEW ZEALAND SOCIETY OF NEPHROLOGY

The ANZSN has agreed to hold its annual convention in conjunction with IPNA. Their conference usually attracts between 250-300 people, of whom approximately 15-20 will be potential IPNA delegates.

This aspect of the report was the only one which attracted a lot of discussion (see below).

DEVELOPMENTAL NEPHROLOGY WORKSHOP

The 9th International Workshop on Developmental Nephrology is now likely to be held in South Australia preceding the IPNA conference. The All Seasons Barossa Valley Resort, which is 1 hour drive from Adelaide has been booked for the workshop. This was done following the visit of Bob Chevalier to Melbourne and Adelaide in March 2000.

(Bob Chevalier reported that the potential rift between the Adrian Spitzer and the IPNA vision for the Developmental Nephrology workshop had been sealed with an agreement that would see the following changes.

1. The International Workshop on Developmental Nephrology will now become an official, regularly scheduled meeting held under the IPNA auspice.
2. An international organising committee will be formed to develop the program and to determine the location of the workshop, which will be held in proximity to the IPNA meeting.
3. The Chair of the International Organising Committee will be chosen by the Committee of the previous workshop.
4. The Chair of the International Organising Committee will present the draft of the proposed programme for the IPNA Council for approval.
5. IPNA will provide administrative and financial support for the meeting.

These changes mean that our proposed Workshop, headed by John Bertram, will now see John Bertram probably on the International Organising Committee which will be headed by Bob Chevalier (informal discussions with Bob Chevalier)).

BUDGET

An initial budget was prepared for the conference bid. The break-even number of delegates has been set at 500, with and early IPNA registration fee of US$435 (assuming 60% registered at this rate). A standard IPNA registration fee of US$498 (assuming 20%), an early non-member registration fee of US$498 (assuming 20%) and a standard non-member registration fee of $561 (assuming 0%).

The effect of the GST commencing on the 1st July 2000 has not been incorporated into the IPNA budget.

A copy of the proposed budget can be obtained from either of the Congress co-chairman.

TIMELINE

An initial timeline has been established with a list of tasks. Dates and responsibilities now need to be allocated to those tasks. A copy of this time line can be obtained from either of the Chairman.

SPONSORSHIP and WEBSITE

An initial website has been designed.

The URL is www.ipna2004.com

The website will become a focal point of the Congress, promoting the Congress as well as the destination, handling receipt of papers, delegate registration and payments and providing sponsors with promotional opportunities.

Some initial sponsorship ground work has been carried out, exploring possibilities with the Department and Industry and Trade in South Australia, as well as an IT company that may help with the website. A formal sponsorship proposectus is in the production stage.

SCIENTIFIC PROGRAMME

The broad development of the Scientific Programme was outlined. This will involve co-opting a wide committee to observe IPNA 2001 in Seattle. A review of 2001 will be undertaken and completed by March 2002. An Executive Committee will be formed in June 2002 to run through to the end of the Conference. A series of Theme Organsiers comprising local and international members of IPNA will be selected. These Theme Organisers will define their themes by September 2002. Theme Development Committee will organise sessions with choice of chair and co-chair. A choice of speakers will be made in January 2003 and the 2nd round choice will be made in July 2003. A call for papers for abstracts will be made in September 2003.

Our choice of conference programme is for the program to run for 4 days from Monday to Thursday. If the ANZSN were to have their meeting in a conjoint manner to IPNA 2004 they would have their meeting from Wednesday to Friday. The Wednesday sessions of the two conferences would be separate, the Thursday session would be conjoined dealing with issues such as ethical aspects, and management of the teenager, glomerular nephritis, genetics, adult outcomes of paediatric disease etc, and the Friday session would remain separate.

DISCUSSION REGARDING THE REPORT

Discussion mainly focused around the proposal to have the ANZSN meeting coincide with the IPNA meeting.

1. Some delegates felt that the following were threatened

   (i) Paediatric nature of the meeting.
   (ii) The focus and "branding" of the meeting as being IPNA rather than ANZSN.
   (iii) The organisation/agenda of the meeting by IPNA and its delegates (Australian Organising Committee).

Branding is seen by the IPNA Council as being particularly important as Paediatric Nephrology strives to maintain its own independent identity in the US, some European countries (in both cases, encroachment by other specialties is the concern) and third world countries (specialties not developed).

2. Financial concerns were also raised.

   (i) Delegates wish to know how the Trade Display revenue would be shared
   (ii) Concern was raised about the corporate sponsorship that ANZSN has, and how that would affect our fund raising efforts, and how the Executive of the ANZSN would be prepared to distribute that money.
   (iii) Registration fee issues were raised.

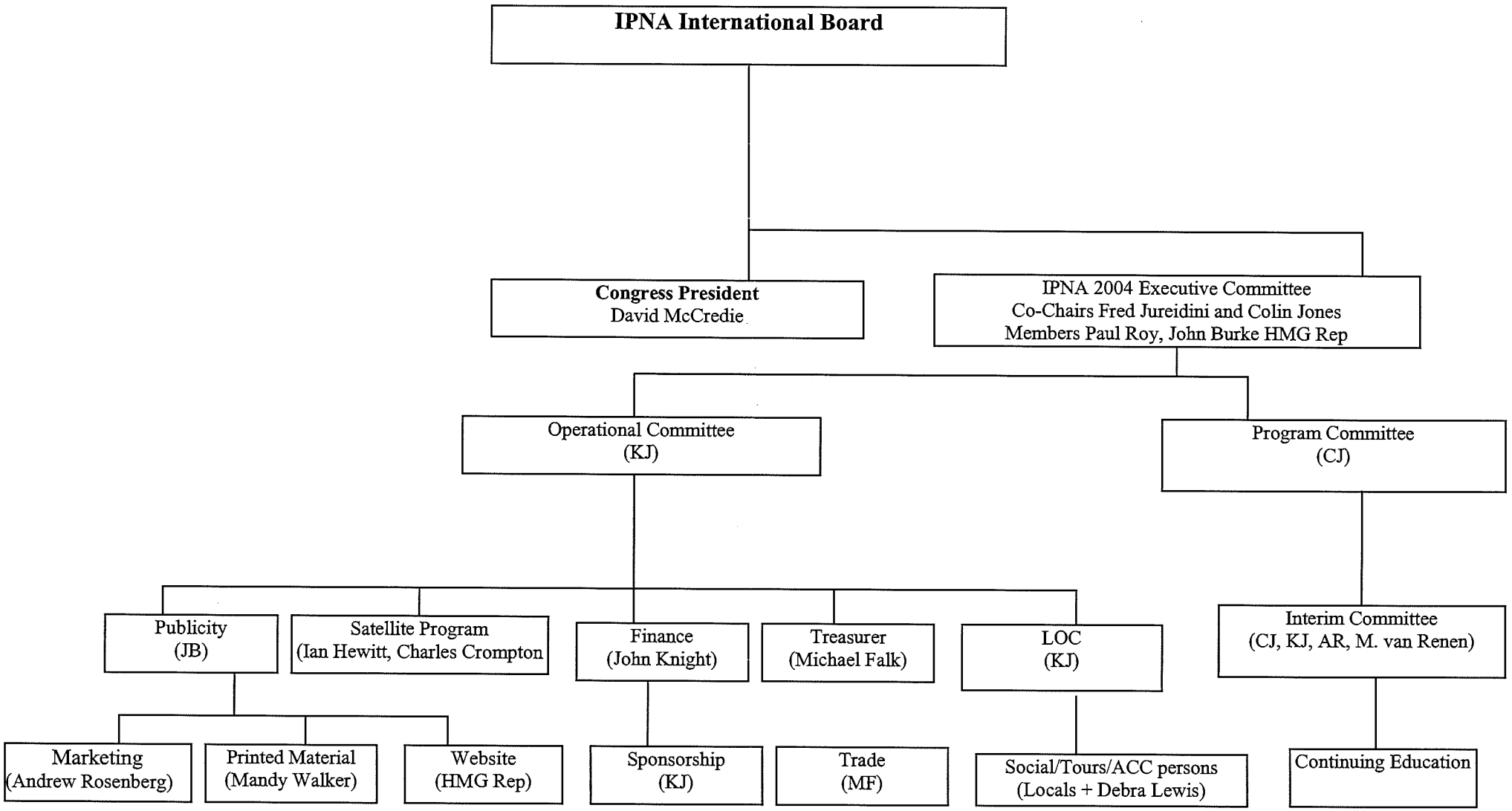
Several members made it clear that any profits were the property of IPNA and similarly, any losses would be borne by IPNA. It is clear that IPNA Council will not entertain any idea of profit sharing.

3. Some members also were concerned that IPNA and not ANZSN should choose any speakers to the conjoint session (proposed on Thursday). They were concerned that the conjoined meeting should be seen to be an IPNA one in which the ANZSN joined in.

We agreed to bring these concerns to the attention of the Executive of ANZSN. The budget as detailed to IPNA Council was not contingent upon a conjoint meeting. The problems of not having a meeting with ANZSN were addressed (potential for a competitive meeting for local nephrologists to attend). We do not see involvement by our adult colleagues as threatening, and felt concerns about the branding issue was misplaced.

There are substantial financial concerns. Ken and I have brought these to the attention of Kim Bannister (Treasurer) and Brendan Murphy (President, ANZSN).

We agreed to work out a financial arrangement that was legally binding that we could bring to the IPNA Council in November. If necessary, we agreed to abandon the conjoint meeting with ANZSN if appropriate agreements on the points raised could not be made.


IPNA International Board
Congress President
David McCredie
IPNA 2004 Executive Committee
Co-Chairs Fred Jureidini and Colin Jones
Members Paul Roy, John Burke HMG Rep
Operational Committee
(KJ)
Program Committee
(CJ)
Publicity
(JB)
Satellite Program
(Ian Hewitt, Charles Crompton
Finance
(John Knight)
Treasurer
(Michael Falk)
LOC
(KJ)
Interim Committee
(CJ, KJ, AR, M. van Renen)
Marketing
(Andrew Rosenberg)
Printed Material
(Mandy Walker)
Website
(HMG Rep)
Sponsorship
(KJ)
Trade
(MF)
Social/Tours/ACC persons
(Locals + Debra Lewis)
Continuing Education

IPNA COUNCIL MEETING HELSINKI 16-17 JUNE 2000
(Major Agenda Items.)

Membership – 1600 from 90 countries.

Financial Report – Funds available 185, 000 dollars.

Profit from London Congress is 40,000 dollars. This is a separate charity account which is to be used for education, research.

Journal – 2000 – 12 issues. The distribution was slow earlier this year in some countries. The contract with Springer is under review, and Springer has asked for a ten year contract and this is normally a five – seven year contract.

The present rejection rate of submitted articles is 22% (27% two years ago). The reviewing time is satisfactory with a decision been made on 40% of submitted articles under eight weeks. However, the time of acceptance to publication is 12 months and requires reduction.

New Editors will be appointed in 2002 and a sub committee will be formed to make recommendations to council.

IPNA Congress 2001 – Seattle September 1-5. Present funding obtained from corporate companies 180,000 dollars. Regional societies including ANZPNA has been asked if they require a meeting room on the Tuesday at lunchtime.

IPNA Developmental Meeting 2001 – August 29-31, Victoria, British Columbia. Programme to include genetics.

IPNA Congress 2004 – Adelaide. A progress report was given by K. Jureidini and C. Jones. The relationship between ASN meeting and IPNA to be discussed at next Council meeting.

Continuing Education – Dr P. Niaudet discussed a major benefactor whose donation in a Swiss bank may provide 30,000 dollars per year. Money would be only available for promotion and education for doctors caring for children with kidney disease.

Education programs for third world countries based on evidence based medicine are required. Regional societies are to assist.

Membership fee – Increased from 125 dollars to 175 dollars per year.

IPNA and 2001 congress in Beijing - There was no official request from IPA to IPNA for the scientific program.

AUSTRALIA AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

The teleconference for the Executive of the ANZPNA will be held on Wednesday October 18, 2000 at 4 pm.

AGENDA

1. Confirmation of the Minutes from the meeting of the executive on December 8, 1999
2. Business arising from the Minutes:-
   - IPNA Council representative from 2001
   - IPNA Congress in 2004
   - Growth Hormone subcommittee/ CARI guidelines
   - Benchmarking
   - Accounts of ANZPNA
   - Fund raising for ANZPNA
3. New business:-
   - ANZPNA AGM on May 13, 2001
   - Symposium on antenatal hydronephrosis in RACP meeting on May 14, 2001
     - Title
     - Topics
     - Speakers
     - Funding
   - ANZDATA Registry: special paediatric data
   - Workforce survey: See attached e.mail from Paul Roy.
4. Any other business

Elisabeth Hodson
Secretary
ANZPNA

AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

Minutes of the meeting of the Executive of ANZPNA held by teleconference on Wednesday October 18, 2000 at 4 PM

Present: Paul Roy, Colin Jones, Michael Falk, Elisabeth Hodson

1. Minutes of the meeting held on December 8, 1999 were confirmed as a correct record.

2. Business arising from the minutes:-
   - IPNA Council representative from 2001: John Burke's term as Regional Secretary and ANZPNA representative to the IPNA will cease in 2001 and he does not wish to be considered for a further term. It is understood that IPNA will call for nominations from all IPNA members in early 2001. Nominations will be made directly to the IPNA Council. Council will then forward nominations to the Regional Secretary (John Burke) and the ANZPNA executive will organise a ballot among ANZPNA members if necessary. More information will be available about this process after the next Council meeting in Singapore in November 2000.
   - IPNA Congress in Adelaide, 2004: Colin Jones reported that agreement had been achieved between ANZSN and the congress organisers over some aspects of the organisation of the IPNA Congress and the concurrent ANZSN meeting. There is to be separate sponsorship for both meetings. About $250,000 in sponsorship is required for the IPNA congress. The trade exhibit will be combined and surplus income from this (expected to be between $35,000 and $50,000) will be shared equally. The registration fee for ANZSN will be lower than for IPNA. Paul Roy stressed that the people should register separately for each meeting and pay additional fees if they wished to attend the other meeting. Otherwise there was a risk that people would only register for the ANZSN meeting but would attend the IPNA meeting. Colin Jones reported that 450-500 registrants were needed for the IPNA congress to break even. IPNA has agreed to underwrite the congress. Paul Roy asked for a publicity package on the 2004 meeting to be available for people to take to meetings that they attend in 2001 onwards.
     Action: Colin Jones to arrange for publicity package to be available
   - Growth Hormone Subcommittee: Charlie Crompton has written the first draft of the results of rhGH treatment in Australian children with renal failure using the OZGROW data. The draft has been reviewed by Elisabeth Hodson and Colin Jones. Further drafts are awaited.
   - CARI guidelines: Charlie Crompton and Elisabeth Hodson are writing the guidelines for the management of nutrition and growth in children. The working party convened by Carol Pollock will meet on December 6. The guidelines will be discussed at the Dialysis and Transplant Workshop in Canberra in April 2001.
   - Benchmarking: 132 reports of renal biopsies have been submitted to Colin Jones. Reports of peritoneal dialysis and haemodialysis access have also been submitted. Colin Jones will provide an interim report to ANZPNA members with a full report at the next AGM.
     Action: Colin Jones to provide an interim report now on Benchmarking to ANZPNA members and a full report at the AGM in May 2001

- Accounts/fund raising: Michael Falk reported that the ANZPNA account balance was $5689.96 on October 10, 2000. He had written to several companies about sponsorship for ANZPNA. However companies appeared not to be interested in funding paediatric nephrology. It was suggested that the companies that manufacture rhGH should be approached.
  Action: Elisabeth Hodson to provide names of companies, who manufacture rhGH, to Michael Falk, who will approach these companies for funding for ANZPNA.

3. New business:-
   - AGM 2001: This will be held on Sunday May 13, 2001 commencing at 12 noon. It will be held at the Darling Harbour Conference Centre in Sydney immediately before the Annual Scientific meeting of the RACP.
   - RACP symposium: ANZPNA will organise a symposium on the management of antenatally diagnosed abnormalities of the urinary tract at the RACP meeting on Monday May 14, 2001. The symposium will be designed to provide practical information to paediatricians on the management of common abnormalities. It was agreed that there should be three speakers and that each would speak for 15 minutes. The speakers will address prenatal counselling, post natal investigations and urological management of common abnormalities. In the second part of the symposium the three speakers will take part in a panel discussion with questions from the audience. It is hoped that the symposium will be chaired by a perinatologist.
     Action: Paul Roy to speak to David Henderson-Smart re chairing symposium. Elisabeth Hodson to contact possible speakers for symposium.
   - ANZDATA Registry: Graeme Russ is now the Chief Executive of ANZDATA Registry. Currently Rowan Walker is the Chairperson of the paediatric subsection of the Registry. It is understood that his term is about to be completed.
     Action: Paul Roy is to discuss the arrangements for paediatric representation on the Registry with Graeme Russ.
   - Paediatric Nephrology Workforce Survey: This has been completed and analysed by Paul Roy. Twenty-three completed questionnaires were returned from the 28 members of ANZPNA. Preliminary analysis indicated that ANZPNA comprises a reasonably young group. Women are underrepresented with 6 of 23 respondents being women. Thirteen respondents worked full time in paediatric nephrology. Five of the 10 respondents who worked part time in paediatric nephrology spent more than 50% of their time in adult nephrology.
     Action: Paul Roy is to provide a full analysis of the workforce survey at the AGM in May 2001.

The meeting ended at 5 PM.

ANZPNA members report of the IPNA 2000 meeting Singapore 2-6 November 2000

IPNA council met on 3rd and 4th November 2000. The IPNA 2004 meeting progress report was presented and discussed. The report and attachments are amended to this letter.

IPNA council passed a motion accepting the proposed arrangements for a conjoint day of sessions with the Australian & New Zealand Society of Nephrology, recognising that the meeting was not a joint one but rather two independent meetings with an overlap (conjoint) day. For all intents and purposes, we are now free to go ahead with the organisation of the meeting. It should be noted that ANZSN Council needs to formally approve these proposed arrangements as well.

The Council received a letter from Amir Tejani (Secretary/Treasurer of the International Paediatric Transplant Association). He had suggested a joint meeting of IPNA/IPTA for 2004. Following a long discussion, which we will leave for John Burke to report, a resolution was passed that IPNA would not be involved in a joint meeting. Dr Ira Greifer is to offer the possibility of consideration for a overlap meeting provided

(a) IPNA's branding of the event is not impaired

(b) IPNA's control of the program (through the Scientific Program Committee) is not interfered with

(c) IPNA's earning capacity from the congress is not diluted.

In the event that IPNA and IPTA discussions continue on this issue, a sub-committee of IPNA councilors including the Australian Organisers would meet to formulate plans.

Ken Jureidini and Colin Jones
Co-Chairman, IPNA 2004 Scientific Congress
Dated: 8th November 2000

Progress Report

to the

IPNA Council Meeting

Singapore

2 – 6 November 2000

Seed Funding

As indicated in our last report, we will require of the order of AUD$30,000 in seed-funding for IPNA 2004.

We have received the AUD$15,000 (interest and fee free) loan from the Adelaide Convention and Tourism Authority (ACTA).

In addition to the ACTA seed funding, we understand IPNA will provide further funds.

Stationery

Letterhead and envelopes being produced – a draft copy is included with this report in Appendix 1.

Adelaide Convention Centre

The Adelaide Convention Centre's extensions are going ahead quickly and will be ready for the official opening event on 28 September 2001.

Finances

An updated budget and expenditure statement can be found in Appendix II.

The most significant change to the budget involves the development of a draft Trade and Sponsorship sub-budget to better clarify the likely outcomes from these areas. Further elaboration can be found in the section 'ANZSN Proposed Arrangements'.

Timeline

An updated timeline can be found in Appendix III.

Sponsorship

As we develop a Sponsorship Prospectus for international distribution, we are keen to include benefits that can be offered in the lead up to and following the Congress.

These could include non-Congress related benefits, such as acknowledgment in general IPNA materials (journals, newsletters etc). Can the IPNA Council provide ideas on possible offerings here and any cost implications?

A formal sponsorship prospectus is in the production stage.

Website

The website is online at www.ipna2004.com – at this stage it is very basic, but plans are for it to grow as sponsors come on board and further information becomes available.

We would like to know of any plans for the IPNA general website that might be able to add value to sponsors. For example, links from the IPNA site to the Congress site, links from IPNA site direct to Congress sponsors' sites.

Adelaide Women's and Children's Hospital

The Hospital is potentially willing to fund one speaker in exchange for naming rights, access to the Exhibition and use of the speaker for the Friday following the conference.

registering for ANZPNA. It also provides an easy way for ANZSN delegates to come to an IPNA session in a way that is advantageous to IPNA.

2. **Trade Exhibition**

a. The Trade Exhibition will be run as a separate entity to the respective conferences.

b. IPNA and ANZSN will appoint a Joint Exhibition Committee comprising 1 representative from each body to liaise with the Exhibition Manager (Hartley Management Group) to oversee the project, including the production of a Business Plan (including budget and marketing plans) and the management of the project.

c. ANZSN has a continuing sponsorship arrangement with some major companies. Some sponsors have been provided with an exhibition site included as part of their benefits. In 2004, ANZSN would contribute to the trade exhibition income an amount equal to the selling price of an exhibition booth at the IPNA exhibition.

d. Any surplus/deficit from the Trade Exhibition will be shared equally between the two bodies.

In arriving at this suggestion, we acknowledge ANZSN's history of attracting exhibitors as a positive for IPNA, while IPNA adds an international dimension and a larger audience to ANZSN, allowing sites to sell for a higher price and thus increasing the return to both parties. A 50/50 split seems appropriate in the circumstances.

Trade Exhibition Costs

EXPENDITURE (inclusive of GST)	**BUDGET**	**NOTES**
Fixed costs		
Venue hire	$41,250.00	Estimate based on 3000 sq m @ $2.75 per sq m per day for 5 days
Prospectuses, manuals	$2,000.00	Estimate
Administration (phone, fax, postage, printing etc)	$2,500.00	Estimate
Total fixed costs	$43,750.00	
Variable costs		
Booth hire 3mx3m booths @$500 each	$25,000.00	Based on 50 booths; room for posters and catering
Catering	$20,000.00	Estimate for catering (5 days @ $40 per day for 2 people per booth: excludes social functions)
Power consumption	$5,000.00	$20.00 per booth per day
Trade Exhibition Management	$37,500.00	$55 per hour to a maximum of 15% of Trade and sponsorship income
Total Variable Costs	$86,500.00	
Total Expenditure	$132,250.00	

INCOME	**BUDGET**	**NOTES**
3mx3m booths $5,000	$250,000.00	Based on 50 booths
Total Trade Exhibition income	$250,000.00	
Income less expenditure	$117,750.00	GST payable on 1/11 of surplus
IPNA Share (50%)	$58,875.00	(estimate)

Projected Total Congress Income	**Number of Delegates**		
	500	750	1000
Registration Fee	365,000	547,500	730,000
Sponsorship (nett)	110,000	110,000	110,000
Trade (nett)	50,000	50,000	50,000
TOTAL	525,000	707.500	890,000

Appendix I

THE THIRTEENTH CONGRESS OF THE
INTERNATIONAL PEDIATRIC
NEPHROLOGY ASSOCIATION
ADELAIDE 2004

Hosted by

ANZPNA

Australian and New Zealand
Paediatric Nephrology Association

29 August - 2 September 2004
Adelaide Convention Centre
Australia

Congress President
David McCredie

Congress Co-Chairmen
Ken Jureidini, Colin Jones

Congress Management
Hartley Management Group Pty Ltd
PO Box 20
Kent Town SA 5071
Australia

Telephone +61 8 8363 4399
Facsimile +61 8 8363 4577
Email ipna2004@hartleymgt.com.au
Web http://www.ipna2004.com

Appendix II

IPNA - Draft Budget in AU$ as at 30-10-00

	A	B	C	D	E	F	G	H
1	FIXED COSTS	Actual	Forecast	Budget	All figures in AU$			
2								
3	**Administrative Costs**							
4	Postage, freight & couriers	$18.65	15,000	15,000	Based on UK budget			
5	Telephone & Facsimile	$83.64	4,000	4,000	Based on UK budget			
6	Organising Committee - meetings, site visits	$0.00	5,000	5,000	Based on UK budget			
7	Professional Conference Organiser - Management Fee	$5,312.50	30,000	30,000	Estimate			
8	Audit Fee	$0.00	1,000	1,000	Estimate			
9	**Administrative Costs Sub-Total**	**$5,414.79**	**55,000**	**55,000**				
10								
11	**Social Functions**							
12	Venue hire for Welcome Function + Dinner	$0.00	4,000	4,000	Based on 2 functions away from ACC			
13	Decorations, entertainment for Welcome Function + Dinner	$0.00	10,000	10,000	Based on 2 functions away from ACC			
14	**Social Functions Sub-Total**	**$0.00**	**14,000**	**14,000**				
15								
16	**Speakers and Guests**							
17	Invited Speaker registration costs - 22 @ variable cost	$0.00	6,996	6,996				
18	Invited Speaker travel & accom - 22 @ $4000	$0.00	88,000	88,000	US$1890 air + US$630 accom			
19	Committee hospitality	$0.00	5,000	5,000	Based on UK budget			
20	Bursaries - 80 @ 50% Reg Fee	$0.00	27,600	27,600	Amended as per discussions during famil			
21	Council/Speakers Dinner	$0.00	3,500	3,500	Based on UK budget			
22	Prizes/Gifts	$0.00	2,000	2,000	Based on UK budget			
23	**Speakers and Guests Sub-Total**	**$0.00**	**133,096**	**133,096**				
24								
25	**Facilities**							
26	Venue Hire for conference	$1,000.00	49,700	30,000	Based on 4 halls for 4 days			
27	Poster Boards	$0.00	3,000	3,000	Based on 160 poster sites			
28	Audio-visual hire	$0.00	40,000	30,000	Estimate			
29	Ground Transport	$0.00	5,000	5,000	Estimate			
30	Trade and sponsorship expenses (see separate budget)							
31	Signage	$0.00	5,000	5,000	Estimate			
32	**Facilities Sub-Total**	**$1,000.00**	**102,700**	**73,000**				
33								
34	**Advertising**							
35	Journals, newsletters etc	$0.00	5,000	5,000	Estimate			
36	Web page establishment and updates	$590.00	5,000	5,000	Estimate			
37	**Advertising Sub-Total**	**$590.00**	**10,000**	**10,000**				
38								
39	**Printing & copying**							
40	Logo design	$295.00	1,000	1,000	Estimate			
41	Stationery	$55.00	2,000	2,000	Based on UK			
42	Initial Flyer	$1,595.00	4,000	4,000	Based on UK			
43	Call for Papers	$0.00	8,000	8,000	Based on UK			
44	Registration Brochure	$0.00	10,000	10,000	Based on UK			
45	Final program	$0.00	4,000	4,000	Based on UK			
46	Pocket program	$0.00	1,000	1,000	Based on UK			
47	Book of Abstracts	$0.00	25,000	25,000	Based on UK			
48	Delegate List	$0.00	2,000	2,000	Based on UK			
49	Tickets to functions	$0.00	1,000	1,000	Based on UK			
50	General Copying	$101.52	3,000	3,000	Based on UK			
51	**Printing & Copying Sub-Total**	**$2,046.52**	**61,000**	**61,000**				
52								
53	TOTAL FIXED COSTS	9,051	375,796	346,096				
54								
55	VARIABLE COSTS				NUMBER OF DELEGATES			
56					500	750	1000	
57	**Administrative Costs**							
58	Professional Conference Organiser - Per Head Fee	$0.00	25,000	50	25,000	37,500	50,000	US$32 per delegate
59	Bank/Govt/Credit Card Charges	$0.00	5,482		5,482	7,282	9,081	Based on govt taxes + 35% of income on credit card @ 2.5%
60	Insurance	$0.00	5,500		5,500	6,100	6,800	1% of total income
61	**Administrative Costs Sub-Total**	**$0.00**	**35,982**	**50**	**35,982**	**50,882**	**65,881**	
62								
63	**Catering**							
64	4 morning & 4 afternoon teas	$0.00	20,000	40	20,000	30,000	40,000	Average US$3.15 per tea
65	4 lunches	$0.00	50,000	100	50,000	75,000	100,000	Average US$15.75 per lunch

3

Expenditure (inclusive of GST)		Budget		Notes
Fixed costs				
Venue hire		$41,250.00		Estimate based on 3000 sq m @ $2.75 per sq m per day for 5 days
Prospectuses, manuals		$2,000.00		Estimate
Administration (phone, fax, postage, printing etc)		$2,500.00		Estimate
Total fixed costs		**$45,750.00**		
Variable costs				
Booth hire 3m x 3m booths @ $500 each		$25,000.00		Based on 50 booths; room for posters and catering
Catering		$20,000.00		Estimate for catering (5 days @ $40 per day for 2 people per booth; excludes social functions)
Power consumption		$4,000.00		$20 per booth per day
Trade Exhibition Management		$37,500.00		$55 per hour to a maximum of 15% of Trade & Sponsorship income
Total variable costs		**$86,500.00**		
Total expenditure		**$132,250.00**		
Income (inclusive of GST)		**Budget**		Notes
3m x 3m booths @ $5,000	50	$250,000.00		Based on 50 booths
Total Trade Exhibition Income		**$250,000.00**		
Income less expenditure		**$117,750.00**		GST payable on 1/11 of surplus

IPNA Expenditure as at 30-10-00

$0.00	$590.00	$295.00	$55.00	$1,595.00	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$101.52	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$600.00	
													Variable Costs										
Advertising		Printing & Copying											Administrative Costs			Catering				Handouts			
Journals	Web pag	Logo	Stationary	Initial Flyer	Call for Papers	Reg brochure	Final prgm	Pocket prgm	Abstract	Delegate	Tickets	Copying	PCO Fee	Bank/Govt/CC Charge	Insuranc	M/A Teas	Lunch	Welcome	Dinner	Satchels	Paper/pe	Namebac	Contingency	
	$550.00	$295.00		$1,595.00								$37.50											$160.00	Council Report
	$40.00		$55.00									$64.02											$440.00	Council Report

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Appendix III

IPNA DRAFT TIMELINE

	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R
1	ACTIVITY	WHO	FINISHED	99 - June 00	By Dec 2000	2001	2002	2003	Jan-04	Feb-04	Mar-04	Apr-04	May-04	Jun-04	Jul-04	Aug-04	Sep-04	Oct-04
2	Key Dates																	
3	Initial Announcement - Sep 01																	
4	Second announcement/Call for Papers/Registration Brochure distributed - Sep 03	HMG	YES															
5	Closing date for acceptance of abstracts - Feb 04	HMG																
6	Authors advised of status of abstracts - May 04	HMG																
7	2nd mailing of Registration Brochure distributed - Feb 04	HMG																
8	Program selection form - Jul 04																	
9	Early rate cut off - June 04																	
10	Standard rate cut off - Aug 04																	
11	Conference commences - Sep 04																	
12																		
13	Organising Committee																	
14	Elect Chair	FJ	YES															
15	Determine committee structure	FJ	YES															
16	Allocate committee responsibilities	FJ	YES															
17	Establish meeting schedule with committee and sub-committees	FJ	YES															
18	Appoint Conference Manager	FJ	YES															
19	On-going liaison Conference Committee and PCM	FJ/HMG	Ongoing															
20																		
21	Dates and Venue																	
22	Decide on event dates	FJ	YES															
23	Obtain quote and negotiate contract with ACC	HMG	YES															
24	Pay deposit on venue	FJ	YES															
25	Liaise with venue eg security, catering, access, communication links, speaker preview room	HMG	Ongoing															
26																		
27	Insurance																	
28	Determine requirements, obtain quotes and pay	HMG																
29																		
30	Congress Theme and Structure (also refer to Conference Program section)																	
31	Determine Congress theme	Comm																
32	Determine Congress name	Comm	YES															
33	Determine Congress structure	Comm																
34																		
35	Financial																	
36	Prepare preliminary budget & cash flow for discussion	HMG	YES															
37	Present budget to committee meeting for approval	HMG	YES															
38	Open bank account	MF	YES															
39	Apply for loans and grants	Comm/HMG	YES															
40	Determine registration fee structure and dates (earlybird, standard, on-site)	Comm/HMG	YES															
41	Determine cancellation procedure	Comm/HMG	YES															
42	Monitor budget and cash flow, prepare reports for committee	HMG	Ongoing															
43	Books to auditor	HMG																
44																		
45	Airline/Travel Agent																	
46	Obtain quotes from airlines/travel agents	HMG																
47	Select and negotiate contract with airline/travel agent	HMG																
48	Liaise with airline/travel agent regarding bookings	HMG																
49																		
50	Accommodation																	
51	Obtain quotes from suitable accommodation providers	HMG	YES															
52	Select and negotiate contracts with all accommodation providers	HMG																
53	Liaise with accommodation providers	HMG																
54	Forward accommodation deposits and rooming list 30 days in advance	HMG																
55	Reserve hotel accommodation for event staff & VIP s	HMG																
56	Print final arrival report to hotels and send with final cheques	HMG																
57	Pay remaining master accounts off	HMG																

IPNA DRAFT TIMELINE

	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R
1	ACTIVITY	WHO	FINISHED	99 - June 00	By Dec 2000	2001	2002	2003	Jan-04	Feb-04	Mar-04	Apr-04	May-04	Jun-04	Jul-04	Aug-04	Sep-04	Oct-04
2	Key Dates																	
3	Initial Announcement - Sep 01																	
4	Second announcement/Call for Papers/Registration Brochure distributed - Sep 03	HMG	YES															
5	Closing date for acceptance of abstracts - Feb 04	HMG																
6	Authors advised of status of abstracts - May 04	HMG																
7	2nd mailing of Registration Brochure distributed - Feb 04	HMG																
8	Program selection form - Jul 04																	
9	Early rate cut off - June 04																	
10	Standard rate cut off - Aug 04																	
11	Conference commences - Sep 04																	
02																		
03	Social Program / Accompanying Person / Tours																	
04	Develop concepts for Opening Ceremony & Welcome Reception, Concert, Dinner	Social Comm																
05	Obtain quotes on various options	HMG																
06	Select venues, caterers, entertainment for each function	Social Comm																
07	Produce a running sheet for each function	HMG																
08	Book any transport needed	HMG																
09	Develop concepts for accompanying persons program - tours	Social Comm																
10	Obtain quotes on program options	HMG																
11	Select program and confirm with contractors	HMG																
12	Liaison with contractors regarding final numbers	HMG																
13	Forward dietary requirements to all contractors concerned	HMG																
14																		
15	Marketing Activities																	
16	Formulate marketing strategy, including presence at Seattle	Publicity Comm																
17	Review last event's evaluation forms	Publicity Comm																
18	Compile mailing lists	Publicity Comm																
19	Distribute Initial Announcement	HMG																
20	Distribute Call for Abstracts/Registration Brochure	HMG																
21	Book advertising space	HMG																
22	Manage advertising activites	HMG																
23	Develop and instigate PR/Media strategy	Publicity Comm																
24	Web-site development	HMG	Started															
25	Distribute Press Releases where appropriate	HMG																
26																		
27	Sponsorship																	
28	Prepare sponsorship budget	HMG																
29	Determine areas of the conference to be sponsored	Finance Comm																
30	Compile sponsorship prospectus outlining options and costings	HMG																
31	Contact prospective sponsors	Finance Comm																
32	Mail prospectus and follow up initial contact	HMG																
33	Confirm sponsors and ensure benefits are met as outlines in prospectus	HMG																
34	On-going liaison with sponsors including eg obtaining logo's	HMG																
35																		
36	Printed Materials																	
37	Graphic Designer / Printer																	
38	Develop concept for logo design	HMG	YES															
39	Appoint designer and printer	HMG	YES															
40	Approve logo	HMG	YES															
41	Letterhead and Design																	
42	Design	HMG	YES															
43	Print	HMG																
44	Initial Announcement - Sep 01																	
45	Write copy for approval by committee	HMG																
46	Design	HMG																
47	Proof read	Publicity Comm																
48	Print and distribute	HMG																
49	Second Announcement / Call for Papers - Sep 03																	
50	Write copy for approval by committee	HMG																
51	Design	HMG																
52	Proof read	Publicity Comm																
53	Print and distribute	HMG																

IPNA DRAFT TIMELINE

	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R
1	ACTIVITY	WHO	FINISHED	99 - June 00	By Dec 2000	2001	2002	2003	Jan-04	Feb-04	Mar-04	Apr-04	May-04	Jun-04	Jul-04	Aug-04	Sep-04	Oct-04
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7	2nd mailing of Registration Brochure distributed - Feb 04	HMG																
8	Program selection form - Jul 04																	
9	Early rate cut off - June 04																	
10	Standard rate cut off - Aug 04																	
11	Conference commences - Sep 04																	
189																		
190	Registration																	
191	Process Expressions of Interest from Initial Announcement	HMG																
192	Process Registration Forms and payment and send confirmation	HMG																
193	Register speakers, exhibitors, advertisers and sponsors	HMG																
194																		
195	Satchel Inserts																	
196	Determine cost of inserts	Finance																
197	Obtain tourist brochures from ACTA	HMG																
198	Inform companies booking inserts of delivery deadline	HMG																
199	Satchel packing	HMG																
200	Delivery of satchels to venue	HMG																
201																		
202	Catering																	
203	Choose menus	Social Comm																
204	Confirm morning/afternoon tea, lunches, dinner times and numbers with venue	HMG																
205	Inform all contractors of special dietary requirements	HMG																
206	Book registration staff meals	HMG																
207																		
208	Gifts																	
209	Determine if there will be speaker, delegate and accompanying person gifts	Social Comm																
210	Purchase gifts	Social Comm																
211	Distribute gifts (normally at registration or hotel room)	HMG																
212																		
213	On-Site Management																	
214	Before the event																	
215	Determine further staff requirements	HMG																
216	Determine where registration desk will be and how many desks	HMG																
217	Prepare work schedule giving details of tasks associated with PCM and committee memb	HMG																
218	Prepare a registration desk timetable	HMG																
219	Prepare briefing notes for all staffing the registration desk	HMG																
220	Prepare session notices for doors	HMG																
221	Confirm arrival time with venue	HMG																
222	Book message board	HMG																
223	Book separate conference office if needed	HMG																
224	Equipment to take																	
225	Prepare bits box, paper, namebadges, namebadge inserts	HMG																
226	Spare registration brochures for	HMG																
227	Contact details of suppliers including couriers/taxis	HMG																
228	Conference stationary	HMG																
229	Computers (hire computers if needed)	HMG																
230	Conference files	HMG																
231	Credit card facilities	HMG																
232	Lists of hotels/restaurants/tours etc for delegates	HMG																
233	Petty cash tin and receipt book	HMG																
234	Petty cash	HMG																
235																		
236	Evaluation and Report																	
237	Prepare evaluation forms	HMG																
238	Distribute	HMG																
239	Collect, process and produce report	HMG																
240																		
241	After the event																	

IPNA COUNCIL MEETING SINGAPORE 3-4 NOVEMBER 2000
(Major Agenda Items)

Financial Report – Proposed budget 2001 – income $492,500; Expenditure $490,000. M. Brandis (Secretary General elect.) will require an Administrative Secretary after 2001. Council meetings are becoming more expensive with added members, eg Africa. An increased income stream would be available if IPNA had sustaining members.

Journal – M. Barratt is Chairman of Committee to review format of Journal and new Editors. Each Editor requires 1.5 secretarial staff. Time contribution of each Editor is 10-12 hours per week. Publication time has decreased 6.2 months.

IPNA Congress 2004 – Progress report given by K. Jureidini and C. Jones. Negotiated relationship between IPNA and ASN concerning dates, registration, and financial arrangements was accepted by Council.

A proposal by IPTA (International Pediatric Transplant Association) for a joint meeting with IPNA in Adelaide was not acceptable to Council. There would be a loss of identity for IPNA meeting as IPTA program includes other solid organ transplants.

Developmental Nephrology Meeting – Victoria, British Columbia, August 29-31 2001. Delegates would travel from this meeting to Seattle on the 1st September.

Hypertension Workshop – Half day meeting Seattle 1st September; organiser E. Brewer.

IPNA Congress 2001 – Seattle 1-5 September. Scientific program 2-5. Assisted registration will be available for trainees. Regional societies are asked to make a financial contribution for assisted registrations. (ANZPNA to consider at next meeting).

Insurance for children with congenital renal disease – Mandatory reporting of children with renal abnormalities in USA and UK may cause difficulty in children obtaining insurance policies. IPNA is to prepare a statement.

Cochrane Renal Group – A proposal from ANZPNA for financial support from IPNA was unsuccessful. Some members considered that this would be a contribution to research funding and such a request should be open to tender. Another member expressed concern with the concept of retained equity.

Definition of Pediatric Nephrologists and Training Programs – I. Salusky to present draft document for next meeting. (RACP training program to be forwarded to I. Salusky).

Education – Vladostock, Russia – Two representatives from IPNA and two representatives from ESPN will organise a course in pediatric nephrology to local pediatricians.

ESPN Meeting - 2002 – Bilbao
2003 - ? Berlin with ISN

ANZPNA Assistant Secretary – Assistant Secretaries are appointed by regional societies. Councillors are appointed by IPNA after a call for nominations. ANZPNA now has an Assistant Secretary and not a Councillor. J. Burke retires end 2001 IPNA Seattle Congress.

An election should be organised for a new Assistant Secretary in early 2001 by the Executive of ANZPNA. Previous Councillors are eligible to be appointed as Assistant Secretaries.

J. BURKE

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Parkville 3052

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9th November 2000

INTERIM REPORT – ANZPNA BENCHMARKING

The interim report for the renal biopsy benchmarking, peritoneal dialysis catheter, CVC, and AVF benchmarking is included. The renal transplant benchmarking has not been included.

These reports have been complied by Lil Johnstone and Vicki Burns.

We will have a more complete report at the May 2001 meeting.

The benchmarking project is to last for 2 years and will be complete for most centres at the end of 2001.

The organisers thank-you for your contributions to this stage and recognise the amount of work people in your centres have put in.

Best wishes,

Colin Jones

INTERIM REPORT RENAL BIOPSY

8th November 2000

TOTAL BIOPSY FORMS *151 Forms*

Question 1: Indication for Renal Biopsy

	CENTRE A	CENTRE B	CENTRE C	CENTRE D	CENTRE E	CENTRE F	CENTRE G
Haematuria	3	7	4	4	5	6	6
Proteinuria	1	5	5	4	6	2	6
Nephrotic	1	5	11	2	3	4	3
Nephritic		5		1		2	1
Renal Impairment	1	9	3	7	1	2	3
Transplant	4	7	7	15	5	1	2
Other	2	9	1	1	1	5	

Comments : (1st 122 reports) Indication for biopsy

Haematuria 18%
Proteinuria 14%
Nephrotic Syndrome 18%
Nephritic Syndrome 5%
Renal Failure 17%
Transplant 27%

Question 2: Prebiopsy Tests

	CENTRE A	CENTRE B	CENTRE C	CENTRE D	CENTRE E	CENTRE F	CENTRE G
FBE	5	29	29	29	18	17	16
Coagulation	9	28	29	28	18	17	16
Group/Hold	8	1	29	29	5	15	
Xmatch	1		28	1		4	1
Skin bleed time	1		28		23	4	12

Comments: (1st 122 reports)

FBE and coagulation studies performed in the 95% of cases, 69% of cases have group and hold performed. One centre routinely collects cross match and skin bleeding time prior to biopsy.

Question 7: Require blood transfusion

	CENTRE A	CENTRE B	CENTRE C	CENTRE D	CENTRE E	CENTRE F	CENTRE G
Yes	2	2		0	0	1	

Comments: (1st 122 reports)
Five (4%) require transfusions and in 2 cases no macroscopic haematuria occurred.

Question 8: Patient require readmission because of complication of biopsy

	CENTRE A	CENTRE B	CENTRE C	CENTRE D	CENTRE E	CENTRE F	CENTRE G
Yes	1			1	1	1	0

Question 9: Length of stay greater than 36 hrs

	CENTRE A	CENTRE B	CENTRE C	CENTRE D	CENTRE E	CENTRE F	CENTRE G
Yes length of stay greater 36 hrs		3	1				3
Discharged same day	1	12	10		12		
Discharged following day	5	14	7	12	4	8	10
Other LOS	2	5	13	18		4	1

Comments: (1st 122 reports)
The majority 44% stayed overnight following the procedure, 22% were discharged the same day. Only 5% stayed for longer than 24 hours due to a complication of the biopsy. 33% stayed for more than 36 hours due to ongoing treatment of their underlying disease.

Question 9(a): Length of stay due to complication of biopsy

	CENTRE A	CENTRE B	CENTRE C	CENTRE D	CENTRE E	CENTRE F	CENTRE G
Yes	2	2	3		1	1	

Question 10: Any other condition relevant

	CENTRE A	CENTRE B	CENTRE C	CENTRE D	CENTRE E	CENTRE F	CENTRE G
Yes	2		1	8			

INTERIM REPORT ON CVC

(as at 30/09/00)

5 Centres have contributed dated

Centre	Patients	Interventions (n)	Insertion	Removal (n)	Reason for Removal
A	2	5	3	2	Temp CVC inserted in error, transplant
B	5	14	9	5	infection (3), infection, poor flows
C	3	14	7	7	PUO, AVF created, transplant
D	2	3	2	1	Change to PD
E	2	5	3	2	Malposition, transplant

CVC lines were inserted :

Vascular surgeon	1
General surgeon	5
Transplant surgeon	7
Paediatric urologist	3 (? Assisted general surgeon in one centre on 3 occasions)
General paediatric surgeon	1
Anaesthetist	10 (? Were these acute catheters)

All CVC were used within 24 hours of insertion. All are heparin locked with heparin concentrations varying from 1000U/ml to 5000U/ml. Only 3 catheters were used at times other than dialysis

JOURNAL OF AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

VOLUME 3, No 2. JANZPNA

31.3.2000

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Department of Nephrology
Royal Children's Hospital
Flemington Road
Parkville 3052

Telephone: 03 9345 5054
Facsimile: 03 9345 5611

20th October 1999

Dear ANZPNA Member

Please find enclosed a summary of the successful bid made for the IPNA 2004 Congress. The bid will give you an idea of the commitments we have made to the IPNA Council.

There are not many things that need to be done at the current time. There will be a need to think about the various committees to the Executive (listed on the last text page). In addition, we will need to finalise the Congress date (probably August 22, 2004) and request formal agreement from the ANZSN to run their meeting in conjunction with this meeting.

Yours sincerely,

Colin Jones and Fred Jureidini
Congress Chairmen

SUMMARY OF PRAGUE – September 1999

A summary of the Formal Bid presentation given by Ken Jureidini and the Scientific Program Development presentation given by Colin Jones

Congress President:	Dr David McCredie
Congress Chairman:	Dr Ken Jureidini
	Dr Colin Jones

Local Organising Committee based in Adelaide

Ken Jureidini	Chairman
Ann Martin	Local Scientific Co-ordinator
Margie van Renen	Local Scientific Co-ordinator
Paul Henning	Director, Renal Unit, WCH
Peter Wilby	Renal Unit, WCH
Jill Lawton	Renal Unit, WCH
Graham Russ	ANZSN
Hilary Boucaut	Pediatric Urology
Adrian Porter	Urology
Brian Morris	RACP (Pediatrics)
Glenise Coulthard	Indigenous Co-ordinator
Warwick Prime	Australian Kidney Foundation
Peter Malycha	College of Surgeons (2007)
Nicole Kean (Jureidini)	Accompanying Persons' Program
Kirsty Henning	Accompanying Persons' Program

Adelaide Convention Centre was described:

Located in Central Business District
15 minutes from International Airport
1800 hotel rooms within 5 minutes of Convention Centre
Facilities Refurbished & Extended by 110% in 2001
Full Plenary Mode - 3500 Delegates
Banquets Capacity - 4850 guests
10,450 m^2 of Exhibition Space
Conference Cafe
Speakers' Preparation Suites with On-Hand Technicians
Event Co-ordinators, Catering & Audio Visual Departments all In-House

Congress Venue was described:

See figure of layout of venue

The Harley Management Group is managing the Congress

Incorporated in November 1990
History of Growth & Stability - Owner Managed
Managed 35 National & International Conferences, including 12 Medically related, of up to 1200 delegates
Managed 23 Exhibitions with up to 90 sites
Managed Sponsorship for 22 Conferences with Income up to US$300,000

Established Business Relationships with Medical Suppliers & Pharmaceutical Companies

The accommodation available for the congress was described:

See attached figure

The costs of attending IPNA from various countries was outlined:

	RETURN AIRFARE	REGISTRATION	ACCOMMODATION (5 NIGHTS)	TOTAL
LONDON	US$955	US$435	US$50	US$1440
LOS ANGELES	US$938	US$435	US$50	US$1423
TOKYO	US$899	US$435	US$50	US$1384
SINGAPORE	US$685	US$435	US$50	US$1170
AUCKLAND	US$480	US$435	US$50	US$965

The main reasons for choosing Adelaide were given:

Guaranteed Success
IPNA will be working with a team that has a history of success in managing Medical Conferences

Financial Viability for IPNA and its Members

The Draft Budget is based on

- Breakeven at 500 delegates
- Registration fee of US$435 inclusive of all Social Functions
- Allowance for 80 Bursaries at 50% fee

A New Continent
By holding the Congress in Australia, IPNA can be seen to be promoting its International status & providing members with new professional & personal opportunities

SCIENTIFIC PROGRAM

Introduction

The fundamentals of the Scientific Program will evolve around the science and its development as presented in the London meeting and that will be further developed through the Seattle meeting with its particular emphasis on new forms of information technology and their relationship to paediatric nephrology. We wish to use the strengths of our area of the World in presenting the scientific basis of paediatric nephrology for indigenous populations. We wish to concentrate on the way paediatric nephrology is developing and will be orientating our program to support presentations by the younger paediatric nephrologists and researchers.

Interim Scientific Committee Time Line

Interim Scientific Committee		July 1999
Continuing Review Seattle S.P.C		To Sept. 2001
SPC (Andrew Rosenberg and Colin Jones on Seattle SPC)		
Co-opt all ANZPNA to observe/report on IPNA 2001		Sept. 2001
Review IPNA 2001 Congress		March 2002
with International prospective and strengths		
and weakness		
Executive Committee and Theme Organiser		June 2002
Define Themes		Sept 2002
Theme development committees local and International members		
Choice of speaker	1st round	Jan 2003
	2nd round	July 2003
Call for papers		Sept 2003

Interim Scientific Program Committee Members

Colin Jones (Chairman)
Ken Jureidini
Andrew Rosenberg
Anne Martin

Scientific Program Development

Review of the workings of the Seattle IPNA 2001 Scientific Program Committee. Helped by the presence of Colin Jones and Andrew Rosenberg on the Scientific Program Committee for that meeting. Allison Eddy, co-chair of the Seattle SPC, is an invited speaker at the March 2000 meeting of the Australian and New Zealand Society of Nephrology.

Just prior to the IPNA 2001 meeting in Seattle we will co-opt a wider committee so that we can cover all aspects of the Seattle meeting in detail. Following the completion of the Seattle meeting, we plan to conduct **a full review of the Seattle meeting** taking into consideration views from the Seattle organisers, IPNA members and nephrologists from South East Asia. The aim of this comprehensive review will be to build on the strengths of that Congress and make the 2004 meeting appropriate, up to date and relevant.

Following that review our general timetable for development of the Scientific Program is outlined. **The Executive Committee will be cut down to 3-4 members and theme organisers will be set up** in approximately 5 broad areas. These theme organisers will broadly define their themes and then select a local Theme Committee supplemented by international members. We envisage 3 – 4 members developing each theme and they will

liase through meetings with the Executive and other theme organisers to ensure that we have a coherent program.

A choice of speakers will be made by the theme committees. We will hope that a first round for choice of speakers will be made by January 2003 with a second round to be made in July 2003, and a call for papers in September 2003.

Concurrent ANZSN Scientific Meeting

The Australian and New Zealand Society of Nephrology run a scientific meeting each year which has approximately 200 attendees. Their Executive has agreed in principal to run their meeting in Adelaide in a way that supports our proposed meeting. They would have parallel sessions on a Wednesday, we could have some conjoined sessions on the Thursday and their meeting would conclude on the Friday. As Ken has indicated to you the meeting venue is clearly big enough to take two such meetings without conflict regarding amenities.

The ANZPNA would like to run one or, at most two satellite meetings in conjunction with the IPNA meeting. These meetings would be subject to sponsorship and could cover a range of topics. A selection and development of these topics would be a roll for the interim Scientific Program Committee over the next year

Renal Development Workshop

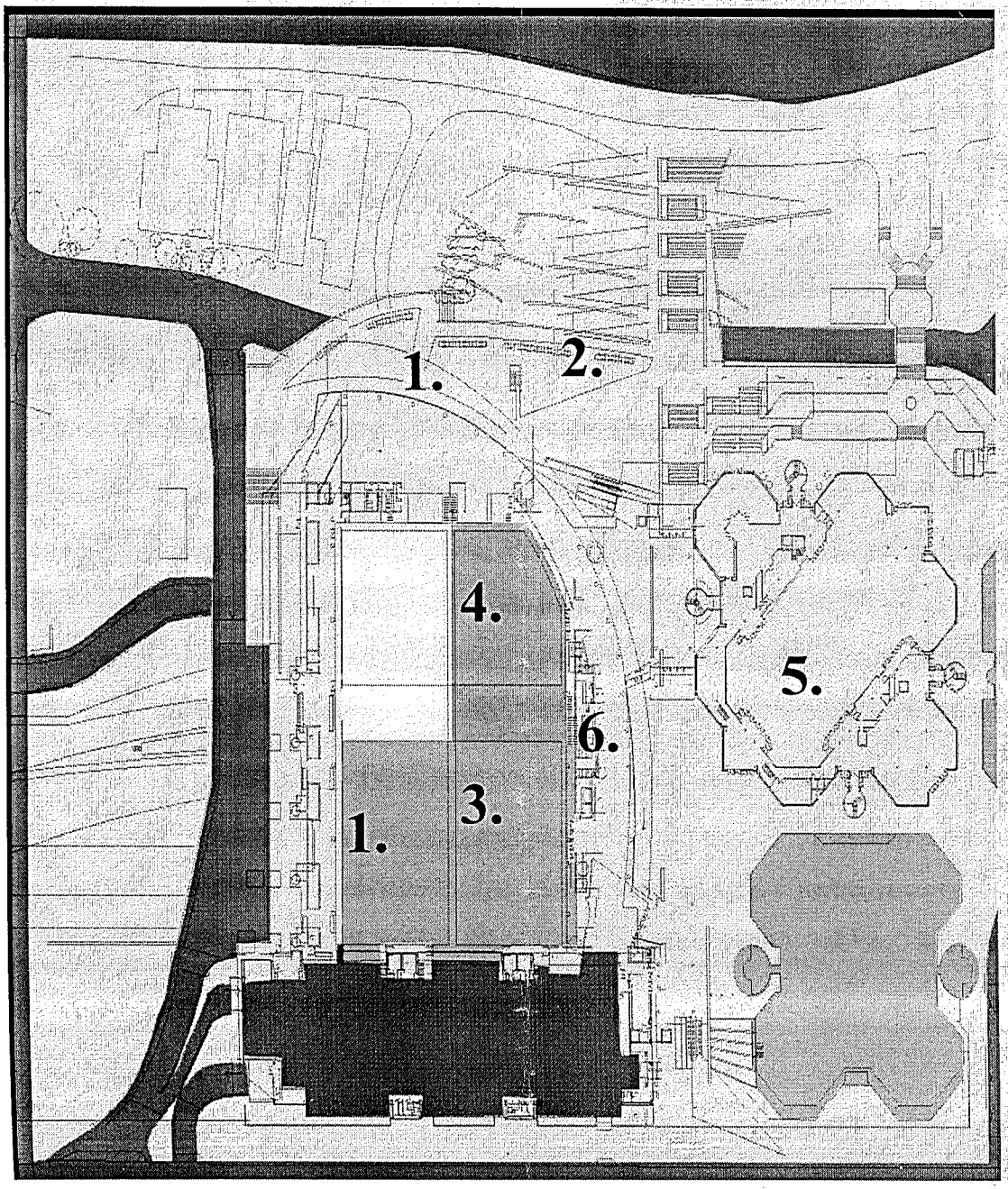
Professor John Bertram is Head of Anatomy at Monash University, Melbourne and has a strong research interest in renal developmental biology. He has agreed to assemble and head an organizing committee for the workshop subject to the approval of the relevant committees of IPNA. He has the necessary experience, administrative skills and infra-structure support to organise the Renal Development Workshop.

Researchers active in various aspects of development in Australia and New Zealand include Professor Eugine Lumbers, Professor Daine Alcorn, Professor Marelyn Wintour and Dr Melissa Little. These people have been approached with regard to helping organize the workshop. They have agreed to support the International Renal Development Workshop in Australia or New Zealand and the represent a geographically diverse selection of people. It may be that there are others to add to this list.

Bob Chevalier who has a role in selecting the venue and organizing the International Renal Development Workshop will have the opportunity to meet with John Bertram when he comes to Melbourne in March 2000.

Details about the Renal Development Workshop have still to be determined. We are looking for a venue that will house 150 – 200 participants and this venue will be outside a major city. There are ranges of potential sites, which are within 2 hours of Adelaide and which have been used for scientific meetings in the past ranging from sites such as Ayers Rock, Cairns, Lorne, or other smaller towns.

CONGRESS VENUE ADELAIDE



LEGEND

1. **Poster Display**

2. **Congress Dinner**

3. **Trade**

   6,000 m^2 of pillarless exhibition space

4. **Catering**

   Banquet Style

   1,700 people, tables of 10

5. **Congress**

   1 Plenary Hall @ 1,100 delegates

   4 Breakout Rooms @ 450 delegates

   9 Breakout Rooms @ 30-180 delegates

6. **Convention Facilities**

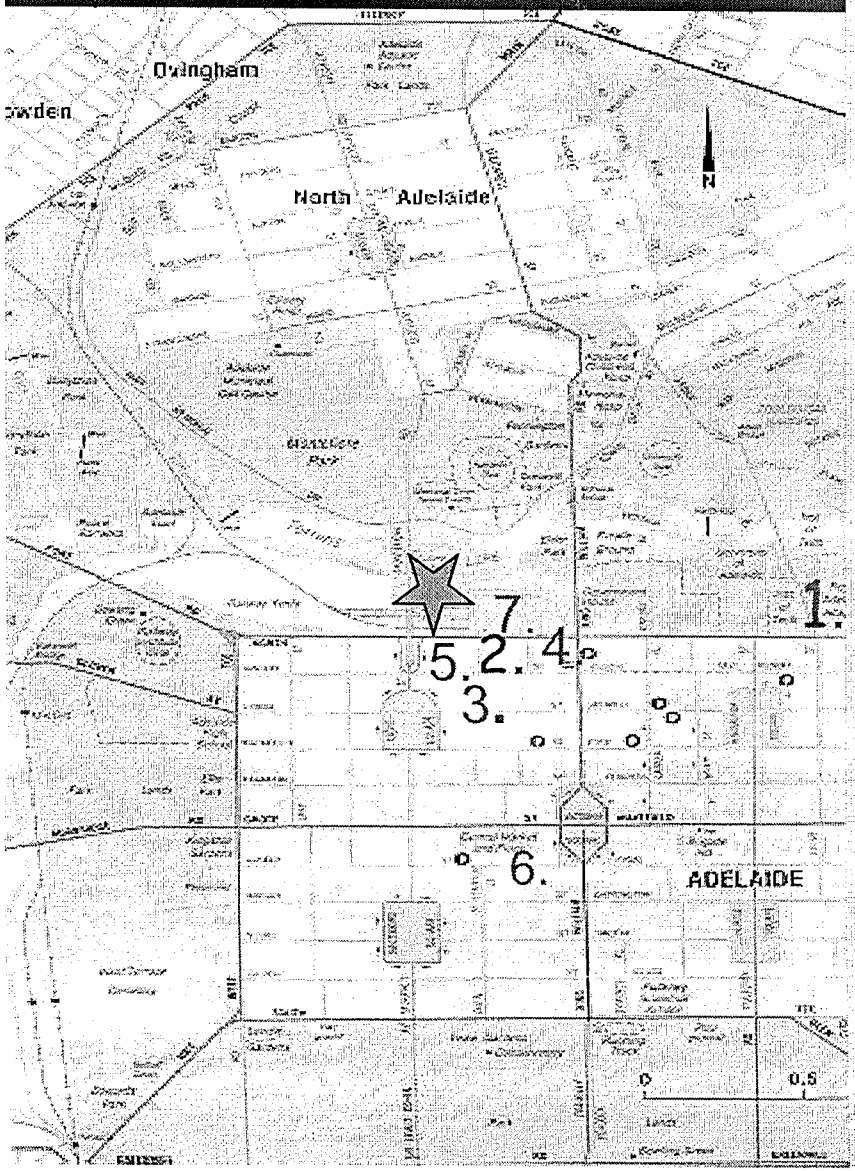
   Conference Organiser's Office

   Speakers' Preparation Suite

   IPNA Secretariat Office

ACCOMMODATION

Convention Centre



1. Royal Adelaide Hospital-Residential Wing

US$10 per room, Rating: Student Quarters Rooms: 100

Distance from Convention Centre -10 min walk

2. Grosvenor Vista

US$78 per room, Rating: *** Rooms: 290 Distance from Convention Centre - 2 min walk

3. Hindley Parkroyal

US$109 per room, Rating: **** Rooms: 178 Distance from Convention Centre - 3 min walk

4. Stamford Plaza

US$109 per room, Rating: **** Rooms: 336 Distance from Convention Centre: 3 min walk

5. Radisson Playford

US$145 per room, Rating: **** Rooms: 182

Distance from Convention Centre: 30 sec walk

6. Hilton International

US$119 per room Rating: ***** Rooms: 380 Distance from Convention Centre: 10 min walk

7. Hyatt Regency

US$135 per room Rating: ***** Rooms: 367Distance from Convention Centre: 30 second walk

IMMEDIATE POST – BID
CONGRESS ORGANISATION

PRESIDENT:

David McCredie

CHAIRMEN:

Ken Jureidini
Colin Jones

EXECUTIVE:

Ken Jureidini	Local Organiser
Colin Jones	Scientific Program Committee Chairman
John Burke	IPNA Council Member
Paul Roy	Chairman ANZPNA

POTENTIAL COMMITTEE TO EXECUTIVE:

Local Organising Committee
Publicity
Finance
Social

Scientific Program

Publications
Satellites
Renal Development Workshop (John Bertram)
Training Course
Continuing Education

Dr Elisabeth Hodson MB BS FRACP
Consultant Physician – Paediatric Nephrology
Provider no: 29665AH

Telephone: 61 2 9845.3430
Fax: 61 2 9845.3432
Email: Elisah@NCH.EDU.AU

Members of ANZPNA

7th February, 2000

Dear Member,

At the Annual General Meeting of ANZPNA in July 1999 it was determined that Clause 11E should be deleted from the Articles of Association. This motion was moved by Dr John Knight and seconded by Dr David McCredie. However, ANZPNA is now an incorporated organisation and under corporation law, changes to the constitution can only be made by a special resolution. The special resolution must be passed by at least 75% of the votes cast by members entitled to vote on the resolution, either in person or by proxy. A special resolution must be passed at a meeting of which at least 21 days written notice has been given.

I enclose the notice of the resolution and also a proxy form. I would request that those of you who are not attending Annual General Meeting of ANZPNA on March 17th 2000 complete the proxy form nominating another member of ANZPNA to hold the proxy for the meeting. The proxy form is only valid if I receive it before the Annual General Meeting.

With best wishes,
Yours sincerely,

Elisabeth

Dr Elisabeth Hodson
Secretary
ANZPNA

AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

Special Resolution to be considered at the Annual General Meeting of the Australian & New Zealand Paediatric Nephrology Association to be held at the Hotel Sofitel on March 17th 2000 at 4.00pm.

Special Resolution: It is proposed that in Article 11, "The membership of any member shall be terminated ipso facto, in any of the following events" sub-clause (e) "if he becomes mentally ill" be deleted and that the amended articles become the Articles of Association of the Australian and New Zealand Paediatric Nephrology Association.

Elisabeth Hodson
Secretary - ANZPNA

The Australian and New Zealand Paediatric Nephrology Association

I _____ of _____

being a Member of the Australian and New Zealand Paediatric Association hereby appoint _____

as my proxy to vote for me and on my behalf at the general meeting of the Company to be held at the Hotel Sofitel, Melbourne on the 17th of March and at any adjournment thereof (or at any meeting of the Company that may be held in the year 2000).

AS WITNESS my hand this _____day of _____

SIGNED by the said _____

In the presence of _____

MEMBERS OF ANZPNA – February 2000

Member	Phone	Fax	Email
Dr J Burke Alexandra House 201 Wickham Terrace Brisbane QLD 4000	07 3832 5421	07 3831.8250	jburke@gil.com.au
Dr J Craig New Children's Hosp PO Box 3515 Parramatta NSW 2124	02 9845.3431	02 9845.3432	jonc@nch.edu.au
Dr C Crompton Dept of Nephrology Princess Margaret Hospital for Children PO Box D184 Perth WA 6840	08 9340 8354 08 9340.8222 0418 917 733	08 9340 8301	c/- Secretary Maureen.Sefton@health.wa.gov.au
Dr M Falk Canberra Hospital PO Box 11 Garran ACT 2601	02 6244.2046 0419 641 449	02 6244.3281	michael.falk@act.gov.au
Dr P Henning Dept of Nephrology Adelaide Women's & Children's Hospital King William Road North Adelaide SA 5006	08 8204.7000 08 8204.7303	08 8204.6048	henningp@wch.sa.gov.au
Dr I Hewitt Princess Margaret Hospital for Children GPO Box D184 Perth WA 6840	08 93408354 08 9340 8222 (switch) 0418 928 983	08 9340 8301	Ian.Hewitt@health.wa.gov.au
Dr E Hodson New Children's Hospital PO Box 3515 Parramatta NSW 2124	02 9845.3430	02 9845.3432	Elisah@nch.edu.au
Dr L Johnstone Nephrology Royal Children's Hosp Clayton Road Clayton VIC 3168	03 9345.5054 Pager – 03 9387 1000	03 9345.5611	c/- Colin Jones or Vicki Burns burnsv@cryptic.rch.unimelb.edu.au
Dr C Jones Dept of Nephrology Royal Childrens' Hospital Flemington Road Parkville VIC 3052	03 9345.5054	03 9345.5611	cjones@cryptic.rch.unimelb.edu.au
Dr KF Jureidini Dept of Nephrology Adelaide Women's & Children's Hospital King William Road North Adelaide SA 5006	08 8204 7000 08 8267 7303	08 8204 6048	jureidinik@wch.sa.gov.au
Dr G Kainer Dept of Nephrology Sydney Children's Hospital High Street **Randwick NSW 2031**	02 9382. 1646	02 9382.1580	G.Kainer@unsw.edu.au

Member	Phone	Fax	Email
Dr J Knight Centre for Kidney Research New Children's Hospital PO Box 3515 Parramatta NSW 2124	02 9845.3037 0416 614 189	02 9845.3038	johnk@nch.edu.au
Dr D Lewis New Children's Hospital PO Box 3515 Parramatta NSW 2124	02 9845.3431	02 9845.3432	dcborahl@nch.edu.au
Dr D Lines Flinders Medical Centre Dept Paediatrics Flinders Drive Bedford Park SA 5042	08 8204.5511 08 8204.4433	08 8204.3945	david.lines@flinders.edu.au
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Dr S McTaggart Dept of Nephrology Royal Children's Hospital Flemington Road Parkville VIC 3052	03 9345.5054	03 9345.5611	mctaggas@crytpic.rch.unimelb.edu.au
Dr F Mackie Dept of Nephrology Sydney Children's Hosp High Street Randwick NSW 2031	02 9382.1737	02 9382.1580	fionamack@yahoo.com
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Dr H Powell Dept of Nephrology Royal Children's Hospital Flemington Road Parkville VIC 3052	03 9345.5054	03 9345.5611	powell@cryptic.rch.unimelb.edu.au
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Dr LP Roy Area Director Paediatric Services King George V Hospital Missenden Road Camperdown NSW 2050	02 9515.5456	02 9515.5551	lpaulroy@yahoo.com

Member	Phone	Fax	Email
Dr P Tomlinson Dept of Paediatrics Southland Hospital Private Bag 828 Invercargill NZ	643 2181949	643 2145720	paultom@southnet.co.nz
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A/Prof R Walker Dept of Nephrology Royal Children's Hospital Flemington Road Parkville VIC 3052	03 9345.5054 03 9342.7053	03 9345.5611	rowan.walker@nwhcn.org.au
Dr F Willis Paediatric Nephrologist Rockingham Family Specialist Centre 221 Willmott Drive Walkiki WA 6169	08 9526.2767 08 9340.8222 08 9476.0838 (pager) 0417 917 042	08 9592.4187	francis.willis@health.wa.gov.au
Dr W Wong University of Auckland Dept of Paediatrics School of Medicine Private Bag Auckland NZ	649 307.4921	649 307.4913	wmwong.@nznet.gen.nz

AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

The teleconference for the Executive of the ANZPNA will be held on Wednesday December 8, 1999 at 4 pm

AGENDA

Business to be followed up from the AGM:

1.Establishment of sub-committee to consider criteria for membership and associate membership
2.Removal of clause 11e from the articles of association
3.Nomination for IPNA representative to succeed John Burke when his term ends in 2001.
4.Establish sub-committee related to Growth Hormone & advocacy re GH
5. Kidney Kids Camp
6.ANZDATA registry data and representative
7. ANZPNA representatives on other committees

Other business:

1. IPNA meeting
2. Fund raising for ANZPNA meetings
3. AGM of ANPNA in 2000
4. Holding scientific meetings to coincide with RACP meeting
5. Bench marking
6. Formal affiliation with Division of Paediatrics of RACP.
7. Any other business

Elisabeth Hodson
Secretary

PLEASE NOTE THAT THESE MINUTES ARE UNCONFIRMED

Minutes of the teleconference of the ANZPNA executive held on Wednesday December 8, 1999

Present: Paul Roy, Colin Jones, Michael Falk, Elisabeth Hodson

Colin Jones confirmed the minutes of the previous meeting on June 18, 1999 as a correct record.

Business arising from the AGM

1. **Membership of ANZPNA**: This is clearly defined under Clause 4 of the Articles of Association so it was decided not to appoint a subcommittee to investigate this further. Trainees in paediatric nephrology who wish to become Associate Members should provide their curriculum vitae to the Executive. The Executive of ANZPNA will consider the application.
2. **Clause 11 (e) of the Articles**: The Articles are to be resubmitted to ASIC with a request that they be re-registered with out Clause 11 (e).
3. **Nomination to IPNA Council**: A call for nominations for a new representative on the Council of IPNA will be made 2 months before the AGM in the year before the term of the previous councillor is to end. Nominations will be closed 1 month before the AGM. A postal ballot will be held if more than one nomination is received. Restrictions on nominations will be in accordance with the Articles of Association of the IPNA.
4. **Growth Hormone subcommittee**: Charlie Crompton has been asked to chair this sub-committee with the following terms of reference:-
   1) To advocate for the continued use of recombinant human growth hormone in children with short stature due to chronic renal failure.

   2) To analyse the growth data from Australian children with chronic renal failure treated with growth hormone.

   3) To produce guidelines for the use of growth hormone in children with chronic renal failure in association with the "caring for Australians with renal impairment" guidelines being established through the Australian and New Zealand Society of Nephrology and the Australian Kidney Foundation.

   4) To ensure that a database of publications on the use of recombinant human growth hormone in children with chronic renal failure is maintained.

   5) To report annually on the activities of the sub-committee at the Annual General Meeting of the Australian and New Zealand Paediatric Nephrology Association.

   Paul Roy is to write to the Pharmaceutical Benefits Branch of the Commonwealth Department of Health and Aged Care again to request that the moratorium on the use of rhGH be extended till ADEC's response to the submission from Novo Nordisk has been determined.

5. **Kidney Kids Camp**: Letters are to be written to all state AKF managers stating that state or regional camps are preferred to national camps and that ANZPNA expects that state branches of AKF will provide some funds and logistic support.
6. **Letters to other societies**: Letters are to be written to ANZSN, TSANZ, RACP (Division of Paediatrics), AKF, ANZDATA Registry Committee, Dialysis and Transplant Sub-committee of ANZSN and AKF to inform them that ANZPNA is now incorporated and that it is willing to provide paediatric nephrological input to other societies.

Other Business

1. **IPNA meeting in 2004**: A meeting is to be held in Adelaide on December 11, 1999.
2. **Fundraising**: Michael Falk will submit a package to the executive on how sponsors might be invited to contribute to the ANZPNA. It was decided that Baxter Healthcare should be offered senior sponsorship in recognition of their support of ANZPNA to date.
3. **AGM/Scientific Meeting**: The AGM/Scientific Meeting in 2000 will be held on March 17 and 18, 2000 after the ANZSN meeting. Dr Harley Powell has agreed to organise the Scientific Meeting. It was agreed that ANZPNA should accept the invitation of RACP to join with them at their scientific meeting in 2001. Subsequently ANZPNA would alternate the timing of their meetings to coincide with the ANZSN and RACP meetings on alternate years.
4. **Affiliation to RACP (Division of Paediatrics) and to ANZSN**: In response to a letter from Dr Jill Sewell, a letter will be written agreeing to examine further some form of formal affiliation with RACP. A letter will also be written to Professor David Harris suggesting that some form of formal affiliation to ANZSN be examined also.
5. **Benchmarking**: The forms for benchmarking activities should be returned regularly to Dr Lilian Johnson.
6. **Secretarial and telephone expenses**: These will be supported from the membership fees.

AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

Annual General Meeting 2000

The Annual General Meeting of The Australian and New Zealand Paediatric Nephrology Association will be held on Friday 17 March, 2000 at 4 pm in the West Tower Suite at Hotel Sofitel, Melbourne.

AGENDA

1. Apologies
2. Confirmation of the Minutes from the Annual General Meeting held at the New Children's Hospital, Westmead on July 25, 1999
3. Report of the Chairman
4. Report of the Honorary Treasurer
5. Report of the Honorary Secretary
6. Election of new members
7. To consider the Special Resolution to remove sub-clause (e) from Article 11 of the Articles of Association
8. Other Business
   - IPNA Council – Representative from 2001
   - IPNA Meeting – Adelaide 2004
   - Report of Growth Hormone Sub-committee
   - Benchmarking
   - Report of clinical studies – VUR
     APSU: Nephrotic Syndrome
     Trial of treatment of FSGS
   - Kidney Kids Camp
   - ANZ Data Registry
9. New Business
   - Formal affiliation with RACP and ANZSN
   - Future AGMs with RACP or ANZSN
   - Future studies with APSU
   - Health in Aboriginal children
   - Cochrane Renal Group
10. Any other business

Elisabeth Hodson
Honorary Secretary

March 13, 2000

Minutes of the 2nd Annual General Meeting
Friday March 17, 2000
Hotel Sofitel, Melbourne
Commencing at 4 pm

1. Apologies: Gad Kainer, John Burke, David Lines, Deborah Lewis, Jonathan Craig, Lilian Johnstone, Charlie Crompton

   Present: Paul Roy, Michael Falk, Elisabeth Hodson, Margot McIver, Mandy Walker, Paul Henning, Andrew Rosenberg, Fiona Mackie, Harley Powell, David McCredie, Rowan Walker, Ian Hewitt, Fred Jureidini, Colin Jones, Frank Willis, John Knight.

   Proxies were received from Gad Kainer, John Burke, David Lines, Deborah Lewis, Jonathan Craig and Lilian Johnstone.

2. Confirmation of the Minutes of the 1st Annual General Meeting held at the New Children's Hospital in Sydney on July 25, 1999.

   Proposed: David McCredie
   Seconded: Andrew Rosenberg
   Accepted unanimously

3. Chairman's Report: Paul Roy spoke to his report (Appendix 1). He reiterated the importance of ANZPNA becoming an incorporated body to enhance its ability to promote the care of children with government agencies and other professional bodies. The 2004 meeting of IPNA to be held in Adelaide will also provide a major opportunity to enhance the profile of paediatric nephrology in Australia. He was gratified to obtain assurance from the Pharmaceutical Benefits Branch that rhGH would continue to be available to children with renal failure while registration matters were being considered. Finally he noted the activities of members of ANZPNA in various fields.
   Acceptance of the Chairman's Report was proposed by Rowan Walker, seconded by Harley Powell and accepted unanimously.

4. Treasurer's Report: Michael Falk spoke to his report (Appendix 2). He reported that as ANZPNA is incorporated, the accounts have to be audited by an accountant registered with the ASIC. The auditor has not yet been appointed. Sponsorship for the 2000 AGM had been obtained from several companies so all costs should be covered. He proposed that levels of sponsorship be set up. He is to pursue tax exempt status for ANZPNA initially by obtaining advice from ANZSN as to processes that that body followed. Resolution of Tax Exempt status before IPNA meeting in 2004 is desirable. 10% GST would need to be added in future to subscriptions of Australian members but not for members from New Zealand or any other countries since the Tax Office regards such memberships as

"export benefits". It was determined that the membership fee for Australian members should be increased to $105.00 (including GST for the period of June 2000 to December 2000) for the 2000 calendar year. Acceptance of the Treasurer's Report was proposed by Rowan Walker, seconded by David McCredie and accepted unanimously.

5. Secretary's Report: Elisabeth Hodson spoke to her report (Appendix 3). It was suggested that ANZPNA should inform the NH & MRC, the Renal Nurses' organisations and the Commonwealth Department of Health and Aged Care of its existence.
   Acceptance of the Secretary's Report was proposed by Andrew Rosenberg, seconded by Paul Henning and accepted unanimously.

6. Election of new members: Elisabeth Hodson proposed and Rowan Walker seconded the motion that Fiona Mackie, Stephen Alexander and Steven McTaggart should be accepted as full members of ANZPNA. The motion was carried unanimously.

7. Special Resolution to remove sub-clause (e) from Article 11 of the Articles of Association. This was moved by Elisabeth Hodson, seconded by Rowan Walker and approved unanimously by 22 of 25 members [including proxies] (Appendix 4)

8. Other business
   1. IPNA Council – Representative from 2001: Australia and New Zealand has only one member on the IPNA Council. That member is now also a regional secretary. Currently John Burke is the Councillor and the Regional Secretary. His term of office as councillor is due to end in 2001. Because of the IPNA meeting in 2004, it may be appropriate to ask John to remain as Councillor until 2004. Following discussion it was agreed that when the IPNA seeks advice from ANZPNA concerning nominations received for a representative from Australia and New Zealand that a ballot be held if there are more one candidates and that the successful candidate be nominated to IPNA as the ANZPNA representative. Ira Greifer is to step down as Secretary-General of IPNA in 2001. Mattias Brandis is the only person nominated to replace him. Bruder Stapleton has nominated to be Treasurer.
   2. IPNA Congress – Adelaide, 2004: Fred Jureidini made a presentation on the preparations to date for this congress (Appendix 5). Seed funding of $25,000 is to be provided by IPNA. Considerable discussion took place as to whether and when it was appropriate to request IPNA for a share of any profits from the congress. It was determined that ANZPNA should receive formal documentation from IPNA to confirm that Adelaide's bid for the congress had been successful and to confirm that IPNA would underwrite the meeting and therefore assume all risk. It was also determined that there should be negotiation with IPNA at an appropriate time about the distribution of any profits. ANZPNA approved the stationery format for the congress. ANZPNA also accepted the organisational structure for the committees except that Finance and Treasurer should be more closely associated.

Colin Jones reported on the Scientific Programme. Following the next congress in Seattle in 2001, the themes for the Adelaide meeting would be developed and theme organisers would be selected. Letters to prospective speakers will be sent in January 2003 with further letters in July 2003. The first information brochure and call for abstracts would go out in September 2003. The International Renal Development Workshop will be held just before the congress. John Knight suggested that the congress should be preceded by a two day education workshop. ANZSN will hold its annual scientific meeting in conjunction with the congress. Rowan Walker suggested that there should be a representative of ANZPNA on ANZSN's Scientific Programme and Education Committee.

3. Growth Hormone Sub-committee: Elisabeth Hodson spoke to Charlie Crompton's report (Appendix 6). The analysis of growth data is proceeding now that much of the missing data has been obtained. Novo-Nordisk has submitted an application to the TGA for approval of Norditropin for use in children with renal failure. Pharmacia is considering re-submitting an application for approval of Genotrophin. It is understood that some members of TGA are concerned about a potential risk of malignancy due to elevated IGF-1 levels with rhGH treatment.

4. Benchmarking: Colin Jones presented preliminary data on the project which commenced in September 1999 and will continue for two years. The project involves renal biopsy, peritonitis is dialysis patients and access complications in haemodialysis and peritoneal dialysis. A number of problems with the forms had been identified and the solutions have been set out in the report (Appendix 7).

5. Clinical Studies:
   a) Asymptomatic ureteric reflux: Paul Roy reported that this study is now closed to new enrolments and that results will be available in 2002. The study will not be unblinded till then.
   b) Incidence of nephrotic syndrome: Elisabeth Hodson spoke to her report (Appendix 8). Ascertainment of new cases will be completed in June 2001 and the study will be completed in June 2002.
   c) Trial of cyclosporin and cyclophosphamide in FSGS: No patients have been entered yet (Appendix 9).

6. Kidney Kids Camp: It was reported that the camp held in Tasmania in January was very successful. It is possible to run a national camp successfully and the families reported that they liked the contact with people from other states. Mandy Walker stated that in future the camp would be held in April and would be shorter. Andrew Rosenberg reported that NSW would prefer to run a regional camp because of the travel involved, the expense and the different philosophies on how the camp should be run. John Knight stated that the Australian Kidney Foundation was prepared to support national or regional camps. The AKF recognised the valuable publicity that it received from the Kidney Kids camp and was examining how it could fund the camp to allow the children to attend without cost to their families.

7. ANZDATA Registry: Rowan Walker is to stand down as the author of the paediatric report. John Knight proposed a motion thanking Rowan for his work and nominating Jonathan Craig as his successor. The motion was seconded by David McCredie and passed unanimously. Colin Jones asked that the list of ANZPNA members holding positions in other professional bodies be circulated annually to ensure that representation on these bodies was maintained. This is to be updated and circulated.

9. New Business

1. Formal affiliation with RACP, ANZSN and other professional bodies: RACP and ANZSN are considering ANZPNA's request for some form of formal affiliation with these bodies. Their responses are awaited. A response is also awaited from TSANZ as to whether they will consider the nomination of a member of ANZPNA to provide formal paediatric input to TSANZ.
2. Future annual general meetings: It was proposed by Andrew Rosenberg and seconded by Elisabeth Hodson that the AGM in 2001 should be held with the RACP meeting in Sydney. The motion was carried with 9 votes for the motion and 4 votes against the motion. The venue of future AGMs will be discussed at future meetings.
3. Health of Aboriginal children: Fred Jureidini reported that a project to provide and evaluate a screening programme for renal disease in aboriginal children was jeopardised through lack of funding. John Knight reported that the Expert Advisory Group on Aboriginal health had determined that standard national guidelines for the screening of adults are to be produced and implemented. However there is currently no evidence that children should be screened. It was agreed that ANZPNA would support research efforts to obtain more information in Aboriginal children or other groups of children who have serious health disadvantage in order to improve health outcomes for such children.
4. Cochrane Renal Group: It was reported that the Cochrane Renal Group is likely to move to the Centre for Kidney Research at the New Children's Hospital in Sydney. ANZSN has approved funding towards this project. Jonathan Craig has requested that John Burke write to IPNA to request further monetary support. John Burke asked that ANZPNA support his letter. Fred Jureidini moved that ANZPNA supports the establishment of the Cochrane Renal Group in Australia and supports the letter that John Burke is to write to IPNA to request monetary support. The motion was seconded by Harley Powell. The motion was passed without dissent; there were six abstentions.

10. Any other business: Ian Hewitt reported that the RACP were proposing to develop a programme for the accreditation of paediatric renal units for training. It was agreed that criteria for the accreditation of paediatric renal units for this purpose should be developed and that these criteria should be developed by ANZPNA.

13/5/01

Australian and New Zealand Paediatric Nephrology Association
Report of the Chair
March 17, 2000

The Association now has a formal identity. This is important for a variety of practical reasons which include facility of financial transactions and legal protection of members and the executive but is most important in enhancing our ability to promote the care of children with governments and their agencies. It will also enable the Association to enter into any formal relationships with other professional bodies without concerns of loss of identity. For these advantages the Association will always be in debt to Colin Jones, Lilian Johnstone and Paul Henning. I am honoured to succeed Colin as Chair.

The issue of continuing approval of Growth Hormone for children with renal failure has been a major concern. The grounds for discontinuation may have had some academic validity but as satisfying these grounds would take many years the action was indefensible from a duty of care perspective. With the new authority of the Association, I was gratified to be able to obtain assurance from the Pharmaceutical Benefits Branch that HGH would continue to be made available while matters concerning registration of the product are under consideration. We must continue to provide as much information as possible to both PBB and relevant drug companies as possible but also apply other pressures to both groups related to the current and possible future distress of children under our care.

The 2004 IPNA meeting will be a major opportunity to enhance community knowledge of the achievements of paediatric nephrology in the care of a peculiarly susceptible group of children and their families. Arrangements are proceeding under Fred Jureidini's guidance and direction. Committees and Working Groups have been set up and I look forward to hearing the details of the current situation.

Communication within the Association and with the broader community has always been a primary goal. Development and formalisation of our relationships with IPNA, RACP and ANZSN need to be advanced in appropriate ways. Further evaluation of a Web site could be a valuable asset if adequate supports are available.

Activities of Members in various fields have been notable. Among them are Fred Jureidini's activities in relation to Aboriginal Health, John Knight becoming Medical Director of The Kidney Foundation, Charlie Crompton's work with the Growth Hormone data, John Burke's appointment as an Assistant Honorary Secretary to IPNA and Elisabeth Hodson and Jonothon Craig's efforts in obtaining and analysing information about diseases and their treatment through APSU and Cochrane Collaboration. There will be those of which I am not aware and for that I apologise.

Your executive looks forward to promoting your goals over the next year.

L Paul Roy
Chair
ANZPNA

ANZPNA Annual General Meeting 2000

Treasurers Report

The funds of the society are still hand to mouth

Current Assets	$2,923.40	Commonwealth Bank Ac # 1034 0611 BSB 2908

Auditing

ANZPNA is registered as a public company. Only an auditor registered with the Securities Commission can audit company books. Our previous auditor Kay Bruggeman is not registered with the ASC. It had been assumed that ANZPNA was an incorporated body for which she was an appropriate person to audit ANZPNA financial accounts.

The treasurer is currently negotiating with a qualified auditor in the ACT to audit the 1998 - 1999 ANZPNA accounts.

Sponsorship

Industry partner	$5,000	per annum
Corporate sponsor	$2,000	per annum
Exhibitor	$1,000	per annum

Annual General Meeting Sponsorship

The following companies have generously agreed to support the ASM for the following amounts

Baxter Healthcare	Cost of Friday night dinner
Gambro	$500
Fresenius	$300
Janssen-Cilag	$300
Roche	$300

Indicated costs for the meeting

Room hire	$300
Audiovisual	$600
Catering	

Tax Exemption Status

ANZSN has offered to let ANZPNA have access to its expert opinion.

$5000 cost should be considerably less

Goods and Services Tax

Application for Australian Business Number is prudent, despite the income being less than the $50,000 threshold.

Documentary evidence of all business inputs should be kept and the 1/11 of cost claimed

Annual membership fees will need to include pro rata GST for Australian members but not members from New Zealand.

Membership subscription

Calendar year 1999 - 2000 fee is due and will include 5% GST for Australian members.

IPNA Meeting

The relationship between IPNA and ANZPNA is currently being established. Issues include:

Seeding money
Distribution of profits / risks
    should be negotiated early
Risk management for ANZPNA members
Risk management for officers of the society
Account signatories
    President of ANZPNA
    Chairman of local organising committee
    Treasurer (obligate signature)

Establish separate bank account

Australian and New Zealand Paediatric Nephrology Association
Secretary's report for Annual General Meeting on March 17,2000
Elisabeth Hodson

The registered office was transferred to the Department of Nephrology at the New Children's Hospital in Sydney in October 1999. I would like to thank Lilian Johnstone, Colin Jones and Vicki Burns, Colin's secretary, for all their help with the transfer. I would like to thank my secretary, Julie Webb, who has added ANZPNA to her other duties. Julie has updated the list of contact addresses, telephone numbers, fax numbers and e-mail addresses. This updated list was circulated with the agenda for this meeting. To reduce the workload and the postage cost, I plan to circulate as much information as possible via e.mail in future.

ANZPNA is now incorporated and subject to the regulations of the Australian Securities and Investments Commission (ASIC). Many actions taken by ANZPNA have to be reported to ASIC including the annual return, the annual statement of the accounts, transfer of the registered office, changes in office holders and changes to the constitution. Failure to complete these formalities within the required time attracts a late fee. The paperwork involved is sufficiently onerous for me to question the decision at the last annual general meeting in July 1999 to move the registered office and change the designated officers every two years with each change in the Executive.

Following the meeting of the Executive on December 8, 1999 the RACP, ANZSN, AKF, TSANZ, the Dialysis and Transplant subcommittee of the ANZSN and AKF and the ANZDATA Registry Committee have been informed of the existence of ANZPNA as an incorporated body. A request has been made to each organisation that ANZPNA be consulted in issues involving paediatric nephrology and that ANZPNA be involved in the nomination of its members to relevant committees. In addition some form of formal affiliation has been sought with RACP and ANZSN. The Executive decided that the AGMs of ANZPNA should be held in conjunction with either RACP or ANZSN meetings. The association of the ANZPNA meeting with the RACP scientific meeting will be discussed at the AGM. These issues will be discussed at the AGM.

Appendix 4

AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

Special Resolution to be considered at the Annual General Meeting of the Australian & New Zealand Paediatric Nephrology Association to be held at the Hotel Sofitel on March 17th 2000 at 4.00pm.

Special Resolution: It is proposed that in Article 11, "The membership of any member shall be terminated ipso facto, in any of the following events" sub-clause (e) "if he becomes mentally ill" be deleted and that the amended articles become the Articles of Association of the Australian and New Zealand Paediatric Nephrology Association.

Elisabeth Hodson
Secretary - ANZPNA

COMMITTEE STRUCTURE

- See attached (1). Letters of invitation have been emailed to a number of members to request help for the operational committee, chaired by Fred.
- Graham Teague, Hartley Management plays a pivotal role.

SEED FUNDING

- $5,000 has just arrived from IPNA
- Ira coming later this year with a further $20,000
- Bank account to be opened - d/w Michael
- $15,000 loan from ACTA forthcoming when paperwork formalised

WEBSITE

- Funding above allows us finally to get this started
- Awaiting confirmation from Ira that "ipna2004.com", in keeping with "ipna2001" is suitable
- SA Minister for IT will provide expertise from his department (see below)
- Website essential ingredient for fundraising
- IT is major theme of IPNA2001 and will pl
- Ideas for website welcomed

MEETING WITH SA MINISTER FOR IT

- Michael Armitage, medico and previously Minister for Health
- Enthusiastically supports IPNA2004
- Website support from his department
- Facilitation of contacts with other departments and ministers - particularly Tourism

SPONSORSHIP

- International - IPNA support will be requested in June
- National - all members requested to seek support from personal contacts
- Local - SA companies with national and international outlook

STATIONERY

- Design for discussion - see attached (2)
- Awaiting Ira's approval
- 5 year calendar

ANZSN

- Agreement in principal for parallel meeting with some overlap - see attached (3)
- Some reservations from both Ira and ANZSN council, but positives appear to outweigh negatives

DELEGATE BOOSTING

- Any relevant conference should be targeted - Singapore, November 2000.
- ANZPNA members requested to boost at any appropriate venue
- Material will be made available by ACTA

SOCIAL PROGRAM

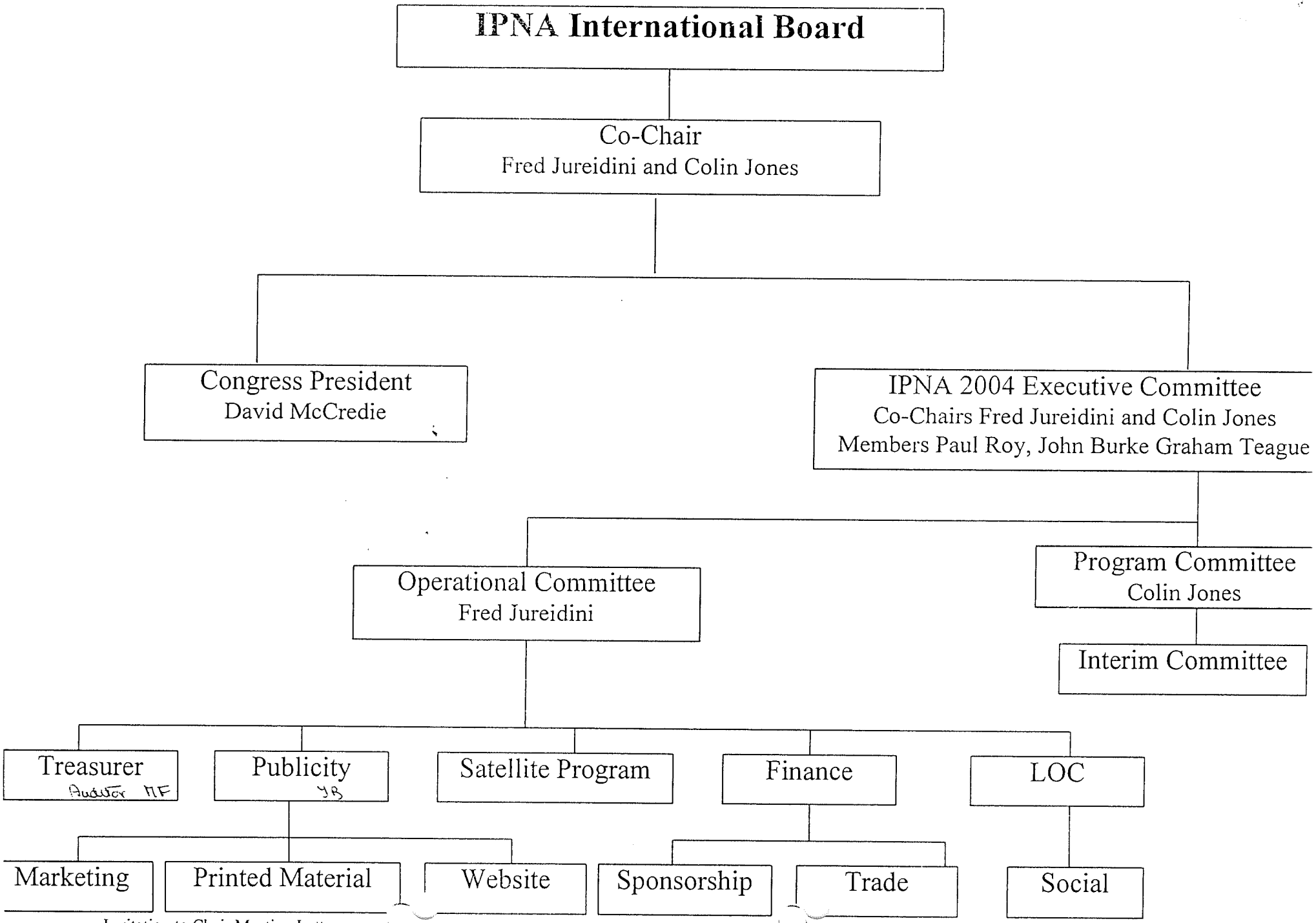
- Debbie as national and Nicole Jureidini as local coordinators
- Adrian Porter will be invaluable - not just your token male
- Incorporate themes - Aboriginal, Maori and SE Asia
- Ideas appreciated

HARTLEY MANAGEMENT GROUP

- Headed by Graham Teague
- Manage all aspects of conference
- National and International Travel Companies
- Checking contract arrangements with IPNA

COMMONWEALTH (A&NZ) MINISTERS/DEPARTMENTS

- Personal contacts please
- Target Tourism


IPNA International Board
Co-Chair
Fred Jureidini and Colin Jones
Congress President
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IPNA 2004 Executive Committee
Co-Chairs Fred Jureidini and Colin Jones
Members Paul Roy, John Burke Graham Teague
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Fred Jureidini
Program Committee
Colin Jones
Interim Committee
Treasurer
Auditor NF
Publicity
YB
Satellite Program
Finance
LOC
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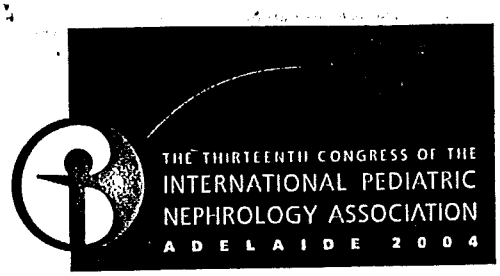
Printed Material
Website
Sponsorship
Trade
Social



2

29 August - 2 September 2004
Adelaide Convention Centre
Australia

Congress President
David McCredie

Congress Co-Chairmen
Ken Jureidini, Colin Jones

Congress Management
Hartley Management Group Pty Ltd
PO Box 20
Kent Town SA 5071
Australia

Telephone +61 8 8363 4399
Facsimile +61 8 8363 4577
Email ipna2004@hartleymgt.com.au
Web http://www.ipna2004.com

(3)

AUSTRALIAN AND NEW ZEALAND SOCIETY OF NEPHROLOGY
145 Macquarie Street Sydney NSW 2000 AUSTRALIA
Tel 61 2 9256 5461 Fax 61 2 9241 4083 Email anzsn@racp.edu.au

ANZSN

25th October 1999

Dr Fred Jureidini
Director of Nephrology
Renal Unit
Women's & Children's Hospital
72 King William Road
NORTH ADELAIDE SA 5006

Dear Fred,

The Council of the Australian and New Zealand Society of Nephrology (ANZSN) at the recent council meeting confirmed its commitment to hold the Annual Scientific Meeting in 2004 in Adelaide in conjunction with the International Paediatric Nephrology Association Meeting.

The ANZSN is happy to advertise the meeting on its webpage under the section on meetings and to provide a link to your site. Would you please let me know exactly what you had in mind so that I can act on your request.

Congratulations on winning the bid!

Kind regards,

A/Professor David Harris,
Honorary Executive Officer.

PRINCESS MARGARET HOSPITAL FOR CHILDREN

PAEDIATRIC NEPHROLOGY SERVICES

Telephone: +61 8 9340 8354 Facsimile: +61 8 9340 8301

8 March 2000

REPORT ON THE ACTIVITIES OF THE ANZPNA GROWTH HORMONE SUB-COMMITTEE

Chairman: Dr Charles Crompton
Committee members: Dr Colin Jones and Dr Elizabeth Hodson

The Subcommittee has met by teleconference on one occasion since the last ANZPNA AGM.

The ANZPNA Executive had suggested Terms of Reference for this group which were accepted and are as follows:

1) To advocate for the continued use of recombinant human growth hormone in children with short stature due to chronic renal failure

2) To analyse the growth data from Australian children with chronic renal failure treated with growth hormone

3) To produce guidelines for the use of growth hormone in children with chronic renal failure in association with the "caring for Australians with renal impairment" guidelines being established through the Australian and New Zealand Society of Nephrology and the Australian Kidney Foundation

4) To ensure that a database of publications on the use of recombinant human growth hormone in children with chronic renal failure is maintained

5) To report annually on the activities of the sub-committee at the Annual General Meeting of the Australian and New Zealand Paediatric Nephrology Association.

Report on Activities:

1. No specific advocacy issues addressed apart from those referred to in following points

2. The OZGROW data analysis. This has not yet been completed.

   The re-analysis of the OZGROW data base was delayed until as much missing data as possible could be gathered, and I was accepting further data until December 1999, at which point I realized there was little to be gained by waiting further. The OZGROW data base is now more complete with respect to renal patients, and even though the growth data may not look any better with the additional information, at least it will have been as complete an analysis as possible.

Improved definition of treatment category through the questionaire has allowed the confirmation of the significantly better response to GH of children with conservatively managed CRF compared to dialysis and transplant groups.

The questionnaire responses have enabled identification of 39 patients who have received Growth Hormone who have reached final adult height. In this group of patients, the mean height SDS at the onset of Growth Hormone therapy was -2.65, and at final height the mean height SDS was -1.98.(Fine et al 1996 described 5 year data with Ht SDS increasing from -2.6 to -0.7).
Further analysis of the data is currently underway, and is in the hands of the biostatistician.

3. Elizabeth Hodson and Charlie Crompton are actively involved with the CARI Guidelines process with respect to Growth and Nutrition in children with chronic renal failure. The first draft should be produced by mid-year.

4. A data-base of Growth Hormone publications will be established once the CARI guidelines process for Growth and Nutrition has been completed, using references obtained from the guidelines search. Software such as Reference Manager or End-Note will be used if possible. This would be updated 6 monthly if necessary.

Other business

- It has been reported that new applications for rHGH for children with short stature due to chronic renal failure will still be considered until the Novo-Nordisk application has been processed, which could take another 12-15 months. Prior to this information being available, I circulated a note to all ANZPNA members requesting that copies of Growth Hormone applications and their outcome be sent to me so that further action might be taken through the "Kidney Kids" of Australia support group or media, if applications were knocked back. It appears that this is not currently necessary, but maybe in the future.

- It is understood that one or more members of the TGA are concerned about potential complications of Growth Hormone therapy, particularly malignancy. The Subcommittee is unaware of any data supporting such complications.

- Novo-Nordisk has submitted an application to the TGA for product approval for Norditropin. Elisabeth was extensively involved as the Clinical Expert . The documents were lodged late last year and a decision on the application is expected to take up to 18 months.

- I have spoken to representatives from Pharmacia Upjohn who report that the company will be re-submitting an application for Genotropin, having previously been rejected. I will provide the company with final height data if requested.

Charles Crompton
Chairman

COMMONWEALTH OF AUSTRALIA

Health Access and Financing Division
GPO Box 9848 ACT 2601
Telephone: (02) 6289 7274 Fax: (02) 6289 8633

Commonwealth Department of Health and Aged Care

98/29429

Professor Paul Roy
Chairman
Australian New Zealand Paediatric Nephrology Association
Department of Nephrology
New Children's Hospital
PO Box 3515
Parramatta NSW 2124

Dear Professor Roy

Re: Use of growth hormone in children with chronic renal failure

Thankyou for your letter dated 17 December 1999 regarding the subsidisation of human growth hormone for the treatment of children with short stature associated with chronic renal failure.

I apologise if the letter from Mr Alan Stevens of 1 October 1999 was unclear. Human growth hormone will continue to be made available as a pharmaceutical benefit for eligible children with chronic renal failure from 1 January 2000, while matters concerning the registration of somatropin for the treatment of short stature in these patients are under consideration.

I hope this clarifies the situation for you.

Yours sincerely

Axel Godeck
Pharmaceutical Benefits Branch
10 January 2000

MINUTES OF THE ANZPNA GROWTH HORMONE SUB-COMMITTEE TELECONFERENCE HELD ON WEDNESDAY 19 JANUARY 2000 at PRINCESS MARGARET HOSPITAL

PRESENT: Charles Crompton, Elisabeth Hodson, Colin Jones

This was the first meeting of this Sub-Committee.

Item 1
Terms of Reference for the Sub-Committee
The guidelines are as follows:

1) To advocate for the continued use of recombinant human growth hormone in children with short stature due to chronic renal failure

2) To analyse the growth data from Australian children with chronic renal failure treated with growth hormone

3) To produce guidelines for the use of growth hormone in children with chronic renal failure in association with the "caring for Australians with renal impairment" guidelines being established through the Australian and New Zealand Society of Nephrology and the Australian Kidney Foundation

4) To ensure that a database of publications on the use of recombinant human growth hormone in children with chronic renal failure is maintained

5) To report annually on the activities of the Sub-Committee at the Annual General Meeting of the Australian and New Zealand Paediatric Nephrology Association.

These were discussed and agreed to be appropriate.

Item 2
Data base of publications
It was suggested that a data base of publications be established, using references obtained from the search underway for the CARI guidelines. Six monthly updates would follow. Other sources of information would include IPNA Conference Proceedings, as well as the EPSN and ASN meetings.

Item 3
Update on Novo-Nordisk Submission to TGA
Elisabeth reported that the submission was forwarded to TGA late last year, and that the review process will take at least 12 months. Elisabeth has heard unofficially that potential long-term complications of rhGH may be at the heart of TGA resistance to supporting growth hormone use, but the Sub-Committee was unaware of any clinical data suggesting long term complications such as malignancy. The group is unaware of any other pharmaceutical company making further submissions to the TGA.

Minutes of ANZPNA Growth Hormone Sub-Committee
Teleconference held on Wednesday 19 January 2000
at Princess Margaret Hospital

Item 4
Update on OZGROW Analysis
Charlie reported that the gathering of missing data for the data base was as complete as possible, and that he advised that the data was now being analysed by the Princess Margaret Hospital Biostatistician. There are approximately 34 patients that have achieved final adult height which will be analysed separately. This group's final height will be compared to predicted height based on pre-growth hormone treatment measurements. Hopefully the data analysis will be ready for presentation at the ANZPNA AGM in Melbourne in March.

Item 5
Parent/Family Pressure Groups, Media
The status of the "Help the Kidney Kids of Australia" petition was discussed. The driving force behind the partition is the family of one of Elisabeth's patients, and she reports that so far this has not been taken any further. The co-ordinators of the petition are kept informed of progress on the issue of growth hormone. It was agreed that further use of this support group or the media would not be considered unless there were well documented difficulties with access to growth hormone following the expiry of the moratorium.

Item 6
Other Issues
a) New applications for rhGH for children with chronic renal failure
   It was decided that the Sub-Committee should seek to keep track of any new applications since the beginning of this year for rhGH or children with chronic renal failure. If the application for growth hormone was rejected, consent from the patient's family and physician would be requested, such that full documentation of the case could be obtained. This could then be used in an approach to the TGA, and potentially the media. Charlie will contact all members of the ANZPNA to request that copies of applications be sent.
b) Elisabeth commented that unofficially new applications for rhGH for chronic renal failure may not be knocked back by the TGA, and that new applications should be put forward.
c) Review of OZGROW data collection.
   After completion of the OZGROW data analysis, and in light of difficulties in using the data base, recommendations should be made about future data collection

A report on the activities of the Sub-Committee will be forwarded for the AGM of the ANZPNA in March 2000. A date for the next meeting has not been set, but will be held by the middle of the year.

CHAIRPERSON – Dr Charles Crompton DATE – 27 January 2000

BENCHMARKING

- Forms sent and data collection commenced September 1999.
- All centres contributing to renal biopsy questionnaire and questionnaires regarding PD catheters, CVC insertion/removal and AVF creation.
- Two centres collecting data regarding child health outcome and renal transplantation.
- Forms received from 4 centres to date with following distribution.

Centre	Biopsy	PD	AVF	CVC
1	5	3		2
2	5		2	1
3		5	1	2
4	10			
Total	20	8	3	5

More forms eagerly waited

For interest:

Renal biopsy

- All use ultrasound
- All use spring loaded biopsy device
- 16 (80%) of children have general anaesthetic
- 75% use 6G or 18G needle
- 16 discharged same (3/16) or following (13/16) day
- 1 "inadequate sample" of 6 glomeruli
- 1 child required transfusion following procedure.

Problems

1. Renal Biopsy Form

(a) Question 9 causes confusion
Length of stay greater than 36 hours

☐ Same day
☐ Discharge following day
☐ Other please specify

Suggested change to:

Length of stay ☐ Same day
☐ Discharge following day

If greater than 36 hours due to _____ (please specify)

Length of stay >24 hours due to complication of biopsy

☐ Yes

☐ No

(b) Front Sheet
Underlying renal condition – should this be the diagnosis post Biopsy eg: FSGS or the symptoms/findings eg. Haematuria which are included in question 1

2. AVF – question 1 regarding date of first use.
Obviously there is some delay for maturation of AVF. Suggest the following:

(a) Complete form at time of use of AVF but will miss some if never used
(b) I contact Renal Clinical Nurse specialist at later date.

3. Please note that each procedure concerning a catheter ie. Insertion or removal requires another form completed.

4. Return of forms every 3 months. We will send e-mail reminder every 3 months from Vicki Burns (03) 9345 5054 e-mail burnsv@cryptic.rch.unimelb.edu.au

Australian and New Zealand Paediatric Nephrology Association
Report on the study of nephrotic syndrome through the APSU
Elisabeth Hodson, Jonathan Craig, Narelle Willis and Sandra Puckeridge

This study commenced in July 1998 and will continue for three years. Data to October 1999 were presented in a poster at the ANZSN meeting. The study has been accepted for oral presentation at the RACP meeting in Adelaide in May.

Between July 1998 and October 1999, there were 91 notifications to the APSU of which 56 patients were eligible for inclusion. Of these 55 had idiopathic nephrotic syndrome and 1 had congenital nephrotic syndrome. The incidence is 1.15 per 100,000 population below 15 years (95% CI 0.84,1.53). The incidence varies from 0.94 (95% CI 0.38,1.94) in Queensland to 1.52 (95% CI 0.94,2.33) in New South Wales. No eligible cases have been reported to date from the Northern Territory or Tasmania.

To date there is no significant difference in incidence between males and females [males;1.29 (95% CI 0.88,1.89): females; 0.99 (95% CI 0.60,1.55)]. As expected the incidence decreases with age. There is no significant difference in incidence between groups when the parents' birthplace is overseas or in Australia.

Data from the first questionnaire on steroid regimes, pneumococcal vaccine and antibiotic usage and family history have not been analysed yet.

FSGS Trial Newsletter

Department of Nephrology
Royal Children's Hospital
Melbourne

February 2000
Issue 1

Welcome to the first issue of the FSGS Trial Newsletter. The aim of the newsletter is to provide up-to-date information of the progress of the trial and to help remind everybody to be on the look out for suitable patients to enrol. If anybody has any suggestions or queries regarding the newsletter please don't hesitate to contact me.

Steven McTaggart. Ph: (03) 9345 5054. E-mail:mctaggas@cryptic.rch.unimelb.edu.au

Aims of the FSGS Trial

The aim of the trial is to test the ability of cyclophosphamide to maintain a cyclosporin-induced remission in patients with FSGS.

Time Line

The trial officially commenced on 30 August 1999. Patients are to be recruited over a two year period with the trial to end one year after the completion of recruitment.

Ethics Notes

Ethics approval has been granted by the Institutional Ethics Committee of The Royal Children's Hospital. Copies of this approval, with the trial protocol were distributed at the last ANZPNA meeting. If anybody requires further information regarding Ethic's approval, please contact me.

Current Status

So far there have been no patients recruited!

The trial inclusion and exclusion criteria are as follows:

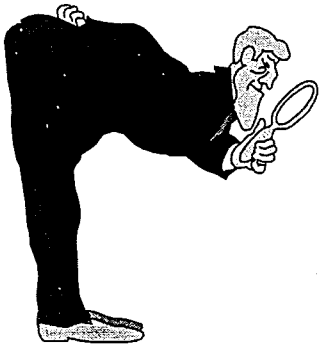
Inclusion Criteria

1. Male or female between 12 months and 25 years of age.
2. Renal biopsy performed within 26 weeks of onset of nephrotic syndrome showing FSGS.
3. Proteinuria > 4 mg/hr/m^2.
4. No response to a daily prednisolone regimen of 60 mg/m^2 for a minimum of 4 weeks.
5. Patient is able to receive oral medication.
6. Patient has no known contraindication to administration of cyclosporine or cyclophosphamide.
7. The patient or patient's parent/ guardian understands the purpose and risks of the study and is willing to sign a statement of informed consent.

Exclusion Criteria

1. Patient has identifiable medical disease associated with FSGS.
2. Patient has active systemic infection.
3. Patient has known allergic or other severe reaction to either cyclosporine or cyclophosphamide.
4. Patient has not received cyclosporin or cyclophosphamide previously.

Remember, we only need **8** patients in total to show a diffence between the two treatment groups, so please keep your eyes and ears peeled for potential subjects.



Trial of Cyclophosphamide in FSGS

Study Design

This is an open-label multicentre study in children and young adults with newly-diagnosed, biopsy-proven steroid-resistant FSGS being managed in Australia and New Zealand.

The study is to be conducted in two stages. The first stage involves induction of remission with cyclosporin and prednisolone. Patients who enter remission will enter Stage 2 of the trial and will be randomised to either the treatment (experimental) group or act as non-treated controls. Patients in the experimental group will be treated with cyclophosphamide for a period of 8 weeks.

Patients remain in the study for one year post randomisation.

Inclusion Criteria – All answers must be YES to enrol patient in study	**YES**	**NO**
1. Male or female between 12 months and 25 years of age.	☐	☐
2. Renal biopsy performed within 26 weeks of onset of nephrotic syndrome showing FSGS.	☐	☐
3. Proteinuria > 4 mg/hr/m^2.	☐	☐
4. No response to a daily prednisolone regimen of 60 mg/m^2 for a minimum of 4 weeks.	☐	☐
5. Patient is able to receive oral medication.	☐	☐
6. Patient has no known contraindication to administration of cyclosporine or cyclophosphamide.	☐	☐
7. The patient or patient's parent/ guardian understands the purpose and risks of the study and is willing to sign a statement of informed consent.	☐	☐
Exclusion Criteria – All answers must be NO to enroll patient into study		
1. Patient has identifiable medical disease associated with FSGS.	☐	☐
2. Patient has active systemic infection.	☐	☐
3. Patient has known allergic or other severe reaction to either cyclosporine or cyclophosphamide.	☐	☐
4. Patient has not received cyclosporin or cyclophosphamide previously.	☐	☐

If patient meets all inclusion and exclusion criteria, patient is eligible to participate in study →

PLEASE CONTACT Dr Steven McTaggart or Dr Colin Jones Ph: 03-9345 5054

APPENDIX 10

COMMITTEE	ANZPNA MEMBER	DATE OF APPOINTMENT
ROYAL AUSTRALASIAN COLLEGE OF PHYSICIANS		
1. Nephrology Specialist Advisory Committee	Ian Hewitt	1998 – 2005
2. Representative of the Paediatric Society of New Zealand to the Board of Paediatrics and Child Health, RACP	Max Morris	Elected for 2 years – renewable
3. The Written Exam Committee	Colin Jones – to end 2000	William Wong from 2001
4. Victorian State Committee	Mandy Walker	2000 – 2003
5. Director of Physician Training (Monash)	Mandy Walker	1999 – 2005
6. Director of Physician Training (NCH)	Deborah Lewis	1999 – 2005
ANZSN		
1. Council	Michael Falk (SPEC) John Knight	2001 In attendance
2. Dialysis and Transplant Sub-committee	John Knight Rowan Walker (appointed and elected Chairman)	Ex officio Finishes end 2000
3. Pharmaceutical Spokesperson (Paediatrics)	Andrew Rosenberg	End 2000
4. Chairman – Cari Guidelines Steering Committee	John Knight	1999
TSANZ		
1. Renal Failure Advisory Group	Rowan Walker	Elected Victorian Representative
2. Council	Michael Falk	Elected until 2001
IPNA		
1. Council	John Burke	Completes term 2001
2. Continuing Medical Education Programme	Mandy Walker	2000
ANZDATA		
1. Council	Michael Falk John Knight	By invitation Ex Officio
2. ANZDATA Registry Committee	Rowan Walker	Appointment
3. ANZDATA Paediatric Report	Rowan Walker	Appointment
AKF		
1. Victorian State Committee (Vice Chair)	David McCredie	Elected – ongoing
2. Victorian State Committee	Mandy Walker	Elected – ongoing
3. NSW State Committee	Michael Falk	Appointed
4. AKF Board	John Knight	In attendance
5. AKF Board Executive	John Knight	
6. AKF M&SAC	John Knight	

COMMITTEE	ANZPNA MEMBER	DATE OF APPOINTMENT
7. AKF National Education Committee	John Knight	
8. AKF National Education Committee Executive	John Knight	
9. AKF Aboriginal Outreach Management Committee	John Knight	
10. AKF Aboriginal Outreach Management Committee (Chair)	John Knight	
OTHERS		
1. South Australian Transplantation and Organ Donation Advisory Committee – SA Government	Paul Henning	
2. The Pharmacology and Therapeutic Advisory Committee of New Zealand	Paul Tomlinson	2003
3. The National Sub-committee for Paediatric Continence. Countinence Foundation of Australia	Lil Johnstone	
4. APSN	Rowan Walker	Elected
5. Chairman – Renal Physicians of NSW & ACT	Andrew Rosenberg	End 2000
6. Member - Transplant Advisory Committee – NSW/ACT	Michael Falk	2000 - 2002
7. National Aboriginal & Torres Strait Islander Renal Disease Scientific Working Group – Chair – Implementation Subcommittee	John Knight	

JOURNAL OF AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

VOLUME 3, No 1. JANZPNA

15 October 1999

CONTENTS

MINUTES OF THE ANZPNA ASSOCIATION
1st ANNUAL GENERAL MEETING OF THE ANZPNA, Sunday, 25th July 1999 at the New Children's Hospital, Westmead.

1. **Apologies:** Margot McIver, David Lines, Paul Roy, Mandy Walker and Jonathan Craig

   Present: Fred Jureidini, David McCredie, Ian Hewitt, Paul Tomlinson, William Wong, Andrew Rosenberg, John Burke, Charles Crompton, Max Morris, Michael Falk, John Knight, Elisabeth Hodson, Harley Powell, Rowan Walker, Lil Johnstone, Debbie Lewis, Paul Henning and Colin Jones.

2. **Confirmation of Minutes AGM 19/07/98 Royal Pines Resort**

   Proposed: Rowan Walker Seconded: Ian Hewitt.

   Passed unanimously

3. **Executive Report**

   3.1 Chairman's Report

   3.1.1 The Index Volume 2 of the Journal of the Australian New Zealand Paediatric Nephrology Association was distributed (Appendix 1). Colin noted that the first volume of the Journal related to previous meetings of the ANZPNA and provided the memory of the organisation. It included the abstracts of the first clinical meeting, however the second clinical meeting was not included and distributed as a separate booklet. The focus of the second volume was on the Executive Minutes therefore providing a corporate memory however he also wished them to be a focus for points of discussion. However, the Journal had not succeeded in achieving this, nor had it been used as a forum for the distribution of literature reviews or Grand Round presentations that members may have taken part in.

3.1.2 Publications of the ANZPNA. He spoke to the Transplant Booklet that had been prepared for education of families considering living-related donation and thanked those who reviewed and commented on its development. The plan is that it will be updated every 2-3 years and input is welcome. The proceedings of the 2nd clinical meeting were distributed and Colin apologised for the delay in distribution due to printing problems. He acknowledged the assistance of Baxter in paying for production of the booklet.

3.1.3 Logo. A logo for the ANZPNA had been designed and distributed to members and it was important that it be used for correspondence relating to the ANZPNA. John Burke noted that it was important to put the full title of the organisation, that is the Australian & New Zealand Paediatric Association at the top of the letter as a true letterhead as many people who receive the letter would not know what the ANZPNA stood for despite the fact that it was placed as a footer to the letter.

3.1.4 Incorporation. The ANZPNA is now an incorporated Association limited by guarantee and thanks were expressed to Paul Roy for his efforts in this.

3.1.5 Colin spoke to the relationship of the ANZPNA with the Division of Paediatrics, Royal Australasian College of Physicians. There was discussion as to whether sub-specialty groups should be faculties of the division of Paediatrics. He currently saw the ANZPNA as an intermediate body between the RACP and the ANZSN.

3.1.6 Benchmarking. To be discussed further by Lil Johnstone.

3.1.7 Communication. Communication between the group had been variable according to the question asked. There was a need to follow through with communication. There had been consideration for establishment of a web site which may improve communication between ANZPNA members and there was discussion as to

whether the Website access could be via the RACP or ANZSN. The majority of members has access to e-mail and/or the web and would request correspondence in that way.

3.1.8 Acknowledgements of members of the ANZPNA. David McCredie was acknowledged as an honorary life member of the IPNA and for his recent publications in the New England Journal of Medicine and Science. Charlie Crompton was acknowledged for his efforts in analysing the Ozgrow Data and trying to establish the final height data for children with renal failure on growth hormone. Lil Johnstone was acknowledged as Secretary of the ANZPNA and for her efforts towards the Articles of Association. Ian Hewitt and Charlie Crompton were acknowledged for re-establishing a Paediatric Haemodialysis Facility in Western Australia. John Burke was recognised as a member of Council and for his assistance in preparing the IPNA bid and for his negotiations with the IPNA Council concerning that bid. Elisabeth Hodson was acknowledged for organising the current meeting and the Clinical Meeting on the 26th July. Fred Juriedini's efforts were acknowledged with respect to the IPNA bid. John Knight was acknowledged as providing a significant improvement in the functioning of the Australian Kidney Foundation. Amanda Walker and Deborah Lewis were acknowledged for their recent appointments as Directors of physician training at their respective hospitals. Michael Falk was acknowledged for his appointment as Head of Renal Services in Canberra, and Paul Henning was acknowledged for becoming Head of the Department at The Women's & Children's Hospital, Adelaide. The members requested that a letter of acknowledgement be sent to Paul Roy concerning the Articles of Association.

3.2 Treasurer's Report. Paul Henning spoke to this item. The Statement of Receipts and Payments was distributed (Appendix 2). Subscriptions had been received from nearly all members. Paul draw attention to the fact that the only out goings of the ANZPNA had been related to the registration fee for the incorporation. He noted that none of the costs of the Executive are currently being borne by the Association. Other sources of funding e.g.: corporate sponsorship as discussed in 1998 had not been addressed. There are currently 24 members of the ANZPNA. It was noted that the ANZPNA is not a charitable institution so therefore no tax deductibility for donations is available. John Knight noted however that charitable donations could be made to the Australian Kidney Foundation with a covering letter requesting that the donation be directed to the ANZPNA and therefore tax deductibility could be obtained. With respect to the issues of costs by the Association, e.g. teleconference, mail outs etc. the question was raised whether independent support should be utilised in the way that other societies do, for example, via the RACP. It was noted that Aviva Rosenfeld currently supports the ANZSN and the TSANZ. There was concern whether she in fact would have time available to support the ANZPNA and what costs would be incurred. The Statement of Receipts and Payment was moved and accepted by Paul Henning, seconded Lil Johnstone and accepted unanimously. It was decided to keep subscriptions at the current level. No member is currently in arrears of 2 years fees, therefore is not at risk of losing membership of the Association.

3.3 Secretary's Report. Lil Johnstone noted that the ANZPNA is now an incorporated body limited by guarantee. An A.C.N (Appendix 3) number needs to be attached to all correspondence of the group. It was proposed that the registered office would move with each new Executive and that similarly the Directors and Secretary would change with the new Executive. Material support had been previously discussed. Lil Johnstone acknowledged the tireless efforts of Vicki Burns in supporting her and the Association over the last 2 years.

4. **Election of New Members.**

No new members have been proposed. It was noted that there are two Australian paediatric nephrologists who have been working overseas and that they should be invited to be part of the group. There are 3 trainees in Nephrology at present. Caroline Booth is undergoing a 3 year traineeship in the United Kingdom. Steven McTaggart is in the 2nd year of training in Melbourne and Michelle Sanders is wishing to commence PhD. There was discussion as to whether they should be invited to be associate members. As a result of discussion concerning the issue of Associate Membership, **David McCredie moved that a sub-committee be appointed to consider the conditions and eligibility for membership and associate membership. Seconded Fred Juriedini, carried by the majority**. It was noted that there are current vacancies in paediatric nephrology in Australia. A Fellow's position is likely to be available in Adelaide. An 0.6 EFT position for a staff nephrologist at the Sydney Children's Hospital has been advertised. New Children's Hospital is currently interviewing for a full time paediatric nephrologist. Max Morris indicated that it is likely that a Fellow's position will be established in Auckland in the next couple of years.

With respect to the Articles of Association John Knight noted that clause 11e was in the current Articles of Association and at discussion at the AGM in 1998 the membership had decided to remove it. Advice from Paul Roy was to retain it as it was easier to keep it included than not have it available and reinsert it. **John Knight moved a motion that the new Executive make the necessary arrangements to remove clause 11e from the Articles of Association, seconded David McCredie, carried unanimously.**

5. Other Business.

5.1 IPNA Council. John Burke spoke to the attached summary of the Council meeting. (Appendix 4).

5.1.1 IPNA is viable financially.

5.1.2 Pediatric Nephrology Journal change in layout was noted. The Editor and a representative of the Publisher attend Council meetings. There was a decision that advertising may be included. There was still an unhappy relationship with the Paediatric transplant journal – Paediatric Transplantation

5.1.3 London meeting was a success. There was a surplus of 66,000 pounds. Fourteen registrants from Australia and New Zealand attended. The number of attendees from the United States was reduced. A booklet had been produced concerning the attendees, their country of origin, the companies that supported the meetings and profit and loss.

5.1.4 Nomination to the IPNA Council. A member of the European Society of Paediatric Nephrology had been concerned about the methods of appointment to the IPNA Council as they were determined by the ESPN Executive. It would appear that the ANZPNA is the only society to vote for its representative to Council. There had been a resolution and vote of the IPNA Council that the regional secretary would decide who would be proposed to Council as a member. John Burke suggested that in 2000 given that his term finishes in 2001 nominations for a new member of Council as representative of the ANZPNA should be received and an election occur.

5.1.5 Ira Greifer. A sub-committee had been formed from the regional secretaries and others to determine Ira's replacement. This sub-committee will put a number of names to Council for consideration.

5.1.6 IPNA Bid 2004. John Burke had made a submission to Council on behalf of Fred and Colin and had acknowledged the support of the Adelaide Convention & Tourism Authority. The bid had been well received by Council with the advantages being that Australia is politically safe with a low crime rate and that Adelaide has relatively cheap accommodation compared with Sydney and that it is easy to travel to other parts of Australia or New Zealand. A site visit to Adelaide will occur on 27th July with Mathias Brandis and Robert Chevalier attending. It is expected that Budapest will present its bid at the Council meeting in Prague. Plans for the Seattle meeting in 2001 are going well.

5.1.7 The International Children's Kidney Fund is being established and is seeking monies from regional societies. It was felt that the ANZPNA was not in a position to contribute. The Asian Congress of Paediatric Nephrology is being held in Singapore, 4-6 November 2000. John Burke would encourage ANZPNA members to go and this will also help to promote the meeting in Adelaide. The Council is considering an application from PanArab Paediatric Nephrology Association.

5.1.8 The IPNA Council plans to strengthen its relationship with Paediatric Urology.

5.1.9 General statements had been produced supporting paediatric transplantation and avoiding female genital mutilation. Resolutions 1 and 3 were included on page 90 of the Journal, however resolution 2 was not included.

5.2 IPNA Bid. Fred Jureidini spoke to this item. The local organising committee has been established consisting of Fred, Anne Martin, Margie Van Reenen, Adrian Porter, Hiliary Bouquot, David Lines, Warwick Prime (Chair of AKF, SA), Peter Mallick, and Glenys Coulthard (Aboriginal Co-ordinator of Renal Services, South Australia), Graham Russ, (who has also provided a letter of

support from the ANZSN). The ongoing support of the Adelaide Convention and Tourism Authority is acknowledged and has been very helpful. The developmental workshop will run prior to the meeting with a different organising committee and Colin Jones has asked John Bertram to be responsible for that meeting (Appendix 5). Another potential satellite meeting has been proposed by Judy Savige concerning ANCA and Crescentic GN and Alport's. It was thought that possibly the ANZSN's meeting could occur at a similar time. John Knight raised the issue of the financial arrangements with IPNA and given that the meeting would tend to run well and tend to earn money, we should negotiate an arrangement where the ANZPNA has the potential to benefit from that. Obviously there was a need to be careful to minimise risk. John Burke noted that if the bid was dependent on Australia gaining financially from the meeting we were unlikely to be successful in the bid. However, should the bid be successful, one could then negotiate expenses for the ANZPNA with IPNA. It was felt that any discussion concerning financial arrangement should take place after the bid is secure. There was brief discussion about the Scientific Committee, which will be the responsibility of the local committee.

5.3 ANZDATA Registry. Michael Falk, Rowan Walker, and John Knight are involved. Rowan is currently Chair of the Dialysis and Transplant Sub-committee of the ASN who interact with the ANZDATA Registry. Rowan is responsible for the paediatric report, however the ANZPNA could have the opportunity to nominate who writes that report. Rowan was keen to have input as to what should appear in the report and noted that it does not have to be a solo report. He also noted that there was a need to review the paediatric form as there was a poor record of record keeping and was the data being currently collected useful. He felt a need to create projects where the ANZDATA Registry could be involved to record the data over a 1-2 year period. The ANZDATA Registry is currently looking at different forms of analysis including multivariate analysis. Michael and Rowan are currently working on a paper concerning paediatric transplantation from the

ANZDATA Registry. There was discussion concerning the age at which paediatric nephrology stops. In New South Wales currently the age is 14 years and 11 months. There was also discussion about the transmission of data with a desire of the Registry to receive data electronically. It apparently will set up data sheets via the Web and the report is now available via the Web.

5.4 Multi-centre trials.

5.4.1 Vesico-Ureteric Reflux Trial. This is now closed to new entries. The last child will complete follow up at the end of next year. There are approximately 40 children enrolled.

5.4.2 APSU – Study of Nephrotic Syndrome. The first year of data collection is now complete. Fifty cases have been notified with 35 having complete data. The largest numbers have come from New South Wales. Two age groups have been noted. The 2-7 year old as expected and young teenagers. The majority of affected children appear to be Caucasian. The dose regime for prednisolone are very variable. 50% do not receive antibiotic prophylaxis. Pneumovax is not given in approximately 50%. Elisabeth Hodson requested that forms be returned in a timely fashion.

5.4.3 Trial of Treatment for FGS. Colin distributed letters for each institutions' Ethics Committee and apologised that they had not been distributed prior to the meeting. Approval was only gained recently from the Royal Children's Hospital (Melbourne) Ethics Committee. There was little opportunity to discuss this. It was noted that the age limit for inclusion in the study was now 25 years and the Royal Melbourne Hospital has been approached to take part. Colin indicated that he was happy for the proposed study to be taken to affiliated adult hospitals.

5.5 Benchmarking. Lil Johnstone spoke to this item. She thanked members who had contributed to the questionnaires and improved the questionnaires. Only South Australia and Victoria will take part in administering the Child Health

questionnaire as a pre and post transplant assessment of child health outcome. All other groups where happy to take part with the questionnaires concerning renal biopsy and dialysis access procedures. It was noted that the form of sedation would be useful on the biopsy form and there was discussion about whether the duration of stay for greater than 24 hours secondary to complications of the biopsy should be included. Elisabeth Hodson and Andrew Rosenberg requested that the forms be sent by e-mail. The forms are to be identified by the centre abbreviation and by consecutive numbers. Once forms are completed they are to be returned to Lil Johnstone in Melbourne. An undertaking to publish the data in the ANZPNA Journal and hopefully in a peer review journal was made.

5.6 Growth Hormone. Charlie Crompton spoke to this item. Initially analysis was performed in 1998 with John Knight, Jonathan Craig, Elisabeth Hodson, and Charlie Crompton. There were problems with the Ozgrow Data as it was often incomplete, particularly concerning the category of patient (that is chronic renal dialysis or transplant) and the pubertal information. One hundred and eighty-three patients were obtained from the data base and a number do not have renal disease therefore we presume we have missed others who do have renal disease. A questionnaire was then distributed with 100 responses obtained and final height data available from 26 of those 100 patients. The purposes of this questionnaire were to complete pubertal staging, define the treatment group, determine the renal disease and assess final adult height. Of the 26 individuals growth hormone had been used for 1-8 years with a mean of 3.1 years. Of the total group 125 were male and 55 were female. Growth hormone had been used for periods of 3 months to 9½ years. There was a +.346 improvement in height standard deviations score for the whole group with a range of .054 through 1.79. The overall impression was that height had been improved but the question is by how much and is there a long term benefit. Fred Juriedini noted that in the first 12 months of growth hormone use growth velocity doubles. Colin Jones commented that the involvement in this has demonstrated the *bonafides* of the

group in trying to establish information for our patient population. Further discussion occurred concerning the fact that there are no control data nor is there data on improved final height and even the North American Paediatric Renal Transplant Co-ordinating Services (NAPRTCS) have insufficient data to conclude final height. Elisabeth Hodson noted that there is a company planning a submission to the TGA for use of growth hormone in chronic renal failure but was not sure on what time lines they were operating. The conclusions of the group were that final height data will never be truly established, that growth hormone does increase growth velocity in the short term, and that we may compromise the health and social functioning of our patients by compromising their final height. It was thought that there was a need to submit the official view of the group to the Minister along the lines that there was evidence that growth hormone improved growth velocity over 1-2 years, there was no good data regarding the long term outcome, but no evidence of harm or a poorer outcome, and that it was difficult to ethically justify a placebo controlled trial over a 10 year period. The new Executive was asked to propose this and to establish a sub-committee. Paul Tomlinson who is a member of the PTAC in New Zealand noted that Novartis Nordisk have approval for use of growth hormone in chronic renal failure in New Zealand. It appeared to him that the Pharmaceutical Benefits Advisory Committee in Australia had made a rigid decision based on the absence of randomised controlled trials but in fact the advice to the PBAC was from ADEC that it should not be approved. In New Zealand clinicians can actually approach the PTAC and he wondered whether the situation also existed in Australia. **A motion was then put that this Association considers, that in light of strong evidence of systematic reviews of randomised controlled trials of clinical benefit from growth hormone over a period of 2 years, that no long term trial will ever be undertaken for ethical reasons. We therefore recommend that growth hormone should continue to be funded through the Pharmaceutical Benefits Advisory Committee. This was proposed by John Knight, seconded by Gad Kainer and voted**

unanimously by the group. Michael Falk proposed that a sub-committee be established to be chaired by Charlie Crompton.

5.7 New Drugs. No written submission had been received from Fred Juriedini regarding the use of Cardiprine intravenously for the management of acute hypertension. It was noted that intravenous labetalol was used at the New Children's Hospital and is brought in from New Zealand.

5.8 Aboriginal Sub-Committee. John Knight submitted a summary (Appendix 6) and spoke to it. Lots of progress had been made and he acknowledged the efforts of those involved including Fred and David. Fred noted that independent funding existed in South Australia for similar work and will redirect this via the AKF. John noted that there was no major role for a sub-committee within the ANZPNA given that there was good paediatric representation on the National group and therefore the sub-committee was disbanded. He noted the project under the auspices of Wendy Hoy involving the use of ACE inhibitors to slow progression of renal disease.

6. New Business

6.1 Kidney Kids Camp. Discussion paper (Appendix 7 with replies from Michael Cassar and Amanda Walker). Andrew Rosenberg had met with the AKF soon after the last camp and noted that the AKF gains publicity from the camp but makes a limited contribution and felt that Tasmania was not a good centre for the camp. John Knight felt that the AKF's role excludes responsibility for the camp, but State based camps are better than national camps, and that the eligibility criteria previously determined by the AKF should move to the individual unit staff. Ian Hewitt noted that in Western Australia they have run a camp independently for the last 15 years as it is too expensive for the majority of their children to attend a national camp. Elisabeth Hodson similarly noted that children in New South Wales would prefer a State based camp. Ian Hewitt felt there were major advantages in a State camp as the children got to know the caring team and other children. Their major issue related to funding as they had recently lost their sponsor. He felt a need for central funding from the AKF to assist the running of the State based camps.

The group felt there was a need to clarify the relationship with the AKF regarding fund raising and provision of funds to the camp(s) as it was noted that in fund raising the Kidney Kids Camp was often mentioned with the implication that funding to the camp then occurred. **A motion was then put that Kidney Kids Camp should be organised on State or regional lines and that the AKF should guarantee a certain amount of funding to each State camp and that the AKF State Committees be encouraged to provide organisational support in view of the prominent role of the Kidney Kids Camp in AKF fund raising activities.** This was proposed by Colin Jones and seconded by Andrew Rosenberg, carried unanimously.

6.2 Division of Paediatrics, Annual Scientific Meeting. The letter of Louise Bauer was noted (Appendix 8). There was some merit in being involved or attached to the meeting. There was concern that the Clinical Meeting of the ANZPNA was intended to include nursing, dietetic and other staff involved with paediatric nephrology and whether this would fit in to the format. There was concern about who the planned international speakers are and whether the ANZPNA could be involved in the selection of international speakers. There was also the question as to whether the ANZPNA Annual General Meeting and Clinical Meeting should be linked to another major meeting that the majority of ANZPNA members attend.

6.3 Membership of Committees (Appendix 9). It was noted that Colin Jones is currently finishing his term on the Written Exam Committee and David Isaac is looking for a new member. It was proposed that William Wong consider this. The Paediatric Specialty Advisory Committee no longer exists and a letter is to be written to Frank Oberklaid as Chair of the Continuing Education Committee to determine whether it is appropriate that there is some forum. The Specialist Advisory Committee Debbie Lewis is currently our representative (Nephrology). Ian Hewitt expressed interest when her term is complete. ANZDATA Registry currently represented by Rowan Walker, Michael Falk and John Knight. It was requested that the New Executive write

to Alex Disney and to Rowan Walker as Chair of the Dialysis and Transplantation sub-committee concerning paediatric input to the Registry.

7. New Executive.

Nominations were received from Paul Roy to be Chair, Elisabeth Hodson as Secretary, and Michael Falk as Treasurer. No other nominations were received, and therefore they were elected unopposed. Colin Jones remains on the Executive as the Immediate Past Chair.

The meeting closed at 6.00 pm. The meeting was followed by the presentation of the IPNA Bid by Fred Juriedini with comments from members.

PAGE NO/ITEM	ACTION	TO BE ACTIONED BY
3	Letter to Paul Roy acknowledgement for Articles of Association	Lil Johnstone
4	Notification of Change of Office	Lil Johnstone
4	Notification of Change of Directors	Lil Johnstone
5	Application of membership forms for Steve Alexander and Fiona Mackey to be provided.	Elisabeth Hodson
5	Sub-committee to be appointed to consider membership and associate membership	New Executive.
5	Removal of Clause 11e from Articles of Association	New Executive
6 (5.1.4)	Year 2000 call for nomination for IPNA representative	New Executive
6 (5.1.9)	Resolution 2 of the IPNA Council to be provided to members of the ANZPNA	John Burke
8 (5.3)	Canvass members of ANZPNA re: Data to be collected on the paediatric form	Rowan Walker and establish sub-committee if required
9 (5.4.3)	Comments from members concerning the proposed FSGS study	All members ASAP
12	Establish a sub-committee related to growth hormone. Write to Minister re group consensus. Approach drug company considering submission to ADEC	New Executive and Charlie Crompton
12 (5.7)	Cardiprine	Fred Jureidini to provide information
12 (6.1)	Letter Warwick Prime – AFK Telephone Funding raising with reference to Kidney Kids Camp	New Executive
13 (6.3)	ANZPNA representative to the Written Exam Committee	William Wong to contact New Exec
13 (6.3)	Letter to Frank Oberklaid, Chair of Continuing Education Committee regarding Paediatric Specialist Advisory Committee	New Executive
13 (6.3)	Letter to Alex Disney, letter to Rowan Walker regarding ANZ Data Registry and paediatric input	New Executive

Appendix 2.

AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

STATEMENT OF RECEIPTS AND PAYMENTS FOR THE YEAR ENDED 30 JUNE 1999

		$
OPENING BALANCE		
(Transferred from ANZPNA Commonwealth Bank a/c 10021898)		1349.89
RECEIPTS		
Subscriptions	2200.00	
Bank Interest	2.30	
TOTAL	2202.30	
PAYMENTS		
Registration Fee (incorporation of ANZPNA)	405.00	
Postage	10.90	
Bank Fees, Duties and Taxes	15.20	
TOTAL	431.10	
EXCESS OF RECEIPTS OVER PAYMENTS = 1771.20		
BALANCE AS AT 30.6.99		3121.09

Treasurer's Statement

Certified as a true and accurate account of the financial affairs of the Australian and New Zealand Paediatric Nephrology Association for the financial year ending 30 June 1999.

P. Henning
Hon. Treasurer

Audit Report

This is to certify that I have audited the Statement of Receipts and Payments of the Australian and New Zealand Paediatric Nephrology Association for the year ended 30 June 1999. The accounting records made available to me indicate that the financial affairs of the Association have been maintained in order. The Statement of Receipts and Payments correctly represents the financial position of the Association as at 30 June 1999.

Kay Bruggemann B Acc, CPA
Hon. Auditor

Appendix 3.

Lilian Johnstone
Victorian Paediatric Renal Services
Department Of Nephrology Royal Childrens Hospital
Flemington Rd
Parkville VIC 3052

Remove this top section if desired before framing

Certificate of Registration of a Company

ASIC
Australian Securities & Investments Commission

This is to certify that

AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

Australian Company Number 087 155 780

is a registered company under the Corporations Law of Victoria.

The company **is limited by guarantee.**

The company is a **public** company.

The day of commencement of registration is **the fifteenth day of April 1999.**

Issued by the
Australian Securities and Investments Commission
on this fifteenth day of April, 1999.

Alan Cameron
Chairman

(17)

Appendix 4.

MINUTES

I.P.N.A. COUNCIL MEETING – NEW YORK – 9-10 MARCH 1999
"MAJOR AGENDA ITEMS"

Financial Report -	American account	$115,000.00
	European account	$117,000.00

The present aim is to have a twelve month reserve for all expenses.

Journal – Springer – Verlag

Continue to be the printers of pediatric nephrology. This company has now been taken over by a larger company and it is likely that there will be access to advertising. There has been a delay of one month in the printing of one issue earlier this year.

IPNA Congress – London 1988

The number of registrants was 1,018. Of these 950 paid registration. Number of abstracts received was 793 and 210 were rejected. A full report including financial statement was tabled. The number of registrants from USA was 110 and this was a significant decrease. There were 14 registrants from Australia and New Zealand.

Corporate sponsorship at the meeting was not high and the IPNA Congress is not well established with major companies. These companies are more likely to support the Congress for prestige rather than profit.

The surplus for the meeting is £66,000. For taxation reasons this money cannot be paid directly to IPNA so a Charitable Trust has been established and based in London. The Trustees are I. Greifer, Cyril Chantler, Martin Barratt and K. Venier-Jones.

A number of assisted registrations were given for this Congress. The guidelines for these participants are to be reviewed by a sub-committee of Council. Some money has been donated from regional societies.

Nominations – IPNA Council

At the general meeting of IPNA in London, some European Members expressed concern as to the appointment of Council Members. Regional Societies make the appointments to Council. There will now be a change with nominations to be forwarded to Council and selection will be made by the Regional Secretaries for approval by the full Council.

Secretary-General –

A selection process will commence in the near future by a sub-committee of Council for the appointment of a new Secretary-General to replace I. Greifer.

13th Congress 2004 –

Presentation on behalf of ANZPNA made by J. Burke for Adelaide.
S. Turi was to have made a presentation on behalf of Budapest – Hungary, but did not attend.

12th Congress Seattle 2001 –

Bruder Stapleton and Sandra Watkins report a satisfactory progress for both the scientific and business aspects of the meeting. A seeding grant of $16,000 from Council has been given.

International Children's Kidney Foundation – Corporation is proceeding.

It is likely that the money from the London meeting will be paid into this account.

Pan Arab Pediatric Nephrology Association (PAPNA) –

This association has made a request to be affiliated with IPNA. A representative is to speak at the next Council meeting in Prague in September.

Developmental Renal Physiology Workshop –

This meeting was held in Stockholm in 1998 prior to the London meeting. The number of registrants was 110 with approximately 15 Nephrologists. Future meetings including date and location are to be approved by IPNA Council. The budget for this meeting is approximately $50,000. R. Chevalier will chair a sub-committee and made a recommendation for the next meeting.

Programme Development for Nephrology Education –

This material is to assist education of Doctors in undeveloped countries. Martin Barratt is to prepare a report.

Union of Pediatricians of Russia –

A request was received from this group to provide education in pediatric nephrology. This would include financial assistance for both travel and living expenses in Western Europe and North America.

Future Meetings –

European Pediatric Nephrology	-	Prague	-	September 2-5, 1999
European Pediatric Nephrology	-	Helsinki	-	June 18-20, 2000
Asian Congress of Pediatric Nephrology	-	Singapore	-	November 4-6, 2000

J. Burke

M O N A S H U N I V E R S I T Y

DEPARTMENT OF ANATOMY
Head: Professor John F. Bertram

Dr. Colin Jones,
Department of Nephrology,
Royal Children's Hospital,
Flemington road,
Parkville,
Vic 3052

Re: International Renal Development Workshop, 2004

Dear Colin,

Further to our recent telephone conversations I advise that I am willing to organise the International Renal Development Workshop in 2004.

As you know, Australia has quite an active research community investigating various aspects of renal development. In addition to myself, investigators include Professor Eugenie Lumbers (School of Pharmacology and Physiology, University of New South Wales), Professor Diane Alcorn (Department of Anatomy and Cell Biology, University of Melbourne), Professor Marelyn Wintour (Howard Florey Institute) and Dr. Melissa Little (University of Queensland).

I have considerable experience in organising national and international scientific meetings. In 1991 I organised a 3 day meeting of the Image Analysis Society of Australia and New Zealand, and I am currently the Chairman of the Local Organising Committee of the Xth International Congress for Stereology which will be held at the University of Melbourne in November this year. I therefore have the necessary experience, organisational skills and infrastructure support to organise the Renal Development Workshop.

Australia is very active in research into developmental biology, and I would aim to attract a good number of registrants who do research on developmental mechanisms but not necessarily kidney research. In this way we could bring ideas from researchers on the nervous system, body patterning, stem cells, cell determination and so on to the meeting. I am sure that this would add greatly to the scientific standard and attractiveness of the meeting.

I understand that the Workshop is typically held in a non-urban setting. There are excellent venues in close proximity to Melbourne (e.g. Lorne), Sydney (eg. Blue Mountains) and Brisbane, and so we would have plenty of attractive venues to choose from. These venues are frequently used for scientific meetings.

Once I have approval to organise the Workshop I will set up an organising committee consisting in part of some of the researchers named above, and will set about selecting and booking a venue. I also look forward to meeting with Bob Chevalier in April 2000 to discuss this proposal and discuss planning.

I am excited at the prospect of organising this Workshop in Australia and look forward to further developments.

With best wishes.

Yours sincerely,

Professor John F. Bertram
Head of Department

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CLAYTON, VICTORIA, 3168 AUSTRALIA FAX: (61) (3) 9905 2766 TELEPHONE: (03) 9905 2751 IDD: +61 3 9905 2751
EMAIL: J.Bertram@med.monash.edu.au

Appendix 6.

ANZPNA Business Meeting
25th July 1999

Report on Progress in Aboriginal Renal Disease
JF Knight

RECENT EVENTS

- Numerous presentations on research in adults and children at ANZSN in Brisbane in March 1999
- Proposal received by AKF from Dr Wendy Hoy to roll out the 'Tiwi Islands' program of early intervention on a national basis. Received and adopted with enthusiasm by AKF Board
- New grant of $300,000 for Aboriginal Health initiatives from Rio Tinto negotiated by AKF
- South Australian renal forum in Flinders Ranges
- The progress achieved by the Umoona kidney project (Fred Juredeini and Lindsay Barratt) suggests that a whole-family approach is more productive than a purely paediatric approach
- Grant to AKF of $1.5 million over four years for Hoy project negotiated with Dr Michael Wooldridge
- OATSIHS (Office for Aboriginal and Torres Strait Islander Health Services) – a part of DHFS (Commonwealth Department of Health and Family Services) – is providing Bayer automated blood and urine screening machines to Aboriginal health services throughout Australia
- Mark Shepherd (Flinders Medical Centre, SA) has developed a QA program and computerised data entry program which can be used with these devices

FUTURE EVENTS

- Contract between AKF and OATSIHS for delivery of national program should be ready for signing in early August
- National summit on Aboriginal renal disease to be convened by OATSIHS in September 1999 to bring together all interested players and develop a national strategy
- Umoona model of cooperation between regional adult and pediatric nephrologists, and local health care providers is ideal.

Appendix 7.

DISCUSSION PAPER

AUSTRALIAN KIDNEY KIDS CAMP

Over the past few years the Australian Kidney Foundation has been organising and managing the Kidney Kids Camp. The camp has been organised on a national basis although some states have elected to run their own camps. Recently problems have emerged which necessitate changing the organisation of the camp.

1. The recent camp

   (a) Did not provide dialysis on site.
   (b) Did not have the continuous presence of a registered medical officer.
   (c) Excluded one child (a child with severe disability) who would have benefited and this child's exclusion occurred immediately prior to the camp and was handled in a very poor manner.
   (d) Despite the camp being held in New South Wales only 6 New South Wales children attended (compared with around 20 from Victoria).

1. There is a different approach to the camp from different units around the Country. This is reflected in the structure of the camp with regards to the presence of a medical officer, dialysis on site and encouragement of those with significant disabilities to attend.
2. One of the major people involved in running the camp, Roy Knudson is no longer playing an active role.
3. The Australian Kidney Foundation provides incomplete funding for the camp which leaves much money to be raised by parents (particularly for air fares). Also siblings of children with renal problems are not funded for the camp. This leads to considerable financial difficulties for some families.

PROPOSAL

1. That the national camp be broken up into historically based regional camps. For example the Southern camp would service Victoria, South Australia, Tasmania, New Zealand and Western Australia. Another would service children from New South Wales and Queensland and Northern Territory. Children from other States to attend other regional camps but may pay a fee to do so.
2. The camp occur at 3 distinct locations which are changed on a yearly basis. For instance, for the Southern camp, Tasmania Year 2000, Victoria 2001, and South Australia 2002. The camp be held at one location within each date every 3 years (to enable site facilities to be well known to the nephrology community).
3. Consideration be made to performing dialysis off site so that the nursing and technical input to the camp be minimised.
4. That the camp be under the auspice of the ANZPNA and the Australian Kidney Foundation with input from the units through an official organising committee (AKF, Renal Unit Medical Staff and Renal Unit Nursing Staff). That the AKF provide one set fee and significant subsidy for air fares. If sufficient funding is not provided by the AKF, the regional camp through ANZPNA members would be free to seek separate funding selling the marketing of the camp.
5. Patients that will present particular problems be catered for through arrangements made well ahead of time.

The aim of the above changes are to enable continuation of the Kidney Kids Camp, to avoid fatigue of nursing staff from having to perform a camp every year, to provide a camp in safe medical surroundings that is good fun, and to minimise financial costs for the people most in need of the Kidney Foundation's help.

Colin Jones

Appendix 7.

AUSTRALIAN KIDNEY FOUNDATION
ACN 008 464 426

"30 Years of Giving & Living"

1 July, 1999

Dr Colin Jones
Director – Department of Nephrology
Royal Children's Hospital
Flemington Road
PARKVILLE VIC 3052

Dear Colin,

I refer to your Discussion Paper on the Australian Kidney Kids Camp.

I agree with the direction of the paper and hope that it is received well at the Australian and New Zealand Paediatric Nephrology Association meeting this month.

I have discussed the paper with Michelle Diener, National Education Manager and by now you would have received her reply.

I particularly support the concept of rotating the camp between Tasmania, Victoria and South Australia, although I feel that a fourth location could be found in Queensland.

In keeping with the Camp being organised under the auspices of the Australian Kidney Foundation, it is felt that the Organisation Committee Chairperson should come from within the host State Committee and report to the National Education Committee in respect to policy matters.

Furthermore, this would give Camp Committees in those other states not hosting the Camp the ability to make preliminary plans up to eighteen months before their camp is due. In between years these committees should be encouraged to focus on securing alternate ways of funding to reduce the cost of travel and camp fees for the children attending from their state.

Hope this is of some help and will look forward to hearing about the response the paper receives at your meeting.

Sincerely

Michael Cassar
Executive Manager

6th Floor, 11 Queens Road Melbourne Vic. 3004 GPO Box 9993, Melbourne Vic. 3001
Telephone: (03) 9866 3300 Facsimile: (03) 9866 6344

Appendix 7.

Paediatric Nephrology
Monash Medical Centre
246 Clayton Road
Clayton 3168

9th July 1999

Dr Colin Jones
Director
Department of Nephrology
Royal Children's Hospital

Dear Colin,

Re: Discussion Paper "Australian Kidney Kids Camp".

Regarding your proposal,

1. I agree.
2. I have concerns regarding the camp occurring in Tasmania where there are no paediatric nephrologists.
3. PD will remain on site but haemodialysis may be performed off site.
4. I agree.
5. Refusal to take campers (Kidney Kids) be discussed well prior to the camp. The number of participants and their names should be finalised by end November/early December. The AKF should undertake to improve communication to family. In 1999 some families did not receive confirmation of registration until Friday before camp (air flight on Saturday). Other families did not receive any communication regarding the camp until well after the closing date for applications.

   The poor communications between camp organisers and families can create a considerable anxiety for these campers and their families.

   If campers are refused then campers and Renal Unit should retain the right to appeal.

   Volunteers should be adequately trained and have a clear understanding of their responsibilities.

I think these are the main points and I will let you know if I think of others.

Cheers,

Dr Amanda Walker
Consultant Nephrologist.

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Appendix 7.

AUSTRALIAN KIDNEY FOUNDATION

A.C.N. 008 464 426

4 June 1999

Colin Jones
Director - Department of Nephrology
Royal Children's Hospital
Flemington Road
Parkville 3052

Dear Colin

Thank you for forwarding to me for comment the proposals for redesigning the Australian Kidney Foundation's National Kidney Kids Camp.

The comments that I offer on your discussion paper are:

With reference to Point 1 (b), it is the preference, indeed a policy, of the Australian Kidney Foundation that a registered medical officer is present at the camp at all times, and this position was made very clear to the camp organising committee in NSW, but was ignored. Certainly the comment in Point 2 about the different approach to camp by different renal units contributed to this decision.

With regard to the five proposed points:

Point 1: This seems a sensible option, as the units grouped together have historically demonstrated a similar view of the purpose of camp.

Point 2: A good option, enabling all stakeholders to plan ahead, and local community support for the camp to be sought well in advance, facilitating fundraising efforts.

Point 3: While there will always be some people that support the idea of dialysing the kids on-site, dialysing off-site means that an enormous load is taken off of camp organisers. It seemed to work well at the 1999 camp, and is planned for the 2000 camp in Tasmania.

Point 4: Having the camp under the auspices of the AKF, with an official organising committee as suggested, is an effective way of ensuring that all stakeholders are involved in camp decision making.
I would anticipate that under the proposed system of a three-year rotation, each State's committee would then have a large task each three years in camp planning and implementation, and a less-intense role in fund-raising for the other two years.

The position of the AKF in terms of siblings attending camp has been that if space was limited at a camp, first preference would always be given to kidney kids then if space allowed, siblings would be invited. Obviously there are some kids who would benefit from having their siblings along more than others, indeed some kids wouldn't go to camp without them, so each situation must be handled accordingly.
While it would be possible to have one set fee rather than a separate fee for siblings, the issue of providing a significant subsidy for air fares needs to be explored further.

National Education and Health Promotion Office

All correspondence addressed to: G.P.O. Box 9993 Adelaide 5001
Unit 2, 1st Floor, 82 Melbourne Street, North Adelaide, S.A. 5006
Telephone: (08) 8267 4555 Facsimile: (08) 8267 4450

It has been the policy that each State has a responsibility for contributing to air fares, and this is handled in different ways in each State. The model proposed previously is to have the renal unit and the State AKF branch working together to gather the funds to send kids to camp.

Point 5: While children with multiple disabilities have attended camp in the past, I think it is important to ensure:

- ◊ that preference is given to those kids who's primary disability is renal disease
- ◊ that adequate, professional support staff are on hand, and organised well in advance, to ensure that these kids are safe and well cared for, and don't become an unreasonable strain on camp resources
- ◊ that parents clearly define the disabilities their child has, to enable the camp committee to make an informed decision about whether or not to accept the child.

The National Kidney Kids Camp is one of the projects the Australian Kidney Foundation provides for people with renal disease, and as such, the AKF supports the continuation of the camp.

It is, however, a project that requires a significant contribution, both financially and in terms of staff time. Around $40 000, excluding staff time, was required from the AKF to run the 1999 camp. It is one of several projects that need funding annually, and it is important that we look at ways of sharing resources equitably.

I hope that these comments are useful. Please feel to contact me to discuss any of this, on 08 8267 4555.

Yours faithfully

Michelle Diener
National Education Manager

Appendix B.

The Royal Australasian College of Physicians
A.C.N 000 039 047
145 Macquarie Street Sydney NSW 2000
Telephone: (02) 9256 5444 Facsimile: (02) 9252 3310

DIVISION OF
PAEDIATRICS

Telephone: (02) 9256 5408
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E-mail: paed@racp.edu.au

8 March 1999

Dr Colin Jones
Chairman
Australian and New Zealand Pediatric Nephrology Association (ANZPNA)
Department of Nephrology
Royal Children's Hospital
Flemington Road
PARKVILLE VIC 3052

Dear Dr Jones

RACP Division of Paediatrics, Annual Scientific Meeting, Sydney 2001

I wrote to you towards the end 1998, inviting your Group to consider joining with the RACP Division of Paediatrics for its Annual Scientific Meeting in Adelaide in May 2000. I realise that the year 2000 may be just too difficult a time to have a joint meeting. Therefore, I would like to ask your Group to consider joining with the Division of Paediatrics for its Annual Scientific Meeting in May 2001 in Sydney. The meeting is currently scheduled to run from 15th–18th May, 2001 at the Sydney Convention Centre.

Several paediatric sub-speciality groups have indicated that they may be interested in joining with the Division of Paediatrics in 2001. I would, however, like to formalise this as soon as possible as this will have implications for our planning for the meeting.

I look forward to hearing from you in reply.

Yours sincerely

A/PROFESSOR LOUISE BAUR
Chair
Scientific Program Committee

27

APPENDIX 9

Committee	ANZPNA Member	Date of Appointment
Royal Australasian College of Physicians.		
1. Nephrology Specialist Advisory Committee	Deborah Lewis	1993 – 1998 New appointment to be decided by ANZPNA, ? Ian Hewitt
2. Representation of the Paediatric Society of New Zealand to the Board of Paediatrics and Child Health, RACP	Max Morris	Elected
3. MOPS Review Committee	Andrew Rosenberg	Completes term 2000
4. The Written Exam Committee	Colin Jones	2000 ? William Wong to be nominated
ANZSN		
1. Council 2. Dialysis and Transplant Sub-committee 3. Transplantation Society of Australia and New Zealand. Renal Failure Advisory Group Council i. Renal Failure Advisory Group i. Council M. Falk.	M. Falk (SPEC) John Knight M. Falk John Knight R. Walker (appointed and elected Chairman) R. Walker M. Falk	 By invitation Ex officio Elected Victorian Representative
IPNA		
1. Council	John Burke	2001
ANZDATA		
1. Council 2. ANZDATA Registry Committee 3. ANZDATA Paediatric Report	Michael Falk John Knight R. Walker R. Walker	 Ex-Officio Appointed Appointed

OTHERS		
1. AKF	D. McCredie (Victoria)	
(i) South Australian Organ Donation Sub-committee	Paul Henning	
(ii) The Pharmacology and Therapeutic Advisory Committee of New Zealand.	Paul Tomlinson Lil Johnstone	
(iii) The National Sub Committee for Paediatric Continence, Continence Foundation Australia.		
2. APSN	R. Walker	Elected

AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

STATEMENT OF RECEIPTS AND PAYMENTS FOR THE YEAR ENDED 30 JUNE 1999

		$
OPENING BALANCE		
(Transferred from ANZPNA Commonwealth Bank a/c 10021898)		1349.89
RECEIPTS		
Subscriptions	2200.00	
Bank Interest	2.30	
TOTAL	2202.30	
PAYMENTS		
Registration Fee (incorporation of ANZPNA)	405.00	
Postage	10.90	
Bank Fees, Duties and Taxes	15.20	
TOTAL	431.10	
EXCESS OF RECEIPTS OVER PAYMENTS = 1771.20		
BALANCE AS AT 30.6.99		**3121.09**

ANZPNA Business Meeting
25th July 1999

Report on Progress in Aboriginal Renal Disease
JF Knight

RECENT EVENTS

- Numerous presentations on research in adults and children at ANZSN in Brisbane in March 1999
- Proposal received by AKF from Dr Wendy Hoy to roll out the 'Tiwi Islands' program of early intervention on a national basis. Received and adopted with enthusiasm by AKF Board
- New grant of $300,000 for Aboriginal Health initiatives from Rio Tinto negotiated by AKF
- South Australian renal forum in Flinders Ranges
- The progress achieved by the Umoona kidney project (Fred Juredeini and Lindsay Barratt) suggests that a whole-family approach is more productive than a purely paediatric approach
- Grant to AKF of $1.5 million over four years for Hoy project negotiated with Dr Michael Wooldridge
- OATSIHS (Office for Aboriginal and Torres Strait Islander Health Services) – a part of DHFS (Commonwealth Department of Health and Family Services) – is providing Bayer automated blood and urine screening machines to Aboriginal health services throughout Australia
- Mark Shepherd (Flinders Medical Centre, SA) has developed a QA program and computerised data entry program which can be used with these devices

FUTURE EVENTS

- Contract between AKF and OATSIHS for delivery of national program should be ready for signing in early August
- National summit on Aboriginal renal disease to be convened by OATSIHS in September 1999 to bring together all interested players and develop a national strategy
- Umoona model of cooperation between regional adult and pediatric nephrologists, and local health care providers is ideal.

Appendix 2

JOURNAL OF AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

Volume 2, ~~1999~~-2000 1998 - 1999

INDEX

Page No.

( ) refers to Volume Number

JOURNAL OF AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

VOLUME 2, NO. 5 JANZPNA

28th June 1999

PAGE

CONTENTS

ANZPNA Minutes – Teleconference 18th June 1999

Present: Colin Jones, Lilian Johnstone, Fred Jureidini, John Burke.

Apologies: Paul Henning

Chairman's Report:

A letterhead and logo for the ANZPNA have been prepared and printed. Copies of the letterhead will be sent to Fred Jureidini and John Burke for use in correspondence of the Executive. The ANZPNA has now been incorporated and an A.C.N. number allocated.

IPNA Bid:

Colin has corresponded with Robert Chevalier who has been appointed by the I.P.N.A. Council to look at the planning of the Developmental Workshop. Robert Chevalier will be involved in choosing the next site for the developmental workshop and is looking for a venue to accommodate 150 people which is close geographically and in timing to the I.P.N.A. meeting. Colin has spoken to John Bertram about the possibility of holding the Developmental Workshop in Melbourne.

John Burke reported that the I.P.N.A. Council were unhappy with the Developmental Workshop meeting in Stockholm as few Paediatric Nephrologists attended and would like it to be closer in time and location to the I.P.N.A. meeting.

Judy Savige has corresponded with Colin and indicated that she would be keen to hold a Workshop or Satellite Meeting on Alports and associated diseases and possibly other inherited renal disease.

Ira Greifer has faxed John Burke and indicated that he has asked Mathias Brandes to head a delegation which will include a Council member from the American Society of Paediatric Nephrology, the European Society of Paediatric Nephrology and the Japanese Society of Paediatric Nephrology to do a site visit to Adelaide. John and Fred have spoken and subsequently Fred has spoken with the Adelaide Convention and Tourist Authority organisers and a program has been worked out for site visit commencing Monday, 26th July 1999. Fred will ring Ira to confirm this date and to determine any requirements. Following that phone call, John Burke will contact Mathias Brandes to discuss the site visit with him. It was planned that John Burke, Colin Jones, and David McCredie would visit Adelaide for 1-2 days during the site visit. There was discussion as to whether those involved in the Workshops e.g. John Bertram and Judy Savige should also be invited and similiarly whether Graham Russ and Robert Atkins should be invited. It was felt that the I.P.N.A. Council should be encouraged to pay for the delegates' site visit.

Other Business:

The provisional Agenda for the A.G.M. was approved with Fred Jureidini requesting discussion of Cardiprin and whether it would be possible to encourage a company to bring the drug into Australia for us to trial for the management of acute hypertension. Fred will provide some documentation for the A.G.M.

The lack of Nominations for the Executive was noted and a notice has been sent encouraging members to re-think the possibility of nominating for the Executive. We would be keen to encourage a New Zealand member of the ANZPNA to be a member of the Executive.

The support of Baxter Healthcare was acknowledged. Members attending Sydney should have confirmed their airfares and send the receipts to Colin Jones for presentation to Baxter. Members are also reminded that they are responsible for arranging their own accommodation.

Meeting closed 1.30 pm.

Next Meeting: A.G.M. Sunday 25th July 1999.

NOTE

Due to the variation in arrival and departure times, we will not be arranging bus transport from the airport to Westmead or for return the next day. Please organise your own transport.

AGENDA

AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION – Annual General Meeting 25th July, 1999

Commencing at 12.00 pm at New Sydney Children's Hospital – Westmead.

1. Apologies

2. Confirmation of Minutes, Annual General Meeting held Royal Pines Resort, 19th July 1998.

3. The Executive Report

   3.1 Chairman's Report
   3.2 Treasurer's Report
   3.3 Secretary's Report - **Appendix 1**

4. Election of new Executive

5. Election of new Members

6. Other Business

   6.1 IPNA Council - **Appendix 2**
   6.2 IPNA Bid
   6.3 ANZ Data
   6.4 Multi-centre trials
   - VUR
   - APSU: Nephrotic Syndrome
   - Trial of Treatment for FSGS

   6.5 Benchmarking - **Appendix 3**
   6.6 Growth Hormone
   6.7 Drugs

7. New Business Kidney Kids Camp
   Division of Paediatrics, Annual Scientific Meeting - **Appendix 4**

8. Next Meeting

Between 6.00 pm and 7.00 pm, Fred Jureidini will run through the Bid Presentation that he will make to the IPNA Council in September.

Lilian Johnstone
Victorian Paediatric Renal Services
Department Of Nephrology Royal Childrens Hospital
Flemington Rd
Parkville VIC 3052

Remove this top section if desired before framing

Certificate of Registration of a Company

ASIC
Australian Securities & Investments Commissior

This is to certify that

AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

Australian Company Number 087 155 780

is a registered company under the Corporations Law of Victoria.

The company **is limited by guarantee.**

The company is a **public** company.

The day of commencement of registration is **the fifteenth day of April 1999.**

Issued by the
Australian Securities and Investments Commission
on this fifteenth day of April, 1999.

Alan Cameron
Chairman

AGM - Appendix 2

MINUTES

I.P.N.A. COUNCIL MEETING – NEW YORK – 9-10 MARCH 1999
"MAJOR AGENDA ITEMS"

Financial Report -	American account	$115,000.00
	European account	$117,000.00

The present aim is to have a twelve month reserve for all expenses.

Journal – Springer – Verlag

Continue to be the printers of pediatric nephrology. This company has now been taken over by a larger company and it is likely that there will be access to advertising. There has been a delay of one month in the printing of one issue earlier this year.

IPNA Congress – London 1988

The number of registrants was 1,018. Of these 950 paid registration. Number of abstracts received was 793 and 210 were rejected. A full report including financial statement was tabled. The number of registrants from USA was 110 and this was a significant decrease. There were 14 registrants from Australia and New Zealand.

Corporate sponsorship at the meeting was not high and the IPNA Congress is not well established with major companies. These companies are more likely to support the Congress for prestige rather than profit.

The surplus for the meeting is £66,000. For taxation reasons this money cannot be paid directly to IPNA so a Charitable Trust has been established and based in London. The Trustees are I. Greifer, Cyril Chantler, Martin Barratt and K. Venier-Jones.

A number of assisted registrations were given for this Congress. The guidelines for these participants are to be reviewed by a sub-committee of Council. Some money has been donated from regional societies.

Nominations – IPNA Council

At the general meeting of IPNA in London, some European Members expressed concern as to the appointment of Council Members. Regional Societies make the appointments to Council. There will now be a change with nominations to be forwarded to Council and selection will be made by the Regional Secretaries for approval by the full Council.

Secretary-General –

A selection process will commence in the near future by a sub-committee of Council for the appointment of a new Secretary-General to replace I. Greifer.

13th Congress 2004 –

Presentation on behalf of ANZPNA made by J. Burke for Adelaide.
S. Turi was to have made a presentation on behalf of Budapest – Hungary, but did not attend.

12th Congress Seattle 2001 –

Bruder Stapleton and Sandra Watkins report a satisfactory progress for both the scientific and business aspects of the meeting. A seeding grant of $16,000 from Council has been given.

International Children's Kidney Foundation – Corporation is proceeding.

It is likely that the money from the London meeting will be paid into this account.

Pan Arab Pediatric Nephrology Association (PAPNA) –

This association has made a request to be affiliated with IPNA. A representative is to speak at the next Council meeting in Prague in September.

Developmental Renal Physiology Workshop –

This meeting was held in Stockholm in 1998 prior to the London meeting. The number of registrants was 110 with approximately 15 Nephrologists. Future meetings including date and location are to be approved by IPNA Council. The budget for this meeting is approximately $50,000. R. Chevalier will chair a sub-committee and made a recommendation for the next meeting.

Programme Development for Nephrology Education –

This material is to assist education of Doctors in undeveloped countries. Martin Barratt is to prepare a report.

Union of Pediatricians of Russia –

A request was received from this group to provide education in pediatric nephrology. This would include financial assistance for both travel and living expenses in Western Europe and North America.

Future Meetings –

European Pediatric Nephrology	-	Prague	-	September 2-5, 1999
European Pediatric Nephrology	-	Helsinki	-	June 18-20, 2000
Asian Congress of Pediatric Nephrology	-	Singapore	-	November 4-6, 2000

J. Burke

Patient UR: _____

Circle Country/State/Hospital: WA VicRCH, VicMMC, NSWNCH, NSWSCH, Qld, SA, NZ, Other _____

Underlying renal condition: _____

Body weight (kg) _____

Age _____

AV FISTULAE AND GRAFTS

INSTRUCTION

Insertion: Answer Q1, 2, 3

Removal or Transplant: Answer Q4

Any surgical manipulation counts as insertion: Answer Q1, 2, 3

1. AVF

L radial ☐ L brachial ☐

R radial ☐ R brachial ☐

Other: _____ Side: _____

Date of creation: _____

Date of first use: _____

2. **AV Grafts**

PTFE/Gortex ☐ Thoratec ☐

Site of graft: _____

Date of creation: _____

Date of first use: _____

3. Frequency of Access _____ /week
(AVF or AV Graft)

Size of Needle _____

Single Needle ☐ Double Needle ☐

Is device accessed at times other than dialysis Yes ☐ No ☐

Previous AV access formations: Yes ☐ No ☐

If yes give details: _____

Access created by vascular surgeon/ general surgeon/ transplant surgeon/ paed urologist/ general paed surgeon other

Aspirin Used: Yes ☐ No ☐

Warfarin Used: Yes ☐ No ☐

4. **Reasons for intervention:**

Date: _____

Clotted
Malposition
Stenosis
Change of modality
Transplant
Infection
Other _____

Patient UR: _____

Circle Country/State/Hospital: WA VicRCH, VicMMC, NSWNCH, NSWSCH, Qld, SA, NZ, Other _____

Underlying renal condition: _____

Body weight (kg) _____

Age _____

CHRONIC PERITONEAL DIALYSIS

INSTRUCTION

Insertion of catheter: Answer Q1, and Q2

Removal of Catheter: Answer Q3

Transplantation: Answer Q3

Complete questionnaire for all patients commencing or continuing chronic dialysis. Do not include acute short term PD e.g. For HUS or metabolic conditions

1. **PD catheter type**

Straight ☐ Swan neck ☐
Single Cuff ☐ Double Cuff ☐

Catheter brand and type: _____

2. **Technique of PD Regime:**

Date of catheter insertion: _____

Partial omentectomy Yes ☐ No ☐

Date of Admission _____

Date dialysis commenced _____

Date of Discharge/Death _____

Catheter flushed until dialysate clear Yes ☐ No ☐

Catheter rested Yes ☐ No ☐

Dialysis commenced immediately Yes ☐ No ☐

If catheter use deferred, catheter flushed at _____ intervals

Catheter exit site determined pre-operatively Yes ☐ No ☐

Direction of exit site superior/ inferior/medial/lateral

External suture at exit site Yes ☐ No ☐

Initial dressing left intact for _____ days

Is catheter securely immobilized by tape at all times Yes ☐ No ☐

Staph aureus isolated within patient/family Yes ☐ No ☐ Not swabbed ☐
Staph aureus treated with Mupirocin Yes ☐ No ☐ N/A ☐
Any other conditions relevant to this procedure _____

Planned Ongoing PD Regime:

Date	*CAPD/APD*	*Connection System*	*Regime*

3. **Reasons for removal:** (please circle)

Infection- Peritonitis
Catheter track infection
Exit site infection
Hernia
Cuff extrusion
Mal-position
Change of modality
Transplant
Other

Patient UR: _____

Circle Country/State/Hospital: WA VicRCH, VicMMC, NSWNCH, NSWSCH, Qld, SA, NZ, Other _____

Underlying renal condition: _____

Body weight (kg) _____

Age _____

INDICATION ADEQUACY and SAFETY of RENAL BIOPSY

INSTRUCTION

Please answer all questions

1. Indications for renal biopsy (please circle)

Haematuria, Proteinuria, Nephrotic Syndrome, Nephritic Syndrome, Renal Impairment, Transplant, Other (please specify) _____

2. Prebiopsy tests (please circle)

FBE/Coagulation Screen/group + hold/Cross-match skin bleeding time

3. Biopsy device: _____

Needle size 14G/16G/18G/20G

4. Guidance Yes ☐ No ☐

Specify _____

5. Adequate diagnostic sample of tissue taken

(i.e. cortex consisting of at least 10 glomeruli) Yes ☐ No ☐

If no, number of glomeruli _____

6. Development of macroscopic haematuria within 24 hrs of procedure: (ie. in patient without preceding macroscopic haematuria.

Yes ☐ No ☐

Duration of macroscopic haematuria :

- < 6 hours ☐
- 6-12 hours ☐
- 12-24 hours ☐
- > 24 hours ☐

7. Did this patient require a blood transfusion as a result of post biopsy bleeding: Yes ☐ No ☐

8. Patient required readmission because of complication of the procedure Yes ☐ No ☐

If yes (specific complication) _____

Patient UR: _____

Circle Country/State/Hospital: WA VicRCH, VicMMC, NSWNCH, NSWSCH, Qld, SA, NZ, Other _____

Underlying renal condition: _____

Body weight (kg) _____

Age _____

CHRONIC HAEMODIALYSIS - CVC's

INSTRUCTION

Insertion: Answer Q1, 2, 3

Removal or Transplant: Answer Q4

Any surgical manipulation counts as insertion: Answer Q1, 2 3

Do not include acute short term H.D.

1. CVC Type

Type of catheter: Non cuffed ☐ Cuffed ☐ Single lumen ☐
Straight ☐ Pre-curved ☐ Double lumen ☐

Brand: _____
Size: _____
Which vessel: R ☐ L ☐

2. Date of insertion _____
Date of first use _____
Access created by vascular surgeon/ general surgeon/ transplant surgeon/ paed urologist/ general paed surgeon/ other

External suture at exit site: Yes ☐ No ☐

Catheter position confirmed radiologically before use Yes ☐ No ☐

Staph aureus isolated patient/family: Yes ☐ No ☐ Not swabbed ☐

Staph aureus treated with Mupirocin: Yes ☐ No ☐ Not Applicable ☐

Dressing left intact for _____ days

Previous CVC's: Yes ☐ No ☐
Any other condition relevant to this procedure _____

3. Haemodialysis Regime

Frequency of dressing changes _____
Type of dressing _____
"Heparin Lock" used Yes ☐ No ☐
Concentration of heparin _____ U/ml
Frequency of HD _____/week
Is device accessed at times other than dialysis Yes ☐ No ☐

3. Removal of catheter

Date: _____

Reason please circle:

Infection
Transplant
Mal-position
Change of Modality
permanent HD access
peritoneal dialysis
Other

AGM - Appendix. 4

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DIVISION OF PAEDIATRICS

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E-mail: paed@racp.edu.au

8 March 1999

Dr Colin Jones
Chairman
Australian and New Zealand Pediatric Nephrology Association (ANZPNA)
Department of Nephrology
Royal Children's Hospital
Flemington Road
PARKVILLE VIC 3052

Dear Dr Jones

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Several paediatric sub-speciality groups have indicated that they may be interested in joining with the Division of Paediatrics in 2001. I would, however, like to formalise this as soon as possible as this will have implications for our planning for the meeting.

I look forward to hearing from you in reply.

Yours sincerely

A/PROFESSOR LOUISE BAUR
Chair
Scientific Program Committee

DISCUSSION PAPER

AUSTRALIAN KIDNEY KIDS CAMP

Over the past few years the Australian Kidney Foundation has been organising and managing the Kidney Kids Camp. The camp has been organised on a national basis although some states have elected to run their own camps. Recently problems have emerged which necessitate changing the organisation of the camp.

1. The recent camp

   (a) Did not provide dialysis on site.
   (b) Did not have the continuous presence of a registered medical officer.
   (c) Excluded one child (a child with severe disability) who would have benefited and this child's exclusion occurred immediately prior to the camp and was handled in a very poor manner.
   (d) Despite the camp being held in New South Wales only 6 New South Wales children attended (compared with around 20 from Victoria).

1. There is a different approach to the camp from different units around the Country. This is reflected in the structure of the camp with regards to the presence of a medical officer, dialysis on site and encouragement of those with significant disabilities to attend.
2. One of the major people involved in running the camp, Roy Knudson is no longer playing an active role.
3. The Australian Kidney Foundation provides incomplete funding for the camp which leaves much money to be raised by parents (particularly for air fares). Also siblings of children with renal problems are not funded for the camp. This leads to considerable financial difficulties for some families.

PROPOSAL

1. That the national camp be broken up into historically based regional camps. For example the Southern camp would service Victoria, South Australia, Tasmania, New Zealand and Western Australia. Another would service children from New South Wales and Queensland and Northern Territory. Children from other States to attend other regional camps but may pay a fee to do so.
2. The camp occur at 3 distinct locations which are changed on a yearly basis. For instance, for the Southern camp, Tasmania Year 2000, Victoria 2001, and South Australia 2002. The camp be held at one location within each date every 3 years (to enable site facilities to be well known to the nephrology community).
3. Consideration be made to performing dialysis off site so that the nursing and technical input to the camp be minimised.
4. That the camp be under the auspice of the ANZPNA and the Australian Kidney Foundation with input from the units through an official organising committee (AKF, Renal Unit Medical Staff and Renal Unit Nursing Staff). That the AKF provide one set fee and significant subsidy for air fares. If sufficient funding is not provided by the AKF, the regional camp through ANZPNA members would be free to seek separate funding selling the marketing of the camp.
5. Patients that will present particular problems be catered for through arrangements made well ahead of time.

The aim of the above changes are to enable continuation of the Kidney Kids Camp, to avoid fatigue of nursing staff from having to perform a camp every year, to provide a camp in safe medical surroundings that is good fun, and to minimise financial costs for the people most in need of the Kidney Foundation's help.

Colin Jones

AUSTRALIAN KIDNEY FOUNDATION
A.C.N. 008 464 426

4 June 1999

Colin Jones
Director - Department of Nephrology
Royal Children's Hospital
Flemington Road
Parkville 3052

Dear Colin

Thank you for forwarding to me for comment the proposals for redesigning the Australian Kidney Foundation's National Kidney Kids Camp.

The comments that I offer on your discussion paper are:

With reference to Point 1 (b), it is the preference, indeed a policy, of the Australian Kidney Foundation that a registered medical officer is present at the camp at all times, and this position was made very clear to the camp organising committee in NSW, but was ignored. Certainly the comment in Point 2 about the different approach to camp by different renal units contributed to this decision.

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It has been the policy that each State has a responsibility for contributing to air fares, and this is handled in different ways in each State. The model proposed previously is to have the renal unit and the State AKF branch working together to gather the funds to send kids to camp.

Point 5: While children with multiple disabilities have attended camp in the past, I think it is important to ensure:

- ◊ that preference is given to those kids who's primary disability is renal disease
- ◊ that adequate, professional support staff are on hand, and organised well in advance, to ensure that these kids are safe and well cared for, and don't become an unreasonable strain on camp resources
- ◊ that parents clearly define the disabilities their child has, to enable the camp committee to make an informed decision about whether or not to accept the child.

The National Kidney Kids Camp is one of the projects the Australian Kidney Foundation provides for people with renal disease, and as such, the AKF supports the continuation of the camp.

It is, however, a project that requires a significant contribution, both financially and in terms of staff time. Around $40 000, excluding staff time, was required from the AKF to run the 1999 camp. It is one of several projects that need funding annually, and it is important that we look at ways of sharing resources equitably.

I hope that these comments are useful. Please feel to contact me to discuss any of this, on 08 8267 4555.

Yours faithfully

Michelle Diener
National Education Manager


ANZPNA

JOURNAL OF AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

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MINUTES OF THE EXECUTIVE MEETING HELD ON 9TH APRIL 1999 BY TELECONFERENCE

Members present: Colin Jones, Lilian Johnstone, Paul Henning (Executive), John Burke and Fred Jureidini (both co-opted).

Item 1: Chairman's report

1.1 Annual General Meeting – Wollongong, Sunday 25th July 1999

Members have already received written notification concerning this meeting, and Elizabeth Hodson has agreed to put together the Scientific Program for Monday, 26th July. It is planned that following the Annual General Meeting, Fred Jureidini will present as a trial run his proposal of the IPNA Bid which he will be presenting to the IPNA Council in Prague in August. The other major item of business will be the election of the new Executive. Items for general business are requested to be put in writing and sent to the Secretary as soon as possible. Individual members are to arrange their own transport to Sydney, and Baxter has agreed to provide travel from Sydney to Wollongong probably by bus. There will be no capacity for members to be transported individually and therefore we would ask that Members coincide their arrival time in Sydney. Members are reminded that once their flight details are arranged to please notify Vicki Burns on (03) 9345 5054 so that transfer from Sydney to Wollongong can be organised.

1.2 Benchmarking

Letters have been distributed concerning Benchmarking with responses received from Elizabeth Hodson and Harley Powell. We apologise for the number of typographical errors. David Lyons and Margot McIver have indicated that they cannot take part in benchmarking given the nature of their practices. A number of amendments were suggested to the forms and these will be incorporated and new suggested forms distributed. Discussion was held concerning the value of the Child Health Questionnaire with respect to what it measures and how it would benefit the practices and understanding of Paediatric Nephrologists. The Executive felt that the questionnaires concerning procedures were more pertinent in terms of practice and that administration of the Child Health Questionnaire in this setting was unlikely to be helpful. Therefore, it was decided that the Child Health Questionnaire should be administered to transplant participants pre and post transplant as previously decided but would not be administered to those children undergoing renal biopsy or creation of dialysis access. It was felt that it was important that the Child Health Questionnaire be administered to the dialysis population to access their general health on dialysis but the timing needs to be determined and a decision was not made today. Paul Henning indicated that South Australia is happy to take part.

1.3 Growth Hormone

Paul Henning noted that AZA are considering a submission to the TGA and have spoken with Charlie Crompton. They are trying to establish basic data concerning the incidence and prevalence of renal failure, the incidence and

prevalence of children with renal impairment and the number of children receiving growth hormone because of growth impairment due to renal impairment. Paul was aware that his centre acts as a single centre for South Australia and Northern Territory and therefore may have some data that can be extrapolated for Australia and he will contact AZA. Colin reported that he had been contacted by Melissa Dunn, a representative of PAREXEL International who are a clinical research organisation who organise research trials on behalf of a company. He requested written information from her concerning the nature of any trial so that this could be submitted to the Annual General Meeting in July.

1.4 Registration of Association

The Regulations and Articles of Association were submitted to the Australian Securities & Investments Commission and were returned due to a number of amendments to the Corporation Law since Paul Roy prepared these documents for us. The documents have been modified to comply with the current requirements of the Corporations Law and have been re-submitted.

1.5 Logo for the ANPNA

It was felt that the ANZPNA should have a logo for two reasons. Firstly in presentations and submissions to IPNA and other Paediatric Nephrology Associations it would be helpful to have an identifiable logo, and secondly the Association is now required under the Corporations Act once registered to have its own letterhead on all its documents which incorporates the A.C.N. Colin Jones has asked the Educational Resources Centre at the Royal Children's Hospital to create a logo and they have said that this will cost approximately $500 - $600. Paul Henning is to check with the in-house design team at the Adelaide Women's and Children's Hospital to see if this seems a reasonable price or not. If reasonable the Executive has determined to go ahead with the creation of a logo.

1.6 IPNA Bid 2004 (See Appendix 1)

John Burke presented the ANZPNA Adelaide bid for IPNA 2004 to IPNA Council in mid-March in New York. He spoke for half an hour and provided the Council members with professionally prepared details and attractively packaged information prepared by Adelaide Convention and Tourism Authority Limited (ACTA). The data prepared included an invitation to Ira Griefer and IPNA Council to host IPNA 2004 in Adelaide from John Olsen, a similar letter from the Mayor of Adelaide, detailed financial analysis of the numbers of delegates and costs of staging the congress, and details of travel and accommodation costs for members attending from different parts of the World with comparisons to costs achieved in similar conferences.

No other preliminary bid was put to Council. The Freiburg Germany and Manila Philippines bids did not materialize and it appears our only rival is Hungary.

Council has asked for a final bid to be presented to the Prague meeting of Council in September (accompanying the 33rd Annual Meeting of the

European Society for Paediatric Nephrology). Further information has been sought from Ira Greifer as to whether there is a specific bid document but it does not appear that this is the case. Ira indicated that he plan to read the submission and would compare it to the outcome of the London bid. Martin Brandis spoke to John Burke following the Council meeting and suggested that a letter of support from the adult nephrology community would be helpful. It is expected that other societies will present at this final opportunity. Ken Jureidini will present the financial and administrative aspects of the bid and Colin Jones will present an overview of the Scientific programme.

Ken Jureidini has began soliciting pharmaceutical support. (See Appendix 1).

Professors John Bertram (Anatomy at Monash University) and Daine Alcorn (Anatomy and Cell Biology, University of Melbourne) have been approached and are assessing the possibility of hosting the Renal Development Workshop in Australia at a time linked to the IPNA Congress (as is the usual pattern).

The organisation of the bid to this stage has been by Ken Jureidini with liaison with ACTA and subsequent liaison to John Burke and myself.

If the bid is successful, an executive chaired by Ken Jureidini will be formed together with a series of support committees including state organising committees, scientific and continuing education committee, satellite symposia, etc. will be formed.

The Executive would be grateful for your thoughts on the Scientific Programme. Obviously, this will only be presented in overview in Prague with emphasis on process rather than content. Colin Jones is on the IPNA 2001 Scientific Programme Committee and it is interesting to compare the evolving themes Seattle is developing with the one used successful in London.

London	Seattle
Physiology and Pharmacology Genetics developmental biology and immunology Clinical Nephrology and Urology Renal Failure	Clinical Nephrology Genetic and Molecular basis of Renal Disease Chronic and End Stage Renal Disease Informatics and Outcomes in Paediatric Nephrology

The overall theme of the 2001 Congress is "Nephrology for the Future". John Burke suggested that we look at our role in the Asian Pacific arena and suggested that it may be worthwhile visiting enmasse the Asian Paediatric Nephrology meeting in Singapore in 2000.

It is unclear when a site visit will occur. Ira Greifer has indicated that he may visit with another representative in the next 12 months. John Burke thought it most likely that a site visit would occur following the October/November 2000 Council which is to be held in Singapore. He also felt it likely that a site visit would only occur if the bid was successful.

The ANZSN and AKF have been notified of our bid.

The AKF has agreed to provide secretarial support should the bid be successful and are located in close proximity to the Adelaide Women's and Children's Hospital.

2. **Treasurer's Report**

Paul Henning noted that the current balance is $3,328.00 with $200 to be added to this. There are three members who are to pay their membership.

3. **General Business**

Fred Jureidini noted published reports on the use of intravenous Nicardepine as a means of treating acute severe hypertension. It has been used in children and infants in reputable studies and he feels that it would be worth looking at as a drug to request approval for use. He also felt that the adult community may be interested. Fred will write to Colin with details of the use of Nicardepine including the abstracts or references and this will be included in the next Newsletter for discussion at the Annual General Meeting.

Meeting closed: **3.20 pm.**

Next Meeting: **18th June 1999 at 2.30 pm EST**

Appx. 1.

Women's and Children's Hospital
ADELAIDE

RENAL UNIT
Direct Dial (08) 8204 7303
Facsimile (08) 8204 6048

72 King William Road
North Adelaide
South Australia 5006
Telephone: (08) 8204 7000
Facsimile: (08) 8204 7459
Web: http://www.wch.sa.gov.au

DR PH HENNING, F.R.A.C.P.
DR KF JUREIDINI, F.R.A.C.P.
DR AA MARTIN, Ph.D

31 March 1999

Mr Jamie Stokoe
Managing Director
Gambro Pty Ltd
PO Box 6604
BHBC
BAULKHAM HILLS NSW 2153

Dear Jamie,

As we recently discussed, the Australian and New Zealand Paediatric Nephrology Association is bidding for the August/September 2004 triennial meeting of the International Paediatric Nephrology Association in Adelaide, fully supported by the total membership. I shall be arranging the meeting per se and Colin Jones the scientific program. David McCredie will be the nominal president and it is very much an ANZ meeting rather than SA and there will be a strong emphasis on SE Asia. It appears that our only rival is Hungary. We stand an excellent chance of winning the bid.

Clearly, the major obstacle is to convince the Europeans and Americans that the distance and expense of the flight is worthwhile. We can probably overcome this by the fact that it is to the significant advantage of the South East Asians and Indians, who actually have a large number of members (but rarely attend the meetings in the Northern Hemisphere). They will come in droves and the South Americans say that it is at least as cheap and desirable to come to Australia as to Europe. Another advantage we can sell is the safety for the North Americans. The expense factor can be overcome by the relative cheapness of registration and accommodation we can provide, the excellent facilities and the great pre and post trips in SA and wider Australia and New Zealand.

To ensure that we can keep the prices to a minimum, we shall require serious support. We have set three levels of support with increasing benefits to the donors with the increasing amounts - $10,000, $30,000 and $50,000. It seems to me that it would be very much to SE Asia Gambro's benefit to be a major donor. You can of course negotiate the terms, but I should imagine that the $50,000 donors would have their name on the video, the program and any other means of recognition. From our point of view, it would be preferable to receive $10,000 per year for 5 years, but you could give it any way you wanted. Yours is the first company that we have approached.

There is little doubt that, if it is held in Adelaide, it would attract a really large number of delegates from the nearby regions with the obvious benefits to Gambro.

We are most keen to win the bid and would very much appreciate your serious consideration, since we should like to have significant sponsorship stitched up before the final presentation of the bid in Prague in late August this year.

With kind regards,

Yours sincerely,

KEN JUREIDINI
RENAL PHYSICIAN

Copy to: Dr Colin Jones, Department of Nephrology, Royal Children's Hospital Parkville Victoria 3052

Graham Teague, Hartley Management Group

NOTICE OF ANNUAL GENERAL MEETING

Notice is hereby given that the Annual General Meeting of the Australian and New Zealand Paediatric Nephrology Association will be held on Sunday, 25th July 1999 at 12.30pm at the Novotel North Beach Wollongong.

An agenda will be distributed two weeks prior to the meeting.

Members who wish to raise items of business should submit these in writing to the Secretary at least 28 days prior to the Annual General Meeting.

Lilian Johnstone.

Lilian Johnstone
Honorary Secretary
ANZPNA.

ANZPNA NOMINATION FORM

I, ... wish to nominate

..... for the position of:

☐ Chairman

☐ Secretary

☐ Treasurer

Signed: _____

Date: _____

Seconded by: _____

Signed: _____

Date: _____

I, ... Agree to be nominated for the above position.

Signed: _____

Date: _____

JOURNAL OF AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

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17th February, 1999

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MINUTES ANZPNA – Executive Meeting – Teleconference 12th February, 1999

Present: *Paul Henning, Fred Jureidini, Lil Johnstone, Colin Jones.*

1. IPNA Bid

Colin referred to the faxed received today from Fred concerning the IPNA Bid. A member of the Adelaide Convention and Tourism Authority (ACTA)had managed to talk Ira Greifer by phone when he visited New York. Further to that conversation, Fred has since received information from Ira Greifer concerning the requirements for a bid and an indication that a presentation will need to be made at the Council meeting in March. The majority of the costs associated with the meeting have already been quoted. The costing will be less than $500 USD (probably closer to $350 USD) if 750 delegates attend. The outstanding important facets of the bid still to be organised are the need for major sponsorship and Fred indicated that it was likely that a major events committee in Adelaide may also support the conference. The other urgent need was to establish the Scientific Committee which Colin will attend to. It appears that Ira's expectation is that John Burke will make the general presentation in March however, both Colin and Fred felt that they should be present. It was not clear whether this is an initial presentation or the final presentation and certainly if it is the final presentation a request will be made for that to occur in September given that the lack of notification from Ira Greifer. During the course of the teleconference, John Burke was contacted by phone, and asked to ring Ira Greifer.

2. Treasurer's Report

The current bank balance is $3,320.00. Membership dues have been received from 20 of the 25 members and Paul is planning to follow up those members who have not yet paid by phone. A request was made to Paul for a cheque for $405 to be paid to the Australian Securities Commission for payment associated with submission of the Articles of Association.

3. Benchmarking

Colin Jones (PD and HD access) reported that he has created a simplified medical questionnaire about the placement of catheters and complications in addition to the Child Health Questionnaire that has been validated in Australian conditions. Paul reported that he will be using the Child Health Questionnaire to assess patients pre and post transplantation, and Lil is still awaiting consultation with Debbie Lewis concerning renal biopsy benchmark. It is planned to send a covering letter to all members of the ANZPNA which will include the 4 sets of questionnaires. This will request review by the membership concerning additional questions they wish to ask or questions they wish to remove and will also give information about completion of the questionnaire, analysis and how the data will be returned to the membership.

4. Other Business

4.1 *SAC Nephrology Representative.*

A letter from Debbie Lewis was tabled indicating that she had finished her 6 year term as paediatric representative on the SAC Nephrology. Colin will confirm that this position is still unfilled. [Post meeting – Colin contacted John Kelly, SAC Secretary and Debbie Lewis. Debbie Lewis to continue until the ANZPNA meeting and a new delegate will then be appointed].

4.2 *Growth Hormone.*

Colin had received correspondence from Charlie Crompton concerning the OZ Grow data and final height data. He has received a number of patient questionnaires to complete concerning final height data.

4.3 *Annual Scientific Meeting RACP*

A letter from Jill Sewell was tabled concerning the letter from Louise Bauer. Further action needs to be taken concerning a meeting of the ANZPNA as part of the Royal Australasian College of Physicians Meeting in 2000.

5. Next Meeting

Friday, 9th April 1999 time to be confirmed.

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5th February, 1999

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MINUTES OF MEETING OF EXECUTIVE, ANZPNA, TELECONFERENCE FRIDAY, 6TH NOVEMBER 1998.

Item 1 **Corporate sustaining membership.**

The Executive determined that a Financial Subcommittee would be established under the Chairmanship of Paul Henning. Paul to write to Michael Falk and Ian Hewitt and request that they serve on the sub-committee. A time line was given for the sub-committee to report at the Annual General Meeting in July 1999. The subcommittee will need to determine what guidelines should exist for corporate sustaining membership and also determine how the money is to be used.

Item 2 **Associate Membership for Trainees in Paediatric Nephrology.**

The Executive determined that Associate membership should be offered to trainees in Paediatric Nephrology. Associate members would have no voting rights. It was determined that a nominal $10.00 subscription fee apply. Lil to write to Paul Roy to add to the Articles of Association such that the definition of Associate Membership can be determined from time to time by the Executive.

Item 3 **Co-opting members to the Executive.**

Further to the Annual General Meeting, it was decided to co-opt John Burke to the next meeting of the Executive where the Agenda will focus on the IPNA bid. Lil to contact John Burke to determine a convenient time in December.

Item 4 **Articles of Association.**

A letter has been sent to Paul Roy concerning amendments and queries to the Articles of Association. Further amendment noted today with respect to Associate Members (as above). Lil to contact Paul Roy regarding final amendments to the Articles of Association, and to request that the ANZPNA be incorporated legally by February 1999 if possible so that all is in place prior to the IPNA bid.

Item 5 IPNA

5.1 IPNA Bid

Little to add. Berlin, Hungry and Australia appear to be the bidders. *Paul to speak to Fred* concerning potential visit of Ira Greifer to Adelaide and whether an official invitation needs to be extended. Query whether concrete instructions concerning presentation of the bid will be received from Ira Greifer. Colin noted that he has written to Ira and has since faxed requesting confirmation that the letter had been received concerning the IPNA bid and potential visit to Adelaide.

5.2 IPNA Council

John Burke tabled details concerning the IPNA Council meeting in London, a position statement on the relationship of Paediatric Nephrology and Urology and a resolution concerning female genital mutilation, the IPNA Budget details, the Constitution and by-laws of IPNA, and a Certificate of Incorporation of the International Children's Kidney Foundation Inc. (Appendix 1).

Item 6 **IPNA Meeting, London, September 1998**

This was a successful meeting with 13 Australian delegates. There was a brief meeting of the members of the ANZPNA in London which focused on Growth Hormone and the IPNA bid.

Item 7 **VUR Trial.**

Further to the AGM in July, notice has been received that enrollments will close at the end of 1998 and those enrolled will continued to be followed.

Item 8 **Standards for a Paediatric Nephrology Unit.**

It was proposed at the AGM that standards be developed. Colin suggested that the document that he prepared for the Paediatric End Stage Renal Failure Symposium in July of 1997 be used as a template. This will be distributed with requests for comments and modifications to develop further standards (Page 104 Vol. 1, 1997).

Item 9 **Benchmarking.**

The Executive determined that benchmarking should be investigated and established. Colin will take on insertion and survival of PD Catheters and insertion and survival of haemodialysis catheters or access devices. Lil will look at renal biopsy in terms of complications, and Paul will address transplants in terms of patient satisfaction. The Executive determined that in the first instance the Child Health Questionnaire tabled at the AGM would be used to determine patient satisfaction with respect to transplants. All units will be invited to take part. It was thought that the form should be trailled for a 2 year period starting February 1999. Lil is to investigate how the form is assessed, and is to write to John Knight concerning the performance indicators they currently use and for information concerning the health outcome measurements assessment forms created by Craig Mellis.

It was felt that there were two things to assess in benchmarking. Firstly, patient/family satisfaction and secondly, best practice amongst paediatric renal units.

Item 10 **Aboriginal Health Subcommittee**

Colin Jones has written to John Knight concerning this matter.

Item 11 **ANZPNA Representatives.**

The Executive felt that it was important that other involved bodies be aware of the function of the ANZPNA. To that end, a letter will be sent to the ANZSN and the TSANZ; and with respect to the activities of the college, Colin will prepare a letter and discuss with Jill Sewell the appropriate distribution of it.

Item 12 **Treasurers Report**

Paul reported that 13 members had paid their subscription and 12 were still owing. The current balance is $2,338.00 with $300 to be banked. Reminder notices concerning subscriptions will be sent. It was noted that currently the costs of administering the ANZPNA are absorbed into the Department of Nephrology, RCH Budget, but that these need to be accurately costed so that the membership is aware of these costs.

Item 13 **Growth Hormone**

Colin noted a letter received from the Manager of the Pharmaceutical Benefits Branch, Commonwealth Department of Health and Family Services (Appendix 2) which would suggest that there are very few avenues to follow. It was noted that a patient initiated petition has been developed to present to the Commonwealth Government. Colin has written to the Pharmaceutical Benefits Advisory Committee and Therapeutic Goods Administration requesting more time for consideration of this decision. The Executive noted the e-mail message from Chris Cowell and the document produced by Glynnis Price which has been submitted to the ADEC in support of Sarano. A letter is being prepared to be reviewed by both Jenny Batch (Chair Australia Paediatric Endocrine Group) and Colin Jones to send to Canberra. Colin is also aware of efforts made by John Knight and Elizabeth Hodson in particular to informally discuss the problems with members of the Pharmaceutical Benefit Advisory Committee. The Executive discussed further what action should occur. It would

appear as of January 1st, further growth hormone supplies will not be available to children with chronic renal failure. It was felt that it was reasonable to propose a publicity campaign that can be put to members of the Association. To that end, Paul Henning will prepare a press release and Colin will produce a summary of the processes worked through to date. Lil will speak with the organisers of the petition to determine whether they have a publicity campaign planned. Following preparation of the press release and summary, it will distributed amongst the membership for consideration and amendment, and the Executive would be hopeful that it would be supported by the membership.

(Later) Decision to defer de-listing of rGGH until 1st January, 2000 was communicated on 24th November 1998 (Appendix 2 (c)).

Letter from Parliamentary Secretary with executive responsibility for the TGA dated 21st December 1998.

Item 14 Other Business.

14.1 E-mail noted from Tony Seymour concerning pooling of biopsies particular with those children with FSGS and congenital nephrotic syndrome in the context of the APSU study on nephrotic syndrome (Appendix 3).

14.2 Letter tabled from Louise Bauer (Appendix 4). Colin will respond to this in the affirmative pending ongoing sponsorship from Baxter or other interested companies. Members requested to consider the planning of this meeting regarding content particularly given other paediatric sub-specialists who will be present.

Item 15 Next Meeting.

This will be held in December at a convenient time to John Burke and Paul Henning. The agenda will be limited, focusing on the IPNA bid and growth hormone.

Appx 1.

IPNA COUNCIL MEETING LONDON 11 SEPTEMBER 1998
(MAJOR AGENDA ITEMS)

Financial Report – Financial statement is enclosed

Regional Societies – There is no African society for paediatric nephrology and no representative from Africa on IPNA Council. African society for paediatric nephrology needs to be formed and IPNA would consider financial support for a scientific meeting.

IPNA Constitution – Enclosed is a revised version of the Constitution and by-laws. It is noted now that the Australian and New Zealand representative is included as an Assistant Secretary.

Journal – It was noted that some good paediatric nephrology articles are being published in adult nephrology journals. One article concerning live related transplantation in children was rejected for ethical reasons by Pediatric Nephrology has subsequently been published in an adult nephrology journal. The decision for the majority of articles to accept or reject is now 8 weeks.

IPNA Congress London 1998 – 720 abstracts were submitted and 132 were presented for oral presentation and 400 posters. The abstracts not accepted were checked by two further reviewers. The number of registrants was 945 before the start of the meeting. Assisted registration was given to 64 of 120 who applied. All had accepted abstracts.

IPNA Congress Seattle 2001 – Progress is satisfactory and discussion took place as to whether the meeting should be 4 or 4.5 days.

Resolutions – Position statements
1. International Paediatric Nephrologists Association Relationship of Paediatric Nephrology and Urology
2. Renal Transplantation in Children
3. Support of Abolition of Female Genital Mutilation

were discussed and voted by the IPNA General meeting.

Enclosed are statements which should be forwarded to the appropriate Bodies in each countries. These statements will be published in a subsequent edition of the journal "Pediatric Nephrology".

ESPN – Their annual meeting for 1999 will be held in Prague between September 2-5, 1999.

IPNA Congress 2004 – Council was informed that the Australian and New Zealand Paediatric Association intended to make a formal application. C. Jones, Chairman is required to make a formal written application. Hungary is also making an application for that Congress.

Growth & Development in Children with Chronic Renal Failure Workshops – This meeting will be held in New York March 11-13 1999. Organisers are Rick Kaskel, Burkhard Tonshoff.

International Children's Kidney Foundation Incorporation – A draft document was circulated for further discussion. Enclosed is a copy of that document.

J. BURKE

Appx 1.

INTERNATIONAL PEDIATRIC NEPHROLOGY ASSOCIATION

RELATIONSHIP OF PEDIATRIC NEPHROLOGY AND UROLOGY

A POSITION STATEMENT

1. Sick children have a right to medical care tailored to their needs, every bit as skilled and well-resourced as that available to adults. They should be treated in an environment designed to accommodate modern medical practice in a manner which is non-intimidating to the children and their families, and by staff who are specially trained and equipped for their care.

2. Pediatric Nephrology and Urology are different aspects of the same discipline, much as Pediatric Cardiology/Cardiac Surgery and Neurology/Neurosurgery. The one specialty cannot thrive without a close association with the other.

3. The International Pediatric Nephrology Association views with admiration the growth of Pediatric Urology in many areas of the world, and wishes to explore ways in which the two specialties might collaborate without loss of identity or compromise of relationship with their "adult" colleagues.

4. Therefore, the leadership of IPNA should make every effort to strengthen the specialty of Pediatric Urology around the world in cooperation through the Regional Societies of our Association.

Appx 1.

RESOLUTION

SUPPORT OF ABOLITION OF FEMALE GENITAL MUTILATION

The International Pediatric Nephrology Association is very concerned about the physical and psychological trauma, including death, caused by female mutilation (female circumcision).

It opposes all such rituals and urges its member societies to join with other organizations who oppose such acitivities to seek its abolition in their own countries.

Appx 1.

KLINIKUM DER
ALBERT-LUDWIGS-
UNIVERSITÄT FREIBURG

International Pediatric Nephrology Association

International Pediatric Nephrology Association
I P N A • Mathildenstraße 1 • D-79106 Freiburg

Treasurer:
Prof. Dr. M. Brandis
Tel. 0761/270-4306 - Telefax 0761/270-4481
8th September 1998

IPNA BUDGET FOR 1999

Income		**Expenses**	
Membership Dues	$ 197.000,--	Ped. Neph. Journal	$ 150.000,--
Royalties	$ 30.000,--	Editorial Support	$ 70.000,--
Journal Income	$ 110.000,--	Council Meeting	$ 35.000,--
Corporate and Foundation Support	$ 150.000,--	Regional Meetings	$ 20.000,--
		Workshops	$ 110.000,--
		Continuing Medical Education	$ 25.000,--
		Mailing, Billing and Audit	$ 7.000,--
		1/2 Time Administrative Assistant	$ 16.000,--
Total	***$ 487.000,--***	***Total***	***$ 433.000,--***

Projected income over expenses **$ 54.000,--**

International Pediatric Nephrology Association
Financial Statement
(August 31, 1998)

1	Funds available		
	New York Bank	$110,000	
	Freiburg Bank	$ 69,495	
			Total: $179,495
11	Funds available		
	Royalites	$34,000	
	Corporate Support	$40,000	
		$74,000	
			Total Funds Available: $253,495
lll	Expenses		
	Journals	$15,000	
	Mailing	$ 4,000	
	Editorial Office	$50,000	
		$204,000	- $204,000
			Projected Income Over Expenses $49,495

Appx 1.

CONSTITUTION AND BY-LAWS

INTERNATIONAL PEDIATRIC NEPHROLOGY ASSOCIATION

1013-1

CONSTITUTION

1. **Name**

The Association shall be named the **International Pediatric Nephrology Association (IPNA).**

2. **Purposes**

The Association shall promote knowledge and communication among those interested in pediatric kidney disease, to improve care and treatment of diseases of the kidney and urinary tract in children throughout the world. To accomplish these objectives, the Association will pursue the following activities:

a. Publication of a scientific Journal **"Pediatric Nephrology"**, which will serve scientific and educational goals.

b. Conduct an international Congress every three years at which time all members from the basic sciences, clinical sciences, and clinical care disciplines, will meet to disseminate knowledge of pediatric nephrology.

c. Support activities and development of regional medical meetings, and training facilities, so as to disseminate information on pediatric nephrology to all areas of the world.

d. Support and conduct basic science workshops and satellite symposia, which stimulate interest in, and disseminate information, on new and innovative research; and provide a forum to stimulate young physicians in pediatric nephrologic research.

e. To develop and support educational programs in pediatric nephrology for physicians actively involved in the care of children through regional and national pediatric associations.

3. Affiliation

Continental and/or Regional or National Societies will be encouraged to affiliate with IPNA and to cooperate in its work. The Association shall not replace nor compete with Continental or National Societies of Pediatric Nephrology, but shall cooperate, support and compliment them in all activities.

4. <u>Membership</u>

A. Member

1. A member may reside anywhere in the world.
2. A member must have an active interest in pediatric nephrology and be medically qualified.
3. Members of Regional and/or National Pediatric Nephrology Societies will be eligible for membership in IPNA.
4. All individuals seeking membership will apply directly to IPNA.
5. A register of members will be kept by the Secretary-General and published from time to time.
6. Members will pay annual dues, the amount of which will be decided from time to time by the Council, and which

will include a subscription to **"Pediatric Nephrology."** Failure to be current in payment of dues will lead to loss of membership.

B. Honorary Membership - Honorary Membership may be bestowed on individuals who have retired, and have made outstanding contributions to pediatric nephrology. An Honorary Member shall pay no dues and will not be eligible to vote. Potential Honorary Members may be proposed to the Council, which will make the final decision as to on whom this honor will be awarded.

C. Associate Membership - can be obtained by any individual qualified as a medical doctor who contributes to or participates in the care of children with kidney and urologic diseases, or specializes in the care of individuals with kidney and urologic diseases.
Associate Members will pay annual dues, the amount of which will be decided from time to time by the Council, and will include a subscription to **"Pediatric Nephrology."** An Associate Member will not be eligible to vote.

5. The Council

The Council will be responsible for managing and controlling the property and affairs of the Association, and assisting with arrangements for the International Congress of Pediatric

Nephrology, including selection of the venue and the Congress President.

The Council membership will consist of:

a. i. Secretary General

ii. Treasurer

iii. Assistant Secretaries, one from each of the affiliated Regional or National Pediatric Societies.

iv. The Secretary-General-<u>elect</u> for three years prior to the commencement of his term.

v. The outgoing Secretary General for three years following his term of office as Secretary General.

b. Twenty Councillors at large, who will be elected by the General Membership attending the Congress, and will consist of:

i. Six Councillors from North America, (including one from Canada);

ii. Seven Councillors from Europe, (including one from Central Europe and one from Eastern Europe);

iii. One Councillor from Japan;

iv. Three Councillors from Latin America; and

v. Three Councillors from the Asian Pacific Region, including one from China and one from India.

c. The Congress President of the forthcoming International IPNA Congress.

d. <u>Ex-Officio Members</u>

i. The Editor and Co-Editor of the Journal **"Pediatric Nephrology".**

ii. Chairpersons of workshops and symposia.

iii. Chairpersons of standing and special committees.

6. Nominating Committee

Membership of the Nominating Committee will include the Assistant Secretaries, and 1 Councillor at large. The Chairman shall be appointed by the Secretary General with the consent of the Council.

The Committee will present a slate of new Councillors to the Council which will then, upon approval, present the slate for confirmation by the membership attending the General Assembly at the International Congress.

a. Term of Office

i. Councillors at large will serve 6 year terms and cannot be reelected.

ii. Assistant Secretaries term of office shall be commensurate with their term as General Secretaries of their respective Regional or National Societies.

7. The Secretariat

The Secretary General will conduct the day to day affairs of the Association, and on the Chief Executive Officer of the Association. He will arrange to have minutes kept of meetings. He will be responsible for the organization of the work of the Council and for compiling a register of members. He will serve a term of six years, and may not be reelected for additional terms, but will serve on the Council as Past Secretary General

for three years.

The Secretary General-elect will be proposed to the General Assembly by the Council, which will act as the Nominating Committee, and will be elected by the General Assembly three years prior to the commencement of his term of office, and will serve on the Council immediately upon his election.

The Assistant Secretaries will assist the Secretary in the geographical areas from whence they come and in other more general respects and keep the Secretary General informed on local happenings. Assistant Secretaries will be nominated by Council on the advice of the Regional or National Societies and approved by the members.

8. Treasurer

The Treasurer will be nominated by the Nominating Committee, approved by the Council and elected by the membership. He will be responsible for funds of the Association in cooperation with the Secretary General. he will serve for a period of six years and may be reelected for additional terms. His election shall be at a three year interval from that of the Secretary General.

9. Meetings

The General Membership of the Association will meet every three years during the International Congress of Pediatric Nephrology. The Council will meet at least on a yearly basis. The time and venue of meetings will be decided by the Secretary General in consultation with the Council membership.

10. Language

The language of the Council, including any correspondence, will be English. At the International Congress symposia and workshops, other languages can be used as decided by the Congress President, Chairmen of Workshops, symposia and the Council.

11. Voting

Voting shall be a simple majority of members or Councillors either at a general meeting or on postal ballot, except when alteration to the Constitution is concerned a two-thirds majority is required.

12. Publications

The International Pediatric Nephrology Association owns and operates the Journal **"Pediatric Nephrology"**. The contract for the publication of the Journal will be negotiated by the Secretary General, and Treasurer, and approved by the Council.

13. Committees

There shall be the following standing Committees; the members of whom shall be appointed by the Secretary General and approved by the Council:

a. Committees

i. Nominating Committee

ii. Special workshops and symposia

iii. Publications Committee

iv. National and International Disaster Committee

v. Continuing Medical Education Committee

The Council or the Secretary General may, from time to time, authorize and appoint any other Committees as in their discretion they deem necessary or appropriate to assist the Association's programs or activities.

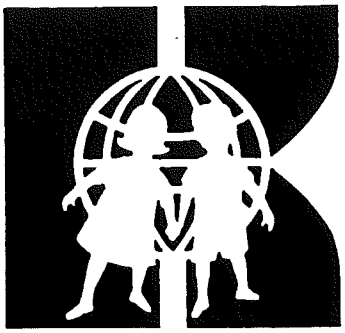
14. Scientific Meetings

IPNA shall run an International Congress every three years. The venue and Organizing Committee will be the decision of the Council.

There shall be International Workshops and symposia carried out on a regular basis by the Association on topics in Pediatric Nephrology that are consistent with the goal of the Association and meet the scientific educational needs of the International Membership.

15. Alterations to the Constitution

Alterations to the Constitution and By-Laws shall be proposed by ten or more members who live in two or more Continental regions, or by the Council. A two-thirds majority of those voting either in the General Assembly or by postal ballot, is required.



Certificate of Incorporation

of

International Childrens Kidney Foundation Inc.

Statement of purposes

1. To fund the development of resources necessary to improve the health and care of children with kidney and urological diseases.

2. To fund training programmes for physicians and other health professionals in the diagnosis and treatment of kidney disease in children.

3. To fund and support professional education for physicians , nurses and other health professionals dealing with children with kidney and urological diseases.

4. To sponsor and/or fund meetings, lectures and symposia as deemed appropriate to provide opportunities to health care professionals for continuing their education, advancing their knowledge and learning of new methods in the diagnosis and treatment of children with kidney and urological diseases.

5. To develop and provide information on the causes and effects of kidney and urological diseases on children through associated international regional and national societies of paediatric nephrologists.

6. To support and fund centres for training the health professionals in paediatric nephrology to enhance the care of children throughout the world.

7. To fund and support the compilation and dissemination of information on resources available for physicians and health professionals in their training programmes.

8. To fund special needs of children with kidney and urological problems who may need urgent help in underdeveloped and developed countries of the world.

9. To support through international and regional societies the coordination of research and education among all professionals working in the field of paediatric nephrology.

10. To use its funds to support international, regional and national programmes whose goal is to improve the diagnosis, treatment and general well being of children with kidney and urological diseases.

11. To fund and support the initiation of collaborative research programmes which brings new knowledge in the treatment of, and the diagnosis of kidney and urological diseases in children.

Issues to be discussed

1. Governing body
   - (a) Officers
     - President
     - Chairman
     - Secretary
     - Treasurer
     - Vice-President
   - (b) Directors
     - How many directors?
     - Medical
     - Public
     - International distribution
   - (c) Relationship to IPNA Regional Structure

2 Special Committees
- Medical Advisory Board
- Scientific Advisory Board
- Finance
- Fundraising
- Marketing

3 Development of goals and the approval of programmes
- (a) Governing body
- (b) Advisory Boards

CERTIFICATE OF INCORPORATION

OF

CHILDREN'S INTERNATIONAL KIDNEY FUND, INC.

(Under Section 402 of the Not-for-Profit Corporation Law)

The undersigned, being a natural person over the age of eighteen years, desiring to form a corporation pursuant to the provisions of the Not-for-Profit Corporation Law, does hereby certify as follows:

1. The name of the corporation is: INTERNATIONAL CHILDREN'S KIDNEY FUND, INC.

2. The corporation is a corporation as defined in subparagraph(a)(5) of Section 102 of the Not-for-Profit Corporation Law, and shall be a Type B corporation under Section 201 of the Not-for-Profit Corporation Law.

3. The purposes for which the corporation is formed are to conduct the following activities, which are exclusively charitable within the meaning of Section 501(c)(3) of the Internal Revenue Code of 1986, as the same may be amended for time to time (the "Code"):

(a) To receive and administer funds exclusively for charitable purposes within the meaning of the Code and, to that end, to hold any property, or any undivided interest in property, without limitation as to amount or value.

(b) To promote professional education and training in the diagnosis and treatment of children with kidney disease in developing and developed nations throughout the world, and, without limiting the generality of the foregoing, in the absolute discretion of the Board of Directors, to make donations, gifts, contributions and loans without interest out of its annual net income or assets, or both (without limit as to the amount going to any one recipient, or, in the aggregate, to all recipients), to or for the use of any and all individuals, corporations, organizations, foundations, institutions or individuals.

(c) To purchase, receive, take by grant, gift, devise, bequest or otherwise acquire, own, hold, manage, improve, employ, use and otherwise deal in and with, real or personal property, wherever situated, from any source, and without limit as to the amount, including without limiting the generality of the foregoing, lands and buildings, and to hold, invest, reinvest, use, mortgage, pledge, sell, lease, assign, give, exchange, transfer or otherwise dispose of the same.

(d) To invest, reinvest, or deal with the principal or the income form any such disposed property in such manner as, in the judgment of the directors, will best promote the purposes of the corporation without limitation, except such limitations, if any, as may be contained in the instrument under which such

property is received, this Certificate of Incorporation, the By-laws of the corporation, or any applicable laws.

(e) To do any other act or thing incidental to or connected with all of the foregoing purposes or in advancement thereof as shall from time be found appropriate, but not for the pecuniary profit or financial gain of the corporation's directors or officers, except as permitted under Article 5 of the Not-for-Profit Corporation Law.

4. In furtherance of the foregoing purposes, the corporation shall have all of the general powers enumerated in Section 202 of the Not-for-Profit Corporation Law. The corporation shall have the right to exercise such other powers as now are, or hereafter may be, conferred by law upon a corporation organized for the purposes hereinabove set forth or necessary or incidental to the powers so conferred, or conducive to the furtherance thereof, subject to the limitations as may be prescribed by law, by this Certificate of Incorporation or the By-laws of this corporation; provided, however, that:

(a) nothing herein contained shall authorize this corporation, directly or indirectly, to engage in or include among its purposes any of the activities specified in paragraphs (b) through (u) of Section 404 of the Not-for-Profit Corporation Law; and

(b) nothing herein contained shall authorize the corporation, directly or indirectly, to engage in any activity not permitted to be engaged in by a corporation exempt from federal income taxation under Section 501(c)(3) of the Code.

5. The principal office of the corporation within the State of New York is to be located in the County of Bronx, City of New York.

6. The affairs of the corporation shall be managed by the Board of Directors, whose number, qualifications and manner of election shall be as stated in the By-laws. The name and address of the person constituting the initial Board of Directors of the Corporation is:

NAME	ADDRESS
Ira Greifer, M.D.	1825 Eastchester Road Bronx, NY 10461
_____	_____
	_____
_____	_____
	_____

7. The corporation hereby designates the Secretary of State as its agent upon whom all process in any action or proceedings against it may be served within the State of New York.

8. The address to which the Secretary of State shall mail a copy of process in any action or proceedings against the corporation which may be served upon him or her is:

NAME	ADDRESS
Ira Greifer, M.D.	1825 Eastchester Road Bronx, NY 10461

9. It is the intention of this corporation at all times to qualify and remain qualify and remain qualified as an organization described in Section 501(c)(3) of the Code. Accordingly:

(a) The corporation shall not be conducted or operated for profit, and no part of its net earnings shall inure to the benefit of, or be distributable to, any private individual (except that reasonable compensation may be paid for services rendered to or for the corporation pursuant to one or more of its purposes, as permitted under Article 5 of the Not-for-Profit Corporation Law); nor shall any net earnings, property or assets of the corporation be used other than for the purposes of the corporation.

(b) Except as may otherwise be permitted by the Code or the laws of the State of New York, no substantial part of the activities of the corporation shall consist of carrying on propaganda, or otherwise attempting to influence legislation; nor shall the corporation participate in, or intervene in (by the publishing or distribution of statements or otherwise) any

political campaign on behalf of (or in opposition to) any candidate for public office.

(c) Upon the dissolution, liquidation, termination or winding up of the corporation (whether voluntary or involuntary of by operation of law), and after the payment of all debts and liabilities, the Board of Directors shall dispose of all the property or assets of the corporation in furtherance of the purposes of the corporation in such manner, or to such organization or organizations qualified under Section 501(c)(3) of said Code, as the Board of Directors shall determine. Any such assets or property not so distributed shall be disposed of in accordance with the direction of a Court of competition jurisdiction in such manner as will best accomplish the purposes for which the corporation was organized. None of the property or assets of the corporation shall be made available in any way to any trustee, director or office of the corporation or to any private individual.

IN WITNESS WHEREOF, the undersigned has made and signed this Certificate as of the day of , 1998 and affirms the statements contained herein as true under penalties of perjury.

IRA GREIFER, M.D.

Appx 2(a)

THE TREASURY

Liaison Unit
The Treasury
Parkes Place
CANBERRA ACT 2600

22 OCT 1998

Dr C. Jones
Director - Department of Nephrology
Royal Children's Hospital
Flemington Road
PARKVILLE VIC 3052

Dear Dr Jones

Thank you for your facsimile of 4 September 1998 to the Treasurer concerning the Australian Drug Evaluation Committee.

As the matter falls more directly within the portfolio responsibilities of the Minister for Health and Aged Care, your correspondence has been referred to the Hon Dr Michael Wooldridge, MP for his attention.

Yours sincerely

R. Bandte

Rolf Bandte
Acting Manager, Liaison

Appx 2(a)

COMMONWEALTH OF AUSTRALIA
Health Benefits Division
floor 3 Alexander
Furzer Street Woden, Canberra ACT 2606
Telephone: (02) 6289-7085 Fax: (02) 6289-8846

Commonwealth Department of
Health and Family Services

Dr C Jones
Director
Department of Nephrology
Royal Children's Hospital
Flemington Road
PARKVILLE VIC 3052

Dear Dr Jones

Thank you for your letter of 4 September 1998 to the Minister for Health and Family Services, the Hon Dr Michael Wooldridge, concerning the availability of human growth hormone as a pharmaceutical benefits for the treatment of children with chronic renal failure. Due to the establishment of a Caretaker Government, I am responding on the Minister's behalf.

For some years, the Pharmaceutical Benefits Advisory (PBAC) has sanctioned the use of hGH as a pharmaceutical benefit for several indications outside marketing approval. This was contrary to the usual PBAC guidelines. Advice was accepted from specialist paediatric endocrinologists in the expectation that the lack of data would be overcome by accessing the patient data collected through the OZGROW database and other sources. The intervening period should have allowed sufficient time for data to be collected on the efficacy of human growth hormone treatment of children with chronic renal failure.

When the Australian Drug Evaluation Committee (ADEC) assessed the data presented by one of the sponsors in support of hGH treatment for chronic renal failure, they found that there was insufficient evidence of efficacy. This is different from a situation where there is lack of data, and the PBAC had no alternative but to remove the long- standing sanction for the use of hGH for this purpose.

If, as you say, there is plenty of data available to support the use of hGH for chronic renal failure, both in Australia and overseas, then perhaps the Australian and New Zealand Paediatric Nephrology Association, of which you are Chairman, could assist sponsors by providing this data to support future applications to ADEC.

The Government is not unsympathetic to the optimum treatment of children with chronic renal failure, and realises that these children have many health problems. However, it is not possible for the Government to finance drugs through the Pharmaceutical Benefits Scheme that have been assessed as not efficacious.

Yours sincerely

Alan Stevens
A/g Manager
Pharmaceutical Benefits Branch
13 October 1998

Appx 2 (d)

October 30, 1998

Professor Don Burkett
Chairman, Pharmaceutical Benefits Advisory Committee
Pharmaceutical Benefits Scheme Branch
GPO Box 9848
Canberra, ACT 2601

Dear Professor Burkett

The Australasian Paediatric Endocrine Group (APEG) and the Australian and New Zealand Paediatric Nephrology Association (ANZPNA) have been informed by the Pharmaceutical Benefits Advisory Commission that, following advice from the Australian Drug Evaluation Committee, Chronic Renal Insufficiency/Renal Failure have been deleted as indications for the use of somatropin (recombinant human growth hormone). This decision will take effect from January 1, 1999. On behalf of the members of APEG and ANZPNA, we wish to request that the Pharmaceutical Benefits Advisory Committee consider the attached submission on the use, efficacy and side effects of the use of somatropin in children with renal failure and short stature.

We strongly believe that the published data demonstrates;

- the short and long term (five years) efficacy of somatropin in children with chronic renal failure, children on dialysis and in children with renal transplants.
- that final adult height is significantly improved in young people with renal transplants, who received somatropin, compared with a matched control group in a study from Holland (see attached abstract). It should be recognised that children with chronic renal failure progress to dialysis and renal transplantation in the first or second decade of life so that final adult height data will only be available in transplanted children.
- that somatropin therapy is well tolerated in children with chronic renal failure with a low frequency of adverse events similar to children receiving GH for other indications.

There are currently approximately 60 children with chronic renal failure receiving somatropin and responding well to it – we could not justify cessation of this therapy which is providing them an opportunity to achieve catch-up growth. Furthermore, somatropin is licensed for the indication of chronic renal failure in the United States, New Zealand and many European countries.

We would like to request that the decision to delete chronic renal insufficiency/renal failure from the indications for use of somatropin be delayed for at least two years to allow APEG and ANZPNA to analyse the Australian data held in Ozgrow on the efficacy of somatropin in these children and to allow additional pharmaceutical companies who market somatropin to provide submissions to the Australian Drug Evaluation Committee. We would also like to request that those children who are already receiving and responding to somatropin be allowed to remain on it.

With best wishes
Yours sincerely

Dr Colin Jones
Chairman
ANZ Paediatric Nephrology Association

Professor Jennifer Batch
President
Australasian Paediatric Endocrine Group

c.c. Professor Martin Tattersall, Chairman, Australian Drug Evaluation Committee
Ms Enid Rushworth, Pharmacist- in-Charge, Growth Hormone Programme
Dr Geoffrey Byrne, Chairman, Growth Hormone Advisory Committee

USE OF HUMAN GH IN GROWTH FAILURE ASSOCIATED WITH CHRONIC RENAL FAILURE

Background

Growth retardation, often severe, is a serious complication of chronic renal failure (CRF) in children. This has become increasingly important as chronic dialysis and renal transplantation have enabled survival to adulthood. According to the European Dialysis and Transplant Association registry, 62% of males and 41% of females who started renal replacement therapy before the age of 15 years, have a final adult height below 2 standard deviations (SD) of the normal mean (Rizzoni 1985). The time of onset of CRF influences the extent of growth impairment with congenital renal disease having the most profound effect.

Impairment of growth may begin when the glomerular filtration rate, a measure of renal function, falls below 50% of expected for age but becomes common at a glomerular filtration rate of less than 25%. The pathogenesis of growth failure in CRF is multifactorial. Unfortunately, correction of possible contributing factors such as anorexia and malnutrition, acidosis, renal osteodystrophy, salt-wasting and anaemia does not uniformly correct growth. In addition, growth after renal transplantation may be seriously impaired by the high doses of glucocorticoids needed for immunosuppression as well as gradual graft dysfunction.

Growth Hormone/Insulin-like Growth Factor axis

The pathogenesis of uraemic growth failure has become clearer with a more detailed understanding of the GH/insulin-like growth factor axis. GH is the main regulatory hormone of the body's growth. Much of this effect is mediated through liver-derived, circulating as well as locally-produced peptide, insulin-like growth factor (IGF-I). Circulating IGF-I is bound by carriers called binding proteins and only the tiny free fraction is active.

There is peripheral resistance to the actions of GH in children with CRF, as evidenced by growth failure in the presence of normal or elevated levels of GH (reviewed in Tönshoff 1995). The mechanisms underlying this are complex and include a decrease in GH receptors in target organs, increased IGF binding capacity with subsequent decreased bio-availability of IGF-I and possibly a decrease in IGF-I production.

In the 1980's it was shown in animal experiments that using supraphysiological doses of GH to overcome the relative GH insensitivity in uremia resulted in improved growth (Mehls and Ritz 1983). This was later confirmed in the first of the clinical trials using recombinant GH in children with CRF (Koch 1989). It has subsequently been shown that levels of free IGF-I rise in the serum during GH treatment, and this increase correlates positively and significantly with the change in height (Powell 1997).

Aims and evaluation of GH therapy

Growth has been shown to be of significant concern to more than 90% of children with CRF (Reynolds 1995). GH therapy aims to enable the short child to attain a height more in keeping with his/her peer group, thereby decreasing social disadvantage and improving

quality of life. Ultimately, the goal is attainment of a child's genetic height potential or an achievement of a normal population-related final height, i.e. a height > the 3rd percentile. To date there is only one study on final adult height of patients with renal failure treated with GH therapy. This indicates that final height is significantly greater in young people with renal transplants and treated with GH compared to untreated transplant patients.

In addition to final adult height, efficacy of GH treatment can be evaluated by demonstrating acceleration of growth rate, maintained over time, in order to "catch-up" lost growth. Calculation of the Standard Deviation Score (SDS) with standard references collected from an appropriate population base, allows comparison of absolute measurements such as height and height velocity within small groups independent of age or sex.

The effectiveness of GH treatment on catch-up growth can be assessed by growth data:

a) Height velocity in cm/year
b) Height velocity as a change in standard deviation with reference to the mean value for chronological or bone age (SDS_{CA} or SDS_{BA})
c) Change in standardized height (Height SDS).

Clinical trials with recombinant human GH.

Clinical studies have examined the effects of GH on growth in children with CRF for varying durations of therapy, pubertal stage as well as in different categories of renal management. These are conservative management in preterminal CRF, dialysis in end stage renal failure (ESRF) and post renal transplantation. A dose of 28-30IU/m^2/week or equivalent of GH was used in almost all of the studies (see Dose, page 4). This was given in seven equal daily doses because this dosing frequency has been shown to be beneficial to patients with idiopathic GH deficiency (Guyda 1987). Patients in these studies were maintained on fairly standard renal failure treatment protocols that included vitamin D analogues, phosphate binders and calcium supplements. . Inclusion growth entrance criteria varied between studies. In some (7 and 8) only height SDS < -2 was required, whilst others required either a height and/or a velocity restriction. The limit to glomerular filtration rate limit varied between 20 and 75 ml/min/1.73m^2. All studies excluded patients who had another cause for growth failure, clinical or radiological evidence of renal osteodystrophy, other endocrine abnormalities or those who had been on any growth promoting medication.

Studies in children with chronic renal failure

Clinical studies, detailed in Table 1, with results in Table 2, report a significant positive effect of GH on the growth of children with CRF. Two of these studies are randomized placebo-controlled trials whilst the others are open labelled prospective trials, confirming and extending the information with regard to increasing duration of GH treatment, special categories of patients and Australian data. Three are large multicenter studies which cover Germany (3), the rest of Europe and the UK (4), Europe and Australia (5). The latter, although containing patient information to some extent from (3) and (4), was

included because of the Australian data. It is impossible to breakdown the overlapping information further.

The results reflect an obvious increase in growth rate with GH treatment as assessed by height velocity (cm/year) and height velocity SDS for chronological age. The patients also experienced catch-up growth as reflected by an improvement of their mean height SDS. Improvement in growth was particularly marked in the first year of treatment with height velocity approximately doubling from 4 cm/year to 9 - 10cm/yr. The reduced growth stimulating effect during the second and subsequent years was similar to that which has been noted in patients treated for idiopathic GH deficiency (Rosenfeld, 1990). However, data from studies (7 and 8) showed that improvement in growth continued over 3 years (7) and 5 years (8 – see figure l). Both the placebo-controlled studies (1 and 2) showed an improvement in growth on placebo but the increase on GH therapy was significantly greater than the placebo effect.

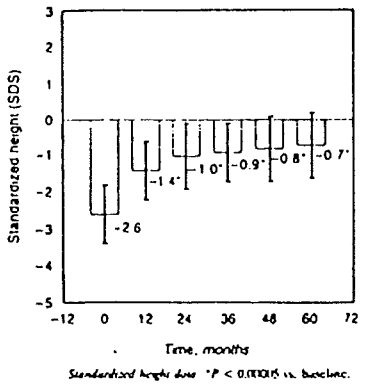


Fig.1.

The increased growth rate during GH treatment was not accompanied by undue advancement of bone age. This suggests that final height will not be compromised by the use of GH and that the potential exists of an improved final height outcome.

The German study group (5) has recently published more extensive 2-5 year follow-up dataa in children with preterminal CRF (17, see Table 6). All were prepubertal, mean age range 5.8-7.8 years and extremely short at onset of GH, mean height SDS range –3.4 to –3.7. The increase in height SDS after 2, 3, 4 and 5 years of GH therapy was 1.3, 1.6, 2.0 and 1.5 respectively, all attaining a mean height close to the third centile. There was no acceleration of bone age in these groups so the change in predicted adult height was significant, 4.9, 7.7, 11.4 and 10.3 cm after 2 to 5 years of GH therapy respectively.

There was no correlation in any of the studies between responses to provocative stimulation tests of GH secretion or 24 hour GH profile and growth rates achieved during treatment. Children with CRF therefore respond to GH irrespective of their GH status. The type of primary renal disease, although included in some of the studies, was not found to be a statistically important indicator of response to GH. The factors found to be most predictive of their response include younger age at onset of GH and their GFR (17).

GH Treatment in Children on Dialysis

Children in end stage renal disease (ESRD), either on peritoneal dialysis or on haemodialysis, have also been found to respond to GH treatment although this response is both less pronounced (3) and less persistent (5) than in patients in preterminal CRF. The former found an increase in height velocity of 4.2 cm/year to 7.3 cm/year with an increase in height velocity SDS of –2.6 to 1.4 ($p<0.01$) after 1 year's GH treatment. This compares to an increase from 4.3 cm/year to 10.0 cm/yr and height velocity SDS of –2.6 to 4.4 ($p<0.001$) in children with preterminal CRF. During the 2nd year of therapy the European/Australian Study Group (5) showed a decrease in the growth rate to a value approximating the pretreatment level.

The German study group (17) has published data in 1998 on 13 and 6 subjects treated for 2 and 3 years respectively showing an increase in height SDS of approximately 0.8 SDS, a response less than found in those with preterminal CRF (Table 6).

GH in Children with Renal Transplants.

The North American Pediatric Renal Transplant Cooperative Study (NAPRTCS) report for 1996 shows a mean height SDS of –2.08 at the time of transplantation and of –2.27 at 5 years after transplantation. Good growth post-transplant seems to be confined mainly to young patients with near-normal graft function and a low-dose, preferably alternate-day glucocorticoid regimen.

Clinical studies on the use of GH (at a dose of 28-30 IU/m^2/week) in renal transplant recipients with growth failure are detailed in Table 3. The results demonstrate a marked improvement in growth within the first year of GH therapy as illustrated in Study 12 with a doubling of linear growth velocity from 2.47 (1.83) cm/year to 7.17 (2.97), as well as improvement in height velocity SDS and height SDS. Thereafter, the response to GH diminishes as in other groups of GH treated patients. Factors such as renal graft function, dose of immunosuppressive corticosteroids, episodes of acute or chronic rejection need to be considered in analysing the data.

Dose of GH

In view of the GH resistance of uraemic states, supraphysiological doses of GH have been administered in most trials of GH in CRF compared to GH deficient children. Two double-blind studies by Hokken-Koelega have examined this critically. In the first (13), 23 prepubertal children with CRF given either 2 or 4 IU/m^2/day over 2.5 years, catchup-growth was only sustained with the larger dose. In the second trial (14), no significant difference in growth response was obtained using 4 or 8 IU/m^2/day GH over 2 years in 18 pubertal post-renal transplantation patients with growth retardation. Bone age advancement or renal function did not differ with dose in either study. It therefore seems appropriate to advocate a dose of 1 IU/kg/week or 28-30 IU/m^2/week in children with growth failure in CRF.

Australian Data
In Australia guidelines have until now allowed GH administration to children with CRF (glomerular filtration rate<30mL/min per 1.73 m^2), with short stature (height < 25^{th} percentile for chronological) and height velocity < 25^{th} percentile for bone age. The data on these children are collated on a central database called "Ozgrow".

There are 3 sources of information on the use of GH in children with CRF in Australia. One is a brief analysis of the Ozgrow database and 2 are open label pilot studies. Details of these studies and analysis are outlined in Table 4.

The analysis of the Ozgrow database shows that up to 1994 a total of 56 patients with CRF treated with GH at a number of different centres throughout Australia. It confirms the findings of other, international studies by showing a significant improvement in growth over the first year of treatment in both prepubertal and pubertal patients. There was also a sustained improvement in height velocity and height SDS over the second year of treatment. Similar to the findings of other studies (3), patients with CRF appeared to show a more significant improvement than those requiring dialysis (see Figure 2).

Both studies, one in Melbourne (15) in 7 prepubertal children, aged 2-14 years, and the other in Adelaide (6) in 9 pubertal and prepubertal children, confirmed the positive effects of GH on mean height velocity and mean height velocity SDS. The children were treated with daily GH at 1U/kg/week (equivalent to 30IU/m^2/week) for 1 year and demonstrated a doubling of height velocity from 4-5 cm to 9-10 cm/year. In addition, the authors found no change in the rate of deterioration of renal function during treatment with GH.

Final Height
Much of the published short term data has been from children with preterminal CRF. Considering the natural history of CRF, these subjects will be treated in the future with renal transplant and/or dialysis, treatment strategies which may attenuate their response to GH. It is in this context that the only available final height data is particularly useful. A Dutch study has presented the final height data in 18 subjects treated with GH, dose 4 or 8 u/m^2/week for 3-6 years (18). All subjects had had a renal transplant and were pubertal at the time of commencing GH (mean age 15.6 years). The GH treated group had a mean increase in height of 19 cm to final height compared to an increase of 9.4 cm in a control group who did not receive GH. The improved pubertal growth was more apparent in those who commenced GH in early puberty. Their was no significant change in graft function during 4 years of therapy (see attached abstract).

Adverse Events
The spectrum of reported adverse events to GH is similar to other children receiving GH, with a low frequency of reported adverse outcomes. The possible exception to this is the reported frequency of intracranial hypertension in CRF. The highest incidence of this complication in GH treated patients is in the group with CRF. However, it is not known whether GH itself increases the risk of intracranial hypertension in these patients as there is a higher incidence of this problem in children with CRF without GH therapy. Issues

such as the long term impact of hyperinsulinism on the development of vascular disease complications in the setting of uraemia and transplantation remain to be elucidated.

Of most concern in the use of GH therapy in children with CRF is whether it adversely affects renal function. There is no convincing evidence in children with preterminal CRF that its use accelerates the natural decline in glomerular filtration rate. In patients with renal transplants, most evidence supports its safety in this regard but there are a number of reports of a decline in renal function temporally associated with the use of GH. In addition, the question of whether GH increases the incidence of acute and chronic rejection has not yet been definitively answered. The use of GH in this group of patients is still controversial, particularly in those who have a history of previous rejection episodes and those on high doses of glucocorticoids, where efficacy of GH is reduced.

Summary Statement

There is convincing evidence of the efficacy of GH in promoting linear growth in children with pre-terminal CRF managed conservatively, those on dialysis and post-renal transplantation. The best growth is seen in the first group of patients and within the first few years. As with other groups of short stature patients, there is a declining growth response with continued use of GH. However, studies with 3-5 years follow-up continue to show catch-up growth in patients with CRF. The bone maturation data suggests that GH therapy will not limit genetic height potential and the continued catch-up growth may lead to improved final height. The limited final height data suggest a significant benefit may be possible for this important outcome.

With regard to safety issues, evidence from the studies cited suggests that GH therapy is well tolerated in children with CFR. The spectrum and incidence of general adverse events does not seem to be different to that seen in other groups of GH recipients with the exception of intracranial hypertension.

In view of the sustained catch-up growth and improved final height in published reports to 1998, GH therapy is recommended in all children with CRF who have growth failure despite optimisation of their medical therapy. The available data suggests continuing the current recommended dose of GH of 28-30 IU/m^2/week given daily by subcutaneous injection.

Prepared on behalf of the Australasian Paediatric Endocrine Group and Australia and New Zealand Paediatric Nephrology Association by;

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Date; 2nd November, 1998

Table 1. Clinical Studies of GH Therapy.

No.	Study Design	Authors	Length therapy	Subject No.	Renal Management		
					Conservative	Dialysis	RT
1	Placebo-controlled, double blind, cross-over	Hokken-Koelega ACS, et al.	6m	20	9	11	
2	Placebo-controlled, double-blind, multicenter	Fine RN, et al	2 yrs	125	125		
3	Open, non-controlled; multicentre	Tonshoff B et al + Member of German Study Grp	1-2 yrs	61	20	24	17
4	As above	Van Es for European Study Grp	2yrs	98	43		55
5	Combined data; 8 independent trials	Mehls O + Broyer M, for European/Australian Study Grp	2 yrs	103	69	34	
6	Open, non-comparative	Van Renen et al	1 yr	9	9		
7	As above	Fine et al	1-3 yrs	9	9		
8	As above (long-term follow up of pts from 2)	Fine et al	5 yrs	20	20		

Table 2. Efficacy Data

Study No.	Height Velocity (cm/year)					Ht Velocity SDS				Height SDS		
	0	6m	1yr	2yr	3yr	0	6m	1yr	2yrs	0	1yr	2yrs
1	3 (1.40)	10.4[a] (2.4)				-3.2 (1.4)	6.9[a] (2.4)					
2										-2.94[b] (0.86)	-1.93 (1.01)	-1.55[b] (1.16)
3	4.1 (2-5.3)		9.3[c] (6.8-11.4).	6.6[d] (6.1-8.7)		-2.4 (-4.9-0)		4.2[c] (1 – 8.2)	1.8[d] (0.9 – 4.4)			
4	4.2		9.8	6.8		-1.8		4.5	2.1			
5	4.6		9.8	6.8		-1.5		4.3	1.7			
6 prep	4.6 (1.3)		9.0[e] (1.3)			-1.2 (0.6)		2.3[e] (0.9)		-2.2 (0.5)	-1.5[f] (2.3)	
pub	5.4 (1.4)		10.4[f] (1.8)			-0.4 (0.5)		1.9[f] (1.1)		-1.9 (0.9)	-1.3[h]	
7	5 (1.4)		8.5 [a] (1.3)	8.2 [g] (1.6)	8.1 [c] (1.8)							

a: p<0.0001; b p<0.00005; c p<0.05; e p<0.001;f p<0.01; g p<0.004; h p<0.02 vs baseline; d p<0.05 vs previous year

Table 3. GH trials in renal transplant patients

Study No.	Design	Authors	Subject No.	Duration therapy
9.	Placebo-controlled, double-blind, randomised	Hokken-Koelega et al	11	6m
10	Multicentre, prospective, open, controlled	Maxwell H et al	16	2 yrs
11	Multicentre, open, placebo-controlled, randomised	Broyer M for Pharmacia and Upjohn Study Grp	203	2 yrs
12	Analysis of data on cohort of renal transplant recipients from 2 databases	Mentser M et al (National Cooperative Growth Study + North American Pediatric Renal Transplant Cooperative Study	59	3 yrs
3	See Table 1			
4	See Table 1			

Table 4. Australian Data

Study No.	Source	Patient grp and no.	Ht Velocity (cm/yr)		Ht Velocity SDS		Ht SDS		
			0	1yr	0	1yr	0	1yr	2yr
15	Melbourne	7; prepubertal crf	5.14 (2.42)	9.45[b] (1.53)	-2.87 (2.33)	3.39 (1.58)	-3.15	-2.46[a] (0.91)	
6	Adelaide	9; crf prepubertal (n=5);	4.6 (1.3)	9.0[a] (1.3)	-1.2 (0.6)	2.3 [a] (0.9)	-2.2 (0.5)	-1.5 [c] (2.3)	
		Pubertal (n=4)	5.4 (1.4)	10.4 [c] (1.8)	-0.4 (0.5)	1.9 [c] (1.1)	-1.9 (0.9)	-1.3 [d]	
16	Ozgrow database	n=56 crf=29; ESRD=19 RT=8							
		Prepubertal					-3.02 (1.23)	-2.57 [e] (1.22)	-2.35 [f] (1.09)
		Pubertal					-2.61 (1.15)	-2.17 [c] (1.21)	-1.78 [g]

A p=0.001; b p=0.006; c<0.01;d p,0.02; e p<0.0001 vs baseline; f p=0.001 vs baseline and = 0.06 vs previous year; g p<0.01 vs baseline and < 0.05 vs previous year.

Table 5. Further Analysis of Ozgrow Data

Results of 1 year treatment with rhGH in prepubertal and pubertal patients with CRF divided according to severity

	Prepubertal		Pubertal	
No. (Prepub/pubertal)	Baseline Mean (s.d.)	12 months Mean (s.d.)	Baseline Mean (s.d.)	12 months Mean (s.d.)
CRF: no dialysis (n = 25/4)	-2.91 (0.99)	-2.5 (1.00)[a]	-3.2 (0.84)	-1.77 (1.16)[b]
CRF + dialysis (n = 13/6)	-3.48 (1.87)	-3.38 (1.88)	02.97 (0.53)	-2.63 (0.53)[b]
Transplant (n = 7/1)	-4.20 (2.13)	-4.02 (2.38)	-3.38	-2.57

[a] P<0.0001 12 months vs baseline. [b] P<0.05 12 months vs baseline

Table 6. Effect of 1 to 5 yr of rhGH therapy on height SDS in prepubertal children with CRF on conservative and on dialysis treatment

	n	Age	rhGH therapy					
			Baseline	**1 yr**	**2 yr**	**3 yr**	**4 yr**	**5 yr**
Height (SDS)								
conservative								
treatment	74	8.3	-3.4 ± 0.1	-2.6 ± 0.1				
	41	7.8	-3.4 ± 0.2	-2.5 ± 0.2	-2.1 ± 0.2			
	19	6.3	-3.4 ± 0.2	-2.5 ± 0.2	-2.0 ± 0.3	-1.8 ± 0.3		
	8	6.2	-3.7 ± 0.4	-2.8 ± 0.4	-2.2 ± 0.5	-1.9 ± 0.5	-1.7 ± 1.5	
	6	5.8	-3.4 ± 0.4	-2.5 ± 0.4	-2.0 ± 0.5	-1.9 ± 0.5	-1.8 ± 0.5	-1.9 ± 1.5
dialysis	29	8.8	-3.6 ± 0.2	-3.1 ± 0.3				
	13	7.4	-3.8 ± 0.3	-3.2 ± 0.4	-3.0 ± 0.4			
	6	6.3	-4.4 ± 0.6	-4.0 ± 0.7	-3.7 ± 0.7	-3.7 ± 0.8		

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LONG-TERM AND FINAL HEIGHT RESULTS OF GH TREATMENT IN RENAL TRANSPLANT PATIENTS

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PEDIATRIC ENDOCRINOLOGY ROTTERDAM

INTRODUCTION:

Persistent growth retardation despite successful renal transplantation (RT) is a serious problem for many allograft recipients.
RT usually results in some growth improvement but seldom to sufficient catch-up growth. Final height falls below the third percentile (P3) in 72% of RT patients.
Various studies have demonstrated that biosynthetic growth hormone (GH) therapy in a dose of 4 IU/m²/day increases height velocity of these patients. However, only long-term data, including data on final height, can substantiate that GH-therapy is truly effective and safe for these patients.

PATIENTS \ TREATMENT:

35 Dutch children with severe growth retardation (height standard deviation score (hSDS) < -2) following RT were treated with Norditropin® for 3-6 years [mean age at start 12.6(4.6) years].
18 pubertal patients [mean age at start 15.6(2.3) years] were blindly assigned to one of two GH doses (4 or 8 IU/m²/day) and the other patients received 4 IU/m²/day.
All children received prednisone, administered daily or on alternate days, in combination with azathioprine and/or cyclosporin A.

METHODS:

Growth, bone maturation, renal graft function, plasma insulin-like growth factors (IGF), serum IGF binding proteins -1 and -3 and other biochemical parameters were checked regularly.
Glomerular filtration rate (GFR) and effective renal plasma flow (ERPF) were tested with ^{125}Thalamate and ^{131}Hippuran.
Data on growth and GFR of GH-treated patients were compared with those of matched, non-GH-treated controls.

RESULTS

FINAL HEIGHT

18 pubertal patients have attained FH. Their mean [SD] increment in height from the start of GH therapy until FH (19.9 [7.9] cm) was significantly greater than that of their matched controls (9.4 [7.9] cm) (P< 0.0001; Table 1). Results were similar for the two GH dosage groups (4 and 8 IU/m²/day).
The difference with matched controls was even greater for patients who started GH therapy during early puberty (Tanner stage 2/3) (Table 2).
Long-term GH therapy in patients who did not yet attain FH, resulted in significant improvements in predicted final heights.
Figures 1 and 2 show examples of individual growth charts during long-term GH therapy.

BONE MATURATION

Bone maturation did not accelerate during long-term GH therapy.

RENAL GRAFT FUNCTION

Mean GFR and ERPF did not change significantly during 4 years of GH therapy. The incidence of > 25% reduction in GFR during 4 years was not significantly higher in GH-treated patients than in non-GH-treated matched controls. The results were similar for the two GH dosage groups (4 and 8 IU/m²/day).
Eight of 35 GH-treated patients had a serious deterioration of their renal graft function, six of them returned to dialysis or had a new RT and two stabilized at a lower GFR > 20 ml/min. A relation with GH therapy was not found.
Figure 3 shows the individual GFR's during GH therapy.

CONCLUSION

Long-term GH therapy in a dose of 4 IU/m²/day results in a significant improvement of final height in most patients with growth retardation after renal transplantation.

ΔHeight (cm)	GH therapy	Matched controls	Difference
0-2 yr	15.7 (5.1)*	5.8 (3.7)	9.9 (p<0.0001)
2 yr - FH	3.3 (3.2)	3.6 (6.0)	-0.3 (p=0.80)
0 -FH	19.0 (7.9)*	9.4 (7.9)	9.6 (p<0.0001)

Table 1
Mean (SD) height increment from start of GH therapy until final height (FH) in 18 pubertal renal transplant patients in comparison with matched controls. * = *significantly different compared to matched controls*

ΔHeight 0-FH (cm)	GH therapy	Matched controls	Difference
all patients	19.0 (7.9)*	9.4 (7.9)	9.6 cm (p<0.0001) [95% CI=4.9 to 14.3 cm]
early pubertal	22.8 (7.2)*	11.7 (9.1)	11.1 cm (p=0.01)
late pubertal	12.4 (3.6)*	5.5 (2.9)	6.9 cm (p=0.01)

Table 2
Mean (SD) height increment from start of GH therapy until FH in early and late pubertal RT patients in comparison with matched controls
* = *significantly different compared to matched controls*

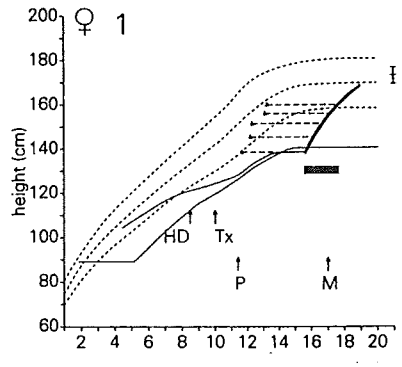

Figure 1
Individual growthchart and final height of a pubertal renal allograft recipient who received GH therapy.

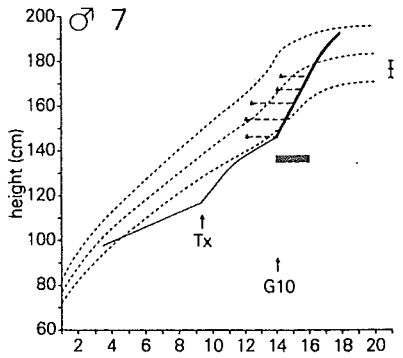

Figure 2
Individual growthcharts of 3 pubertal girls, representing the difference in final height between the girl who received GH therapy and the 2 matched controls.

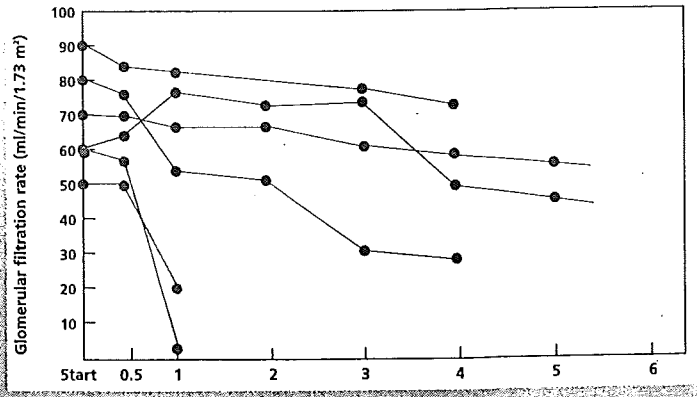

Figure 3
Individual glomerular filtration rates (GFR's) during GH therapy.

This study was supported by Novo Nordisk A/S, Denmark

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Abstracts

&

Lawson Wilkins Pediatric Endocrine Society (LWPES)

Guest Editor:
Martin Ritzén, Stockholm (Sweden)

in collaboration with the Australasian Paediatric Endocrine Group (APEG), the Japanese Society for Pediatric Endocrinology (JSPE) and the Latin American Society for Paediatric Endocrinology (SLEP)

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LONG-TERM AND FINAL HEIGHT RESULTS OF GH TREATMENT IN RENAL TRANSPLANT PATIENTS

A.C.S. Hokken-Koelega, M.C.J.W. de Jong, E.D. Wolff, J.W. Groothoff, M. Lilien.
Dept. of Pediatrics, Subdiv. of Endocrinology and Nephrology, University of Rotterdam, Nijmegen, Amsterdam and Utrecht, The Netherlands.

35 children (mean age 12.6 yr) with severe growth retardation after renal transplant have been treated with biosynthetic growth hormone (GH) for 3-6 years. 20 patients have attained final height (FH). All received prednisone, dministered daily or on alternate days, with azathioprine and/or cyclosporin A. 18 were blindly assigned to one of two GH doses (4 vs 8 IU/m^2/day), the others received 4 IU GH/m^2/day. Growth, bone maturation, renal graft function, plasma insulin-like growth factors, serum binding proteins and other biochemical parameters were checked regularly. Glomerular filtration rate (GFR) and effective renal plasma flow (ERPF) were tested with ^{125}I-Thalamate and ^{131}I-Hippuran. Data on growth and GFR of GH-treated patients were also compared with those of matched non-GH-treated patients.

Results: The mean (SD) increment in FH of GH-treated patients was significantly greater (9.9 (4.3), P< 0.0001) than that of matched controls. Results were similar for the two GH dosage groups. Bone maturation was not accelerated during GH therapy. Mean GFR and ERPF did not change significantly during 4 yr of GH therapy. The incidence of a > 25 % reduction in GFR during 4 yr was not significantly higher in GH-treated patients than in non-GH-treated controls. Eight out of 35 patients had a deterioration of their graft function, but we could not find a relation with GH therapy.

In conclusion: Our results show that significant improvement of final height can be achieved with 4 IU GH/m^2/day in severely growth-retarded children after renal transplant.

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GROWTH HORMONE (GH) THERAPY FOR 145 ACHONDRO-PLAS TIC CHILDREN.

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Achondroplasia is one of the most common causes of severe rhizomelic dwarfism. We previously reported growth

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COMMONWEALTH OF AUSTRALIA

Health Benefits Division
Furzer Street Woden Canberra ACT 2606
Telephone: (02) 6289 7274 Fax: (02) 6289 8633

Commonwealth Department of Health and Aged Care

Dear Doctor

RE: GROWTH HORMONE FOR CHILDREN WITH CHRONIC RENAL FAILURE

For some time, the Pharmaceutical Benefits Advisory Committee (PBAC) has been urging sponsors of human growth hormone (hGH) to validate the previously accepted use of hGH for chronic renal failure, by obtaining official approval from the Therapeutic Goods Administration (TGA).

However, during 1998, one sponsor's application to the Australian Drug Evaluation Committee, seeking a recommendation for the extension of the indications for hGH to cover chronic renal failure, was rejected as it was considered that efficacy had not been established. This decision by ADEC, and the subsequent rejection by TGA, left the PBAC and the Department in the invidious position of having hGH listed on the Pharmaceutical Benefits Scheme for chronic renal failure, when approval had been denied on the grounds that there was no proof that it is effective when used for this purpose.

It was decided that there was no choice but to remove the indication of chronic renal failure from the Guidelines, and this was to have occurred on 1 January 1999.

Following representation from various nephrologists, doctors and patients, this decision has been amended. **The Department has agreed to keep the present criteria with regard to the eligibility of children with chronic renal failure to receive hGH treatment as a pharmaceutical benefit, until 1 January 2000.**

This is intended to allow plenty of time for at least one of the sponsors of hGH to have the necessary approval from TGA. (Should this not occur, the Pharmaceutical Benefits Scheme subsidy for new patients with chronic renal failure will cease from 1 January 2000.)

Appdx 2(d)

Senator the Hon Grant Tambling

Senator for the Northern Territory

Parliamentary Secretary to the Minister for Health and Aged Care

Parliament House
Canberra ACT 2600

Telephone (02) 6277 3436
Fax (02) 6277 3704

3/80 The Esplanade
GPO Box 4196 Darwin NT 0801

Telephone (08) 8981 3567
Fax (08) 8981 3022

Dr C. Jones
Director
Department of Nephrology
Royal Children's Hospital
Flemington Road
Parkville VIC 3052

Dear Dr Jones

Thank you for your letter of 4 September 1998 to the Treasurer, the Hon P.H. Costello MP, concerning the use of growth hormone in children with chronic renal failure. Your letter has been referred to the Minister for Health and Aged Care, the Hon Dr Michael Wooldridge. As Parliamentary Secretary with executive responsibility for the Therapeutic Goods Administration (TGA), I am responding on behalf of the Government.

In your letter, you have provided some of the history of the listing of growth hormone on the Pharmaceutical Benefits Scheme (PBS). By way of additional background, before genetically engineered human growth hormone (somatropin) was available, the hormone extracted from the pituitary glands of deceased people was in short supply, so was supplied under the PBS on a limited basis in accordance with the advice of an expert committee. Because of the unique origins of the medicine, its history with the PBS in terms of the listing process has also been unique.

Genetically engineered somatropin has been supplied under a special section of the PBS for some years, in accordance with established guidelines. The usual use of the medicine is for children with short stature who are deficient in growth hormone. However, as you note, it has also been used to treat growth retardation in children with chronic renal failure. Patients are assessed by paediatric endocrinologists in public hospitals, then each application is individually assessed in accordance with the guidelines by officers in the Department of Health and Aged Care.

The guidelines for subsidy of somatropin were established by a group of paediatric endocrinologists. These guidelines were based on the information available at that time and on the opinion of these experts. Some of the uses for somatropin (including chronic renal failure) were included in the guidelines on the advice of the paediatric endocrinologists, even though the medicine only had marketing approval for short stature due to growth hormone deficiency. This situation was allowed to continue pending the provision by the medicine's sponsors of evidence to support their claims that the medicine was effective in-patients with chronic renal failure.

To extend the registered use of a drug in Australia to include an additional indication, it is necessary for a sponsor to submit an application together with supporting data to the TGA. The TGA evaluates the application to ensure that the quality, safety and efficacy of the product have been demonstrated adequately for the proposed use. The TGA seeks the advice of the Australian Drug Evaluation Committee before taking a decision to approve or reject an application. Whilst account is taken of drug approval decisions made in other countries with drug regulatory systems similar to our own, Australia does make its own decisions on drug approvals.

For reasons of commercial confidentiality the TGA is not able to comment on applications which may or may not have been through the evaluation process or which may currently be under evaluation. You would need to discuss with the relevant sponsors the status of any application to extend the indications for somatropin to include use in children with chronic renal failure. If you have data relevant to such an application, you should also discuss this with the appropriate sponsors to determine how such data might be included in an application.

The Department of Health and Aged Care has allowed until 1 January 2000 for relevant specialists to work with sponsors of somatropin to present clinical evidence that the medicine is effective in children with chronic renal failure. The medicine will no longer be available for this use under the PBS from this date if satisfactory evidence is not provided.

Any decision to stop subsidising the medicine for use in chronic renal failure after 1 January 2000 will only affect new patients. It is important to note that patients with chronic renal failure who receive somatropin at a subsidised rate up until 1 January 2000 will continue to receive the subsidy after that date provided they meet other aspects of the guidelines. In addition, any patients who satisfy the guidelines for subsidy in relation to other criteria (including short stature and low growth rate) will also continue to have access to the medicine at the subsidised rate – whether or not they have chronic renal failure.

Yours sincerely

GRANT TAMBLING 21/12/98.

Elizabeth Hodson, 09:41 AM 10/23/98, Re: congenital and idiopathic

Date: Fri, 23 Oct 1998 09:41:46 +1000
From: Elizabeth Hodson <ElisaH@nch.edu.au>
To: cjones@cryptic.rch.unimelb.edu.au
Subject: Re: congenital and idiopathic nephrotic syndrome -Reply
-Forwarded

I've attached some email correspondence that I have been having with Tony Seymour about renal pathology. I would be interested in your comments.
ElisabethReceived: From [10.7.10.10] astro.kids
By fs_6 (GroupWise SMTP/MIME daemon 4.11)
Tue, 13 Oct 98 14:39:53 EST
Received: by astro.kids; id AA110643592; Tue, 13 Oct 1998 14:39:52 +1000
Received: from mutley-internal.nch.edu.au(203.34.41.26) by astro.kids via smap (3.2)
id xma011058; Tue, 13 Oct 98 14:39:44 +1000
Received: by mutley.nch.edu.au; id AA128753575; Tue, 13 Oct 1998 14:39:35 +1000
Received: from unknown(203.55.184.9) by mutley.nch.edu.au via smap (3.2)
id xma012863; Tue, 13 Oct 98 14:39:16 +1000
Received: from adepa02.gribbles.com.au (adepa02.gribbles.com.au [203.55.186.178])
by mail.gribbles.com.au (8.9.0/8.9.0) with SMTP id OAA24742
for <ElisaH@nch.edu.au>; Tue, 13 Oct 1998 14:40:36 +1000
Message-Id: <1.5.4.32.19981013051139.0067e1bc@melmail.gribbles.com.au>
X-Sender: tseymo@melmail.gribbles.com.au
X-Mailer: Windows Eudora Light Version 1.5.4 (32)
Date: Tue, 13 Oct 1998 15:11:39 +1000
From: Tony Seymour <tseymo@gribbles.com.au>
To: ElisaH@nch.edu.au
Subject: Re: congenital and idiopathic nephrotic syndrome -Reply
Mime-Version: 1.0
Content-Type: text/plain
Content-Disposition: inline

Dear Elizabeth

I have no grand plan - it just seemed a good idea, on the spur of the moment, when I read about your study to think about teaching ourselves as pathologists as well as clinicians, Most of what has been written about congenital NS has been either from national centres (Rene Habib etc) or big groups with unusual populations (Minnesota). Nothing is known (to me) about the types and prevalence of congenital NS in Australia. And I am sure you will agree that FGS remains a very uncertain "entity" with great variation in definition around the country. Perhaps the idea of pooling the biopsies might be floated at Council and/or the ANZSN meeting next year to see whether other people can see any value in such an exercise and if there are pathologists other than myself who might be interested in taking part. There should be no need for extra money, bx can easily be forwarded from one pathologist to another and, if a combined viewing is needed, this could be organised around one of the pathology meetings each year.

It was really just a thought - and (I suppose) an opportunity to learn about an area in which my ignorance is greater than others - why don't you float the idea around some of your colleagues and see whether there is any interest (or, as the Americans say, run it up the flag pole and see if anyone salutes)?

Regards

Tony Seymour

At 06:32 PM 10/12/98 +1000, you wrote:
>I apologise for the delay in replying to your email. I have been away.
>
>We had not considered doing any pathological studies. However most of
>the children with FSGS will be cared for by the paediatric nephrologists
>so it would be relatively easy to get access to the biopsies later. What
>do you think we should do in the way of further study & how should it be
>organised?
>

>Elisabeth Hodson
>
>>>> Tony Seymour <tseymo@gribbles.com.au> 4/September/1998
>07:12pm >>>
>Dear Dr Hodson
>
>I received your material on this study via the A&NZSN - congratulations, it
>will be a valuable contribution to knowledge about these conditions in our
>part of the world.
>
>As a pathologist, I will not be able to contribute patients to your study
>but I wonder whether you plan to add a pathological component to your
>clinical review? There is little to learn about epithelial cell disease
>(minimal lesion) after the ISKDNSC but considerable confusion still reigns
>about FGS and I do not know of any published data on congenital
>nephrotic
>syndrome in this country.
>
>I would be interested in your comments.
>
>Kind regards,
>
>Tony Seymour
>Associate Professor A E Seymour
>1 Goodwood Road, Wayville, South Australia,
>Australia 5034
>
>Email tonys@gribbles.com.au
>tel   08 8372 5000
>fax   08 8205 5651
>
>
Associate Professor A E Seymour
1 Goodwood Road, Wayville, South Australia,
Australia 5034

Email tonys@gribbles.com.au
tel   08 8372 5000
fax   08 8205 5651

Appx 4.

The Royal Australasian College of Physicians
A.C.N 000 039 047
145 Macquarie Street Sydney NSW 2000
Telephone: (02) 9256 5444 Facsimile: (02) 9252 3310

DIVISION OF PAEDIATRICS

Telephone: (02) 9256 5408
Facsimile: (02) 9256 5465
E-mail: paed@racp.edu.au

15 October 1998

Dr Colin Jones
Chairman
Department of Nephrology
Royal Children's Hospital
Flemington Road
PARKVILLE VIC 3052

Dear Dr Jones

Re: Annual Scientific Meeting - Adelaide, May 2000

I write to you as Chair of the Scientific Program Committee of the Division of Paediatrics, RACP.

In the year 2000, the Division of Paediatrics will be holding its Annual Scientific Meeting in conjunction with the RACP at the Adelaide Convention Centre from 1st to 5th May, 2000. The year 2000 marks the 50th anniversary of the foundation of the Australian Paediatric Association (later to become the Australian College of Paediatrics) - an auspicious occasion.

It would therefore be an excellent opportunity to have several of the paediatric special societies meet with the Division of Paediatrics and the RACP so that we could have something akin to a "paediatric congress".

I would therefore like to invite the Australian and new Zealand Paediatric Nephrology Association to consider meeting with the Division of Paediatrics in Adelaide in May 2000. This could, for example, be as a satellite meeting, with some overlap of meeting content.

If you have any queries about this, I would be happy to discuss this further with you. I can be contacted by e-mail: lbaur@mail.usyd.edu.au but formal replies should be sent to the Divisional Office. I look forward to hearing from you in the near future.

Yours sincerely

Dr Louise Baur
CHAIR
SCIENTIFIC PROGRAM COMMITTEE

(Append. 4 B)

Children's
Hospital & Regional Medical Center

Division of Pediatric Nephrology

Division Head
Allison Eddy, M.D.

Director of Clinical Nephrology Medical Director of Dialysis
Sandra L. Watkins, M.D.

Attending Physicians
Rob Holleman, M.D.
Ruth McDonald, M.D.
Janet L. Rowe, M.D.
Greg Sliman, M.D.
F. Bruder Stapleton, M.D.
Susan Thomas, M.D.

Nephrology Clinical Manager
C[illegible] Meyers, RN, BSN

Clinical Nurse Specialist
Jane Driscoll, MSN

Clinical Nurse
Tina Tennant, RN, BSN

Hemodialysis Home Training Coordinator
Barbara Holden, RN, CNN

Nephrology Social Work
Kathleen Spikes, MSW

Nephrology Dietitians
Linda Astrom, MS, RD
Lori Brizee, MS, RD

Patient Care Coordinator
Suzanne Jones

Administrative Coordinator
Jennifer Samson

Administrative Director
J[illegible] Dougherty

Fellows
Debbie Gipson, M.D.
Sangeeta Hingorani, M.D.
Stephanie Jernigan, M.D.
Fangming Lin, M.D.
Khawla Rahim, M.D.
Craig Wong, M.D.

Dialysis Nurses
Shelia Bailey, RN
Lara Germino, RN
Catherine Hansen, RN
Kristi Klee, MSN
Nancy McAfee, RN, CNN
Kathleen O'Connell, RN
Pam Sligh, RN, CNN

Transplant Nurse
Marley Prescott, RN, BSN

December 22, 1998

→ Colin Jones RCH

Dr. Graeme R. Russ
President
Australia & New Zealand Society of Nephrology
145 Macquarie Street
Sydney NSW 2000
AUSTRALIA

Dear Dr. Russ:

I would be honored to visit Australia in the year 2000 as the Janssen-Cilag Visiting Lecturer at the Annual Meeting of your society to be held in Melbourne from March 14-17, 2000. I understand from your letter that you would like me to spend about two weeks in Australia and/or New Zealand visiting other academic centers as well. At this point in time my schedule is open in March 2000 and I would be happy to do this. However, I would suggest that we establish some tentative dates for the two-week visit as schedules have a habit of filling up. I would assume that the travelling would occur after the main meeting in Melbourne but please let me know if you think otherwise.

Two months before this meeting I celebrate my 50th birthday and I have been thinking about what to do for this historic occasion. I have proposed to my husband and son (who will be eight at that time) that we should make this a family trip. At this point they are excited about this idea but logistics of making such plans will be simplified if we finalize the dates soon.

Once again, I am honored to be invited to Australia and pleased to accept this invitation. I look forward to working with you on my itinerary and lecture topics.

Sincerely,

Allison Eddy

Allison Eddy, M.D. F.R.C.P.(C)
Professor of Pediatrics
Division Head, Nephrology
aeddy@u.washington.edu.

cc: Dr. B. Murphy

11/6/97;\\chmc07\nphrlgy\ALLISON\CORRESPO\Graeme Russ.doc

ANZPNA Minutes – Teleconference 18th December 1998

Present: Colin Jones, Lilian Johnstone, Paul Henning, John Burke (Co-opted)

Item 1 Growth Hormone

The letter from the Commonwealth Department of Health was noted (Appendix 1 and letters appendixed to 6th November teleconference) concerning the decision to defer the cessation of use of Growth Hormone for CRF until the end of 1999. It was felt that this had occurred due to the letters generated, the Media interest, the active parent group and the efforts of Elizabeth Hodson, Charlie Crompton, John Knight and Chris Cowell. Colin reported that Charlie is analysing the OZGROW data and his initial assessment shows a poorer rate of growth in children compared to overseas studies and we are going to look at specific sub-groups to see if there are other causes. There certainly was an improvement in height z scores with growth hormone but not as great as that reported overseas. Charlie had also reported to Colin that a lot of the OZGROW data did not contain pubertal data and that this will need to be obtained. It was proposed that once Charlie accesses the OZGROW data in terms of names of individual patients that he would write to the appropriate Paediatric Nephrologists with the names and obtain the pubertal data from them. It would appear that everyone has received their letter from Charlie requesting permission to access individual patient data from the OZ Grow Registry. Colin acknowledged the involvement of the Australian Paediatric Endocrine Group but was keen to ensure that the data analysis by Charlie is produced under the auspices of the ANZPNA. It was acknowledged that there had been a delay in distributing the minutes from the last Executive Meeting which summarised the current state of play with respect to the Growth Hormone issue. There is extensive involvement continuing between Charlie Crompton, Elizabeth Hodson, Chris Cowell and John Knight. It would appear that the issue now is to establish which of the other Growth Hormone manufacturers intend to or are submitting an application for approval for use of Growth Hormone in chronic renal failure to the TGA and PBAC and that if there is a company willing to do so then every effort should be made by the ANZPNA to support their application. Obviously if no company submits an application there will be no avenue for Growth Hormone to be considered for use in chronic renal failure.

Item 2 IPNA Bid

Colin noted that he had a recent conversation with Fred (confirmed by Paul) that no response had been heard from Ira Greifer. It was noted that Ira has a new address for correspondence and it was suggested that the letters concerning the IPNA Bid should again be sent and that acknowledgement should be requested. John Burke noted that it is not unusual for Ira Greifer to take some time in responding to letters and faxes. Paul Henning noted that he had written again 3 weeks ago and had yet not received a response. John reported that Hungary had definitely submitted a bid and is unclear whether Berlin is going to. He

thought it was likely that the presentation will be held at the Council Meeting in September as opposed to March and he also noted that Ira Greifer was usually keen to visit bidding units. The role of the satellite meetings, particularly the Developmental Renal Physiology Meeting were raised and it was thought worthwhile to write to Anita Aperia to inform her that Adelaide and the ANZPNA were bidding for the IPNA Congress in 2004. John felt that there were some political issues with respect to the Paediatric Transplantation Group and it was probably wiser at this point in time not to include them. It was decided that the IPNA Bid needed to be well underway and bundled up by the end of March so that when the date for presentation was known very little additional work would need to be done. Currently the date of the meeting is provisionally determined, the venue is provisionally determined, and some costings of the meeting have been made. The various Committees and their memberships need to be determined. Colin will write to Fred about preparing all the information by March.

Item 3 Other Business

3.1 Articles of Association

Lil reported that she had received correspondence from Paul Roy concerning the Articles of Association. Final amendments will be made and then the Articles of Association will be submitted to the Australian Securities Commission for registration early in 1999.

3.2 Benchmarking

Paul Henning will distribute copies of the Child Health Outcomes Questionnaire to other Paediatric Nephrology Units in January. The plan is to use this questionnaire for assessment pre-transplant and post-transplant. Colin also intends to use the same questionnaire with additional questions for dialysis access for PD and HD. Lil is to contact Debbie Lewis concerning Renal Biopsy Indicators. It is hoped that each department will agree to take part. The Child Health and Outcome Questionnaire has been validated as an Australian version and there is computer software for analysis of the results available at the Department of Community Health and Ambulatory Paediatrics, Royal Children's Hospital, Melbourne.

Item 4 Next Meeting

The next meeting will be held on Friday, 12th February 1999.

Letters received - Appendix 2. Kevin Forsyth re: Electronic Teaching Material
Appendix 3. Stephen Leader re: Appropriate care of children with CRF
Appendix 4 Paediatric Ibuprofen: No action taken

Appx. 4. 1.

AZA: AN AUSTRALIAN COMPANY
SUPPORTING AUSTRALIAN RESEARCH

November 16, 1998

Dr Lilian Johnstone
Honorary Secretary, ANZPNA,
Victorian Paediatric Renal Services
Department of Nephrology
Royal Children's Hospital
Flemington Road
PARKVILLE VIC 3052

Dear Dr Johnstone

Re: Aza Research Position on Chronic Renal Impairment

Thank you for your letter to Jehangir Sidhwa, informing us of the Australian & New Zealand Paediatric Nephrology Association's (ANZPNA) interest in maintaining the availability of growth hormone for use in children and adolescents with chronic renal impairment and end stage renal failure.

We are still evaluating the various options available to us at this stage, which does include the possibility of submitting a package to the TGA. However, we are still waiting for the regulatory dossier on CRI which will not arrive until Q1, 1999. After our Medical Director, Dr Danial Thiebaud, has reviewed the dossier, we will make a decision on our best course of action. At this stage we may take up your group's offer for assistance.

I thought both yourself and Dr Colin Jones would be interested in the paper clipping from The Sydney Morning Herald that appeared last week on page 5 with a photograph of a patient, Nicholas Wilson.

With kind regards,

Yours faithfully,
AZA RESEARCH PTY. LTD.,

Richard C Gooderham,
Marketing Manager.

Attachment: 1.

Business
Aza Research Pty Ltd
ACN 066 475 652
112 Wharf Road West Ryde NSW 2114
Telephone (02) 9325 4563 Facsimile (02) 9325 4573
Toll Free 1800 023 764

Research
Aza Research Pty Ltd
ACN 066 475 652
384 Victoria Street, Darlinghurst NSW 2010
Telephone (02) 9361 2050 Facsimile (02) 9332 4876

Appx 1.

Michael and Ada Wilson
C/- The Kidney Kids
Growth Therapy Petition
Po Box 673
Gladesville NSW 2111

02.11.98

Dr Colin Jones
Director
Department of Nephrology
Royal Children's Hospital
Flemington Road
Parkville VIC 3052

Re:Growth Hormone Subsidy for Renal Children

Dear Colin

Our names are Michael and Ada Wilson and we are the parents of eight year old Nicholas who is suffering from Congenital Nephrotic Syndrome.

Nicholas is attending haemodialysis three days per week at the The New Children's Hospital at Westmead.

As many of us are aware the Government is going to cease the subsidy of Growth Hormone drugs for Renal children .

We are greatly concerned and know the full effect that this will play on our son.

I am currently urging fellow Renal parents to write to their local Members of Parliament expressing there disapproval about this decision.

As Paediatric Renal Consultants I am sure that you would be also concerned about this decision and I know you would understand the extreme disappointment and anger that I am feeling now.

I am writing letters and trying to rally support from the parents , family and friends of The Kidney Kid's through out Australia .
These letters are aimed to reach out to these families that will be effected by this decision and I am asking if you can help me achieve this.

I have a letter titled **" The Withdrawal of Growth Hormone Therapy for Renal Children is both Unfair and Unaffordable"** which I am hoping to distribute to Fellow Renal families throughout Australia. I also know that a lot of families who have had children on these drugs in the past may also want to be involved.

I am asking you if the accompanying copies of this letter could be distributed to these families so I can give them the chance to be part of my plight .
There is no obligation for them to partake, but given the opportunity I am sure we will have a large response similar to the responses we are receiving within the Renal community at The New Children's Hospital.

As a minority group, my idea is to build a majority voice on such an unfair decision that is going to push the progression of treatment for Renal children back to the dark ages.

Our Health Minister has to also look to the of treatment Renal children more closely, in comparison to Europe and the USA who promote the use of this therapy for Renal kid's.

Australia wide there are 59 children benefiting from these drugs .
I am finding it almost criminal that they will be robbed of great chances that this drug is offering.
Has the government considered the effect this will have on these children psychologically , socially and importantly their future employment ?

Included with this letter are copies of the petition that I am circulating in Sydney and I would hope that you could make this petition available within your Dialysis unit and hospital for those who wish to sign.

Please mail this petition to either :

The Kidney Kids Growth Therapy Petition
PO Box 673
Gladesville NSW 2111

OR

The Dialysis Unit
The New Children's Hospital
Royal Alexandra Hospital for Children
PO Box 3515 Parramatta NSW 2124

We are gathering these petitions to present to the Hon Dr Michael Wooldridge the Minister for Health in hope that he might reverse this decision.

If you have any queries, please do not hesitate to contact me on 02 9807 2906
We have full support of our plight from Dr Elisabeth Hodson (Nicholas's renal consultant) and Dr Debbie Lewis from The New Children's Hospital - Westmead

Maybe you have ideas that we can use also, so please don't hesitate to contact us.

Thank you

Yours Sincerely

Michael Wilson Ada Wilson

Appx 1.

The withdrawal of Growth Hormone Therapy for Renal Children is both unfair and unaffordable!!

"You can help to make a difference"

Our children need and deserve this drug, so help us fight the Federal Governments decision to stop the subsidy!

Please supply us with your:

Name (Parent): .....

Your Child's Name: .....

Mailing Address: .....

Renal Consultant's Name: .....

Hospital your child is attending: .....

We will supply you with information on how you can help us reverse the Governments decision.

Please reply to:

The Kidney Kids Growth Therapy Petition
PO Box 673 Gladesville 2111
Phone: 02 9807 2906
Contact: Michael Wilson

App x 1.

Support for the reinstatement of Commonwealth Funding of Growth Hormone Treatment for the Kidney Kid's of Australia

As family and friends of children suffering with Kidney disease, we would like to formalise our complaint about the withdrawal of the Growth Hormone funding in Australia.

Without this drug, Kidney Kid's will no longer be given the chance to grow!

I strongly oppose the Governments withdrawal of funding for the Growth Hormone Therapy for the Children suffering with Kidney failure. I urge the Federal Government to reintroduce the funding of The Growth Hormone for these children.

Name	Address	Signature	Date

Please reply to:

The Kidney Kid's Growth Therapy Petition
PO Box 673 Gladesville NSW 2111

This information will not be sold, disclosed or forwarded to any Third Party

App K 1.

Kidney Kid's Petition

UPDATE

The latest update to transpire is that the Sydney Morning Herald covered our situation on Wednesday 11 November 1998.

By telling our side of the story we were hoping this would add pressure to the Government.

Myself, Ada and Nicholas were then approached by a Current Affair who wanted to conduct an indepth interview in which we were able to detail more of our plight.

The cover story was supposed to go to air on Monday 16 November or Tuesday 17 November. The respective Government body was notified prior to going to air and requested A Current Affair to delay the story as they had now decided to postpone their original decision and undertake a further 12 months research.

The good news is that the Government advised that the Kidney Kids who are on the growth hormone would maintain their treatment. Any child who becomes eligible will also receive the treatment.

I've been advised that by July 1999, the Government may hand down its decision. In the meantime, our renal consultants our now able to collect further data and assess that the hormone treatment is effective for our children.

This does not mean that the petition will cease, as we are not guaranteed that the decision will be reversed in the year 2000. We now have approx 6-12 months to prepare ourselves for yet another battle with the Government and we hope to again add pressure so they will permanently reverse their decision.

I strongly urge you to continue writing to your local member and collect petition signatures from the community. We have had a great response from family and friends and we are still receiving many petition letters. The response so far has greatly contributed to the Government reconsidering its position.

I'm sure you would agree that we should maintain our action. If the decision is not reversed A Current Affair have ensured me that they will resume the coverage of our story.

I will keep you informed on the Government's decision and what action we will need to take.

Yours faithfully

Michael Wilson

App X 2

DEPARTMENT OF PAEDIATRICS & CHILD HEALTH

Flinders University of South Australia

Flinders Medical Centre
Bedford Park
South Australia 5042
Australia

15th September 1998

Dr Colin Jones
Chairman
Department of Nephrology
Royal Children's Hospital
Flemington Road
Parkville Vic. 3052

Dear Dr Jones

Re: Involvement of your Paediatric Specialist Group in provision of material for a National Medical Student Paediatric Electronic Learning Environment Network

The Academic Paediatric Departments in Australia and New Zealand have agreed to co-operatively develop a bi-national web site that will assist in meeting the training needs of medical students undertaking their paediatric attachment. This web site, which is in the early stages of development, is being supported by an overseeing Board. The architecture of this web site is not yet fully articulated, but will have as one major component clinical cases which can be delivered electronically to students, irrespective of time and place. The intention is to provide the elements of an interesting case each week. The major paediatric disciplines will all be represented, essentially requiring each discipline to provide one case approximately every three months.

We know student learning of clinical medicine is enhanced if this learning is structured around problem solving of clinical cases. Hence we intend to provide a case where there is a brief stem of text followed by appropriately resources, perhaps x-rays, videos, still pictures etc. which embellish and make more real the case to the students. Once the student has digested the brief stem of the case using the text and visual clues, there would need to be a series of brief questions, perhaps three in total, which encourage critical reasoning from the student.

Telephone
(08) 8204 4433

International
(618) 8204 4433

Facsimile
(08) 8204 5593

International
(618) 8204 5593

Email:
Kevin.Forsyth@flinders.edu.au

We will provide the digitising that is required and the assembly of the case in the electronic form that will be needed for web delivery.

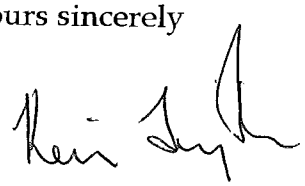
I am keen to see the Paediatric Specialty Groups assist in the provision of resources for our medical students. We will provide the required informed consent for clinical material which might identify, or potentially identify, clinical subjects who are used for this teaching purpose. We will also provide full acknowledgments from the individuals who provide this source of material and the specialty group concerned.

I hope you feel that you are able to participate in this exercise. I would be grateful as a first step, if you are willing to be engaged, to provide me with the name of a link person that the Board could communicate with to advance this proposal into concrete cases.

Please feel free to contact me if you require clarification on any elements of this initiative.

Kind regards.

Yours sincerely



Kevin Forsyth

Appx 3.

NHMRC

National Health and Medical Research Council

Health Advisory Committee

Contact for this correspondence:
Name: Monica Johns
Telephone: (02) 6289 5676
Facsimile: (02) 6289 5923

In reply please quote: Chronic Renal Failure

Dr Andrew Rosenberg
Convenor, ANZPNA
Department of Nephrology
The Prince of Wales Children's Hospital
High Street
RANDWICK NSW 2031

Dear Dr Rosenberg

I am most embarrassed to say that a letter that you sent to the NHMRC in February has only now come to my attention. I offer you my sincere apologies for that.

The matter you raised in that letter – appropriate care of children with chronic renal failure – is clearly important and I am grateful that your Association is taking it with an appropriate degree of seriousness.

I was wondering if this is an issue that deserves the development of clinical practice guidelines: they may already exist, if this is the case pardon my ignorance. But if they do not, and you feel that there is solid evidence of deleterious variation management of this problem, you may wish to consider developing guidelines. The Health Advisory Committee is committed to working with groups who are developing guidelines and there are various practical ways in which we can assist. Please give it some thought and if this is of interest, let me know. I promise not to be so tardy in replying to your next letter.

Sincerely

Stephen Leeder

Chair
Health Advisory Committee

6 August 1998

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Date:	November 9, 1998
T	Dr Colin Jones, Renal Unit Royal Children's Hospital
Fax:	03 9345 5611
From:	George Krassas
Subject:	PEADIATRIC IBUPROFEN
Page(s):	2 including this sheet

Dear Dr Jones,

As discussed the NDPSC are considering the rescheduling of paediatric ibuprofen from S4 to S2, which means it could be sold in pharmacy without the supervision of a pharmacist and could be advertised directly to the consumer.

If in your opinion you believe this may not be in the best interest for the appropriate use of ibuprofen you may want to consider writing to the NDPSC and expressing your opinion.

If you decide to do this you should forward your letter to:

The Secretary
National Drugs and Poisons Schedule Committee
PO Box 100
WODEN ACT 2606

Note the NDPSC are meeting the week commencing 16 November 1998 to review this decision.

Please call me if you need any supporting documentation as I have several papers which investigate this issue including those listed below.

Renal papers	*Comments made*
Moghal NE et al. Care in the use of ibuprofen as an antipyretic in children. Clin Nephrol 1998 May; 49 (5):293-5.	In the ill, febrile child, hypovolemia may develop because of increased evaporative loss, possibly compounded by diarrhoea and vomiting. Prescribing a NSAID in this situation may cause unopposed renal vasoconstriction, renal hypoperfusion, decreased glomerular filtration rate and renal ischemia. We discuss the mode of action of ibuprofen and recommend that its use as an antipyretic in children should be avoided in actual or potential intravascular volume contraction and in cases with pre-existing renal problems.
Henrich WL et al. Analgesics and the kidney: Summary and recommendations to the scientific advisory board of the National Kidney Foundation from an ad hoc committee of the National Kidney Foundation. Am J Kid Dis 1996; 27 (1): 162-165	The use of NSAIDs is safe when the drugs are taken in therapeutic doses for a limited period. Patients with preexisting risk factors including ... volume depletion, are susceptible to potentially life threatening nephrotoxicty, including acute renal failure and serious fluid and electrolyte disorders.

Note, patients who were 10% dehydrated were excluded from many studies investigating the use of ibuprofen in children, which Dr Elizabeth Hodson indicated is a not uncommon event in young children.

Also note, paediatric ibuprofen is indicated for use in patients from 6 months.

Yours sincerely,

George Krassas
Medical Marketing Manager

REGULATIONS FOR MANAGEMENT AND ARTICLES OF ASSOCIATION OF A COMPANY LIMITED BY GUARANTEE

THE AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

1. NAME:

The name of the Company is "The Australian and New Zealand Paediatric Nephrology Association" (hereinafter called "ANZPNA").

2. OBJECTIVES:

The objectives for which the ANZPNA is established are:

(a) To encourage promote foster and develop the study of paediatric nephrology in Australia and New Zealand.

(b) To promote and maintain the highest standards of diagnosis and management of disorders of the kidneys and urinary tract in infants, children and young people and advance the practice of paediatric nephrology in Australia and New Zealand and to encourage and stimulate research in Paediatrics.

(c) To act as a consultant and advisory body on paediatric nephrology in Australia and New Zealand and elsewhere.

(d) To promote personal intercourse and friendship among persons engaged in paediatric nephrology in Australia and New Zealand and elsewhere.

(e) To become a member of subscribe to or affiliate with or to grant affiliation with it to any other organization whether incorporated or not having objects altogether or in part similar to those of the ANZPNA or having for its objects or one of its objects the promotion fostering or developing of paediatric nephrology or allied sciences provided that the ANZPNA shall not subscribe to or support with its funds any organisation which does not prohibit the distribution of its income and property among its members to an extent at least as great as that imposed on the ANZPNA under and by virtue of Clause 4 of these Regulations.

(f) Subject to Section 383 of the Corporations Law to take over the property assets and effects and liabilities of the present unincorporated Association known as Australian and New Zealand Paediatric Nephrology Association and for that purpose to execute and carry into effect any contract deed or other instrument which may be necessary.

(g) To cultivate and maintain the highest principles of practice and ethics in persons engaged in paediatric nephrology in Australia and New Zealand.

(h) To promote arrange and conduct conferences meetings lectures discussions and demonstrations on or concerning paediatric nephrology and to diffuse information concerning diseases of the kidneys and urinary tract in infants, children and young people and as to the causes and effects thereof and the prevention and cure of the same.

(i) In furtherance of these objects to consider originate and promote so far as relates to the objectives of the ANZPNA alterations and improvements in the law and to oppose or support alterations therein and for such purposes to petition Parliament and take such action or proceedings as may be deemed expedient.

(j) To acquire establish print and publish magazines periodicals journals transactions treatises leaflets papers or other literary or scientific works which the ANZPNA may think desirable in furtherance of these objects or any of them.

(k) To make and grant awards or other benefactions and establish scholarships and prizes for or in connection with the study of and research in paediatric nephrology.

(l) Subject to Section 383 of the Corporations Law, to accept any gift endowment or bequest made to the ANZPNA generally or for the purpose of any specific object and to carry out any trusts attached to any such gift endowment or bequest.

(m) To undertake and execute any trusts the undertaking whereof may be necessary or convenient for the carrying out of any of the objects of the ANZPNA.

(n) To procure the ANZPNA to be registered or recognized in any country or place outside the State of Victoria.

(o) Subject to any restrictions as may for the time being be imposed by law to purchase take on lease or in exchange hire or otherwise acquire any real and personal property where-so-ever situate and any rights or privileges which the ANZPNA may think necessary or convenient for the purposes of the ANZPNA.

(p) To construct maintain and alter any buildings or works necessary or convenient for the purposes of the ANZPNA.

(q) To sell improve manage develop exchange lease mortgage dispose of turn to account or otherwise deal with all or any part of the property and rights of the ANZPNA.

(r) To borrow or raise or secure the payment of money in such manner as the ANZPNA shall think fit and in particular by the issue of debentures or debenture stock perpetual or otherwise charged upon all or any of the property of the ANZPNA both present and future and to purchase redeem or pay off any such securities.

(s) Subject to Section 383 of the Corporations Law to invest and deal with the moneys of the ANZPNA not immediately required in such manner as may from time to time be determined. Provided that such moneys shall be invested only in such forms of investment as may be permitted by law for the investment of trust funds.

(t) To draw make accept endorse discount execute and issue promissory notes bills of exchange warrants debentures and other negotiable or transferable instruments.

(u) From time to time to make rescind or alter such by-laws not being inconsistent with any Statute or with these objectives or with these regulations the ANZPNA for the time being in force for the regulation of any of the affairs of the ANZPNA as may be deemed necessary or convenient.

(v) To do all such other things as are incidental or conducive to the attainment of the above objects or any of them.

The intention is that unless the context shall otherwise require the objects specified in each paragraph of this clause shall be independent main objects and shall be in no wise limited or restricted by reference to or inference from the terms of any other paragraph or the name of the ANZPNA. And it is hereby declared that in case the ANZPNA shall take or hold any property which may be subject to any trusts the ANZPNA shall only deal with the same in such manner as allowed by law having regard to such trusts.

3. INCOME AND PROPERTY:

The income and property of the ANZPNA from whatsoever source derived shall be applied solely towards the promotion of the objects of the ANZPNA as set forth in these regulations and no portion thereof shall be paid or transferred directly or indirectly by way of dividend bonus or otherwise howsoever by way of profit to members of the ANZPNA provided that nothing herein contained shall prevent the payment in good faith of reasonable and proper remuneration to any officers or servants of the ANZPNA or to any member of the ANZPNA in return for any services actually rendered to the ANZPNA nor prevent the payment of interest at a rate not exceeding the rate for the time being charged by bankers in Melbourne for overdrawn accounts on money borrowed from any member of the ANZPNA or reasonable and proper rent for premises demised or let by any member to the ANZPNA, but so that no member of the Council or Governing Body of the ANZPNA shall be appointed to any salaried office of the ANZPNA or any office of the ANZPNA paid by fees and that no remuneration or other benefit in money or money's worth shall be given by the ANZPNA to any member of such Council or Governing Body except repayment of out-of-pocket expenses and interest at the rate aforesaid on money lent or reasonable and proper rent for premises demised or let to the ANZPNA provided that the provision last aforesaid shall not apply to any payment to any Railway Gas Electric Lighting Water or Telephone company of which a member of the Council of Management or Governing Body may be a member or to any other company in which such member shall not hold more than a one-hundredth part of the capital and such member shall not be bound to account for any share of profits he may receive in respect of any such payment and that the said provision shall not apply to the payment in good faith of reasonable and proper remuneration and expenses in any one year to not more than one-third in number of the members of the Council of Management or Governing Body of the ANZPNA for their services as Examiners Lecturers or Demonstrators in connection with the teaching and examining work of the ANZPNA in which case when by reason of their ability or their ability and other reasons the Council or Governing Body is of the opinion that such services of such members are pre-eminently desirable in the interests of the Council.

4. ALTERATIONS:

No alteration addition or amendment shall be made to or in these regulations for the time being in force unless the same shall have been previously submitted to and approved by the Australian Securities Commission.

5. SECTION 383 AUSTRALIAN SECURITIES COMMISSION

The third and fourth paragraphs of these regulations contain conditions upon which a license is granted by the Australian Securities Commission to the ANZPNA in pursuance of the provisions of Section 383 of the Corporations Law .

6. LIABILITY

The liability of the members is limited.

7. WINDING UP

(a) Every member of the ANZPNA undertakes to contribute to the assets of the ANZPNA in the event of its being wound up while he is a member or within one year afterwards for payment of the debts and liabilities of the ANZPNA contracted before the time at which he ceases to be a member and the costs charges and expenses of winding up and for the adjustment of the rights of contributories among themselves such amount as may be required not exceeding twenty dollars

(b) If upon the winding up or dissolution of the ANZPNA there remains after satisfaction of all its debts and liabilities any property whatsoever the same shall not be paid to or distributed amongst the members of the ANZPNA but shall be given or transferred to a corporation set up by Royal Charter or Act of Parliament having objects substantially similar to the objects of the ANZPNA or to some other institution or institutions having objects similar to the objects of the ANZPNA and which shall prohibit the distribution of its or their income and property among its or their members to an extent at least as great as is imposed on the ANZPNA under or by virtue of the fourth paragraph hereof such institution or institutions to be determined by the members of the ANZPNA at or before the time of dissolution and in default thereof by the Chief Judge in Equity of the Supreme Court of Victoria or such other Judge of that Court as may have or acquire jurisdiction in the matter, and if and so far as effect cannot be given to the aforesaid provision then to some charitable object.

8. ACCOUNTS:

True accounts shall be kept of the sums of money received and expended by the ANZPNA and the matters in respect of which such receipts and expenditure take place and of the property credits and liabilities of the ANZPNA and subject to any reasonable restrictions as to time and manner of inspecting the same that may be imposed in accordance with the regulations of the ANZPNA for the time being the same shall be open to the inspection of the members. Once at least in every year the accounts of the ANZPNA shall be examined and the correctness of the balance sheet ascertained by one or more properly qualified auditor or auditors.

ARTICLES OF ASSOCIATION

of

THE AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

Interpretation

1. In these articles of association unless the context otherwise requires-

"The ANZPNA" means the company registered as "The Australian and New Zealand Paediatric Nephrology Association".

"Executive" means the governing body of the ANZPNA herein provided for.

"Member" means a member of the ANZPNA.

"General Meeting" means an annual general meeting or an extraordinary general meeting and any adjourned holding thereof.

"Annual Meeting" means the annual general meeting of Members.

"Office" means the registered office of the ANZPNA for the time being.

"The Chair, "The Honorary Secretary", and "The Honorary Treasurer", mean those respective officers for the time being of the ANZPNA and include any persons appointed to perform the duties of those respective officers temporarily.

"In writing" and "written" include typing, printing or lithographing and other modes of representing or reproducing words and figures in a visible form.

Words importing the singular number include the plural number, and words importing the plural number include the singular number.

Words importing the masculine gender shall include the feminine gender and vice versa.

Words importing persons shall include corporations and companies.

"Month" means calendar month.

"By-laws" means the by-laws of the ANZPNA passed pursuant to these articles of association.

"The Law " means the Corporations Law as amended from time to time.

Membership

2. The subscribers to the Articles of Association and such other persons as shall be admitted to membership in accordance with these articles of association and none others shall be members of the ANZPNA.

3. For the purposes of registration the ANZPNA is declared to consist of Twenty Four (24) Members but the Executive may from time to time register an increase in the number of Members.

Membership Requirements

4. Medical Practitioners who hold a medical qualification conferred by an institution recognised by the ANZPNA and have a substantial involvement in paediatric nephrology shall be eligible to be admitted to membership of the ANZPNA.

Every applicant for membership of the ANZPNA must be proposed and seconded by Members and he or she must sign and deliver to the Honorary Secretary not less than one month before a general meeting an application for membership framed in such terms as the Executive shall require.

Every applicant for membership of the ANZPNA shall in his application state his agreement to abide by the articles of association and by-laws of the ANZPNA and to pay his annual subscription so long as he shall remain a Member.

All valid applications will be submitted to the next general meeting.

Trainees in Paediatric Nephrology may be admitted as Associate Members under conditions determined by the Executive from time to time.

Notification of Membership

5. When an applicant for membership of the ANZPNA has been admitted notice to that effect shall be sent to him by the Secretary together with a request for the payment of the annual subscription payable on his admission.

Subscription

6. No person shall be deemed to be a Member nor shall his admission to membership be effective until he shall have paid the annual subscription payable on his admission.

Membership Non-Transferable

7. The rights and privileges of a Member shall be to himself and shall not be transferable.

Membership Dues

8. There shall be payable to the ANZPNA by each Member (other than an Honorary Member) for each year during which he remains a Member an annual subscription which shall become payable in advance on the first day of January in each year. The annual subscription shall be such a range as the ANZPNA shall from time to time in general meeting determine. The Executive may in its absolute discretion reduce the subscription of any Member or class of Members to such an extent as the Executive shall determine.

Honorary Member

9. Honorary Members may be elected from medical practitioners who have rendered outstanding Service to paediatric nephrology in Australia and New Zealand for which the ANZPNA desires to confer honor. Honorary Members shall be elected by the membership at a General Meeting. Honorary Members may enjoy all the privileges and benefits of membership of the ANZPNA.

Resignation of Member

10. Any Member may resign his membership on giving to the Council three months notice in writing of his intention to resign and his resignation shall take effect at the expiration of such notice provided that no resignation of a Member shall be accepted or take effect unless and until all arrears of subscription due by such Member to the ANZPNA have been paid.

Termination of Membership

11. The membership of any Member shall be terminated ipso facto in any of the following events.

(a) On his death.

(b) If he ceases to retain any of the qualifications rendering him eligible for admission to membership of the ANZPNA.

(c) If he be in arrears with his annual subscription for two years and if after that period he shall fail to pay such arrears within two months after application is made to him in writing by the Honorary Treasurer to pay the same.

(d) If he become or be made bankrupt or insolvent under any of the laws relating to bankruptcy or insolvency for the time being in force in Australia and New Zealand, but the Executive shall have power to declare that the membership of a Member shall be deemed not to have been terminated by his bankruptcy or insolvency and thereupon the membership of such Member shall continue as though he had not become bankrupt or insolvent.

(e) If he becomes mentally ill.

(f) By expulsion from membership by the ANZPNA in general meeting on the ground that the conduct of the Member is or has been detrimental to the honor and/or interests of the medical profession or of the ANZPNA or is or has been calculated to bring the medical profession or the ANZPNA into disrepute or contempt or on the ground that he has wilfully and persistently refused to comply with or has committed a wilful breach of these articles of association or of any by-laws of the ANZPNA provided however that a Member shall not be expelled from the ANZPNA except upon a resolution of a majority of at least three-fourths of the Members present and voting at an extraordinary general meeting of the ANZPNA at which there shall be present at least one-half of the Members for the time being and of which meeting such Member shall have been given at least seven clear days' notice. The notice shall state the purpose of the meeting and what is alleged against the Member concerned and such Member shall be entitled to attend such meeting and be given the opportunity to be heard in his own defence and of stating his case to the meeting, but the Member concerned shall not be permitted to be present at the voting or permitted to otherwise take part in the proceedings of the meeting except as the meeting allows.

Continuing Membership

12. Every Member shall remain a Member until his membership is terminated in accordance with the provisions of these articles of association.

Arrears of Subscription

13. If any Member shall by any means cease to be a Member of the ANZPNA he shall nevertheless remain liable for and pay to the ANZPNA all moneys which at the time of his ceasing to be a Member may be due from him to the ANZPNA.

Readmission

14. No person who shall have been a Member and ceased to be such shall be eligible for readmission until he shall have paid all arrears of subscription, if any, due from him to the ANZPNA at the date when his former membership ceased.

Register of Members

15. There shall be a register of Members kept by the ANZPNA and there shall be entered in such register the full name and address and occupation of each Member and such other particulars as shall be by Statute required to be entered therein and such further particulars as the Council shall from time to time prescribe.

General Meetings

16. The first annual meeting of the ANZPNA shall be held at such time during the year One thousand nine hundred and ninety-nine and at such place as the Executive may determine.

Time of Annual Meeting

17. Subsequent annual meetings of the ANZPNA shall be held once in every year at such time not being more than fifteen months after the holding of the last preceding annual meeting at a time and place as the Executive may determine.

Extraordinary Meeting

18. The meetings referred to in the last preceding article shall be ordinary meetings; all other meetings shall be called extraordinary meetings.

19. The Executive may whenever it thinks fit convene an extraordinary meeting. Extraordinary meetings shall also be convened and held as provided for in the Law.

Notice of AGM.

20. Not less than five weeks notice of a general meeting specifying the place the day and the hour of meeting and in case of special business the general nature of such business shall be given to the Members in manner hereinafter mentioned or in such other manner (if any) as may be prescribed by the ANZPNA in general meeting but the non-receipt of such notice by any Member shall not invalidate the proceedings at any general meeting.

21. The accidental omission to give such notice of meeting to any of the Members shall not invalidate any resolution passed at any such meeting.

Proceedings at General Meetings

Business of AGM.

22. The business of an annual meeting shall be:

(a) To receive and consider the report of the Executive.

(b) To receive and consider the accounts of the ANZPNA for the past year.

(c) The Declaration by the Chair of the result of the election of members of the Executive.

(d) To admit persons as Members.

(e) To consider any motion of which at least twenty-eight days notice in writing shall have been given to the Honorary Secretary.

(f) Any other business which may be lawfully transacted at the annual meeting.

All other business transacted at the annual meeting and all business transacted at an extraordinary meeting shall be deemed special.

Quorum AGM.

23. No business shall be transacted at any general meeting unless a quorum of Members is present. Except as hereinafter provided thirty percent of the membership or 10 members whichever is the greater personally present and entitled to vote shall be a quorum for a general meeting.

Quorum Not Present

24. If within one-half hour from the time appointed for meeting a quorum of Members is not present the meeting if convened upon the requisition of Members shall be dissolved. In any other case it shall stand adjourned until the following day at the same time and place and if at such adjourned meeting a quorum of Members is not present those Members who are present shall be a quorum and may transact the business for which the meeting was called.

Chairman AGM.

25. The Chair shall except as hereinafter provided preside as chairman at every general meeting of the ANZPNA.

Alternative Chairman AGM.

26. If at any meeting the Chair is not present within fifteen minutes after the time appointed for the holding of the same, or being present is unwilling or unable to act as chairman the members present shall elect one of their number to be the chairman of the meeting.

Adjournment of Meeting

27. The chairman may with the consent of the meeting adjourn any meeting from time to time and from place to place but no business shall be transacted at any adjourned meeting other than the business left unfinished at the meeting from which the adjournment took place.

Voting at Meeting

28. Every question submitted to a meeting shall be decided in the first instance by a show of hands and in the case of an equality of votes the chairman shall both on a show of hands and at a poll have a casting vote in addition to the vote to which he is entitled as a Member.

Record of Motions

29. At any general meeting unless a poll is demanded by the chairman or at least five members present a declaration by the chairman that a resolution has been carried or carried by a particular majority or lost or not carried by a particular majority and an entry to that effect in the book of proceedings of the ANZPNA shall be conclusive evidence of the fact without proof of the number or proportion of the votes recorded in favour of or against such resolution.

Poll

30. If a poll is demanded in manner aforesaid the same shall be taken in such manner either by way of postal vote or otherwise as the chairman directs and either at once or after an interval or adjournment or otherwise and the result of such poll shall be deemed to be the resolution of the ANZPNA in general meeting. The demand of a poll shall not prevent the continuance of a meeting for the transaction of any business other than the question on which a poll has been demanded. A demand for a poll may be withdrawn.

Votes of Members

Vote at Meeting

31. On a show of hands every member present shall have one vote and on a poll other than by way of postal vote every member present in person or by proxy shall have one vote and on a poll by way of postal vote every member shall have one vote.

Non Financial Members No Vote

32. No Member shall be entitled to vote at any general meeting unless all moneys presently payable by him to the ANZPNA have been paid.

Proxy

33. Votes may be given either personally or by proxy. The proxy shall be appointed in writing under the hand of the Appointor. A proxy must be a Member.

Instrument of Proxy

34 The instrument appointing a proxy shall be valid only if received by the Honorary Secretary before the time of holding the meeting at which the person named in such instrument proposes to vote. No instrument appointing a proxy shall be valid after the expiration of twelve months from its date unless it is expressly stated therein that it is to extend for a longer period.

35. Any instrument appointing a proxy shall be in the following form:

The Australian and New Zealand Paediatric Nephrology Association

I of

being a Member of the Australian and New Zealand Paediatric Nephrology Association hereby appoint

as my proxy to vote for me and on my behalf at the (annual ordinary or extraordinary as the case may be) general meeting of the Company to be held

on the of and at any adjournment thereof
(or at any meeting of the Company that may be held in the year 19)

AS WITNESS my hand this day of

SIGNED by the said

In the presence of

Governing Body - The Executive Committee

36. The affairs of the ANZPNA shall be managed and controlled by an Executive Committee which shall composed of Chair, Immediate Past Chair, Honorary Secretary and Honorary Treasurer. There will be no immediate Past Chair in the initial Executive Committee. The Executive shall have the power to coopt additional members from time to time.

The Honorary Officers

37. There shall be the following honorary officers of the ANZPNA namely a Chair, the Honorary Secretary and an Honorary Treasurer who will be Members. The Officers will be elected by the Members at the Annual General Meeting, will serve for two (2) years and will not be eligible for immediate re-election. The retiring Chair will serve an additional term of two (2) years as Immediate Past Chair.

Term of Executive Committee

38. Subject as otherwise herein provided members of the Executive shall retain office until the conclusion of the Annual Meeting at which their successors are declared elected or assume office.

39. No member of the Executive shall receive any remuneration for his or her services in the capacity of a member of the Executive.

40. (a) **Powers of Incomplete Executive**
In default of and until the election of any member or members whereby the number of members of the Executive is incomplete all the powers conferred on the Executive shall belong to and may be exercised by such members of the Executive as shall then be in office.

(b) **Vacancy on Executive**

Provided that in the case of a vacancy in the Executive occasioned by failure to elect at an election, the Members of the Executive then in office may appoint a Member to fill the vacancy. Any casual vacancy in the Executive may be filled by the Executive. A Member so elected or appointed to fill a vacancy as aforesaid shall, subject to the provisions of Article 41, retain his office only until the conclusion of the next Annual Meeting at which the relevant Executive Member is to retire.

41. **Vacation of Office of Executive Members**

The office of a member of the Executive shall be vacated if the member:

(a) holds any office of profit under the ANZPNA.

(b) becomes bankrupt or makes any arrangement or composition with his creditors generally; or

(b) becomes prohibited from being a director of a company by reason of any order made under the Law ; or

(d) becomes of unsound mind or a person whose person or estate is liable to be dealt with in any way under the law relating to mental health; or

(e) resigns his office by notice in writing to the ANZPNA; or

(f) ceases to be a Member ; or

(g) ceases to be a member of the Executive by virtue of the Law ; or

(h) for more than six months is absent without permission of the Executive from meetings of the Executive held during that period; or

(i) is directly or indirectly interested within the meaning of the Law in any contract with the ANZPNA or participates in the profits of any contract with the ANZPNA. Provided however that a member of the Executive shall not vacate his office by reason of his being a member of any corporation society or association which has entered into contracts with or done any work for the ANZPNA if such corporation society or association is among the class of companies referred to in the last proviso to Clause 4 of the Regulations of the ANZPNA and if he shall have declared the nature of his interest in manner required by the Law . A member of the Executive shall not vote in respect of any contract in which he is interested or any matter arising there out and if he does so vote his vote shall not be counted.

Vacancy in Executive Offices

42. In the event of the death during his term of office or resignation of the Chair the Honorary Secretary shall discharge the duties of the Chair until the conclusion of the next Annual Meeting.

Honorary Secretary's Duties

43. The Honorary Secretary shall summon all meetings of the ANZPNA and of the Executive and be responsible for entering the minutes of meetings of the ANZPNA and of the Executive in the books to be provided for that purpose.

Treasurer's Duties

44. The Honorary Treasurer shall manage the financial affairs of the ANZPNA and present the annual accounts of the ANZPNA to the Executive.

Frequency of Executive Meetings

45. The Executive shall meet not less than twice in each year and one of such meetings shall be held as soon as practicable after the close of the Annual Meeting of the ANZPNA in each year and one of such meetings shall be held immediately before the Annual Meeting of the ANZPNA to be held in each year. For the purposes of this Article a year shall be the period commencing at the conclusion of an Annual Meeting and ending at the conclusion of the next succeeding Annual Meeting.

46. Subject to the provisions of Article 55 the Executive shall meet for the transaction of business at such times or places at it may from time to time by resolution determine or as the Honorary Secretary may direct.

Executive Quorum

47. No business shall be transacted at a meeting of the Executive unless a quorum of the members thereof is present. Unless otherwise determined two members personally present or communicating by telephone or video conference shall constitute a quorum.

Chairman of Executive Meeting

48. At every meeting of the Executive the Chair or in his absence the Honorary Secretary shall be chairman.

Executive Voting

49. Questions arising at any meeting of the Executive shall be decided by a majority of votes and each member present shall have one vote and in the case of an equality of votes the chairman of the meeting shall have a second or casting vote.

Written Resolution

50. A resolution in writing signed by all members of the Executive shall be as valid and effectual as if it had been passed at a meeting of the Executive duly convened and held and such resolution shall be entered by the Honorary Secretary in the Minute Book and ratified by the Executive at its next meeting.

Proxy at Executive Meetings

51. In the event of a member of the Executive being unable to attend any meeting of the Executive he may nominate another Member to act as his substitute or to be his proxy at such meeting. The nomination of a substitute or proxy shall be in writing and signed by the member of the Executive making the nomination and must be produced at the meeting of the Executive in respect of which it is made.

Powers of the Executive

Powers of Executive

52. The management and control of the business and affairs of the ANZPNA shall be vested in the Executive and the Executive may exercise all such powers and do all such acts and things as the ANZPNA is by its Regulations or otherwise authorised to exercise and do and are not hereby or by Statute directed or required to be exercised or done by the ANZPNA in general meeting but subject nevertheless to the provisions of the Regulations of any Statute or of these presents.

Delegation of Executive Power

53. The Executive may delegate any of its power to other Committees consisting of such member or members of its body as it shall think fit and may from time to time make such delegation. Any Committee so formed shall in exercise of its powers so delegated conform to any regulations that may from time to time be imposed upon it by the Executive.

Secretary

54. A Secretary shall in accordance with the Law be appointed by the Executive for the performance in relation to the ANZPNA of the statutory duties and functions required to be performed by the Secretary of a company at such remuneration and upon such conditions as the Executive shall deem advisable and any Secretary so appointed may be removed by the Executive and provided that any duty act or thing required by these Articles to be performed or done by the Honorary Secretary may if the Executive so directs be performed or done by the Secretary. Nothing herein shall prevent the Executive from appointing a Member as Honorary Secretary and any Member so appointed shall forthwith become an officer of the ANZPNA and if not already a Member of the Executive ex-officio a Member of the Executive and he shall be subject to Clause 4 of the Regulations.

Funds

55. The Treasurer shall receive all funds of the ANZPNA and disburse the same. Unless and until the Executive shall otherwise determine cheques shall be signed by the Honorary Treasurer and one of such other persons as shall be authorised for such purposes by the Executive.

Seal

56. The Executive shall provide for the safe custody of the Seal of the ANZPNA and the same shall never be used except by the authority of the Executive previously given and in the presence of at least two members of the Executive who shall sign every instrument to which the Seal is affixed and every instrument to which the Seal is affixed shall be countersigned by the Honorary Secretary or some other person appointed by the Executive for that purpose.

Accounts

57. The Executive shall cause proper accounts to be kept with respect to:

(a) All sums of money received and expended by the ANZPNA and the matters in respect of which the receipt and expenditure takes place.

(b) All sales and purchases of goods by the ANZPNA.

(c) The assets and liabilities of the ANZPNA.

Statements of Account

58. The Executive shall from time to time cause accounts to be kept as provided by Clause 8 of the Regulations and shall from time to time in accordance with the Law cause to be prepared and to be laid before the ANZPNA in general meeting such income and expenditure accounts balance sheets and reports as are required by the Law to be prepared and laid before the ANZPNA made up to a date not more than six months before the date of the meeting.

Distribution of Balance Sheet before AGM.

59. A copy of every balance sheet (including every document required by law to be annexed or attached thereto) which is to be laid before the ANZPNA in general meeting shall not less than fourteen days before the date of the meeting be sent to all persons entitled to receive notice of general meetings of the ANZPNA.

Auditors

60. Auditors shall be nominated and appointed and their duties regulated in accordance with the Law and Clause 9 of the Regulations.

61. Every account of the Executive when audited and approved by a general meeting shall be conclusive except as regards any error discovered therein within three months next after the approval thereof. Whenever any such error is discovered within that period the account shall forthwith be corrected and thenceforth shall be conclusive provided that nothing in this article shall give a conclusive effect to any matter or thing arising out of or involving a breach of Clause 3 of the Regulations.

Notices

Notice to Members

62. A notice may be served by the ANZPNA upon any Member either personally or by sending it through the post in a prepaid envelope or wrapper or by electronic means addressed to such Member at his registered place or address.

63. Every Member whose registered place of address is not in Australia and New Zealand may from time to time notify in writing to the ANZPNA an address in Australia and New Zealand which shall be deemed his registered place of address within the meaning of the last preceding Article.

64. As regards those Members who have no registered place of address a notice posted up in the office of the ANZPNA shall be deemed to be well served on them at the expiration of twenty-four hours after it is so posted up.

Certification of Notice

65. Any notice sent by post shall be deemed to have been served on the day following that on which the envelope or wrapper containing the same is posted and in proving such service it shall be sufficient to prove that the envelope or wrapper containing the notice was properly addressed stamped and put in the post office and a certificate in writing signed by the Honorary Secretary or other officer of the ANZPNA that the envelope or wrapper containing the notice was so addressed and posted shall be prima facie evidence thereof. Any notice sent by electronic means shall have been deemed to have been served on the day sent and in proving such service it shall be sufficient to for the Honorary Secretary to show a certified copy of a delivery statement returned to the sender by the provider of the means of electronic data transfer and a certificate in writing signed by the Honorary Secretary that the message was addressed to the electronic data delivery address supplied by the Member.

Signature of Notice

66. The signature of any notice to be given by the ANZPNA may be written or printed.

Counting Days of Notice

67. Where a given number of days notice or notice extending over any other period is required to be given the day of service shall (unless it is otherwise provided) be counted in such number of days or other period.

Indemnity of Officers

Indemnity of ANZPNA Officers

68. Every member of the Executive, the Honorary Secretary, the Honorary Treasurer or other officer of the ANZPNA or Auditor of the ANZPNA shall be indemnified out of the funds of the ANZPNA against all liability incurred by him as such member, officer or auditor in defending proceedings whether civil or criminal in which judgement is given in his favour or in which he is acquitted or in connection with any application under the Law in which relief is granted to him by the Court.

By-Laws

Regulations or By-Laws/Amendment of Regulations or By-Law

69. Save in so far as otherwise determined by Statute or these articles the ANZPNA shall have full power to make regulations or by-laws not inconsistent with the Regulations or these articles on all matters relating to the affairs of the ANZPNA and the conduct or management of its business and of the business of all committees or otherwise for the purpose of carrying out its objects and also on all matters relating to ethics as concerning Members and the rights and obligations of Members and all regulations or by-laws so made and for the time being in force shall be binding on the Members as if they formed part of these articles and shall have full effect accordingly. Provided that any regulation or by-law so made may be rescinded or amended by resolution of any general meeting of the ANZPNA.

REGULATIONS FOR MANAGEMENT AND ARTICLES OF ASSOCIATION OF A COMPANY LIMITED BY GUARANTEE

Covering letter from Paul Roy (edited):

1. (The Regulations for management and Articles of Association of a Company Limited by guarantee form) a long document. It is intended to serve the association as it grows and becomes influential medically, scientifically and politically. Changes must be registered and a fee is payable.

2. Incorporation will cost $405. $115 of this goes to permission to omit the word Limited from the name of the association.

3. You will notice an Honorary Secretary and a Secretary appear. The latter is a Statutory requirement and must be defined. The Honorary Sec can perform any functions of the Company Secretary.

4. I used documents and suggested layouts from the ASC and the articles of the ACP.

5. It is not necessary to include provision for reimbursement of costs for Executive Members to attend meetings. This can be covered by resolution.

6. There must be at least 5 subscribers. The names etc of these their signatures and the names etc and signatures of witness is completed on the last page as I have indicated by example. If the document is approved the 3 current executive and 2 other members could be filled in as the subscribers and the document lodged with Form 201 and 305 together with a Statutory Declaration in relation to not using "limited", which I will send in the mail with a disk.

PROGRESS REPORT ON THE STUDY "GROWTH HORMONE USE IN PAEDIATRIC RENAL DISEASE"

This project is being undertaken on behalf of members of the ANZPNA. The main focus of the study is to statistically analyse data collected by the OZGROW Data Base with respect to children with renal disease, with the aim of documenting the response to growth hormone therapy in this group of patients. With the Federal Government's recent decision to withdraw funding for growth hormone therapy in patients with renal disease, there is now some urgency in completing the project to enable what will hopefully be a supportive report to be made to the Government.

A preliminary analysis of the data has been performed, but a major difficulty has been incomplete data sets in the OZGROW Data Base, particularly with respect to puberty staging and to the status of patients with chronic renal failure, i.e. whether or not they are on dialysis or have had a transplant. This has prevented thorough analysis.

In an effort to complete the data sets, and to obtain clinical information not currently on the data base, questionnaires and data sheets relating to pubertal staging and final height measurements are currently being mailed out to treating physicians in Australia. It is hoped to obtain as many **final height** measurements as possible, as this could provide the most convincing measure of the benefit of growth hormone therapy.

Preliminary statistical analysis of the currently available data has been carried out using several methods. A "random effects" model analyses changes in Ht SDS over the time course of rhGH treatment, while the "proportional hazards" method will be used to control for the effects of variables detailed in the clinical questionnaire.

A total of 183 patients have been included in the study, treated with rhGH since 1989, when rhGH became available in Australia. The two New Zealand patients entered in the OZGROW Date Base will not be included. There is a gratifying improvement in both Ht SDS and height velocity in this group of patients as a whole, and in particular the pre-dialysis sub-group. Because our data sets are incompete, it is not reasonable to compare these results to published reports such as Fine et al (KI 1996;49:781-785), one of the few publications of 5 year treatment data, in which non-dialysed CRF patients were studied, documenting mean Ht SDS increasing from –2.6 at baseline to –0.7 after 5 years. Our preliminary results do not appear to be as dramatic as this, but nonetheless significant.

A complete report is expected by July 1999. Your assistance in this ANZPNA study is vital and greatly appreciated.

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9th September 1998

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Minutes of the Australian and New Zealand Paediatric Nephrology Association Annual General Meeting held at Royal Pines Resort, Gold Coast Queensland, Sunday 19th July 1998.

Chairman C. Jones
Secretary L. Johnstone

Present: M. Falk, J. Burke, A Rosenberg, J. Knight, P. Henning, H. Powell, M. McIver, R. Walker, F. Juredini, F. Willis, I. Hewitt

1. Apologies: D.Lewis, E. Hodson, J. Craig, D. McCredie, G. Kainer, C. Crompton, W. Wong, P. Tomlinson, D.Lines, M. Walker, P. Roy and M. Morris.

2. Minutes: The minutes of the Annual General Meeting, 20th July 1997, with the amendment *that the motion re-election of new chair (item 10.1, page 6 volume 1 number 1) should read Chair Secretary and Treasurer instead of Chair, Deputy Chair and Secretary/Treasurer.*

Acceptance of the minutes was proposed by J. Knight, seconded J. Hewit and carried unanimously.

3(a) Chairman's Report: C. Jones spoke to his first year as Chair of the ANZPNA. He wished to focus the AGM on the IPNA bid, the Articles of Association and collaborative studies.

He noted that an Executive had been formed with L. Johnstone elected as secretary, and P. Henning elected as treasurer. Telephone conferences of the Executive had been held with the last in March 1998 and the Minutes had been distributed via the journal. He indicated that the aim of the journal was communication with the membership and onto other interested outside parties as appropriate. The journal will continue in 1998-99. He tabled an Index to the journal which will conclude volume 1 (pages 177-179, appendix 1).

He noted a number of tasks that resulted from the Annual General Meeting in 1997 had been undertaken. He thanked Paul Henning for his contributions to the investigations of the ongoing supply of Nifedipine capsules which is not possible. He noted that a bank account had been established based in Adelaide for the ANZPNA but no subscription had yet been raised. He noted the great efforts of Paul Roy in producing the proposed Articles of Association. He noted that this was a major task and hoped that it would be accepted at the

Annual General Meeting to allow the ANZPNA to becoming incorporated. He thanked Michael Falk for his efforts toward developing a web site for the ANZPNA and referred members to page 156 (volume 1, number 4). He also noted that in the past 12 months priority to transplantation for children had been achieved in New South Wales and Victoria. He noted that the issue had been raised at the Dialysis and Transplant Workshop in 1997 and as a result significant progress had been made towards establishing priority for children nationally. He noted the efforts of Fred Juredini in the development of a bid to host the IPNA meeting in Adelaide in 2004.

He commented that a champion team always defeats a team of champions and felt that the major short comings of the ANZPNA were with respect to the conduct of multicentre trials, the lack of development of sub committees and the lack of liaison by the Executive with affiliated organisations.

3(b) Treasurer's Report:

Paul Henning noted that there had been some difficulty in establishing a banking account in Adelaide but now the documentation was completed. The current balance is $1,350.00 and he was not aware of any incoming or outgoing funds over the past 12 months. He will be calling for subscriptions in the next month and that the subscription level is set at $100 per calendar year.

3(c) Secretary's Report:

Lil Johnstone thanked the membership for their communications. She requested that each member identify their preferred method of communication, be it mail, fax or electronic means. She acknowledged the efforts of the secretaries of the Department of Nephrology, Royal Children's Hospital in producing the journal with particular acknowledgement to Kerrin Groves and Vicki Burns.

4. Sponsorship of Meeting:

C. Jones acknowledged the sponsorship of Baxter in supporting the ANZPNA to meet and hold its Annual General Meeting. He noted that there had been a change of Senior Management at Baxter in the last 12 months and as a result there was reduced interest in supporting paediatrics. He was unsure whether Baxter would be prepared to sponsor the meeting in its ongoing form and was to meet with their Senior Executive to discuss this further. He was keen to have an ongoing academic component to the meeting which has been arranged for Monday, 20th July 1998, but again was not sure whether this could be continuing. He felt that the minimal requirement was that there be a meeting of the ANZPNA membership annually and that this meeting could be

conducted at an Airport Hotel in any capital city. He was not adverse to co-sponsoring of the meeting if appropriate. Discussion followed with John Knight indicating his concern that it was inappropriate to be reliant on one company only and that he suggested establishing a partnership with all major companies and broadening sponsorship with the potential of offering corporate membership to interested companies. He was happy for the meeting to be subsidised as opposed to full sponsorship as currently exists. C. Jones wondered whether there would be an adequate turn up if the meeting was not fully sponsored. R. Walker raised two points, namely to determine what the meeting was about and therefore the need to be careful of what the meeting was linked with, and the second point was how to make corporate membership attractive to interested sponsors. C. Jones felt that we should not commit to one company all the time. A. Rosenberg raised the concern that the meeting had developed into a two day meeting, where the ideal would be a one day meeting on a weekend to minimise disruption of work requirements. C. Jones noted that a two day meeting allowed the ANZPNA membership to have an academic component. F. Juredini questioned whether the scientific meeting component could be related to another meeting for example, a link with the urology meeting or an infectious diseases meeting. J. Knight proposed the sustaining membership program with contributions of $2,000 or $5,000 or $10,000 which would help improve the bank balance and broaden the base of support. He suggested that the Executive should explore this and that perhaps a Financial Subcommittee needed to be established. I. Hewitt noted that in Western Australia there is a single health board and employees of that health board are not allowed to receive benefits for travel if it comes from one company due to the ethical concerns. It was noted that the FRACP have ethical guidelines indicating that multi sponsorship of meetings and costs associated with meetings was recommended. P. Henning questioned whether corporate sponsorship would preclude members from attending a meeting sponsored by a single drug company. There were concerns about what sustaining members would get from this sponsorship and it was suggested that access to the mailing list or advertising space in the journal might be considered.

It was proposed that a subcommittee be established to address the sponsorship issue. M. Falk noted the experience of the ANZSN and TSANZ in raising money for meetings and scientific meetings in an adhoc fashion and suggested it was best to raise the money for the society or association and use the money then as

appropriate. He noted the experience of the ANZSN and the TSANZ that the market place had determined the level of sponsorship.

A motion was proposed by J. Knight and seconded by Andrew Rosenberg that the Executive establish a working party to operate over a limited time period to explore corporate sustaining membership for the ANZPNA. The motion was carried unanimously.

5. Membership

5.1 There have been no applications for new membership to the ANZPNA. The criteria for membership was discussed under the Articles of Association.

5.2 The current membership numbers 25 (page 13-15 Vol. 1 No. 1). The number of trainees in paediatric nephrology remains at 4, with the current trainees being Steve Alexander, Fiona Mackie, Michelle Telly, and Steve McTaggart.

5.3 A proposed application form was tabled (appendix 2). *The current membership is requested to complete the form, particularly with respect to their mailing details.*

6. Articles of Association and Incorporation (note pages 138-155)

C. Jones referred the member's attention to pages 138-155 and tabled suggested amendments and queries (appendix 3). The typographical errors were noted and will be corrected. A number of queries will be directed to Paul Roy particularly the definition of "office" and whether this is in the state of registration, whether the registration is to be in Victoria or New South Wales, whether clauses 4 (page 139), clause 3 and 9 (page 153) of the regulations are to be found and does this refer to Section 383 of the Corporations Law and to seek his advice as to the taxation liability, his feelings as to whether point t should be retained or otherwise, and whether the Articles of Association are sufficient enough to establish the ANZPNA as tax exempt, and also whether legal opinion should be sort prior to submission of the Articles of Association. *Lilian Johnstone to write to Paul Roy.*

With respect to Item 4 Membership Requirement of the Articles of Association (page 144) C. Jones has proposed in the appendix that two additional statements be incorporated, namely the member proposing the applicant's membership must know the applicant well in terms of professional expertise and character, and also the proposer must provide substantive evidence that the applicant has an active role in caring for children with paediatric nephrology problems. Discussion followed

indicating that these two statements were too limiting and would therefore render illegible individuals who do contribute significantly to paediatric nephrology but not in a clinical sense. The proposed additional statements were then removed. It was noted that the Annual General meeting 1997 had indicated that associate membership should be available to trainees and therefore a statement was inserted "a category of associated membership will be available for trainees in paediatric nephrology as determined from time to time by the Executive". Paul Henning suggested that the rights of the associate membership need to be decided by the Annual General meeting.

Page 144 Subscriptions – C. Jones noted that no subscription had yet been paid, therefore no one was formally a member if the Articles of Association had been enacted. Subscriptions will be required to be paid in the next month and that this would precede the submission of the Articles of Association for incorporation.

Page 144. Honorary Member *elected by the Council* was changed to *Elected by the Membership at general meetings.* Item 11 (d) (page 145) *Council* was changed to *Executive.* The meeting agreed to remove point 11 (e) (page 145).

Item 23, (page 147) Quorum AGM. It was noted that 10% of the current membership was 2.5 members and therefore this was changed to *30% of the membership or 10 members whichever is the greater.* This items reads personally present and entitled to vote and there was some discussion as to whether teleconferencing or electronic communication should also be included in this point. This was not resolved.

Item 36 (page 150), Governing body of the Executive Committee. J. Burke noted that the Executive should include the representative to IPNA and it was resolved that a statement be added *the Executive shall have the power to co-opt additional members from time to time.*

Item 37 (page 150) The Honorary Offices – M. Falk raised concerns there was no immediate re-election available for members of the Executive and therefore there would be a loss of corporate memory. He proposed that the election of members to the Executive should be overlapped so that there was ongoing continuity or suggested that a president elect be included in the Executive. Following discussion, the following amendments were agreed to:-

Item 6 should now read *the Executive Committee will be composed of a Chair, Honorary Secretary, Honorary Treasurer and immediate past chairman. The immediate past chairman remains for two years.*

Item 37 would be amended that Vice Chair will be deleted and Past chair inserted.

Item 47 (page 151) Executive Quorum – this should now read *unless otherwise determined two members personally present or communicating by electronic means shall constitute a quorum.*

Item 62 (page 154) – this should now read *in a pre-paid envelope or wrapper or by electronic means.*

Item 65 (page 154) – Certification of Notice. This will now read *shall be deemed to have been served on the second day following that on which the envelope or wrapper etc.* It was proposed that the additional sentence be added "where a dispute arises regarding whether a notice has been served by electronic means, the notice will be deemed to have not been sent".

Page 140 (2) – Objectives. It was decided to delete points (k) and (m). Advice will be sought from Paul Roy as to whether point (t) should also be deleted.

Page 141 (6) – Liability. It was noted that liability of members was limited to $20.00. It was questioned whether this should be reduced to $1.00.

A motion was proposed **that the membership accept these regulations and Articles of Association subject to the Executive clarifying the points of discussion with Paul Roy as detailed above. This was proposed by Colin Jones, and seconded by L. Johnstone and passed unanimously**.

The tremendous efforts of Paul Roy were noted and the membership requested that the chair write to Paul Roy to express their thanks.

7. IPNA

7.1 IPNA Bid 2004.

Fred Juredini spoke to this item. It was noted that Adelaide had made the only bid for the IPNA meeting but he stressed the meeting is an Australian meeting and not an Adelaide meeting. Members were referred to the preliminary work on pages 159 to 167 volume 1 no. 4 JANZPNA. Fred proposed that there be a president for the

congress and wished to ask David McCredie to be president, and that he wished to involve Paul Roy in a similar way should he be agreeable. He proposed that he be chair of the local organisational committee and that Colin Jones by chair of the Scientific Meeting. All members of the ANZPNA would be asked to be active in the organisation of speakers or promoting the meeting or chairing sessions or in an administrative capacity. Fred was hopeful that a number of people would be happy to take part. He proposed a local organising committee consisting of himself, Paul Henning, Ann Martin (Hospital Scientist, member of IPNA), David Lines, Jill Lawton and Peter Willoughby (WNCH Dialysis staff), Michelle Tilley (Trainee in Paediatric nephrology), Adrian Porter (ANZ Urology Society), Hiliary Boucaut (Paediatric Urologist), and the CEO of the local kidney foundation. He has good departmental secretarial support.

He has been engaging in active meetings with Catherine Leonard who is the representative of the Adelaide Convention and Tourism Authority Limited, and with Graeme Teague from the Hartley Management Group (see page 163). He tabled a brochure entitled Sensational Adelaide which provides an outline of the bid and is supported by the Adelaide Convention and Tourism Authority Limited. He indicated that Adelaide was a good venue for the IPNA Congress, that the convention centre was able to seat up to 2000 in its main hall and that a number of small halls were available, that there were a number of hotels closely located to the convention centre and that relatively cheap accommodation was available. He indicated that there would be a representative of the Adelaide Convention and Tourism Authority Limited at the IPNA meeting in London 1998 to promote the Adelaide bid. He had written to Cyril Chandler and they had indicated they were happy for the booth to be at the IPNA meeting.

J. Burke indicated the method in which a bidding city is chosen. There will be a vote by the IPNA Council in 1999 to determine the winning bid. The chairman of each bidding group will come to the meeting and present the proposal in a 25 minute talk. He said that the proposal needed to be professional and indicate the venue, the numbers expected, the access and transport to the meeting, the registration costs, and the air travel costs and that there would be an adequate number of people to organise the meeting and also to attend. He indicated that the meeting would have to have an organisational structure similar to that currently being used by the Seattle 2001 meeting and that there would need to be a good organisational

committee, scientific committee and social committee. The cost of the meeting would need to be budgeted and the income from sponsorship would also need to be tabled. He supported the booth at the IPNA London meeting as it would be of benefit to expose Adelaide to the IPNA delegates who could then go back to their council member.

Fred referred to the Sensational Adelaide brochure which contains a time line for the IPNA bid. He displayed a number of potential teasers and mail outs to promote the Adelaide bid to IPNA councilors. He spoke to the costing which had been provided by Graeme Teague and ACTA and based on the costings of the UK meeting. Proposed registration is $475.00 which is relatively cheap but needed to offset the presumed costs of travelling to Australia. He noted that Adrian Porter had managed to raise $400,000 of sponsorship for the National Urological Society meeting in Adelaide. The UK meeting had achieved sponsorship of 175,000 pounds. IPNA is establishing a list of sustaining companies who could be approached at head office level as opposed to approaching individual regional branches. The question was raised as to whether corporate sustaining sponsorship for ANZPNA could be linked to the IPNA meeting and similarly whether non medical sponsorship, for example local wine companies could be sought. Fred indicated that if the bid was accepted he would ask local ANZPNA members to approach local supporting sponsors to determine sponsors who could be then approached by the Financial Committee. M. Falk expressed the importance of a central group (Financial Committee for all fundraising). Fred referred members to the availability of international and local transport into Adelaide and current air fare costings. The intention would be to use major carriers and to get package arrangements from these carriers. It was hoped that 1000 delegates would attend the meeting. Fred noted that the Adelaide Convention and Tourism Authority are prepared to loan $15,000 for establishment and preparation costs. He also noted that he was resigning as Director at the Renal Unit at the end of 1998 and therefore would have more time to devote to the bid. It was felt very important by all present to target Council and to promote the bid to delegates if one was hopeful that the bid would be accepted.

A motion was put **that the ANZPNA bid for the 13th IPNA conference to be held in Adelaide under the auspices of the ANZPNA in 2004** proposed F. Juredini, seconded Paul Henning.

Discussion to motion ensued. Andrew Rosenberg questioned whether the whole membership should have voted to determine whether Australia should make a bid and was referred to page 3 of the Minutes of the Annual General Meeting 1997 at which time it was determined by the members present that a bid should be made. He expressed concerns about the number of people required to support a bid and the amount of actual support available. He indicated that he would actively support Adelaide if the motion was passed. He also questioned what the ANZPNA would achieve as a result of the bid and indicated a wish to renegotiate funding with the IPNA so that the host country could benefit in some of the profits. He noted the problems with the IPNA meeting 1995 in Chile in that few North American nephrologists attended but was unsure why they did not attend. He noted that at a local level, the majority of Sydney Paediatric Nephrologists were not supportive of the bid for either Australia or Sydney.

John Knight noted that the majority have in fact indicated that they support a bid and that the process is now in place and therefore committees need to be formed. He noted his experience of two international meetings, namely the ISN and the meeting of the Transplant Society. Both these meetings were held in Sydney and he felt provided good outcomes for Sydney for both trainees and national members. He also indicated that he wished to re-negotiate the funding so that some profits were returned to the ANZPNA. Ian Hewitt indicated that he was impressed with the work prepared to date and the good access that exists into Adelaide. Rowan Walker indicated that the money issue was critical but suggested that a separate motion be put (which was supported by M. Falk) as there were two distinct issues. It was determined that the AGM needs to be the forum for decisions of the ANZPNA and that it was unlikely if not impossible to get the full membership present.

The motion was put to the vote and passed by the majority with one member abstaining from voting.

Discussion followed concerning the structure and organisation of the meeting. A motion was put **that a two co-chairs be elected and it was proposed that Fred Juredini and Colin Jones be the co-chairs**. Proposed by Fred Juredini seconded by R. Walker, voted unanimously. A further motion was put by L. Johnstone and seconded by H. Powell **that committees be formed with committee chairs for a scientific committee, finance committee, publication committee, publicity committee**

and social committee, and as required, a satellite committee and a continuing education committee. This was carried unanimously. John Burke and Andrew Rosenberg indicated that they have list of the names of all members of all committees for both the Seattle and London meetings. J. Knight suggested that writing to all members of the ANZPNA and requesting those who would be interested to indicate such an interest would be the best way of determining the committee structures and members. John Burke stressed the need to establish committees along the lines of the Seattle meeting and have international members of those committees. He indicated that the IPNA council will assess the bid in terms of the committees and committee members and not on the invited speakers. F. Juredini requested that the AGM of the ANZPNA be held before the IPNA council meeting so that the bid could be heard and presented. C. Jones felt this was a problem as the bid should be well prepared before hand. M. Falk raised concerns about the financial situation of ANZPNA with respect to supporting the bid application, and the concern of potential loans from the Adelaide Convention and Tourism Authority. Andrew Rosenberg indicated that the ISN meeting in Sydney would provide a good model for the meeting and recommended that Fred talk to the organisers of the Sydney meeting. There was some concern about other meetings that may occur in the same year and discussion concerning timing of the bid with respect to international meetings overseas. M. Falk noted that the bid for the International Transplant Meeting to be held in Sydney in 2004 had been rejected in favour of Austria. It was noted that the European Society of Paediatric Nephrologists did not hold a meeting in the year of the IPNA meeting. Information is needed concerning the timing of the Paediatric Transplantation Meeting.

John Burke noted that the IPNA council takes responsibility for the financial outcome of the meeting, and indicated that if the Adelaide bid was successful some seeding money should be provided and that the Treasurer of the IPNA would become part of the financial organising committee. He did not think it appropriate to ask for any profit to be provided as a percentage to the ANZPNA but to link it to specific tasks particularly promotion of paediatric nephrology in regional areas. John Knight noted that once the ANZPNA is incorporated there would be limited liability and therefore there would be no personal liability for any costs associated with the meeting. He proposed a motion **that in the event of the bid being successful, the ANZPNA should enter negotiations with the IPNA council with a view to**

profit sharing. This was seconded by M. Falk and carried unanimously.

7.2 J. Burke spoke to this item. Members are referred to page 172 volume 1. Number 5 JANZPNA. He requested feedback concerning the journal (Paediatric Nephrology). He noted that there was a time delay regarding the publishing of articles and requested feedback concerning the quality of the articles. The weighing of Paediatric Nephrology remains below that of Kidney International and JASN. He drew attention to the meeting March 11 - 13 1999 in New York discussing bone growth and turn over in children with chronic kidney disease. He commented on the position of Secretary General. This will be a six year position following the retirement of Ira Griefer and the position will be determined by election by Council. There has been some discussion about the role of a past president. He noted the financial situation. It costs $220,000 to administer IPNA and some South American and European countries have contributed funds directly to IPNA. They have determined to set up an international kidney children's fund for fundraising and administrative costs and to link centrally with corporate sponsors. He noted that the ANZPNA is now affiliated with IPNA as a recognised regional group. As a result, J. Burke is now a member of the Executive and ANZPNA will always have its representative as a member of Executive whilst it remains an affiliated regional association. It has been proposed that the full council meeting be decreased from twice yearly to annually. If an extra meeting was required, it was proposed the Executive meet only. He noted that there was no African representative on IPNA and IPNA is attempting to promote regional societies with Africa with the aim that there be a north, central, and southern regional association. South Africa has been asked to form a regional association and then nominate a member to Council. He noted that David McCredie and Martin Barratt have been nominated as honorary members and this will be voted upon by Council. Michael Falk asked how the ANZPNA should support under-developed countries and noted that ISN has sister centre arrangements.

It was proposed **that the ANZPNA members attending IPNA meeting should meet on 15th September 1998** (appendix 4). The following members are attending the IPNA meeting: G. Kainer, D. Lewis, I. Hewitt, E. Hodson, J. Burke, P. Henning, H. Powell, D. McCredie, L. Johnstone, A. Walker.

8. **Priority Transplantation:**

C. Jones noted that Victoria has a procedure in place which applies to a small number of children who are eligible to be considered if they commence dialysis prior to the age of 15 and have been dialysed for more than 12 months and have no living related donor and are receiving their first graft and that, that kidney come from Victoria and that there is no 5-6 antigen match available elsewhere in Australia. Since the system was established in February, one graft has been available. The letter from Graeme Rust (Appendix 5b) was noted from the Renal Transplant Advisory Committee which was previously the National Committee for Allocation of Organs. It was noted that within the current system highly sensitised individuals and children where disadvantaged and therefore that the committee had determined that if a very well matched kidney was available that priority be given to a child. M Falk noted that the group had a view that the child needed to be on dialysis for more than one year which he did not share and that 21 children would be available for transplantation with one to two very good matches per year.

The letter of Elizabeth Hodson (appendix 5(c))was noted. J. Knight spoke to this letter and indicated that the New South Wales adult nephrologists had wished to discuss the resolution concerning priority transplantation for children that had been determined by the Dialysis and Transplantation Workshop further. They had met and as a result of reviewing the past history it was found that only 8 children would be available for transplantation and that of these with the proposed system, only 4 of the 8 would be likely to receive a transplantation. Paediatric priority was now established in New South Wales, but no transplants had resulted from the system as yet. The outcome will be reassessed in twelve months time.

F. Juredini congratulated those who had finally raised the priority of children on transplantation lists and acknowledged particularly the efforts of M. Falk and R. Walker. It was noted that no priority exists in South Australia or in Western Australia, but very few kidneys were available in Western Australia.

9. **ANZDATA**

9.1 L. Johnstone spoke to this item. She had written to all units and requested consideration as to whether lipid and left ventricular hypertrophy data could be collected through the ANZDATA registry. Letter from Elizabeth Hodson was tabled (appendix 6). It was felt that the

collection of data would not be difficult however the members felt that data should only be collected as part of a directive study. L. Johnstone is to prepare a protocol for such a study and present it to the membership. M. Falk noted that the ANZDATA registry is now looking for co-morbidity and that lipid data and echo data may well be required annually as part of the ANZDATA registry. It was again noted that the paediatric data collection sheet can be modified if we wish to do so. He felt that it was an important question to address the long term morbidity. He also noted that the Don Jacquot Foundation have created money for a research project which is available by application through the ANZSN.

9.2 M. Falk noted changes in ANZDATA. Alex Disney has devolved areas of responsibility. For example, G. Russ now collates the transplantation data and R. Walker is responsible for the paediatric section over the next three years. It was requested by the membership that the Executive write to the ANZDATA registry to fully endorse Rowan's appointment for the next three years and indicate that the ANZPNA would wish to be involved to assist in any subsequent appointment.

10. Multi centre Trials

10.1 Vesico-ureteric trial. John Knight spoke to this item (appendix 7). He noted that 5 to 6,000 pregnancies had been screened from which 290 infants had been found to have hydronephrosis and of these 16% had vesico ureteric reflux of which 19 had been recruited from screening. The number of children involved in the trail is currently 39, one of whom has been lost and three have completed the three year follow up. One child has had a urinary tract infection but is currently blinded to treatment. His major concern was what to do with the trial as NH&MRC funding ceases at the end of 1998. There is a meeting of the Reflux Trial Committee on July 30th and it was suggested that the outcome of that meeting should be awaited by the membership to determine whether the trial either stops completely, or stops new recruitment after the end of 1998, or continues but is unfunded.

10.2 APSU Nephrotic, Syndrome Study. Notice to members that Nephrotic Syndrome is now included on the APSU data collection as of 1st July.

10.3 Growth Hormone Study. C. Crompton was not available. The membership requested information from him concern the research protocol to determine the goals of the study and how data is to be collected.

11. Drugs

11.1 Nifedipine Capsules.
Paul Henning spoke to this item. It was noted that Nifedipine capsules are no longer available although some hospital pharmacies still have use of stored medication. It was noted by the Therapeutic Goods Administration (TGA) that there was no evidence based medicine to support the use of Nifedipine capsules for treatment of hypertension in children. A round table survey was held to discover how members are currently managing acute hypertension. There are still Nipedipine stores available in Western Australia and South Australia. Margot McIver reported in Dubbo she uses intravenous hydralazine as does Rowan Walker. Harley Powell was using Nifedipine crushed tablets as is Colin Jones, Andrew Rosenberg, and John Knight. C. Jones uses intravenous diazoxide if needed and J. Knight uses intravenous nitroprusside. J. Burke is using calcitriol orally or intravenous infusions of beta blocker.

11.2 Human Growth Hormone. Andrew Rosenberg reported correspondence with drug companies concerning the ongoing use of growth hormone for children with chronic renal failure. The ADEC have not supported the use of growth hormone for this indication and therefore without a permit, growth hormone cannot be funded through the Pharmaceutical Benefits Scheme. It is likely that at the beginning of 1999 patients currently treated with growth hormone will no longer be supplied with growth hormone and similarly no patients can initiate growth hormone treatment. It was felt by the members present that there is compelling data in the favour of growth hormone use despite the lack of final height data to present to ADEC, and therefore there is an urgent need to assess the Ozgrow data to establish final height data. It was requested that the Executive communicate with Charlie Crompton so that final height data can be established from the registry rapidly. (Note appendix 8).

11.3 Liquid Calcitriol (Appendix 9) for members information only.

12. Other business

12.1 Bench Marking. C. Jones spoke to this item and tabled appendix 10.(Child Health Questionnaire) The Royal Children's Hospital Melbourne wishes to bench mark practices concerning health service delivery and quality care. They wish to bench mark against equivalent Australian units using standardised protocols and possibly also against international units. They propose using the Child Health Questionnaire He requested information from any other units that may be interested in taking part

in the bench marking process and suggested possibilities of applying the questionnaire to transplant follow up, or insertion and commencement of peritoneal dialysis, or renal biopsy. J. Knight reported at Westmead they have performance indicators in place for biopsy rates and complications, and peritoneal infections. They make use of a health outcomes assessment measure which has been developed by Craig Mellis and is well validated. He indicated that in principle Westmead were prepared to cooperate with the bench marking process. Ian Hewitt questioned whether bench marking was to establish the least common dominator and therefore cut costs and wondered if standards of the British Paediatric Nephrology Association should be applied. He also questioned whether ANZPNA needed to develop standards. F. Juredini spoke to this also and noted that Adelaide Children's Hospital has bench marking but this does not include the renal unit at this point in time. He felt that minimum standards of paediatric renal unit should be established before bench marking was applied. A Rosenberg noted that he had received a questionnaire which has apparently been sent by the Australian Association of Paediatric Teaching Centres to paediatric renal units although no other members had received this. He had not completed the questionnaire but had returned it with suggested revisions. He felt there were two issues, namely patient satisfaction which is what the Child Health questionnaire established and bench marking. C. Jones will write to associated units to see which other units may want to take part and will possibly use the Health Outcomes Assessment Measure.

12.2 Subcommittee for Aboriginal Health. It was noted that no formal subcommittee had been formed however members continued to have an active interest in Aboriginal health. F. Juredini noted that he had now been given authority by the Aboriginal groups to deal with Aboriginal communities. He had funding for investigation of the prevalence of renal disease in Aboriginal children and by the end of 1998 would have developed a protocol which he hoped will be in practice and will establish a nation wide screening program. J. Knight noted that there were two projects in New South Wales. The Financial Markets Foundation for Children had contributed $75,000 to determine the incidence of renal disease in Aboriginal school children which was being performed through Aboriginal medical services and was hopeful of starting in the next six months. He also noted that the Menzies School of Medical Research in Darwin was funding a PhD scholarship to look at the Tiwi Island population in terms of ultrasound findings of renal size and postnatal

nutritional states. John Burke noted that he had proposed a screening study for adolescent Aborigines to identify the risk for end stage renal failure and this was currently with Aboriginal Affairs. Ian Hewitt noted that in Western Australia there is difficulty in dealing with Aboriginal communities given their previous experience with research.

John Knight was asked to be chair of an Aboriginal Health Subcommittee to link himself, Margo McIver, F. Juredini and I. Hewitt and J. Burke. C. Jones noted that greater knowledge of where each group was in their negotiations with Aboriginal communities would be helpful in terms of directing resources. A motion was put that **John Knight convene and coordinate a state committee on Aboriginal child health as it relates to renal disease in the broader context through co-opted members of ANZPNA as required for initial period of two years.** Proposed C. Jones, seconded J. Burke carried unanimously.

12.3 Paediatric Specialties Advisory Committee. A Rosenberg tabled Appendix 11 for information. He has remained on the Paediatric Specialty Advisory Committee as the ex-chair of that committee and at the request of C. Jones. There was discussion regarding the appointment of members of the ANZPNA to other committees and it was requested that the Executive develop a formal role in choosing representatives to these committees. It was presumed that this will follow incorporation. It was requested that the Executive write a letter to support the people in their current positions and to request input when change of personnel occurred. It was noted that Deborah Lewis was the paediatric representative on the Nephrology Specialty Advisory Committee of the Royal Australasian College of Physicians and that C. Jones was the representative on the written exam committee.

12.4 Trial for treatment of focal segmental glomerular sclerosis. C. Jones spoke to this item (see appendix 12). He is proposing a trial to assess the role of cyclophosphamide in maintaining remission in those children with focal segmental glomerular sclerosis who are bought into remission by the combined use of prednisolone and cylosporin. The general consensus was that all units would be happy to submit patients to a revised protocol. Revisions requested included a definition of FSGS and what biopsy criteria would be required. It was also suggested that a double blind placebo controlled trial would be better. There was discussion as to whether steroid resistance would be a better inclusion criteria as

opposed to a definitive biopsy diagnosis of FSGS. Other revisions related to the concurrent use of ACE inhibitors and lipid lowering agents, and a request for a common information sheet regarding the complications of cyclophosphamide. Discussion followed as to how each individual unit manages children with steroid resistant nephrotic syndrome and it was noted that New Sydney Children's Hospital is the only unit currently following Mendoza protocol. C. Jones is to write to all members requesting their comments in response to a revised protocol following which the trial will be initiated.

13. **Next Meeting**: No date as yet has been determined. It was contingent upon the outcome of C.Jones meeting with Baxter representatives. The meeting closed at 9.00 pm.

Signed as a true and correct record:

.....

CHAIRMAN / /**1998.**

JOURNAL OF AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION
Volume 1, 1997-1998

INDEX

APPLICATION FOR MEMBERSHIP

AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

Title: _____

Surname:_____ Given Names:_____

Date of Birth: _____ Male/ Female

Address (Home): _____

_____State: _____Postcode: _____

Phone: (__)_____ Fax: (__)_____ e-mail: _____

Address (Professional): _____

_____State: _____Postcode: _____

Phone: (__)_____ Fax: (__)_____ e-mail: _____

Preferred address for correspondence: Home/ Professional

Nominated by: Seconded by:

_____ _____

Signature:_____ Signature:_____

QUALIFICATIONS

	Qualification	Conferring Institution	Month and Year Conferred
Undergraduate Education			
Postgraduate Education			
Higher Qualifications			

Medical Registration:

State:_____ Date:___/___/_____ Registration Number:_____

POST GRADUATE EXPERIENCE IN NEPHROLOGY

Appointment	Institution	Commencement date	Completion date

CURRENT APPOINTMENTS:

Appointment	Institution	Commencement Date

MEMBERSHIP OF PROFESSIONAL SOCIETIES

If elected, I agree to abide by the Articles of Association and to pay my Annual Subscription so long as I shall remain a member.

Signature:_____ Date:____/____/_____

NOTES TO THE REGULATIONS FOR MANAGEMENT AND ARTICLES OF ASSOCIATION OF A COMPANY LIMITED BY GUARANTEE

THE AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

1. Typos

   Page 139 bracket after ANZPNA

   Page 139 2(b) – management

   Page 141 line 6 ways in place of wise

2. Where is the "office" – is this in the State of registration of the Association

3. Page 144 I suggest redrafting the Membership Requirement paragraph to read –

   Medical Practitioners who hold a medical qualification conferred by an institution recognised by the ANZPNA and have a substantial involvement in paediatric nephrology shall be eligible to be admitted to the membership of the ANZPNA.

   Every applicant for membership of the ANZPNA must be proposed and seconded by Members. **The member proposing the applicant's membership must know the applicant well in terms of professional expertise and character**. The applicant must sign and deliver to the Honorary Secretary not less than one month before a General Meeting an application for membership framed in such terms as the Executive shall require.

   Every applicant for membership of the ANZPNA shall in his application state his agreement to abide by the articles of association and the by-laws of the ANZPNA and pay his annual subscription so long as he shall remain a Member.

   All valid applications will be submitted to the next General Meeting.

   The proposer must provide substantive evidence that the applicant has an active role in caring for children with paediatric nephrology problems.

The changes conform with the minutes of the 1997 meeting ANZPNA, Volume 1, page 2 and 3.

A category of associated membership was proposed for trainees. Should this be included.

4. Page 144 subscription – no subscription have been paid by anyone at this stage.
5. Page 144 in point 9, Honorary Members shall be elected by the **membership at General Meetings**.
6. Page 145 11(d) replace Council by Executive.
7. Page 145 11(e) remove this point.
8. Page 147 point 23 I propose the quorum be changed from 10% of all members to 30% of all members or 10 members.
9. Page 151 point 47 unless otherwise determined two members personally present **or communicating by tele or video conference** shall constitute a quorum.
10. Page 154 point 62 add ...or wrapper **or by electronic means** addressed ...
11. Page 154 point 65 to have been served **two days** following ....
12. At the end of that paragraph 65 add :

    Where a dispute arises regarding whether a notice has been served by electronic means, the notice will be deemed to have not been sent.

13. Page 140 delete point (t).
14. Page 139 where is clause 4 referred to in 2(e)?
15. Section 5 which are the fourth and fifth paragraph of these regulations?
16. Page 141 the liability of the members is limited **to $20.00**

London, 08 May 1998

Re: IPNA '98 - Regional Meeting

Dear Secretaries:

As you might already know, the Congress has provided for the Regional Meetings to be held on Tuesday 15th September 1998 from 17.30 to 18.30 hrs. I herewith kindly ask you to forward at your earliest convenience your requirements for your meeting; such as numbers of people attending, room set up, Audio Visual etc. I would very much appreciate if you could either fax or e-mail us:

Concorde Services Ltd
10 Wendell Road
London W12 9RT

Fax: +44 (0)181 743.1010
email: ipna@concorde-uk.com

Thank you very much for your time and attention to this matter. With no further reference, I remain.

Sincerely,

Kim Hartge
Conference Organiser

p
23rd April 1998

IPNA 2004 – Adelaide bid

Nineteen members (76%) responded to the request for feedback.

Of those 19, 16 (84%) indicated full support albeit with qualifications.

There was general acknowledgement and support of Fred's efforts.

Concerns raised were:

1. Adelaide
    - No direct flights in to Adelaide may discourage overseas visitors
    - Suggestions that eastern seaboard city should make bid, but no other city has indicated interest
    - Suggestions for satellite meeting in Sydney immediately prior to the IPNA meeting
    - Need to inform/ educate IPNA members about Adelaide as city

2. Finance
    - Concern that inadequate seeding funding or inadequate sponsorship
    - Concerns that ANZPNA should only take this on if there is a cost sharing arrangement with IPNA such that ANZPNA makes a profit
3. Personnel
    - Are there enough people with enough available time to commit to organization of meeting

Lilian Johnstone
Secretary, ANZPNA

INTERNATIONAL PEDIATRIC NEPHROLOGY ASSOCIATION

Secretary General's Office
c/o Ira Greifer, M.D.
Montefiore Medical Center
111 East 210th Street
Bronx, New York 10467, U.S.A.
Tel: (718) 655-1120
FAX#: (718) 652-3136
Membership & Subscription Dept.
IPNA - P.O. Box 220412
Great Neck, NY 11021, U.S.A.

May 14, 1998

John Burke M.D.
Princess Alexandra Hospital
Dept. of Nephrology
Ipswich Road
Wooloongabba
Brisbane Qld 4102
Australia

Dear John:

I received your fax relating to your recommendation for Honorary Membership to IPNA of **Dr. David McCredie,** founding father of Pediatric Nephrology in Australia/New Zealand.

I will be placing this in a letter to our Council Members for their final approval.

With kindest regards.

Sincerely,

Ira Greifer M.D.
Professor of Pediatrics
Albert Einstein College of Medicine/
Montefiore Medical Center

IG:eg

QUEENSLAND HEALTH

PRINCESS ALEXANDRA HOSPITAL
and DISTRICT HEALTH SERVICE

PRINCESS ALEXANDRA HOSPITAL
Ipswich Road
Woolloongabba
Brisbane Qld Australia 4102
Telephone (07) 3240 2111
Facsimile (07) 3240 5577

ENQUIRIES DEPT OF NEPHROLOGY
PHONE 61 7 3240 5080
FAX 61 7 3240 5480
OUR REF JB:fpb NRA
YOUR REF

Dict: 25 May 1998
Typed: 27 May 1998

Dr C. Jones
Director of Nephrology
Royal Children's Hospital
PARKVILLE
MELBOURNE 3052

Dear Colin

The Congress Secretary for the IPNA London meeting has asked whether the Australian and New Zealand Paediatric Nephrology Association wish to have a business meeting on Tuesday 15 September 1998 from 1730 to 1830. Enclosed is a copy of the letter. I suggest we make a room booking for ten to fifteen people. If you agree, please let me know and I will forward a letter to the Congress Secretary.

The proposal for David McCreadie to become an honorary member of IPNA is now being forwarded to Council members for a vote. Harley Power and myself wrote a short account of David's past activities. Enclosed is a copy of the reply from Ira Greifer.

Yours sincerely

John Burke
CONSULTANT NEPHROLOGIST

VICTORIAN PAEDIATRIC RENAL SERVICE
ARBN 10662662Y

DEPARTMENT OF NEPHROLOGY
Royal Children's Hospital
Flemington Road Parkville 3052
Telephone 61-3) 9345 5054
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Email: cjones@cryptic.rch.unimelb.edu.au

DR COLIN L JONES
Director

DR HARLEY R POWELL
A/PROF ROWAN G WALKE
DR DAVID A McCREDIE
DR LILIAN M JOHNSTON
DR AMANDA M WALKER

26 November 1997

A/Professor Rowan Walker
Chairman (Section 8) D & T Workshop
Chairman of the Organising Committee D & T Workshop
Victorian Representative on Interstate Exchange Committee
Department of Nephrology
Royal Melbourne Hospital

Dear Rowan

Thank you for putting the issue of the preferential allocation of cadaveric donor kidneys for paediatric recipients on the agenda for the Melbourne Transplant Group meeting of the 20th November 1997.

After acknowledging that there was a clear endorsement for pursuing some form of preferential allocation of cadaveric donor kidneys for paediatric recipients and noting that this had been a persistent agenda item for the last decade the Group agreed that preferential allocation should take place subject to the following provisions:

1. Paediatric dialysis patients, for the purposes of this purpose, were defined as those starting dialysis less than 15 years of age.

2. Patients would have been on dialysis for one year.

3. Patients would have no medically fit potential living related donor.

4. Paediatric recipients awaiting a second or subsequent graft would be ineligible for this program.

5. The method of allocating kidneys is that following one year on dialysis the Renal Unit looking after the patient would notify the transplant organ co-ordinator (Geoff Scully at MMC, Bette Martin at RCH), the next ABO compatible kidney would be offered to the potential paediatric recipient, and the caring Renal Unit physician would determine whether that kidney was suitable.

6. The program would be capped at three kidneys per year for the first three years and then two per year after (provided the substantial paediatric backlog that exists at the present time is overcome).

7. The program would be reviewed after one year.

I suggest the starting date for this program be the 16th February 1998. This is a couple of weeks into the working year and avoids the time when the Units are relatively short staffed.

Yours sincerely

Late: 8. Kidneys harvested in Victoria only
9. No 5 or 6 antigen matched in Australia

COLIN JONES
Director
Department Of Nephrology

c.c. Dr Harley Powell
Dr Lil Johnstone
Dr Amanda Walker
Dr David McCredie

703/clj/5

RENAL TRANSPLANT ADVISORY COMMITTEE

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c/cjones
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EMAIL gruss@tqehsmtp.tqeh.sa.gov.au

Wednesday 8th July 1998

Dr Colin Jones
Director / Victorian Paediatric Renal Service
Department of Nephrology
Royal Children's Hospital
Flemington Road
PARKVILLE SA 3052

Dear Colin

The Renal Transplant Advisory Committee has discussed the allocation of kidneys to children. Michael Falk may have communicated to you the views of the committee and the changes that have been put into place.

It was decided by the Committee that all paediatric patients be given a bonus of 30,000 points on the national list, which would take them to the top for their matched grade. It was also recommended that 100,000 points be added on the state list, but that this be subject to state discretion.

The definition of a paediatric patient was accepted as one whose current age is less than eighteen years, whose age at first dialysis was less than fifteen years, and that the individuals time on dialysis was greater than one year. This last criterion was applied to provide an incentive for living donor transplantation to be performed in this group if a suitable donor was available.

The Renal Transplant Advisory Committee feels that these proposals would lead to the rapid transplantation of paediatric patients either from the state list or from the national list within their match grade.

Kind regards,

Yours sincerely

Graeme R Russ
Chairman

The New Children's Hospital
Royal Alexandra Hospital for Children

Dr Elisabeth Godson MB BS FRACP
Consultant Physician
Paediatric Nephrology
Telephone: 61 2 9845.3430 Fax: 61 2 9845.3432
Provider no: 29665AH Email - Elisah@NCH.EDU.AU

2th July, 1998
G:data/juliew/johnston.doc

Dr L Johnstone
Secretary - ANZPNA
Department of Nephrology
Royal Children's Hospital
Flemington Road
PARKVILLE VIC 3052

Dear Lilian,

As you know, I am unable to attend the ANZPNA meeting on July 20th. I noted that one of the agenda items is Paediatric Priority for Renal Transplantation. In New South Wales, it has recently been agreed that paediatric patients should have some priority for renal transplants. A paediatric bonus score is now applied to children who commenced dialysis before the age of 15 years and are currently less than 18 years and have been on dialysis for more than 1 year. The bonus score is 100,000 points in New South Wales. The effect of this would be to boost the patient to the top, but not above, his/her HLA match grade on the HLA matching list. I understand that in New South Wales, approximately 40% of kidneys are distributed on the basis of matching. At this stage, it is my understanding that paediatric patients will not get any priority on poorly matched grafts.

In addition, a review of the tissue typing data of the 8 New South Wales children who fit the criteria for priority, indicates that 4 children have a reasonably good likelihood of being offered a cadaveric donor kidney under this new scheme, but the other 4 have a poor chance. The whole scheme will be reviewed in 6 months time. At that time it may be necessary to put some changes in to give an opportunity for transplant for the children who are unlikely to receive a cadaveric kidney under the present scheme. John Knight will be able to tell you more about this scheme.

Dr Alan Watson, from the Nottingham Children's Hospital in the United Kingdom, has just sent me some information about the 1998 Donor Kidney Allocation Scheme for the UK. I thought the members of ANZPNA may be interested in seeing the extent to which children have priority in the UK.

With best wishes
Yours sincerely,

Elisabeth

Dr Elisabeth Hodson
Head -Department of Nephrology
cc: Dr John Knight - Centre for Kidney Research
encl

UKTSSA
United Kingdom Transplant Support Service Authority

Fox Den Road,
Stoke Gifford,
Bristol BS12 6RR
Fax: 0117 975 7577
Tel: 0117 975 7575
Emergency Telephone:
0117 931 4777

When replying please quote: PJM/rb/cmg/141/M322

TO: Directors of Renal Transplant Units
UK and Republic of Ireland

21 January 1998

Dear Colleague

1998 DONOR KIDNEY ALLOCATION SCHEME FOR THE UK

1. On 15 January, Renal Transplant Unit Directors met at the Royal College of Physicians to discuss proposals from the UKTSSA Users' Kidney Advisory Group for revising the protocol used for allocating donated kidneys. The revised protocol for allocation was based on the evidence provided by the recent HLA Task Force analysis of factors influencing outcome of cadaveric renal transplantation in the UK. I am grateful to Directors for their positive and constructive participation in this important meeting.

2. This letter confirms the arrangements agreed by Directors: a second copy is enclosed which I should be grateful if Directors would sign and return to UKTSSA to signify their endorsement and participation in the National Sharing Scheme.

3. With effect from 1 July 1998, donated adult kidneys will be shared on the following basis-

   All donated kidneys will be offered through UKTSSA for comparison with the HLA type of patients on the active National Waiting List for blood group identical patients. On Users' behalf, the National Transplant Database will be used to sort and allocate kidneys as follows:

   Tier 1:
   All OOO mismatches will be offered through the national pool to the most appropriate patient(s) sorted using the following priority order -

   Local Paediatric HSP
   National Paediatric HSP
   Local Paediatric non-HSP
   National Paediatric non-HSP
   Local Adult HSP
   National Adult HSP
   Local Adult non-HSP
   National Adult non-HSP

   Tier 2:

   All favourably matched kidneys (100, 010, 110) will be allocated through the national pool. In this Tier, patients will be sorted using the following priority order -

P2....

Local Paediatric
National Paediatric
Local Adult
National Adult

One of a pair may be retained for the local waiting list.

Tier 3:

Where no 000 or favourable matches are found nationally or locally, the donated kidneys may be retained for local use. If only one favourable match is identified nationally, one of the pair will be exported and the second retained for local, non-favourable use.

A local unit which is unable to use a non-favourably matched kidney will offer it on through UKTSSA who will allocate it to the unit which at that time has the highest positive centre balance. Centres with identical balances will be sorted as described at paragraph 5 below for adult or paediatric recipients.

In the context of this scheme, local refers to a single unit or an alliance where such exists.

4. Where more than two equally matched patients are identified for any one kidney in either Tier 1 or Tier 2, a points score mechanism will be used to determine the choice. Points will be calculated as follows:

Recipient age:	Old to young 1-10 points	to favour younger recipients (HLA Task Force analysis found younger recipients had superior survival)
Donor-recipient age difference:	Large to small 1-10 points	to avoid where possible large differences between recipient and donor age
Waiting time:	Short to long 0.5-5 points	to favour recipients with long waiting time
Matchability:	easy to hard 1-10 points	to benefit recipients with rarer HLA types
Sensitisation level: (Undefined PRA)	high to low 0.5-5 points	to favour those with no or low (undefined) sensitisation with the aim of avoiding positive crossmatches
Balance of Exchange:	low to high 1-10 points	to provide some control on the centres' Balances of Exchange
TOTAL:	5-50 points	

P3.....

TO: Directors of Renal Transplant Units
UK and Republic of Ireland
REF: PJM/rb/cmg/141/M322
21 January 1998

5. Where there is a tie of equally matched recipients, the tie breaker will be the distance between retrieval and recipient centre (ie the shorter of the two) for an adult recipient and waiting time (ie the longer) in the case of paediatric recipients.

6. A separate allocation scheme for paediatric donor kidneys (under 18 years of age) is under consideration: the scheme described here currently applies only to adult donor kidneys.

7. Directors also discussed the most appropriate method of calculating the balance of exchange in the light of its use as one of the points scoring items for equally matched patients, and as the determining factor for distributing an unfavourably matched kidney which could not be used by the local unit/alliance. It was decided that for this scheme, the balance would:

include all kidneys which are transplanted;
count kidneys retained and used locally as well as those which are exchanged;
separate out adult and paediatric donor kidneys;
count every transplanted kidney as one import and one export;
count as one import and one export a pair of kidneys used as a pair for one patient.

8. The balance will be calculated from 1 January 1997 when the new favourable matching scheme was introduced; after three years' accumulation, the balance will be rolled forward each year to retain three year rolling totals.

9. The new scheme will be implemented with effect from 1 July 1998 and will be fully reviewed after two years' operation. The outcome will be reviewed by the UKTSSA Users' Kidney Advisory Group, and Directors of all Renal Transplant Units will again be invited to discuss the findings. A small Group will be established to oversee implementation and audit of the new scheme: Douglas Briggs, Chris Rudge and Phil Dyer have agreed to join me in this, with a UKTSSA team, to work on Users' behalf. Monitoring of the scheme will include logging compliance: non-compliance will be followed up by UKTSSA and the response will be reported to the Kidney Advisory Group without recourse to anonymity.

10. I believe that patients will benefit from our use of the new scheme - the indications are that more favourably matched transplants will result if all Directors keep faith with the protocol for all donor kidneys. This scheme represents an exciting development for renal transplantation in the UK which deserves to be widely published. Publications and presentations are in hand for submission to the British Medical Journal, the Lyon Meeting, the July 1998 Meeting of the Transplantation Society and 'Transplantation'. Other publications and presentations are planned: please contact me if you have proposals for presentation or publication.

11. Directors discussed the effects of local alliances as currently constituted and agreed that, if possible, local allocation of kidneys (whether in a single unit or in an alliance) should follow the points scoring mechanism set out here. Units or alliances wishing to have more details of, or to adopt the national points scoring scheme - or wishing to establish a new alliance - should contact Katharyn Burdon at UKTSSA: please do so as soon as possible if you wish to adopt the national points score simultaneously with the new scheme coming into operation on 1 July.

12. Please confirm that you have agreed to participate in the new allocation scheme as set out here for all adult donor kidneys arising in your unit by signing and returning the copy of this letter which is enclosed. The Paediatric HLA Task Force has yet to conclude proposals for the allocation of paediatric donor kidneys: I will write to Directors again once that work is complete. Enclosed are two posters summarising the new scheme which you might find helpful to have to hand locally. Additional copies are available from the Advisory Group Executive at UKTSSA (Mrs Laraine Joy) who can be contacted on direct telephone line 0117 9757516.

13. I am sending a copy of this letter to the Chief Medical Officers of England, Scotland and Wales for their Information, also to the Presidents of the Royal Colleges of Surgeons and Physicians.

Yours sincerely

Professor Sir Peter Morris FRS
Chairman
UKTSSA Users' Kidney Advisory Group

Enc.

Copies: Heads of Tissue Typing Laboratories
Transplant Co-ordinators
President Royal College of Surgeons
President Royal College of Physicians
Chief Medical Officer England
Chief Medical Officer Scotland
Chief Medical Officer Wales
Chief Medical Officer N. Ireland
Members - Users' Kidney Advisory Group
Members UKTSSA Special Health Authority

The New Children's Hospital
Royal Alexandra Hospital for Children

Dr Elisabeth Hodson **MB BS FRACP**
Consultant Physician
Paediatric Nephrology
Telephone: 61 2 9845.3430 Fax: 61 2 9845.3432
Provider no: 29665AH Email - Elisah@NCH.EDU.AU

22nd June, 1998
G:data/juliew/datacol.doc

Dr L Johnstone
Secretary
ANZPNA
Department of Nephrology
Royal Children's Hospital
Flemington Road
PARKVILLE VIC 3052

Dear Lilian,

Thank you for your letter about the collection of echocardiography and lipid data for the ANZDATA Registry. This issue was discussed at our recent Renal Treatment Centre Management Committee Meeting. The consultants felt that we really could not contribute the data from the New Children's Hospital, unless it was part of a formal research project. As a group, the paediatric nephrologists in Australia have not been good at collecting the growth, puberty and bone xray data that is already part of the ANZDATA Registry. I fear that we would be equally poor in collecting lipid and echocardiography data unless it was part of a formal research study set up by ANZPNA.

I did discuss the collection of data with our Biochemistry Department and the Cardiology Department. In principle, there was no problem in doing the tests or billing the patients through Medicare for these tests. However, the bulk billing fee for HDL cholesterol can only be claimed if the total cholesterol is more than 5.5mmol/l or the fasting triglyceride is more than 2.0mmol/l. Also, LDL cholesterol and VLDL cholesterol are not often measured directly and cannot be done in our laboratory. There is a formula for deriving LDL cholesterol from the fasting values, which is reasonably accurate.

In summary, I believe that the Department of Nephrology at this hospital would not be able to contribute lipid and echocardiography data to the ANZDATA Registry. There are logistic and economic difficulties in collecting the data, so I do not believe that we can collect it, except as part of a formal ANZPNA study.

With best wishes
Yours sincerely,

Dr Elisabeth Hodson
Consultant Physician
Paediatric Nephrology

DEPARTMENT OF NEPHROLOGY
Royal Children's Hospital
Flemington Road Parkville 3052
Telephone 61-3) 9345 5054
Fax 61-3) 9345 5611
Email: cjones@cryptic.rch.unimelb.edu.au

VICTORIAN PAEDIATRI
RENAL SERVICE
ARBN 10662662Y

DR COLIN L JONES
Director

DR HARLEY R POWELL

A/PROF ROWAN G WALKE

DR DAVID A McCREDIE

DR LILIAN M JOHNSTONE

DR AMANDA M WALKER

14 May 1998

Dr Colin Jones
Director
Department of Nephrology
Royal Children's Hospital
Flemington Road
PARKVILLE VIC 3052

Dear Colin

Re: Collection of echocardiography & lipid data for ANZDATA Registry

At last year's ANZPNA Annual General Meeting it was suggested that data pertaining to hyperlipidaemia and left ventricular hypertrophy be collected via the ANZDATA Registry for our paediatric patients.

It was thought that it would be useful in determining the prevalence of abnormalities in our paediatric population and as a database longterm as cardiovascular disease becomes clinically apparent.

The data to be collected would be annual echo using American Society of Echocardiographer's conventions to measure LVISD, LVIDD, PWT, IVST, Aortic root diameter and left arterial diameter and stroke volume and fractional shortening. The lipid data would be fasting cholesterol, triglyceride, LDL-C, VLDL-C and HDL-C.

I would plan to test all dialysis and transplant patients annually.

Would you discuss this with your unit colleagues and with your biochemistry and cardiology departments and indicate to me whether you are interested in collecting this data and whether it is feasible to do so.

I would appreciate your reply by 30 June, so I can speak to it at the AGM in July.

I look forward to hearing from you.

Kind regards

Yours sincerely

Lil

LILIAN JOHNSTONE
SECRETARY
ANZPNA

Princess Margaret Hospital For Children
Perth. Western Australia

Refer Enquiries to:

PAEDIATRIC NEPHROLOGY SERVICES
Telephone: (08) 93408354 Fax: (08) 9340 8301

Telephone:

Princess Margaret Hospital for Children

Roberts Road
Subiaco WA 6008
GPO Box D184
Perth WA 6001
Telephone (09) 340 8222
Facsimile (09) 340 8111
Facsimile (09) 340 8115

26 May 1998

Dr Lilian Johnstone
Secretary
ANZPNA
Department of Nephrology
Royal Children's Hospital
Flemington Road
PARKVILLE VICTORIA 3502

Dear Lilian

Re: Collection of echocardiography and lipid data for ANZDATA Registry

In reply to your letter of the 14 May 1998 I have discussions with Dr Jim Ramsay, Head of Cardiology here at Princess Margaret Hospital, and he sees no difficulty with performing annual echocardiographs on our dialysis transplant population. Similarly, it would be easy to perform lipid estimates on an annual basis and therefore I would fully support collection of echocardiograph and lipid data for the Registry.

Kind regards.

Yours sincerely

Ian

Ian K Hewitt
RENAL PHYSICIAN

Addendum:

The Cardiologists have indicated that it would be easier if the echocardiograms were spread throughout the year, rather than all at one time (possibly around birthdays).

Date: Tue, 02 Jun 1998 15:41:00 +0700 (T)
From: "Henning, Paul (RENAL)" <henningp@wch.sa.gov.au>
Subject: ANZDATA registry, lipids, echo.
To: "'smtp:cjones@cryptic.rch.unimelb.edu.au'"
<cjones@cryptic.rch.unimelb.edu.au>
Cc: "Jureidini, Ken (RENAL)" <jureidinik@wch.sa.gov.au>
Encoding: 11 TEXT

Dear Lilian,
In reply to your letter on this matter, we would have no difficulty with providing the annual echocardiographic data you suggest.
The lipids are OK except that the LDL-chol. is calculated from the values for HDL , total chol. and total triglyceride, and the VLDL can only be estimated. Provided you are satisfied with this, we can also provide these data.

Best wishes,
Paul Henning

ANDREW R. ROSENBERG, MB BS, FRACP
Paediatric Nephrologist
Provider No: 409051X

PHONE: *02 - 9382 1646*
FAX: *02 - 9382 1580*
Email: *A.Rosenberg@UNSW.edu.au*

SYDNEY CHILDREN'S HOSPITAL

High Street, Randwick NSW 2031
Telephone: 02 9382 1111

Wednesday, 3 June, 1998.

Dr Lilian Johnstone
Secretary, ANZPNA
Department of Nephrology
Royal Children's Hospital
Flemington Road
PARKVILLE VIC 3052

Dear Lil,

re: Collection of echocardiology & lipid data for ANZDATA Registry

I agree that it would be useful to determine the prevalence of echocardiographic and lipid abnormalities in our paediatric population. I do think that the ANZDATA Registry will need to formally adopt the suggestion; we should really develop a protocol detailing background literature, justification, whether we would wish ANZDATA to continue collecting the data annually even after the patients have ceased to be under our care, a pre-agreed frequency of data analysis etc.

Kind regards.

Yours sincerely,

Andrew R. Rosenberg

cc Dr G Kainer

Formerly Prince of Wales Children's Hospital.
A facility of the South Eastern Sydney Area Health Service.

Stock S1784 6/97

QUEENSLAND HEALTH

PRINCESS ALEXANDRA HOSPITAL
and DISTRICT HEALTH SERVICE

PRINCESS ALEXANDRA HOSPITAL
Ipswich Road
Woolloongabba
Brisbane Qld Australia 4102
Telephone (07) 3240 2111
Facsimile (07) 3240 5577

ENQUIRIES **DEPT OF NEPHROLOGY**
PHONE **61 7 3240 5080**
FAX **61 7 3240 5480**
OUR REF **MF:mbk**
YOUR REF
Dict: 18 May 1998
Typed: 20 May 1998

Mobile: 0419 641449

Email: klaf@extro.ucc.su.oz.au

Dr Lilian Johnstone
Secretary
ANZPNA
Victorian Paediatric Renal Services
Royal Children's Hospital
Flemington Road
PARKVILLE 3052

Dear Lil

re: COLLECTION OF ECHOCARDIOGRAPHIC & LIPID DATA FOR ANZDATA REGISTRY

Thank you for your recent letter. I would be delighted to participate in the collection of the hyperlipidaemia and left ventricular hypertrophy data to be potentially collected by the ANZDATA Registry. I do not believe the echo or lipid profiles will be particularly difficult to achieve, however will check with the local laboratories and Cardiologists. I will also pursue this in conjunction with Rowan at the ANZDATA Registry meeting to be held at the end of this month.

With warm wishes.

Yours sincerely

Michael

MICHAEL FALK
STAFF NEPHROLOGIST

A multicentre double-blind placebo controlled trial of chemoprophylaxis in children with isolated vesicoureteric reflux

Progress Report
June 1998

Background

The term 'Reflux Nephropathy' refers to the long held belief that vesicoureteric reflux (VUR) leads to urinary tract infection and then to renal damage. Clinicians have therefore attempted to prevent the onset and development of this damage by early identification of those with asymptomatic VUR and treatment of these individuals with chemoprophylaxis and /or surgery. As outlined in the protocol, this theory is not always supported by the clinical data observed. VUR and renal parenchymal damage may not be causally related and appear to exist separately, as well as together. Randomised trials to date have not evaluated a control arm of placebo treatment compared to chemoprophylaxis or surgery. This trial will compare the outcome of children with and without conventional treatment (chemoprophylaxis).

Hypothesis and Aims

The investigators postulate that the renal parenchymal abnormality associated with VUR is congenital and is therefore not altered by postnatal events such as persistent VUR or urinary tract infection.

The study aims to ascertain:

1. if the outcomes are altered by chemoprophylaxis.

2. the prevalence of renal parenchymal damage in newborn children with VUR prior to the onset of symptomatic infection.

3. the natural history and clinical outcomes of VUR as measured by the incidence of urinary tract infection, the development of the glomerular filtration rate, blood pressure, renal growth and the onset of renal damage.

Progress to date

Since its commencement in 1995, this study has screened 297 children with a diagnosis of antenatal renal pelvicalyceal dilatation or a family history of VUR. Of these children, 243 have undergone postnatal evaluation of VUR. The prevalence of VUR in this sample is 15% (36/243). Of the children diagnosed with VUR, 17 were either ineligible for the study or declined participation. Nineteen (14 males, 5 females) children enrolled in the study.

A further 20 (10 males, 10 females) children have been recruited to the study through both private referrals (12), and the Melbourne (7) and Brisbane (1) Centres. Flow chart attached.

To date, three children have completed follow up and one, lost to follow up. No child with renal damage at entry has demonstrated progression of damage, nor has new damage been demonstrated in previously normal kidneys. One child has been diagnosed with a urinary tract infection.

Vesicoureteric reflux trial meeting

Venue: New Children's Hospital, Clinical Science Building, Staff room 1
Time: July 30th, 2 - 4 pm

Agenda

1. Trial progress
    a. recruitment to 1998
    b. entry data

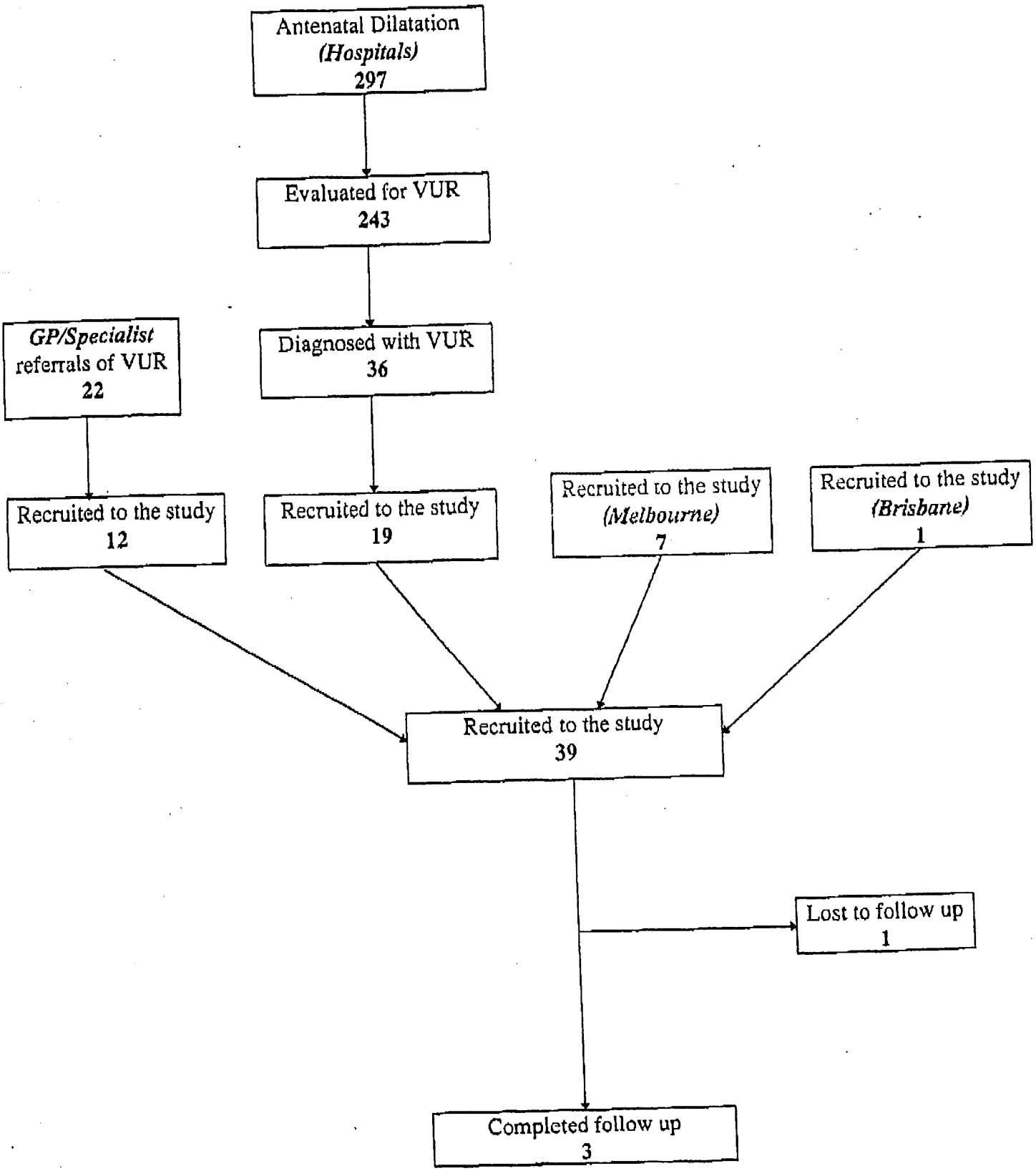
2. Funding

3. Trial continuation options:
    a. stop completely
    b. stop new recruitment after 1998 but continue 3 year follow up of participants
    c. continue the trial

4. Placebo supply

Materials enclosed:
1. Progress report
2. Recruitment to date (Table 1, Figures 1-4)
3. Description of participants (Tables 2-5, Figure 5)

Recruitment to date



Appendix 8

Australasian Paediatric Endocrine Group

PRESIDENT
Professor J. Batch
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Fax (03) 9550 4124

9 July 1998

Dr Lillian Johnstone
Paediatric Nephrologist
Royal Children's Hospital

FAX: 03 93455611

RE: GROWTH HORMONE IN CHRONIC RENAL FAILURE

Dear Lil,

As we discussed a recommendation has recently been made by the PBAC at their meeting in early June regarding the failure of the Pharmaceutical companies to obtain approval for the indications of Turners Syndrome and Chronic Renal Failure.

The recommendation was:

'SOMATROPIN, injections 4iu, 10iu, 12iu, 16iu, 18iu, 24iu and 36iu.

Delete the indications which have been rejected by the ADEC and TGA, Turner Syndrome and Chronic Renal Insufficiency/Renal Failure.

The Sponsors of the drugs and the Growth Hormone Advisory Committee should be advised that the PBAC has no option but to recommend deletion of these indications as no product has formal approval and indeed some had applications rejected by ADEC due to insufficient data to support efficacy. Implementation should be delayed for six months (until the end of 1998) in case the sponsors are able to obtain registration.'

The companies have apparently been contacted by the Growth Hormone Program. It is further noted that with the rejection by ADEC, the PBAC has absolutely no choice but to act on this recommendation at the end of 1998, should approval not be obtained by at least one of the sponsors before then.

This is as much information as we have at present but I will continue to keep you appraised should anything further come to light. I hope this information will be useful to your members.

With kind regards.

Yours sincerely,

Jennifer Batch
Professor of Paediatrics
President of the Australasian Paediatric Endocrine Group

N.S.W. Incorporation No. Y14290-35

6 Byrne Ave
ELWOOD 3184

July 7th 1998

Dr L Johnson
Paediatric Nephrologist
Monash Medical Centre
CLAYTON 3168

Dear Lil,

Further to our discussion about the availability of Somatropin for children with Chronic Renal Failure on the Pharmaceutical Benefits Scheme (PBS), the situation is as follows:

The Therapeutic Goods Administration (TGA) has registered Somatropin for use in Australia but has no say in how Doctors chose to use the drug.

The Australian Drug Evaluation Committee (ADEC) has never approved Somatropin for use in CRF so it has never had a permit for this indication. No evidence has been provided to ADEC that Somatropin is effective in CRF.

The PBS does not normally subsidise drugs that are not approved by ADEC.

The PBS uses a strict evidence based approach when it considers a drug for listing.

Somatropin was listed for CRF on the PBS many years ago before ADEC existed and before the PBS had an evidence based system.

As ADEC and the PBS have not been presented with scientific evidence for the benefits of Somatropin in CRF, the PBS will be withdrawing Section 100 authority for Somatropin as of 1999 for CRF (and also Turner's syndrome).

What can you do?

Get the necessary evidence - present it to ADEC. Lobby the Manufactures to make a submission - they have more resources and time but may feel it is not worth their while if they are not selling enough product for this indication.

Please contact me if you need any further advice/assistance.

Yours sincerely,

Dr Sian Hughes
Paediatrician on PBAC

Women's and Children's Hospital
ADELAIDE

72 King William Road
North Adelaide
South Australia 5006
Telephone (08) 8204 7000
Facsimile (08) 8204 7459

8.4.98

Ms. A. Bickford
Medical Information Associate
Roche Products P/L
Medical Information
4-10 Inman Road
PO Box 255
DEE WHY NSW 2099

Dear Ms. Bickford,

re: Liquid Preparatin of Rocaltrol (Calcitriol) 1 mcg/ml.

I write on behalf of the Australian and New Zealand Paediatric Nephrology Association to support the Australian Paediatric Endocrine Group in its efforts to make the liquid formulation of Rocaltrol available within Australia. A copy of their recent letter to you was handed on to our Association by Dr Gad Kainer.

We whole-heartedly agree that the presently available capsule is unsuitable for small children and limits our ability to use appropriately titrated doses to avoid the risks of hypo and hypercalcaemia. The paediatric renal units around Australia have significant numbers of young children with advanced chronic renal failure who require daily calcitriol to prevent and treat renal osteodystrophy. The advantages of the 1mcg/ml. liquid preparation for these patients would be substantial.

I understand that the liquid preparation would be a suitable candidate for an orphan drugs application to the TGA. If there is anything further that we can do to support or assist your application please do not hesitate to contact me.

Yours sincerely

Paul Henning
Honorary Treasurer
Australian and New Zealand Paediatric Nephrology Association

cc. Dr Colin Jones (Royal Children's Hospital, Melbourne), Dr G. Kainer (Sydney Children's Hospital)

CHILD HEALTH QUESTIONNAIRE Parent Form

Aust CHQ PF-50
Authorised Australian Adaptation

Please note: The Australian Authorised Adaptation of the Child Health Questionnaire -Parent Form (Aust CHQ PF-50) comprises sections 1-9 inclusive.

INSTRUCTIONS

1. This booklet asks about your child's health and well-being. It is private and your individual answers will not be shared with anyone. Your answers will remain confidential.
2. Answer by marking the appropriate box for each question. ☐
3. Some questions may look alike but each one is different. Some questions ask about problems your child may not have. That's great, but it's important for us to know. Please answer each question.
4. There are no right or wrong answers. If you are unsure how to answer a question, please give the best answer you can and make a comment in the margin.
5. All comments will be read, so please feel free to make as many as you wish.

Your child's global health

1.1. In general, would you say **your child's health** is:

☐	☐	☐	☐	☐
Excellent	Very good	Good	Fair	Poor

Your child's physical activities

The following questions ask about physical activities your child might do during the day.

2.1. During the **past 4 weeks**, has your child been limited in any of the following activities due to **health problems**?

		Yes, limited a lot	Yes, somewhat limited	Yes, limited a little	No, not limited
a.	Doing things that take **a lot** of energy, such as playing soccer, running?	☐	☐	☐	☐
b.	Doing things that take **some** energy such as riding a bike or roller blading?	☐	☐	☐	☐
c.	Ability (physically) to get around the neighbourhood playground or school areas?	☐	☐	☐	☐
d.	Walking one block or climbing one flight of stairs?	☐	☐	☐	☐
e.	Bending, lifting, or stooping?	☐	☐	☐	☐
f.	Taking care of her/himself, that is, eating, dressing, bathing, or going to the toilet?	☐	☐	☐	☐

Your child's everyday activities

3.1. During the **past 4 weeks**, has your child's school work or activities with friends been limited in any of the following ways due to EMOTIONAL difficulties or problems with his/her BEHAVIOUR?

		Yes, limited a lot	Yes, somewhat limited	Yes, limited a little	No, not limited
a.	limited in the KIND of schoolwork or activities with friends he/she could do?	☐	☐	☐	☐
b.	limited in the AMOUNT of time he/she could spend on schoolwork or activities with friends?	☐	☐	☐	☐
c.	limited in PERFORMING schoolwork or activities with friends (it took extra effort)?	☐	☐	☐	☐

3.2. During the **past 4 weeks**, has your child's school work or activities with friends been limited in any of the following ways due to problems with his/her PHYSICAL health?

		Yes, limited a lot	Yes, somewhat limited	Yes, limited a little	No, not limited
a.	limited in the KIND of schoolwork or activities with friends he/she could do?	☐	☐	☐	☐
b.	limited by the AMOUNT of time he/she could spend on schoolwork or activities with friends?	☐	☐	☐	☐

Pain

4.1. During the **past 4 weeks**, how **much** bodily pain or discomfort has your child had?

☐ None ☐ Very mild ☐ Mild ☐ Moderate ☐ Severe ☐ Very severe

4.2. During the **past 4 weeks**, how **often** has your child had bodily pain or discomfort?

☐ None of the time ☐ Once or twice ☐ A few times ☐ Fairly often ☐ Very often ☐ Every day or almost every day

Behaviour

Below is a list of items that describe children's behaviour or problems they sometimes have.

5.1. How often during the **past 4 weeks** did each of the following statements describe your child?

		Very often	Fairly often	Sometimes	Almost never	Never
a.	argued a lot	☐	☐	☐	☐	☐
b.	had difficulty concentrating or paying attention	☐	☐	☐	☐	☐
c.	lied or cheated	☐	☐	☐	☐	☐
d.	stole inside or outside the home	☐	☐	☐	☐	☐
e.	had tantrums or a hot temper	☐	☐	☐	☐	☐

5.2. Compared to other children your child's age, in general would you say his/her behaviour is:

☐	☐	☐	☐	☐
Excellent	Very good	Good	Fair	Poor

Well being

The following phrases are about children's moods.

6.1. During the past 4 weeks, **how much of the time** do you think your child:

		All of the time	Most of the time	Some of the time	A little of the time	None of the time
a.	felt like crying?	☐	☐	☐	☐	☐
b.	felt lonely?	☐	☐	☐	☐	☐
c.	acted nervous?	☐	☐	☐	☐	☐
d.	acted bothered or upset?	☐	☐	☐	☐	☐
e.	acted cheerful?	☐	☐	☐	☐	☐

Self esteem

The following asks about your child's satisfaction with self, school, and others. It may be helpful if you keep in mind how other children your child's age might feel about these areas.

7.1. During the **past 4 weeks**, how satisfied do you think your child has felt about:

		Very satisfied	Somewhat satisfied	Neither satisfied nor dissatisfied	Somewhat dissatisfied	Very dissatisfied
a.	his/her school ability?	☐	☐	☐	☐	☐
b.	his/her athletic ability?	☐	☐	☐	☐	☐
c.	his/her friendships?	☐	☐	☐	☐	☐
d.	his/her looks/appearance?	☐	☐	☐	☐	☐
e.	his/her family relationships?	☐	☐	☐	☐	☐
f.	his/her life overall?	☐	☐	☐	☐	☐

Your child's health

The following statements are about health in general.

8.1. How true or false is each statement for your child?

		Definitely true	Mostly true	Don't know	Mostly false	Definitely false
a.	my child seems to be less healthy than other children I know	☐	☐	☐	☐	☐
b.	my child has never been seriously ill	☐	☐	☐	☐	☐
c.	when there is something going around my child usually catches it	☐	☐	☐	☐	☐
d.	I expect my child will have a very healthy life	☐	☐	☐	☐	☐
e.	I worry about my child's health more than other people worry about their children's health	☐	☐	☐	☐	☐

8.2. Compared to one year ago, how would you rate your child's health now:

☐	☐	☐	☐	☐
Much better now than 1 year ago	Somewhat better now than 1 year ago	About the same now as 1 year ago	Somewhat worse now than 1 year ago	Much worse now than 1 year ago

You and your family

9.1. During the **past 4 weeks**, how MUCH emotional worry or concern did each of the following cause YOU?

		None at all	A little bit	Some	Quite a bit	A lot
a.	your child's physical health	☐	☐	☐	☐	☐
b.	your child's emotional well-being or behaviour	☐	☐	☐	☐	☐
c.	your child's attention or learning abilities	☐	☐	☐	☐	☐

9.2. During the **past 4 weeks**, were YOU LIMITED in the amount of time YOU had for your own personal needs because of:

		Yes, limited me a lot	Yes, limited me some	Yes, limited me a little	No, did not limit me
a.	your child's physical health	☐	☐	☐	☐
b.	your child's emotional well-being or behaviour	☐	☐	☐	☐
c.	your child's attention or learning abilities	☐	☐	☐	☐

9.3. During the past 4 weeks, **how often** has your child's **health or behaviour**:

		Very often	Fairly often	Sometimes	Almost never	Never
a.	limited the types of activities you could do as a family?	☐	☐	☐	☐	☐
b.	interrupted various everyday family activities (eating meals, watching TV)?	☐	☐	☐	☐	☐
c.	limited your ability as a family to "pick up and go" on a moment's notice?	☐	☐	☐	☐	☐
d.	caused tension or conflict in your home?	☐	☐	☐	☐	☐
e.	been a source of disagreement or arguments in your family?	☐	☐	☐	☐	☐
f.	caused you to cancel or change plans (personal or work) at the last minute?	☐	☐	☐	☐	☐

9.4. Sometimes families may have difficulty getting along with one another. They do not always agree and they may get angry. In general, how would you rate your family's ability to get along with one another?

☐	☐	☐	☐	☐
Excellent	Very good	Good	Fair	Poor

Facts about your child

10.1. Is your child:

☐ Male ☐ Female

10.2. This child is my: (mark **one** box)

☐ 1st ☐ 2nd ☐ 3rd ☐ 4th ☐ 5th or more

10.3. How many children do you have altogether? (mark **one** box)

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 or more

10.4. What is your child's date of birth?

___/___/___

Date Month Year

10.5. To the best of your knowledge is your child up to date with immunisations for his/her age?

☐ Yes ☐ No ☐ Don't know

10.6. What grade is your child in this year? (mark **one** box)

☐ Preparatory
☐ Year 1
☐ Year 2
☐ Year 3
☐ Year 4
☐ Year 5
☐ Year 6
☐ Year 7
☐ Year 8
☐ Year 9
☐ Year 10
☐ Year 11
☐ Year 12

10.7. Has your child ever repeated a grade?

☐ Yes ☐ No

If **YES**, which grade/s?

☐ Preparatory
☐ Year 1
☐ Year 2
☐ Year 3
☐ Year 4
☐ Year 5
☐ Year 6
☐ Year 7
☐ Year 8
☐ Year 9
☐ Year 10
☐ Year 11
☐ Year 12

10.8. Does your child have any of the following conditions? (Please answer **every** question)

		No	Yes, but does not see a health professional regularly	Yes, and sees a health professional regularly
a.	anxiety problems	☐	☐	☐
b.	attention problems	☐	☐	☐
c.	behaviour problems	☐	☐	☐
d.	asthma	☐	☐	☐
e.	chronic respiratory, lung or breathing trouble (not asthma)	☐	☐	☐
f.	chronic allergies or sinus trouble	☐	☐	☐
g.	chronic orthopaedic, bone or joint problems	☐	☐	☐
h.	chronic rheumatic disease	☐	☐	☐
i.	dental problems	☐	☐	☐
j.	depression	☐	☐	☐
k.	developmental delay or intellectual disability	☐	☐	☐
l.	diabetes	☐	☐	☐
m	epilepsy (seizure disorder)	☐	☐	☐
n.	hearing impairment or deafness	☐	☐	☐
o.	learning problems	☐	☐	☐
p.	sleep disturbance	☐	☐	☐
q.	speech problems	☐	☐	☐
r.	vision problems	☐	☐	☐
s.	does your child have any other chronic medical condition that is affecting what they do or how they feel? (Please describe below)	☐	☐	☐

_____

Please check that you have answered all the questions.
Thank you for your participation!

MINUTES OF THE PAEDIATRIC SPECIALITIES ADVISORY COMMITTEE
Held on Tuesday 17 February 1998 at 5pm

In attendance: Peter Van Asperen (Chairman), Gary Sholler (Paediatric Cardiology Group), Robert Pitt (PEMSIG), Jenny Batch (APEG), Scott MacFarlane (ANZCCSG), Peter McIntyre (Paediatric Infectious Disease Group), Frank Shann (PICSIG), Andrew Rosenberg (ANZPANA), Kevin Collins (CNSG), Peter Marshall (APS), Colin Robertson (APRG), Don Roberton (AMWAC Working Party on Paediatric Workforce)

Apologies: Arnold Smith (AUSPGAN)

MATTERS DISCUSSED

1. Terms of Reference
It was agreed that the current terms of reference were appropriate and that the function of this Committee would be to facilitate bi-directional communication between the paediatric subspeciality groups and the other Boards and committees within the ACP/Paediatric Division of the RACP

2. Membership
During the meeting the potential advantages of having the SAC paediatric representative as the representative on this Committee. It was resolved to allow each speciality group decide on an appropriate representative for this Committee, taking into account that issues in addition to training would be considered by the Committee.

3. MOPS
Peter Van Asperen informed the Committee of the review of MOPS currently being undertaken with a report due in October 1999. He also indicated that the AMC are currently exploring the issue of recertification and that the specialty groups are likely to be consulted in this process. Gary Sholler indicated that their group had developed standards for the practice of paediatric echocardiography and this raised the issue of the development of suitable standards of practice for sub-speciality paediatrics in general.

4. Clinical Indicators and Clinical Practice Guidelines
Peter Van Asperen informed the Committee of the Clinical Indicators Committee of the BCE under the Chairmanship of Jonathan Gillis. This Committee had developed some simple paediatric clinical indicators which were currently being evaluated and they were also examining the potential role of the ACP in establishing Clinical Practice Guidelines for common paediatric conditions. He indicated that consultation with speciality groups was likely to occur. Some member of the Committee indicated that their group had forwarded their currently available Practice Guidelines to the College at the request of Tim Bohane. Peter Van Asperen agreed to follow this up.

5. Annual Scientific Meeting
The wish of the BCE and Scientific Programme Committee for increased involvement of the speciality groups in the ASM was also endorsed by this Committee. The importance of forward planning by the Scientific Programme Committee to allow involvement of the Speciality Groups was emphasised.

6. Paediatric Subspeciality Training
Considerable discussion occurred regarding the mechanism and certification of paediatric subspeciality training. Don Roberton indicated that all paediatric subspeciality trainees would now need approval of training from the CPPT as well as the appropriate SAC. He indicated that a new "mango" book on training requirements was about to be circulated and that this would contain the requirements for paediatric subspeciality training which had been formulated by the speciality groups at the request of Jill Sewell.

7. AMWAC Working Party on Paediatric Workforce
Charles Scarf reported to the Committee on the activities of the AMWAC Working Party on Paediatric Workforce, indicating that all paediatricians would be receiving a questionnaire from AMWAC shortly. He also indicated that the speciality groups would (or may have already) receive a request for workforce requirements for their paediatric subspecialities.

8. Frequency of Meetings
It was agreed that twice yearly teleconferences would be appropriate with the possibility of a face to face meeting at the ASM, depending on how many members would be attending.

Sample size for trial of cyclophosphamide in treatment of FSGS

For Dr Steve McTaggart 17/7/98

The planned study is a randomised trial involving two arms, in both of which cyclosporin is withdrawn over two months, while in the control group (C) no other treatment is used and in the active arm (A) cyclophosphamide is given. The primary analysis proposed is to compare the mean time to relapse between the two arms. It is likely that the distribution of this time will be approximately lognormal, since the variation may be expected to increase with the mean. The sample size calculations are therefore based on comparison using standard t-test methods applied to the log-transformed time-to-relapse. More elaborate survival analysis methods may be needed if not all patients reach the point of relapse by the end of the trial, but the following calculations should still give a reasonable basis for planning.

Given an expected (median) time to relapse of 1 month in the C arm, and a judgment that about 80% of cases would relapse within a two-fold time range above and below this value (i.e. between 0.5 and 2 months), the estimated SD of the log values (natural log scale) is 0.693/1.28 = 0.54. The same relative variation is assumed to apply for the A arm.

Sample size and power then depend on the minimum clinically important difference that it is desired to "detect". This was specified as a 6-fold increase in median time to relapse, i.e. we assume that achieving a median time in the A arm of less than 6 months would not be clinically worthwhile. To ensure 90% power, $n = 4$ would suffice in each arm for this large difference (corresponding to $\delta = \log_e 6 = 1.79$). With the same assumption about variation, differences of 4-fold and 3-fold would require respectively $n = 5$ and $n = 7$, again for 90% power. For such a small study, settling for lower power would seem unwise.

It must be clearly understood that the small numbers suggested here reflect the assumption that this treatment will produce a very dramatic difference, and that a substantially less dramatic difference, if present, would not be clinically important.

John Carlin

Commonwealth Bank
Commonwealth Bank of Australia
ACN 123 123 124

Statement	6 (Page 1 of 1)
Statement begins	2 July 1998
Statement ends	3 August 1998
Closing balance	**$1,349.89 CR**
Enquiries	**13 2221** (8am to 8pm, Mon to Fri)

COLIN L JONES
C O NEPHROLOGY ROYAL CHILDRENS HOSPITAL
PARKVILLE VIC 3052

Cheque Acct Bearing Interest

Account number (06 3349) 10021898

Name: ANZ PAEDIATRIC NEPHROLOGY

Branch: ROYAL MELBOURNE HOSPITAL VIC
Bank, State & Branch number (BSB) 06 3349

Note: Proceeds of cheques are not available until cleared. Please check that the entries listed on this statement are correct. If there are any errors, please contact the Bank immediately on 13 2221.

Date	Transaction detail	Debit	Credit	Balance
02 JUL	1998 OPENING BALANCE			$1,349.89 CR
03 AUG	1998 CLOSING BALANCE			$1,349.89 CR

Opening balance	-	Total debits	+	Total credits	=	Closing balance
$1,349.89CR		Nil		Nil		$1,349.89CR

28th August 1998

Members of ANZPNA

You will recall from our meeting in Queensland that the supply of recombinant human growth hormone to children with renal failure was being withdrawn from the PBS subject to an appeal. That appeal has been unsuccessful. My understanding is that growth hormone will no longer be available for the indication of growth failure due to chronic renal failure from the end of 1998.

I have summarised the situation in a letter (enclosed) to Graeme Russ, President of the Australian and New Zealand Society of Nephrology.

The steps Executive is taking include:

1. Acquainting the College of the ANZ is in of the situation. Graeme Russ feels the issue could be put to the Public Affairs Office of the RACP by the Society. The Society would ask us to handle it through the College Official (who has offered to lobby for specialist groups in appropriate circumstances).
2. Charlie Crompton is analysing the OZ Grow Data with a number of goals.

   (i) In the short term to dig out the benefit of growth hormone across the patient group as a whole and identify the change in height standard deviations score for those who have finished growing.

   (ii) In the longer term to analyse the data with respect to treatment modality, nutritional status (if possible), pubertal status, determining the affect of transplantation. This is a difficult task because the practice of each group around the country is slightly different.

   I enclose Charlie's initial evaluation of the data.

3. I enclose a letter to the Chairman of ADEC. I expect this to be futile.
4. I enclose a draft of a letter to my Federal member. I will accompany it with a version of the letter to Graeme Russ. I need your feedback on changes to this letter to make it more appropriate.
5. Members of ANZPNA will discuss the issues with the Paediatric Endocrine Group. With the success of the Turner's application, I cannot help but feel we have been a bit isolated.

Yours sincerely,

Colin Jones
Director – Department of Nephrology

Charles Crompton FRACP
Consultant Paediatrician &
Paediatric Nephrologist

in association with
Michael Slattery FRACP
Consultant Paediatrician

(2)

MURDOCH
PAEDIATRICS

Appointments 366 1927
Facsimile 366 1947
Pager 480 4713
Mobile 0418 917 733

27 August, 1998

DR COLIN JONES

FAX: 03 9345 5611

Further to our phone discussion yesterday, herewith a few details from OZGROW.

- Total No. of patients receiving rhGH longer than 3 months in Australia from 1989 until present = 185
- Age range 2-21 years
- Length of treatment range 3 months to 9.5 years
- Mean change in HtSDS for whole group = + 0.346
- Centre Effect : Worst +0.054 (19 patients in Group)
  : Best +1.179 (14 patients in Group)

I am sorry I won't have time to find out how many patients were treated in each year, but in 1997 there were approximately 59 patients with renal disease on rhGH in Australia.

Kind regards

CHARLES CROMPTON

Level 2, Medical Centre
St John of God Hospital
100 Murdoch Drive,
Murdoch, 6150

Coolangatta Hospital Medical Suites
360 Ansoldie Road
Duncan Qld

DEPARTMENT OF NEPHROLOGY
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ARBN 10662662Y

DR COLIN L JONES
Director

DR HARLEY R POWELL

A/PROF ROWAN G WALKER

DR DAVID A McCREDIE

DR LILIAN M JOHNSTONE

DR AMANDA M WALKER

4th September 1998

The Honorable Dr Michael Wooldridge
MHR
Ministerial Office
6 Atherton Road
OAKLEIGH 3166

Dear Dr Wooldridge

The Australian community has provided an excellent standard of care for children with kidney failure through the leadership of the Commonwealth Government in providing a range of support for medication, child support allowances, social services and first class medical facilities.

Unfortunately, a decision of the Australian Drug Evaluation Committee (ADE) of the Therapeutic Goods Association will lead to the delisting of growth hormone from the Pharmaceutical Benefit Scheme (PBS) for children with stunted growth due to chronic renal failure. These children will now not grow to their optimal and achievable height and many will carry into their adult life the social problems of being abnormally short. For those families able to afford the medication, the cost will be around $10,000 per year!

It is important to note that following the Australian lead in initially using growth hormone, the United States Federal Drug Administration (FDA) found the scientific basis of growth hormone use in children with renal failure was established and approved growth hormone for this use in 1993. Similarly fourteen European countries have approved its use for this indication.

I enclose a more detailed synopsis of the TGA/ADEC/PBS decision.

I hope you are able to reverse this poor decision.

Yours sincerely,

Dr Colin Jones
Director – Department of Nephrology
Royal Children's Hospital
Chairman, Australian and New Zealand Paediatric Nephrology Association.

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DR LILIAN M JOHNSTONE

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28th August 1998

Dr Graeme Russ
President
Australian and New Zealand Society of Nephrology
C/- Renal Unit
Queen Elizabeth Hospital
28 Woodville Road
Woodville SA 5011

FAX NO: 08 8222 6026

Dear Graeme,

Re: Withdrawal of Growth Hormone for use in Children with Chronic Renal Failure from the PBS

The situation is as follows:

1. Almost a decade ago, the Therapeutic Goods Administration (TGA) registered Somatropin for use in Australia but had no say in how doctors chose to use the drug.

2. Somatropin was listed for Chronic Renal Failure (CRF) on the Pharmaceutical Benefit Scheme (PBS) many years ago before the Australian Drug Evaluation Committee (ADEC) existed and before the PBS had an evidence based system.

3. ADEC has never approved Somatropin for use in CRF so there was not a permit for this indication.

4. Overseas use of Somatropin. An EEC multi-state application for the use of the common and human growth hormone in CRF was approved in 1993 and since this time 14 countries in Europe (including non-EC countries) have approved use of rhGH in CRF. The United States Federal Drug Authority (FDA) approved rhGH for the treatment of growth retardation in CRF in November 1993.

5. In 1997 and 1998 ADEC requested literature based submissions to provide evidence of efficacy and safety. Confidential submissions were provided by Dr Ken Jureidini and Professor Otto Mehls (Heidelberg Paediatric Nephrologist) on behalf of the Pharmaceutical Company.

6. The applications were rejected to ADEC due to insufficient data to support efficacy as reported to ANZPNA by Professor Jennifer Batch (President of Australian Paediatric Endocrine Group) and Dr Sian Hughes (Paediatrician on PBAC) At the meeting of the Pharmaceutical Advisory Committed (PBAC) in early June 1998, the PBAC had no option but to recommend:-

   "Somatropin, injections for 4iu, 10iu, 12iu, 16iu, 18iu, 24iu and 36iu.

   Delete the indications which have been rejected by the ADEC and TGA, Turner Syndrome and Chronic Renal Insufficiency/Renal Failure.

   Implementation should be delayed for 6 months (until the end of 1998) in case the sponsors are able to obtain registration".

7. Pharmacia has subsequently had an appeal rejected. The appeal for Turner's Syndrome was successful. The data for Turner's Syndrome is less substantial. The episode smacks of an unfair and non-scientific process.

8. It seems unlikely that another company will be successful and I don't know if any have applied.

9. It should be noted that:

   The PBS does not normally subsides drugs that are not approved by ADEC.
   The PBS uses a strict evidence based approach when it considers a drug for listing.

Why does ADEC consider there is insufficient data to support efficacy? No detail of the rejection has been given to the Paediatric Nephrologists or the Endocrinologists in the Australasian Paediatric Endocrine Group. Pharmacia has told me that there is no final height (i.e. adult height) data comparing control and treated groups. Good studies showed increased growth rate over a 2 year period with placebo controlled trials and 5 year in open label (not placebo controlled trials) trials. In addition the data on quality of life is said to be poor. Many, many studies have shown increased growth over the first years of growth hormone administration without advancement of bone age, but this has not proven sufficient to sway ADEC. A controlled trial will not be done overseas because it is accepted standard treatment. A controlled trial in Australia would take many years and it will be ethically difficult to allocate people to a placebo group when it is certain (in the minds of the nephrologists and endocrinologists, anyhow) that the drug is effective.

How did the Turners Syndrome appeal succeed? The trials are less well designed but world wide experience with 900 patients was presented (open label). The predicted final height of these patients without the use of growth hormone (method of Leon) was used to compare to their actual achieved height! The heterogeneity (CRF), the change in modality and treatment and confounding effect of anti-growth medication are said to include this approach in CRF.

I am grateful for your suggestion to put this issue before Council and then the Public Affairs Office of the Royal Australasian College of Physicians and would be appreciative of any further advice or help you can give ANZPNA on this matter.

Yours sincerely,

Colin Jones
Chairman
Australian and New Zealand Paediatric Nephrology Association.

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DR DAVID A McCREDIE
DR LILIAN M JOHNSTONE
DR AMANDA M WALKER

4th September 1998

Professor Martin Tattersalls
Chairman
Australian Drug Evaluation Committee
C/- Queen Elizabeth Hospital
Adelaide SA 5000

Dear Professor Tattersalls

Re: Withdrawal of Growth Hormone for use in Children with Chronic Renal Failure from the PBS.

The Pharmaceutical Benefits Advisory Committee has recommended that the indication for Somatropin use in treating growth retardation due to chronic renal insufficiency/renal failure be deleted because ADEC found there was insufficient data to support evidence of efficacy. I have since learnt that the Pharmacia appeal to this decision was not successful. The implementation of the decision was delayed until the end of 1998 in case the sponsors were able to obtain registration.

Members of the Australian and New Zealand Paediatric Nephrology Association, of which I am Chairman, manage all of the children in Australia who have been treated with Somatropin for the indication of chronic renal insufficiency/renal failure. Private communications from members of PBAC and the Pharmaceutical companies informed us there was a problem with the use of Somatropin for this indication. It was disturbing that these problems have been discussed at PBAC level since 1995 but have never been appropriately referred to this Association. The Australian Paediatric Endocrine Group was approached, but they have only a peripheral, and in many cases, no interest in the welfare of these children.

Our Association understands:

1. ADEC has never approved Somatropin for use in chronic renal failure so there was not a permit for this indication.
2. That PBS does not normally subsides drugs that are not approved by ADEC.
3. The PBS uses a strict evidence based approach when it considers a drug for listing.
4. The TGA registered Somatropin for use in Australia before ADEC existed, but had no say in how doctors chose to use the drug.

The Association believes that the withdrawal of growth hormone for this indication in this time frame is unreasonable because:

1. Somatropin has been available since 1989 and used for children with growth retardation due to chronic renal insufficiency/renal failure. The reimbursement under Section 100 of the PBS was a prima facie reason for members of the Association to believe the appropriate regulatory authorities had approved Somatropin for this indication. Consequently there has been no specific study designed to obtain evidence based data that would satisfy criteria ADEC require to provide

Somatropin's efficacy in this situation. Somatropin was registered for use for this indication in the United States by the FDA in 1993 and has been approved for use in 14 European countries. It is reasonable to assume that there is an argument that it does have efficacy for this indication.

2. Investigational studies sponsored by pharmaceutical companies, and independent research funding bodies, are usually performed in the initiation of clinical use of a drug. Now that most overseas regulatory authorities have accepted the evidence for use of Somatropin the incentive to do further studies to approve the drug for Australian regulatory authorities are minimal.

3. The Australian Oz Grow Database does contain data that can be analysed to assess improvement in final height. The database contains details of all patients with chronic renal insufficiency/renal failure treated with growth hormone in terms of their height, bone age, pubertal assessment, and duration in dose of treatment. The Association has asked one of our members (Dr Charles Crompton, Perth) to analyse this data with respect to the clinical course of the children. Using methods similar to those accepted by ADEC for the situation with regard to Turner Syndrome the Association believes efficacy with regard to improvement in final height can be demonstrated.

In view of the above considerations the Association requests that ADEC:

1. Allow the Association to put the data with regard to efficacy together and present it to ADEC.

2. Delay the implementation of the decision to delete the indication for the use of Somatropin in chronic renal insufficiency/renal failure.

Yours sincerely,

Dr Colin Jones
Chairman
Australian and New Zealand Paediatric Nephrology Association.

Cc: The Secretary
Pharmaceutical Benefit Advisory Commission
GPO Box 9848
Canberra ACT 2601

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VICTORIAN PAEDIATRIC RENAL SERVICE
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DR COLIN L JONES
Director

DR HARLEY R POWELL

A/PROF ROWAN G WALKER

DR DAVID A McCREDIE

DR LILIAN M JOHNSTONE

DR AMANDA M WALKER

4th September 1998

The Honorable Peter. Costello MP,
Federal Member for Higgins
1027 High Street
Armadale 3143

Fax No. 98220319

Dear Mr Costello,

The Australian community has provided an excellent standard of care for children with kidney failure through the leadership of the Commonwealth Government in providing a range of support for medication, child support allowances, social services and first class medical facilities.

Unfortunately, a decision of the Australian Drug Evaluation Committee (ADE) of the Therapeutic Goods Association will lead to the delisting of growth hormone from the Pharmaceutical Benefit Scheme (PBS) for children with stunted growth due to chronic renal failure. These children will now not grow to their optimal and achievable height and many will carry into their adult life the social problems of being abnormally short. For those families able to afford the medication, the cost will be around $10,000 per year!

It is important to note that following the Australian lead in initially using growth hormone, the United States Federal Drug Administration (FDA) found the scientific basis of growth hormone use in children with renal failure was established and approved growth hormone for this use in 1993. Similarly fourteen European countries have approved its use for this indication.

I enclose a more detailed synopsis of the TGA/ADEC/PBS decision.

I hope you are able, perhaps with the help of your colleague, Dr Michael Wooldridge to reverse this poor decision.

Yours sincerely,

Dr Colin Jones
Director - Department of Nephrology
Royal Children's Hospital
Chairman, Australian and New Zealand Paediatric Nephrology Association.

WITHDRAWAL OF GROWTH HORMONE FOR USE IN CHILDREN WITH CHRONIC RENAL FAILURE FROM THE PBS

1. Almost a decade ago, the Therapeutic Goods Administration (TGA) registered growth hormone for use in Australia. It was widely used in Australia by Paediatric Nephrologists for treatment of growth retardation in children with chronic renal failure. Rigid guidelines were monitored by an independent group (the Growth Hormone Program, Pharmaceutical Benefits Branch, Department of Health and Family Services) to ensure this expensive medication was not misused.

2. Since then regulatory authorities in many other countries have used growth hormone for these children. A European multi state application for the use of human growth hormone in chronic renal failure was approved in 1993, and since this time 14 countries in Europe (including non EC countries) have approved use of growth hormone in children with chronic renal failure. In the United States, the Federal Drug Authority (FDA) approved growth hormone for this use in November 1993. The regulatory approval in these countries followed a large number of studies which showed that growth hormone increased the growth in these children who have long been known to be stunted. These studies went for as long as 5 years and showed the improvement in growth continued over this period of time and the age at which the skeleton stops growing was not changed by the medicine. Subsequently, with almost universal regulatory approval of the use of growth hormone for this indication, further studies examining this point have not been formed.

3. Thus, growth hormone was listed for chronic renal failure on the Pharmaceutical Benefit Scheme (PBS) many years before the Australian Drug Evaluation Committee (ADEC) existed and before the PBS used a stringent evidence based system for approving medication. ADEC has never approved growth hormone for use in chronic renal failure so there was not a permit for this indication.

4. In 1996 ADEC requested submissions to provide evidence of efficacy and safety for the use of growth hormone in children with growth retardation. Evidence was provided by the Australian Paediatric Endocrine Group, and the Pharmacia & Upjohn Pharmaceutical Company provided confidential submissions prepared by Paediatric Nephrologists of international reputation (Dr Ken Juredini, Adelaide and Professor Otto Mehls, Heidelberg West Germany). The Australian and New Zealand Paediatric Nephrology Association was not approached despite the fact that all of the children with chronic renal failure are managed by members of this group.

5. The applications for registration were rejected by ADEC and in June 1998 the Pharmaceutical Benefit Advisory Committee decided that growth hormone should

not be registered for use in children with growth retardation due to chronic renal failure.

What is the potential impact on Australian children?

Since 1989 until the present time 185 children have been receiving growth hormone for longer than 3 months. The length of treatment has ranged from 3 months to almost 10 years. Detail data regarding their growth is available from the Ozgrow Australian Database and shows quite conclusively that the children have had an increase in their height.

The Australian and New Zealand Paediatric Nephrology Association members believe there is data that shows, as the above Ozgrow Data suggests, that this is an effective drug in this situation. This limited amount of data also shows that the drug has not been misused because around the same number of children have received renal transplants over this period of time: the drug is being used in a small number of patients who are sick enough to require renal transplantation.

The Association wishes to be given the opportunity to present data to the Therapeutic Goods Administration to enable them to make a decision to approve registration of this drug for use in children with growth retardation due to chronic renal failure.

CONFIDENTIAL OPINION

As requested I will try to put into writing our discussion last week about why the indication of chronic renal insufficiency (CRI) for Genotropin has been rejected compared with Turner's syndrome which has been recommended for approval.

The TGA rejected CRI because the data presented established that hGH accelerated growth in the target population but no results were presented to establish clinical gain in final adult height or quality of life.

Controlled studies are available in CRI to a maximum of 2 years and uncontrolled data are available up to 5 years and the results from about 8 studies were quite consistent. However, the position was explained that proving a "growth spurt" was not adequate and there is some evidence that this viewpoint was influenced by results in short-normal children which show hGH increasing short-term growth with no ultimate effect on final adult height.

The main difference between Turner's and CRI is that final height data were available to support the application for Turner's syndrome but no final height data are available for CRI. The final height data for Turners syndrome incorporate results from approximately 900 patients from 14 studies worldwide (i.e. including but not limited to the OZGROW data).

The studies in Turner's syndrome were uncontrolled and it was necessary to compare the actual adult height achieved with projected adult height to estimate final height gain. Compared with CRI, the Turner's population is relatively homogenous although there were still a number of confounding factors in the Turner's studies including androgen therapy and age of commencing oestrogen replacement therapy.

Confounding factors in CRI are anticipated to be even more problematic. Like Turner's, interpretation of uncontrolled studies would be complicated in CRI by the inability to delineate the influence of hGH versus other treatment modalities on ultimate adult height. In contrast to Turner's children with CRI deal with a progressing disease, which makes a change of treatment modalities (conservative management, dialysis, transplantation) necessary with the result that most short renal patients will not be treated without interruption until final height. This is compounded by the fact that most childhood CRF is congenital and the available clinical evidence indicates a better response to treatment at an early age and at an early stage of renal disease.

Confounding variables in addition to discontinuous treatment and differing treatment length include different durations of impaired renal function and variable time periods of treatment with corticosteroids or other drugs which interfere with growth.

A controlled clinical study is also not without many difficulties. Double blinding is hard to achieve and to maintain for the duration needed to collect final height data because the product is injected and there is resistance to injection of placebo. Further, as it is now the case that treatment with hGH is accepted clinical practice in CRI, it would not be ethical to include a placebo arm in future clinical trials.

These arguments were used with the TGA and the ADEC but without success. It is not at all clear to us how we could generate the data requested by the TGA. According to the consultants (local and international) contracted by the company to consider the TGA requests, even a study to generate quality of life data would be extremely difficult to conduct.

I am very sorry that I cannot offer any positive suggestions about how to move forward. I believe we have explored all the available options with registration but have ended with a very unsatisfactory result and that is extremely disappointing.

LONG-TERM AND FINAL HEIGHT RESULTS OF GH TREATMENT IN RENAL TRANSPLANT PATIENTS

A.C.S. Hokken-Koelega, MD, PhD, M.C.J.W. de Jong, MD, E.D. Wolff, MD, PhD, J.W. Groothoff, MD, M. Lilien, MD.
Dept. of Pediatrics, Subdivisions of Endocrinology and Nephrology, University of Rotterdam, Nijmegen, Amsterdam and Utrecht, The Netherlands

Sophia Children's Hospital

PEDIATRIC ENDOCRINOLOGY ROTTERDAM

INTRODUCTION:

Persistent growth retardation despite successful renal transplantation (RT) is a serious problem for many allograft recipients.
RT usually results in some growth improvement but seldom to sufficient catch-up growth. Final height falls below the third percentile (P3) in 72% of RT patients.
Various studies have demonstrated that biosynthetic growth hormone (GH) therapy in a dose of 4 IU/m²/day increases height velocity of these patients. However, only long-term data, including data on final height, can substantiate that GH-therapy is truly effective and safe for these patients.

PATIENTS \ TREATMENT:

35 Dutch children with severe growth retardation (height standard deviation score (hSDS) < -2) following RT were treated with Norditropin® for 3-6 years [mean age at start 12.6(4.6) years].
18 pubertal patients [mean age at start 15.6(2.3) years] were blindly assigned to one of two GH doses (4 or 8 IU/m²/day) and the other patients received 4 IU/m²/day.
All children received prednisone, administered daily or on alternate days, in combination with azathioprine and/or cyclosporin A.

METHODS:

Growth, bone maturation, renal graft function, plasma insulin-like growth factors (IGF), serum IGF binding proteins -1 and -3 and other biochemical parameters were checked regularly.
Glomerular filtration rate (GFR) and effective renal plasma flow (ERPF) were tested with ^{125}Thalamate and ^{131}Hippuran.
Data on growth and GFR of GH-treated patients were compared with those of matched, non-GH-treated controls.

RESULTS

FINAL HEIGHT

18 pubertal patients have attained FH. Their mean [SD] increment in height from the start of GH therapy until FH (19.9 [7.9] cm) was significantly greater than that of their matched controls (9.4 [7.9] cm) ($P < 0.0001$; Table 1). Results were similar for the two GH dosage groups (4 and 8 IU/m²/day).
The difference with matched controls was even greater for patients who started GH therapy during early puberty (Tanner stage 2/3) (Table 2).
Long-term GH therapy in patients who did not yet attain FH, resulted in significant improvements in predicted final heights.
Figures 1 and 2 show examples of individual growth charts during long-term GH therapy.

BONE MATURATION

Bone maturation did not accelerate during long-term GH therapy.

RENAL GRAFT FUNCTION

Mean GFR and ERPF did not change significantly during 4 years of GH therapy. The incidence of > 25% reduction in GFR during 4 years was not significantly higher in GH-treated patients than in non-GH-treated matched controls. The results were similar for the two GH dosage groups (4 and 8 IU/m²/day).
Eight of 35 GH-treated patients had a serious deterioration of their renal graft function, six of them returned to dialysis or had a new RT and two stabilized at a lower GFR > 20 ml/min. A relation with GH therapy was not found.
Figure 3 shows the individual GFR's during GH therapy.

CONCLUSION

Long-term GH therapy in a dose of 4 IU/m²/day results in a significant improvement of final height in most patients with growth retardation after renal transplantation.

ΔHeight (cm)	GH therapy	Matched controls	Difference
0-2 yr	15.7 (5.1)*	5.8 (3.7)	9.9 (p<0.0001)
2 yr - FH	3.3 (3.2)	3.6 (6.0)	-0.3 (p=0.80)
0 -FH	19.0 (7.9)*	9.4 (7.9)	9.6 (p<0.0001)

Table 1
Mean (SD) height increment from start of GH therapy until final height (FH) in 18 pubertal renal transplant patients in comparison with matched controls. ** = significantly different compared to matched controls*

ΔHeight 0-FH (cm)	GH therapy	Matched controls	Difference
all patients	19.0 (7.9)*	9.4 (7.9)	9.6 cm (p<0.0001) [95% CI=4.9 to 14.3 cm]
early pubertal	22.8 (7.2)*	11.7 (9.1)	11.1 cm (p=0.01)
late pubertal	12.4 (3.6)*	5.5 (2.9)	6.9 cm (p=0.01)

Table 2
Mean (SD) height increment from start of GH therapy until FH in early and late pubertal RT patients in comparison with matched controls
** = significantly different compared to matched controls*

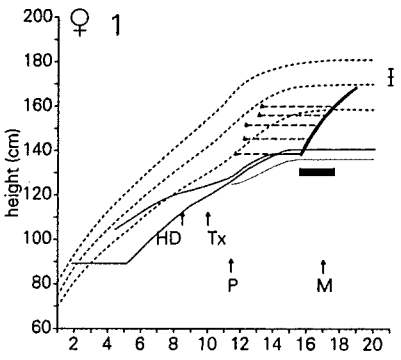


Figure 1
Individual growthchart and final height of a pubertal renal allograft recipient who received GH therapy.

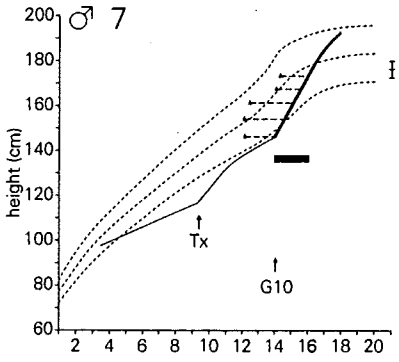


Figure 2
Individual growthcharts of 3 pubertal girls, representing the difference in final height between the girl who received GH therapy and the 2 matched controls.

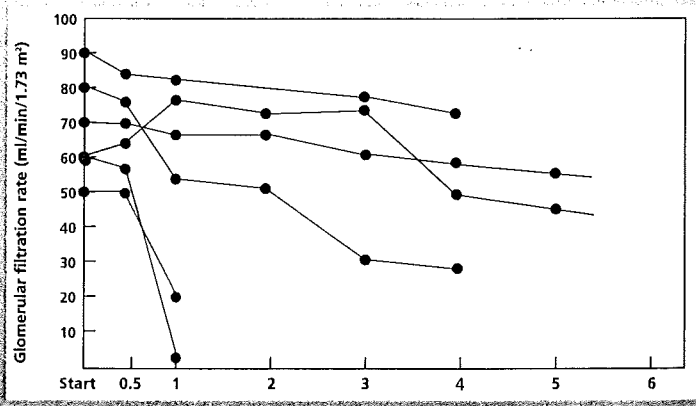


Figure 3
Individual glomerular filtration rates (GFR's) during GH therapy.

This study was supported by Novo Nordisk A/S, Denmark

Novo Nordisk

laim borne out by the emo-
ional farewell by 500 flag-
waving whaling industry wor-
rs and supporters as the sh
powered out of Japanese waters.

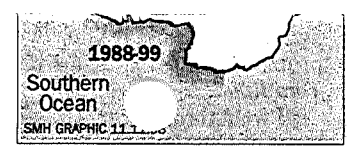
"It is time the international community stopped talking about a moratorium on commercial whaling and instead adopted a permanent international ban

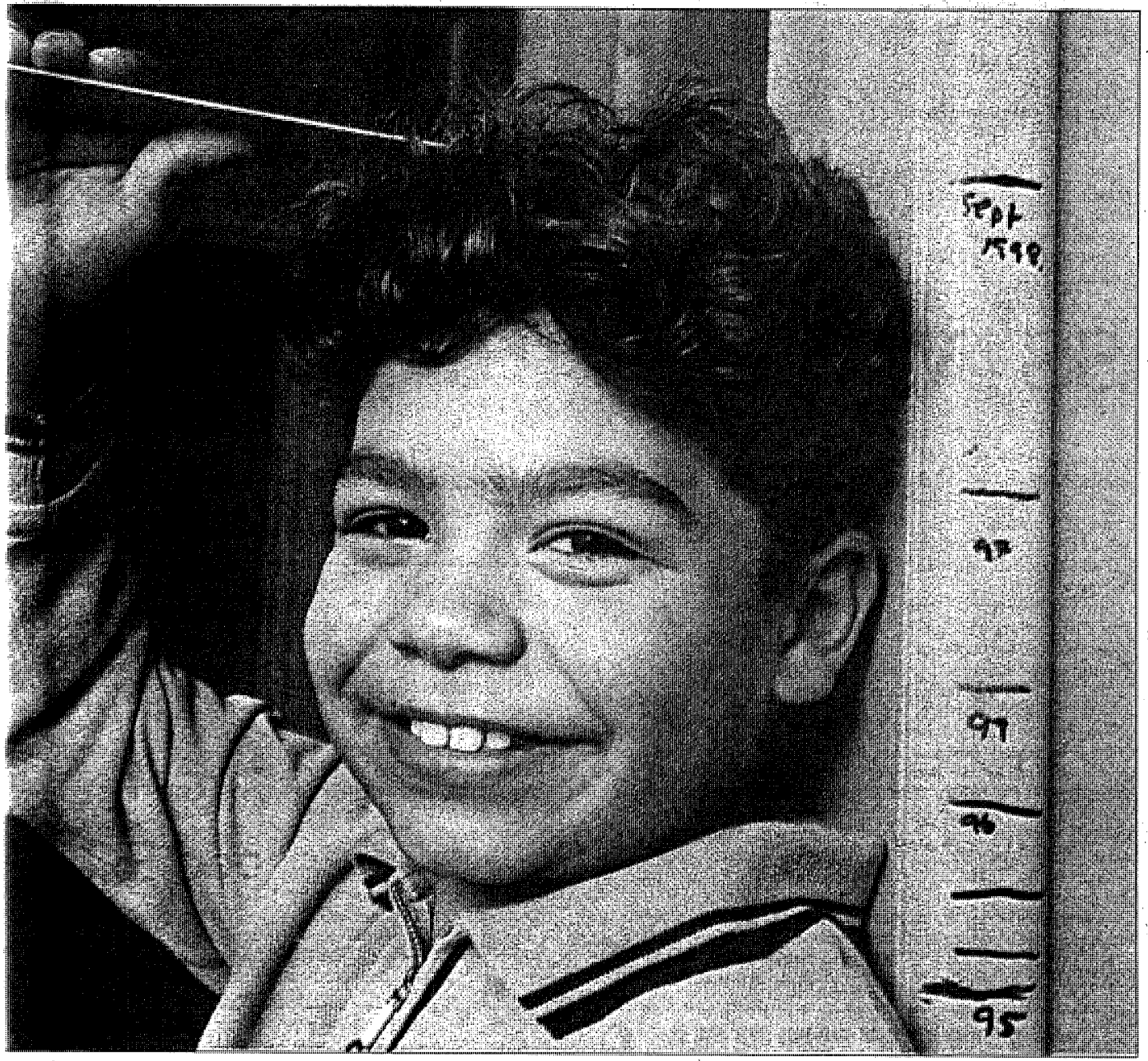
this meat is not from minke whales taken as part of Japan's "scientific" catch and subsequently offered for human consumption but comes from

the program makes a mockery of science.

February, Japan once aga shrugged off attempts to bring its whaling under interna-

high seas, Japan has signalled its true intentions and resolve to ime high seas industrial whaling using factory ships, according to conservationists.





son, 8, a metre tall, has grown 22 centimetres since taking somatropin.

Portrait by ROBERT PEARCE

Drug cut off for short children

By JULIE ROBOTHAM and GEESCHE JACOBSEN

Children whose growth stalls because of kidney failure will be denied a costly growth hormone treatment from next year because of a Federal Government funding decision.

The move has angered doctors who say it will put an extra burden on children already coping with the aftermath of a transplant or frequent dialysis sessions.

The Pharmaceutical Benefits Advisory Committee has ruled there is insufficient proof the synthetic drug somatropin helps the children grow.

A spokeswoman for the Federal Department of Health and Aged Care confirmed that the Government would not subsidise the drug for use in new patients with chronic kidney failure from January 1 unless they met other criteria.

Existing patients would still be entitled to the drug, which costs an average of $10,000 a year.

Children would not qualify for the drug — which replaces a growth hormone normally secreted by the kidneys — unless they were among the shortest 1 per cent of the population for their age, or were growing much more slowly than others. At present, those in the shortest 3 per cent of the population qualify.

Three per cent of five-year-old girls measure less than a metre — the average height for a three-year-old. At age 10, 3 per cent of boys are 126 centimetres or less — average for eight-year-olds.

Doctors say there is ample evidence the treatment is effective.

"There's a lot of data that if you give it to someone before puberty they grow very nicely," said the head of the renal unit at the New Children's Hospital at Westmead, Dr Elisabeth Hodson. "They show what we call catch-up growth."

Fifty-nine Australian children with kidney failure now receive the growth hormone.

Dr Colin Jones, president of the Australian and New Zealand Pediatric Nephrology Association, estimated that fewer than a quarter of them would now be eligible if applying for the first time.

Mr Michael Wilson knows just how much a few extra centimetres can mean to a child whose body cannot grow naturally. His eight-year-old son Nicholas has been on kidney dialysis three days a week for the past five years after a kidney transplant failed, and his hormone treatment costs $24,000 a year.

"He's in desperate need of it. He's just over a metre tall now," said Mr Wilson.

In 2½ years Nicholas has grown 22 centimetres on somatropin — with much of the growth in the last year. "He's been charting himself on the kitchen bench," his father said.

No PBS listing of Growth Hormone for Children with Chronic Renal Failure

. From January 1, 1999 children with short stature due to renal failure will no longer be able to receive growth hormone (GH) as a benefit following a recommendation of the Australian Drug Evaluation Committee (ADEC) to the Pharmaceutical Benefits Advisory Council (PBAC). ADEC made its decision on the basis that no data were presented to it to show that GH improves final adult height of patients with renal failure.

Growth retardation is a serious complication of chronic renal failure. According to the European Dialysis and Transplant Registry, two thirds of boys and one third of girls who started renal replacement therapy before the age of 15 years have a final adult height 2 SD below the mean[1]. In 1989 the first clinical trials[2] demonstrated the efficacy of human recombinant growth hormone (GH) in children with renal failure. Eligible children with renal failure in Australia have received GH since 1990. Currently approximately 60 children with chronic or end stage renal failure receive GH therapy. GH is licensed for use in children with renal failure in the United States, in New Zealand and in 14 European countries

There are data from both randomised controlled trials[3,4] and cohort studies[5] to show that GH consistently accelerates linear growth rates in children with chronic renal failure, in children on dialysis and in children with renal transplants. The European Study Group[5] has recently reported increases in height of 2 SDS in extremely short prepubertal children with chronic renal failure treated for 4 years so that these children achieved a mean height close to the third percentile. In dialysis patients the European Study Group[5] reported improved growth rates of 0.8 SDS following 2 years of therapy. Similarly GH doubles height velocity in transplanted children during 1 – 2 years of treatment[6]. Recently a Dutch study[7] has presented final height data in 18 patients with renal transplants who were treated with GH for 3-6 years. GH treated patients grew 19 cm to their final height compared to 9.4 cm in an untreated group.

The Australian and New Zealand Paediatric Nephrology Association and the Australian Paediatric Endocrine Group have joined forces in an attempt to have the decision by PBAC reversed. We believe that children with renal failure should have the opportunity to achieve catch up growth to attain heights in keeping with their peer groups, thus decreasing social disadvantage and improving quality of life.

Elisabeth Hodson FRACP and Chris Cowell FRACP

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October 30, 1998

Professor Don Burkett
Chairman, Pharmaceutical Benefits Advisory Committee
Pharmaceutical Benefits Scheme Branch
GPO Box 9848
Canberra, ACT 2601

Dear Professor Burkett

The Australian Paediatric Endocrine Group (APEG) and the Australian and New Zealand Paediatric Nephrology Association (ANZPNA) have been informed by the Pharmaceutical Benefits Advisory Commission that, following advice from the Australian Drug Evaluation Committee, Chronic Renal Insufficiency/Renal Failure have been deleted as indications for the use of somatropin (recombinant human growth hormone). This decision will take effect from January 1, 1999. On behalf of the members of APEG and ANZPNA, we wish to request that the Pharmaceutical Benefits Advisory Committee consider the attached submission on the use, efficacy and side effects of the use of somatropin in children with renal failure and short stature.

We strongly believe that the published data demonstrates;

- the short and long term (five years) efficacy of somatropin in children with chronic renal failure, children on dialysis and in children with renal transplants.
- that final adult height is significantly improved in young people with renal transplants, who received somatropin, compared with a matched control group in a study from Holland (see attached abstract). It should be recognised that children with chronic renal failure progress to dialysis and renal transplantation in the first or second decade of life so that final adult height data will only be available in transplanted children.
- that somatropin therapy is well tolerated in children with chronic renal failure with a low frequency of adverse events similar to children receiving GH for other indications.

There are currently approximately 60 children with chronic renal failure receiving somatropin and responding well to it – we could not justify cessation of this therapy which is providing them an opportunity to achieve catch-up growth. Furthermore, somatropin is licensed for the indication of chronic renal failure in the United States, New Zealand and many European countries.

We would like to request that the decision to delete chronic renal insufficiency/renal failure from the indications for use of somatropin be delayed for at least two years to allow APEG and ANZPNA to analyse the Australian data held in Ozgrow on the

efficacy of somatropin in these children and to allow additional pharmaceutical companies who market somatropin to provide submissions to the Australian Drug Evaluation Committee. We would also like to request that those children who are already receiving and responding to somatropin be allowed to remain on it.

With best wishes
Yours sincerely

Dr Colin Jones
Chairman
ANZ Paediatric Nephrology Association

Dr Jennifer Batch
President
Australian Paediatric Endocrine Group

c.c. Professor Martin Tattersall, Chairman, Australian Drug Evaluation Committee
Ms Enid Rushworth, Pharmacist- in-Charge, Growth Hormone Programme
Dr Geoffrey Byrne, Chairman, Growth Hormone Advisory Committee

USE OF HUMAN GH IN GROWTH FAILURE ASSOCIATED WITH CHRONIC RENAL FAILURE

Background

Growth retardation, often severe, is a serious complication of chronic renal failure (CRF) in children. This has become increasingly important as chronic dialysis and renal transplantation have enabled survival to adulthood. According to the European Dialysis and Transplant Association registry, 62% of males and 41% of females who started renal replacement therapy before the age of 15 years, have a final adult height below 2 standard deviations (SD) of the normal mean (Rizzoni 1985). The time of onset of CRF influences the extent of growth impairment with congenital renal disease having the most profound effect.

Impairment of growth may begin when the glomerular filtration rate, a measure of renal function, falls below 50% of expected for age but becomes common at a glomerular filtration rate of less than 25%. The pathogenesis of growth failure in CRF is multifactorial. Unfortunately, correction of possible contributing factors such as anorexia and malnutrition, acidosis, renal osteodystrophy, salt-wasting and anaemia does not uniformly correct growth. In addition, growth after renal transplantation may be seriously impaired by the high doses of glucocorticoids needed for immunosuppression as well as gradual graft dysfunction.

Growth Hormone/Insulin-like Growth Factor axis

The pathogenesis of uraemic growth failure has become clearer with a more detailed understanding of the GH/insulin-like growth factor axis. GH is the main regulatory hormone of the body's growth. Much of this effect is mediated through liver-derived, circulating as well as locally-produced peptide, insulin-like growth factor (IGF-I). Circulating IGF-I is bound by carriers called binding proteins and only the tiny free fraction is active.

There is peripheral resistance to the actions of GH in children with CRF, as evidenced by growth failure in the presence of normal or elevated levels of GH (reviewed in Tönshoff 1995). The mechanisms underlying this are complex and include a decrease in GH receptors in target organs, increased IGF binding capacity with subsequent decreased bio-availability of IGF-I and possibly a decrease in IGF-I production.

In the 1980's it was shown in animal experiments that using supraphysiological doses of GH to overcome the relative GH insensitivity in uremia resulted in improved growth (Mehls and Ritz 1983). This was later confirmed in the first of the clinical trials using recombinant GH in children with CRF (Koch 1989). It has subsequently been shown that levels of free IGF-I rise in the serum during GH treatment, and this increase correlates positively and significantly with the change in height (Powell 1997).

Aims and evaluation of GH therapy

Growth has been shown to be of significant concern to more than 90% of children with CRF (Reynolds 1995). GH therapy aims to enable the short child to attain a height more

in keeping with his/her peer group, thereby decreasing social disadvantage and improving quality of life. Ultimately, the goal is attainment of a child's genetic height potential or an achievement of a normal population-related final height, i.e. a height > the 3rd percentile. To date there is only one study on final adult height of patients with renal failure treated with GH therapy. This indicates that final height is significantly greater in young people with renal transplants and treated with GH compared to untreated transplant patients.

In addition to final adult height, efficacy of GH treatment can be evaluated by demonstrating acceleration of growth rate, maintained over time, in order to "catch-up" lost growth. Calculation of the Standard Deviation Score (SDS) with standard references collected from an appropriate population base, allows comparison of absolute measurements such as height and height velocity within small groups independent of age or sex.
The effectiveness of GH treatment on catch-up growth can be assessed by growth data:

a) Height velocity in cm/year
b) Height velocity as a change in standard deviation with reference to the mean value for chronological or bone age (SDS_{CA} or SDS_{BA})
c) Change in standardized height (Height SDS).

Clinical trials with recombinant human GH.
Clinical studies have examined the effects of GH on growth in children with CRF for varying durations of therapy, pubertal stage as well as in different categories of renal management. These are conservative management in preterminal CRF, dialysis in end stage renal failure (ESRF) and post renal transplantation. A dose of 28-30IU/m^2/week or equivalent of GH was used in almost all of the studies (see Dose, page 4). This was given in seven equal daily doses because this dosing frequency has been shown to be beneficial to patients with idiopathic GH deficiency (Guyda 1987). Patients in these studies were maintained on fairly standard renal failure treatment protocols that included vitamin D analogues, phosphate binders and calcium supplements. . Inclusion growth entrance criteria varied between studies. In some (7 and 8) only height SDS < -2 was required, whilst others required either a height and/or a velocity restriction. The limit to glomerular filtration rate limit varied between 20 and 75 ml/min/1.73m^2. All studies excluded patients who had another cause for growth failure, clinical or radiological evidence of renal osteodystrophy, other endocrine abnormalities or those who had been on any growth promoting medication.

Studies in children with chronic renal failure
Clinical studies, detailed in Table 1, with results in Table 2, report a significant positive effect of GH on the growth of children with CRF. Two of these studies are randomized placebo-controlled trials whilst the others are open labelled prospective trials, confirming and extending the information with regard to increasing duration of GH treatment, special categories of patients and Australian data. Three are large multicenter studies which cover Germany (3), the rest of Europe and the UK (4), Europe and Australia (5). The latter, although containing patient information to some extent from (3) and (4), was

included because of the Australian data. It is impossible to breakdown the overlapping information further.

The results reflect an obvious increase in growth rate with GH treatment as assessed by height velocity (cm/year) and height velocity SDS for chronological age. The patients also experienced catch-up growth as reflected by an improvement of their mean height SDS. Improvement in growth was particularly marked in the first year of treatment with height velocity approximately doubling from 4 cm/year to 9 - 10cm/yr. The reduced growth stimulating effect during the second and subsequent years was similar to that which has been noted in patients treated for idiopathic GH deficiency (Rosenfeld, 1990). However, data from studies (7 and 8) showed that improvement in growth continued over 3 years (7) and 5 years (8 – see figure 1). Both the placebo-controlled studies (1 and 2) showed an improvement in growth on placebo but the increase on GH therapy was significantly greater than the placebo effect.

Fig.1.

The increased growth rate during GH treatment was not accompanied by undue advancement of bone age. This suggests that final height will not be compromised by the use of GH and that the potential exists of an improved final height outcome.

The German study group (5) has recently published more extensive 2-5 year follow-up dataa in children with preterminal CRF (17, see Table 6). All were prepubertal, mean age range 5.8-7.8 years and extremely short at onset of GH, mean height SDS range –3.4 to –3.7. The increase in height SDS after 2, 3, 4 and 5 years of GH therapy was 1.3, 1.6, 2.0 and 1.5 respectively, all attaining a mean height close to the third centile. There was no acceleration of bone age in these groups so the change in predicted adult height was significant, 4.9, 7.7, 11.4 and 10.3 cm after 2 to 5 years of GH therapy respectively.

There was no correlation in any of the studies between responses to provocative stimulation tests of GH secretion or 24 hour GH profile and growth rates achieved during treatment. Children with CRF therefore respond to GH irrespective of their GH status. The type of primary renal disease, although included in some of the studies, was not found to be a statistically important indicator of response to GH. The factors found to be most predictive of their response include younger age at onset of GH and their GFR (17).

GH Treatment in Children on Dialysis

Children in end stage renal disease (ESRD), either on peritoneal dialysis or on haemodialysis, have also been found to respond to GH treatment although this response is both less pronounced (3) and less persistent (5) than in patients in preterminal CRF. The former found an increase in height velocity of 4.2 cm/year to 7.3 cm/year with an increase in height velocity SDS of –2.6 to 1.4 ($p<0.01$) after 1 year's GH treatment. This compares to an increase from 4.3 cm/year to 10.0 cm/yr and height velocity SDS of –2.6 to 4.4 ($p<0.001$) in children with preterminal CRF. During the 2nd year of therapy the European/Australian Study Group (5) showed a decrease in the growth rate to a value approximating the pretreatment level.

The German study group (17) has published data in 1998 on 13 and 6 subjects treated for 2 and 3 years respectively showing an increase in height SDS of approximately 0.8 SDS, a response less than found in those with preterminal CRF (Table 6).

GH in Children with Renal Transplants.

The North American Pediatric Renal Transplant Cooperative Study (NAPRTCS) report for 1996 shows a mean height SDS of –2.08 at the time of transplantation and of –2.27 at 5 years after transplantation. Good growth post-transplant seems to be confined mainly to young patients with near-normal graft function and a low-dose, preferably alternate-day glucocorticoid regimen.

Clinical studies on the use of GH (at a dose of 28-30 IU/m^2/week) in renal transplant recipients with growth failure are detailed in Table 3. The results demonstrate a marked improvement in growth within the first year of GH therapy as illustrated in Study 12 with a doubling of linear growth velocity from 2.47 (1.83) cm/year to 7.17 (2.97), as well as improvement in height velocity SDS and height SDS. Thereafter, the response to GH diminishes as in other groups of GH treated patients. Factors such as renal graft function, dose of immunosuppressive corticosteroids, episodes of acute or chronic rejection need to be considered in analysing the data.

Dose of GH

In view of the GH resistance of uraemic states, supraphysiological doses of GH have been administered in most trials of GH in CRF compared to GH deficient children. Two double-blind studies by Hokken-Koelega have examined this critically. In the first (13), 23 prepubertal children with CRF given either 2 or 4 IU/m^2/day over 2.5 years, catchup-growth was only sustained with the larger dose. In the second trial (14), no significant difference in growth response was obtained using 4 or 8 IU/m^2/day GH over 2 years in 18 pubertal post-renal transplantation patients with growth retardation. Bone age advancement or renal function did not differ with dose in either study. It therefore seems appropriate to advocate a dose of 1 IU/kg/week or 28-30 IU/m^2/week in children with growth failure in CRF.

Australian Data

In Australia guidelines have until now allowed GH administration to children with CRF (glomerular filtration rate<30mL/min per 1.73 m^2), with short stature (height < 25^{th} percentile for chronological) and height velocity < 25^{th} percentile for bone age. The data on these children are collated on a central database called "Ozgrow".

There are 3 sources of information on the use of GH in children with CRF in Australia. One is a brief analysis of the Ozgrow database and 2 are open label pilot studies. Details of these studies and analysis are outlined in Table 4.

The analysis of the Ozgrow database shows that up to 1994 a total of 56 patients with CRF treated with GH at a number of different centres throughout Australia. It confirms the findings of other, international studies by showing a significant improvement in growth over the first year of treatment in both prepubertal and pubertal patients. There was also a sustained improvement in height velocity and height SDS over the second year of treatment. Similar to the findings of other studies (3), patients with CRF appeared to show a more significant improvement than those requiring dialysis (see Figure 2).

Both studies, one in Melbourne (15) in 7 prepubertal children, aged 2-14 years, and the other in Adelaide (6) in 9 pubertal and prepubertal children, confirmed the positive effects of GH on mean height velocity and mean height velocity SDS. The children were treated with daily GH at 1U/kg/week (equivalent to 30IU/m^2/week) for 1 year and demonstrated a doubling of height velocity from 4-5 cm to 9-10 cm/year. In addition, the authors found no change in the rate of deterioration of renal function during treatment with GH.

Final Height

Much of the published short term data has been from children with preterminal CRF. Considering the natural history of CRF, these subjects will be treated in the future with renal transplant and/or dialysis, treatment strategies which may attenuate their response to GH. It is in this context that the only available final height data is particularly useful. A Dutch study has presented the final height data in 18 subjects treated with GH, dose 4 or 8 u/m^2/week for 3-6 years (18). All subjects had had a renal transplant and were pubertal at the time of commencing GH (mean age 15.6 years). The GH treated group had a mean increase in height of 19 cm to final height compared to an increase of 9.4 cm in a control group who did not receive GH. The improved pubertal growth was more apparent in those who commenced GH in early puberty. Their was no significant change in graft function during 4 years of therapy (see attached abstract).

Adverse Events

The spectrum of reported adverse events to GH is similar to other children receiving GH, with a low frequency of reported adverse outcomes. The possible exception to this is the reported frequency of intracranial hypertension in CRF. The highest incidence of this complication in GH treated patients is in the group with CRF. However, it is not known whether GH itself increases the risk of intracranial hypertension in these patients as there is a higher incidence of this problem in children with CRF without GH therapy. Issues

such as the long term impact of hyperinsulinism on the development of vascular disease complications in the setting of uraemia and transplantation remain to be elucidated.

Of most concern in the use of GH therapy in children with CRF is whether it adversely affects renal function. There is no convincing evidence in children with preterminal CRF that its use accelerates the natural decline in glomerular filtration rate. In patients with renal transplants, most evidence supports its safety in this regard but there are a number of reports of a decline in renal function temporally associated with the use of GH. In addition, the question of whether GH increases the incidence of acute and chronic rejection has not yet been definitively answered. The use of GH in this group of patients is still controversial, particularly in those who have a history of previous rejection episodes and those on high doses of glucocorticoids, where efficacy of GH is reduced.

Summary Statement

There is convincing evidence of the efficacy of GH in promoting linear growth in children with pre-terminal CRF managed conservatively, those on dialysis and post-renal transplantation. The best growth is seen in the first group of patients and within the first few years. As with other groups of short stature patients, there is a declining growth response with continued use of GH. However, studies with 3-5 years follow-up continue to show catch-up growth in patients with CRF. The bone maturation data suggests that GH therapy will not limit genetic height potential and the continued catch-up growth may lead to improved final height. The limited final height data suggest a significant benefit may be possible for this important outcome.

With regard to safety issues, evidence from the studies cited suggests that GH therapy is well tolerated in children with CFR. The spectrum and incidence of general adverse events does not seem to be different to that seen in other groups of GH recipients with the exception of intracranial hypertension.

In view of the sustained catch-up growth and improved final height in published reports to 1998, GH therapy is recommended in all children with CRF who have growth failure despite optimisation of their medical therapy. The available data suggests continuing the current recommended dose of GH of 28-30 IU/m^2/week given daily by subcutaneous injection.

Table 1. Clinical Studies of GH Therapy.

No.	Study Design	Authors	Length therapy	Subject No.	Renal Management		
					Conservative	Dialysis	RT
1	Placebo-controlled, double blind, cross-over	Hokken-Koelega ACS, et al.	6m	20	9	11	
2	Placebo-controlled, double-blind, multicenter	Fine RN, et al	2 yrs	125	125		
3	Open, non-controlled; multicentre	Tonshoff B et al + Member of German Study Grp	1-2 yrs	61	20	24	17
4	As above	Van Es for European Study Grp	2yrs	98	43		55
5	Combined data; 8 independent trials	Mehls O + Broyer M, for European/Australian Study Grp	2 yrs	103	69	34	
6	Open, non-comparative	Van Renen et al	1 yr	9	9		
7	As above	Fine et al	1-3 yrs	9	9		
8	As above (long-term follow up of pts from 2)	Fine et al	5 yrs	20	20		

Table 2. Efficacy Data

Study No.	Height Velocity (cm/year)					Ht Velocity SDS				Height SDS		
	0	6m	1yr	2yr	3yr	0	6m	1yr	2yrs	0	1yr	2yrs
1	3 (1.40)	10.4[a] (2.4)				-3.2 (1.4)	6.9[a] (2.4)					
2										-2.94[b] (0.86)	-1.93 (1.01)	-1.55[b] (1.16)
3	4.1 (2-5.3)		9.3[c] (6.8-11.4).	6.6[d] (6.1-8.7)		-2.4 (-4.9-0)		4.2[c] (1 – 8.2)	1.8[d] (0.9 – 4.4)			
4	4.2		9.8	6.8		-1.8		4.5	2.1			
5	4.6		9.8	6.8		-1.5		4.3	1.7			
6 prep	4.6 (1.3)		9.0[e] (1.3)			-1.2 (0.6)		2.3[e] (0.9)		-2.2 (0.5)	-1.5[f] (2.3)	
pub	5.4 (1.4)		10.4[f] (1.8)			-0.4 (0.5)		1.9[f] (1.1)		-1.9 (0.9)	-1.3[h]	
7	5 (1.4)		8.5 [a] (1.3)	8.2 [g] (1.6)	8.1 [c] (1.8)							

a: $p<0.0001$; b $p<0.00005$; c $p<0.05$; e $p<0.001$; f $p<0.01$; g $p<0.004$; h $p<0.02$ vs baseline; d $p<0.05$ vs previous year

Table 3. GH trials in renal transplant patients

Study No.	Design	Authors	Subject No.	Duration therapy
9.	Placebo-controlled, double-blind, randomised	Hokken-Koelega et al	11	6m
10	Multicentre, prospective, open, controlled	Maxwell H et al	16	2 yrs
11	Multicentre, open, placebo-controlled, randomised	Broyer M for Pharmacia and Upjohn Study Grp	203	2 yrs
12	Analysis of data on cohort of renal transplant recipients from 2 databases	Mentser M et al (National Cooperative Growth Study + North American Pediatric Renal Transplant Cooperative Study	59	3 yrs
3	See Table 1			
4	See Table 1			

Table 4. Australian Data

Study No.	Source	Patient grp and no.	Ht Velocity (cm/yr)		Ht Velocity SDS		Ht SDS		
			0	1yr	0	1yr	0	1yr	2yr
15	Melbourne	7; prepubertal crf	5.14 (2.42)	9.45[b] (1.53)	-2.87 (2.33)	3.39 (1.58)	-3.15	-2.46[a] (0.91)	
6	Adelaide	9; crf prepubertal (n=5);	4.6 (1.3)	9.0[a] (1.3)	-1.2 (0.6)	2.3 [a] (0.9)	-2.2 (0.5)	-1.5 [c] (2.3)	
		Pubertal (n=4)	5.4 (1.4)	10.4 [c] (1.8)	-0.4 (0.5)	1.9 [c] (1.1)	-1.9 (0.9)	-1.3[d]	
16	Ozgrow database	n=56 crf=29; ESRD=19 RT=8							
		Prepubertal					-3.02 (1.23)	-2.57 [e] (1.22)	-2.35 [f] (1.09)
		Pubertal					-2.61 (1.15)	-2.17 [c] (1.21)	-1.78[g]

A p=0.001; b p=0.006; c<0.01;d p,0.02; e p<0.0001 vs baseline; f p=0.001 vs baseline and = 0.06 vs previous year; g p<0.01 vs baseline and < 0.05 vs previous year.

Table 5. Further Analysis of Ozgrow Data

Table 6. Effect of 1 to 5 yr of rhGH therapy on height SDS in prepubertal children with CRF on conservative and on dialysis treatment

	n	Age	rhGH therapy					
			Baseline	1 yr	2 yr	3 yr	4 yr	5 yr
Height (SDS)								
conservative								
treatment	74	8.3	-3.4 ± 0.1	-2.6 ± 0.1				
	41	7.8	-3.4 ± 0.2	-2.5 ± 0.2	-2.1 ± 0.2			
	19	6.3	-3.4 ± 0.2	-2.5 ± 0.2	-2.0 ± 0.3	-1.8 ± 0.3		
	8	6.2	-3.7 ± 0.4	-2.8 ± 0.4	-2.2 ± 0.5	-1.9 ± 0.5	-1.7 ± 1.5	
	6	5.8	-3.4 ± 0.4	-2.5 ± 0.4	-2.0 ± 0.5	-1.9 ± 0.5	-1.8 ± 0.5	-1.9 ± 1.5
dialysis	29	8.8	-3.6 ± 0.2	-3.1 ± 0.3				
	13	7.4	-3.8 ± 0.3	-3.2 ± 0.4	-3.0 ± 0.4			
	6	6.3	-4.4 ± 0.6	-4.0 ± 0.7	-3.7 ± 0.7	-3.7 ± 0.8		

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JOURNAL OF AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

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20 August 1997

MINUTES OF AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION HELD ON SUNDAY 20TH JULY 1997, CARLTON CREST HOTEL, MELBOURNE

CONVENOR: **J BURKE**

MINUTES RECORDED BY: **L JOHNSTONE**

PRESENT: **R WALKER, C JONES, M FALK, D LEWIS, H POWELL, A WALKER, P HENNING, C CROMPTON, K JUREIDINI, J KNIGHT, I HEWITT**

1. APOLOGIES: A ROSENBERG, L P ROY, W WONG, M MORRIS, D MCCREDIE, E HODSON, G KAINER

2. MINUTES:

Minutes of meeting of 11th October 1997 accepted as a true and accurate record.

2.1 Business Arising From Minutes:

The group requested that the Chairman elect send a letter to Mrs Ross Bailey to acknowledge the contribution of Ross Bailey to paediatric nephrology and to express the condolences of ANZPNA.

3. MEMBERSHIP AND CONSTITUTION:

3.1 Current membership list complete (appendix 1). *J Burke to discuss the completeness of the current membership list with A Rosenberg*

3.2 Application for membership:

3.2.1 F Willis. **Application for membership was unanimously accepted.**

3.2.2 J Craig. A letter was tabled (appendix 2) re nomination of J Craig to ANZPNA. **Acceptance of his application for membership was proposed by J Knight and seconded by E Hodson and unanimous acceptance.**

3.2.3 Current Trainees. S Alexander, S Mackie, M Tilley, S McTaggert.

3.2.4 Discussion took place concerning application for membership of the ANZPNA, and it was felt that the definition of eligibility criteria specifically "substantial involvement with paediatric nephrology" needs to be further defined. Consensus that the membership should be inclusive not exclusive. K Jureidini expressed concerns that membership should only exclude those who do not have the expertise. H Powell suggested that paediatric urologists should be included. J Knight suggested associate membership for trainees.

3.2.5 Application for membership to be produced. *(Attention L Johnstone)* Proposer and seconder will be required to sign the application form.

Following discussion, the proposer needs to be a member of the ANZPNA and needs to know the applicant well in terms of expertise and character. It is the responsibility of the proposer to provide substantive evidence that the applicant has an active role in caring for children with paediatric nephrological problems.

The application form shall be sent to the Chair of ANZPNA.

3.2.6 Membership will be voted on by members at the annual meeting following receipt of the application.

3.3 Constitution:

J Burke reported that the Constitution is being addressed by P Roy, A Rosenberg and himself. The Constitution of the Australasian Paediatric Endocrine Group and the Rules of the British Association for Paediatric Nephrology were provided for information. K Jureidini proposed and J Knight seconded a motion that **"the offer of Paul Roy to write a draft of a constitution for ANZPNA be accepted"**. This was passed unanimously. *Lil Johnstone to write to P Roy*

3.3.1 Incorporation.

J Burke suggested that the ANZPNA be incorporated for medico-legal reasons, in particular with respect to limitation of liability. M Falk stated that incorporation allows some tax advantages in that the ANZPNA could be recognised as a "not for profit organisation". The estimated cost of incorporation was approximately $1,000. The meeting moved **"to ask P Roy to address the question of incorporation in the draft of the Articles of Association"**.

4. THE INTERNATIONAL PAEDIATRIC NEPHROLOGY ASSOCIATION:

J Burke spoke to his written report of the IPNA council meeting April 1997.

4.1 The ANZPNA is now an official society of IPNA. A summary of ANZPNA's activities needs to be provided to each IPNA council meeting (currently twice yearly). J Burke is the current representative with a six year term. Further representatives will be determined by the ANZPNA Annual Meeting and proposed to IPNA.

4.2 Paediatric Nephrology:

R Walker raised concerns re Paediatric Transplantation taking papers from Paediatric Nephrology. The cost of publication of Paediatric Nephrology was noted and it was suggested that a new publisher eg Blackwells be approached.

4.3 Congress 2004:

J Burke proposed that Australia should submit a proposal to host this congress. He indicated that a submission to the IPNA Council would need to be made by the Chairman of ANZPNA regarding the host city and costings in approximately 18 months time. K Jureidini stated that Australia should make an application for this congress and that the host city be determined. J Knight proposed that the bid should only be made if 50% of the profits were returned to the ANZPNA. A motion was proposed by K Jureidini and seconded by J Knight that **"the meeting agree in principle that ANZPNA bid for the IPNA congress in 2004, and that internal bids re the host**

city and organisation committee be sought from members". This motion was passed with one member voting against the motion.

Extensive discussion was heard regarding the funding of the Congress and financial arrangements with IPNA. It was felt by the group that attempts should be made to generate a profit for both IPNA and ANZPNA. *(J Burke will investigate the financial aspects of funding a congress with the organisers of the London 1998 Congress.)*

4.4 IPNA Secretary General:

Ira Greifer is to retire in 2001. An executive committee of IPNA Council is meeting to determine how his successor is appointed, the tenure of the appointment and the job description. It is expected that the Council will determine the new Secretary General.

5. DRUGS:

5.1 Nifedipine:

The IPNA position statement and letter from ADEC were noted. Short acting Nifedipine capsules have been withdrawn from manufacture as of 1st May 1997. The manufacturing company, Bayer are not proceeding further to have this drug re-established with the ADEC. P Henning reported that it is possible for Nifedipine to be imported under the SAS scheme for a named patient or a clinical trial, and that it may be possible to import Nifedipine for registered physicians. **P Henning is to explore the possibility of importing Nifedipine for registered users and will report back through the Chairman. He will also determine whether Bayer is continuing to manufacture the short acting Nifedipine capsules.** K Jureidini suggested that intravenous Labetalol should be looked at as an alternative to Nifedipine.

5.2 Growth Hormone:

ANZPNA mission statement and letter from PBAC was noted. The group requested that A Rosenberg **should contact all manufacturers of Somatropin to request that they request an extension of registration to include chronic renal failure as per the ANZPNA mission statement** (as per letter from Des Threlfall 19/2/97).

5.3 Dexsal Antacid:

C Jones reported that this has now been withdrawn by the manufacturers, and no further action can be taken.

5.4 Cyclosporin:

The letter from A Rosenberg, December 1996, was noted. The meeting requested that E Hodson **discuss the issue with A Rosenberg as to the current status of acceptance of Cyclosporin as a S100 medication for nephrotic syndrome**. Members indicated that their individual Units were happy to provide the number of patients if required and requested E Hodson to write to Units. The meeting requested E Hodson to determine whether Sandoz has proposed Cyclosporin as a S100 medication.

5.5 Mycophenolate:

C Jones and R Walker reported that the Royal Children's Hospital, Melbourne was involved in an international trial of liquid Mycophenolate as a replacement for azathioprin. The trial is assessing the bioavailability of the liquid preparation as compared to the tablets. C Jones stated that the liquid Mycophenolate preparation is currently not approved for use in children. C Jones spoke to the item, namely that new medications are increasingly unlikely to be approved for use in children when approved for adult use. J Knight stated the ANZPNA should be the advocate for children. The Chairman elect is to write to the manufacturers seeking approval for use of Mycophenolate in children. C Jones proposed that the tablet form of Mycophenolate be approved by the Therapeutic Goods Administration for use in transplantation in children. *R Walker to draft letters* (Note in proof. The above information was supplied by drug manufacturer, review of PBS listing indicates that there is no age restriction from August 1, 1997.)

6. ANZDATA:

6.1 M Falk and I Hewitt are members ANZPNA and on the ANZDATA committee of the ANZSN. I Hewitt stated that paediatric data is collected by the members of the ANZPNA and therefore the data to be collected can be determined by the group.

6.2 Proposal for ANZDATA collection:

6.2.1 I Hewitt suggested that neurodevelopmental data be collected.

6.2.2 C Crompton suggested that the growth hormone data would be of interest. Concern that may overlap with the Ozgrow data collection. D Lewis proposed that the Endocrine Fellow at **the New Children's Hospital, Westmead look at the growth hormone data with reference to chronic renal failure on behalf of the ANZPNA.** Carried unanimously.

6.2.3 J Burke and R Walker proposed that predictors of cardiovascular outcome be looked at. **J Burke and L Johnstone to determine the lipid and echo data to be collected and distribute draft proposal to members.**

6.2.4 J Knight proposed that rehabilitation studies be incorporated into the data collection.

C Jones expressed concern that paediatric renal data collected by ANZPNA members could be published without due credit (authorship) to ANZPNA members. He proposed manuscript be published under the authorship of the group.

7. PRIORITY TRANSPLANTATION:

The Dialysis and Transplantation Workshop held in Leura in 1995 recommended that children be given priority for renal transplantation. J Burke spoke to this and stated that this does not appear to happen. R Walker believed that the recommendation had been take to the ANZSN Council and referred to each State and referred to the Dialysis and Transplantation Workshop Co-ordinators. P Henning spoke to a position statement re priority allocation of kidneys to children for transplantation (appendix 3).

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Priority transplantation to children needs to be determined at State level as the source of major allocation of organs. The national allocation of organs involves transport of fewer kidneys. M Falk indicated children were given priority in Queensland but did not appear to occur in any other State. M Falk stated that part of the problem was knowing which national body "owns" organ allocation. A new organ allocation body is being created and should be in place next year. C Jones suggested that the **recommendation of the Leura workshop be sent to the NH&MRC, the ANZSN, the TSANZ and the Dialysis and Transplantation Workshop.** *The Chairman elect is to write to these bodies.*

J Knight supported P Henning's position statement and raised the question of benchmarking internationally given that children have priority in the UK and the US. K Jureidini raised the UN charter for children stating that children have priority in the presence of limited resources.

8. MULTICENTRE TRIALS:

8.1 Reflux:

J Knight provided updates. The NH&MRC funding ceases at the end of 1997, and further funding has been sought. The concern at present is the number of patients enrolled with 25 infants enrolled to date with only 3 interstate infants enrolled.

8.2 Hypercalciuria

E Hodson was not present to update the meeting.

9. MINIMAL STANDARDS FOR PAEDIATRIC RENAL UNITS:

K Jureidini requested input from others regarding minimal standards. This issue was raised due to concerns about progressive decreases in Hospital funding and that minimal standards will need to be proscribed. C Jones proposed an audit committee to assess the standards. **It was proposed that the guidelines for the care of children with chronic renal failure accepted at last year's meeting should be put to the NH&MRC and the ANZSN.**

10. OTHER BUSINESS:

10.1 Election of a New Chair:

Nominations were received from P Henning and C Jones. Prior to election of the Chair a discussion took place concerning the term. J Burke suggested a minimum of two years and a maximum of three years. C Jones said two years was the most productive time. C Jones proposed that the Chair be seen to move interstate and to New Zealand. J Knight proposed a three person Executive consisting of a Chair, a Deputy Chair and a Secretary/Treasurer.

A motion was put that the Chair be a two year appointment with no option for re-election for two terms thereafter. It was proposed that the Executive consist of a Chair, a Deputy Chair and a Secretary/Treasurer and that the Deputy would be the Chair in the Chair's absence. These were carried unanimously.

The Chairman elect will call for nominations for the Deputy Chair and Secretary positions and a postal vote will determine the outcome.

P Henning formally withdrew his nomination and C Jones took the Chair. J Burke as outgoing Convenor acknowledged the work of A Rosenberg and requested the incoming Chair to write to him.

10.2 Aboriginal Health:

K Jureidini reported that federal funding has been received to screen all Aboriginal children for urinary abnormalities in South Australia. Further funding from the Adelaide Women's and Children's Hospital is available. J Knight reported that he has requested funding to screen urinary sediments in Aboriginal children in New South Wales. D McCredie's involvement in the Northern Territory was noted. I Hewitt reported that Western Australia has no formal screening process and similarly there is no formal approach in Queensland.

K Jureidini will distribute the study protocols and meet with C Crompton and J Knight to discuss the formation of an Aboriginal health sub-committee.

10.3 Membership Subscription:

C Jones proposed $100 as a one off joining fee and that the annual membership fee be determined by the Executive. C Jones is to discuss the current account of the ANZPNA with A Rosenberg. It was proposed that the treasurer seek corporate sponsorship for ANZPNA.

10.4 Newsletter:

C Jones proposed a quarterly newsletter termed the Journal of the ANZPNA. K Jureidini proposed a home page of the world wide web and M Falk will investigate this further.

10.5 Australian Paediatric Surveillance Unit (APSU):

J Knight reported that he has proposed collecting data about the incidence and prevalence of nephrotic syndrome to the APSU.

11. NEXT MEETING:

The group thanked Baxter for their sponsorship of this meeting. Baxter has agreed to fund the meeting of the ANZPNA next year. C Jones proposed that the meeting be held in a capital city separate from the Dialysis Workshop. K Jureidini proposed that it be a two day meeting including clinical discussion. C Jones will discuss options for next year with Baxter over the next 3 months. I Hewitt suggested a formal meeting of the ANZPNA at the ANZSN meetings.

12. CLOSURE:

There being no further business the meeting was closed at 6.10 pm.

Signed as a true and correct record:

.....

CHAIRMAN / /97

APPENDIX 1

ANZPNA MEMBERSHIP

J. BURKE
C. CROMPTON
M. FALK
P. HENNING
I. HEWITT
E. HODSON
L.M. JOHNSTONE
C.L. JONES
K.F. JUREIDINI
G. KAINER
J. KNIGHT
D. LEWIS
D. LINES
D.A. McCREDIE
M. MORRIS
H.R. POWELL
A.R. ROSENBERG
L.P. ROY
P. TOMLINSON
A.M. WALKER
R.G. WALKER
W. WONG

M. McNeil
J. Craig

Dr Lewis
Department of Nephrology
New Children's Hospital

Dear Deborah

Dr Knight
Centre for Kidney Research
New Children's Hospital

Dear John

Dr Rosenberg
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Dear Andrew

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Dear Harley

Dr Jones
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Dear Colin

Dr Jones
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Dear Colin

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Dear Paul

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Dear Charles

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Dear Max

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Dear Paul

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Dear Michael

Dr Kainer
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Dear Gad

Dr McCredie
Department of Nephrology
Royal Children's Hospital
PARKVILLE VIC 3052

Dear David

Associate Professor Walker
Department of Nephrology
Royal Children's Hospital
Flemington Road
PARKVILLE VIC 3052

Dear Rowan

Dr Johnstone
Department of Nephrology
Royal Children's Hospital
PARKVILLE VIC 3052

Dear Lillian

Dr Jureidini
Department of Nephrology
Adelaide Children's Hospital
King William Road
NORTH ADELAIDE SA 5006

Dear Fred

Dr Hewitt
Department of Nephrology
Princess Margaret Children's Hospital
Box D 184
PERTH WA 6001

Dear Ian

Dr Burke
Department of Nephrology
Princess Alexandra Hospital
Ipswich Road
WOOLLOONGABBA QLD 4102

Dear John

Dr Wong
University of Auckland
Department of Paediatric School of Medicine
Private Bag
Auckland

Dear William

Dr McIver
Dubbo Base Hospital
PO Box 739
DUBBO NSW 2839

Dear Margo

Dr J Craig
Department of Nephrology
NCH

The New Children's Hospital

Royal Alexandra Hospital for Children

Dr Elisabeth Hodson MB BS FRACP
Consultant Physician
Paediatric Nephrology
Telephone: 61 2 9845.3430 Fax: 61 2 9845.3432
Provider no: 29665AH

8th July, 1997

G:data\juliew\craiganz.doc

Dr A Rosenberg
Convenor
Australian and New Zealand
Paediatric Nephrology Association
Department of Nephrology
Sydney Children's Hospital
High Street
RANDWICK NSW 2031

Dear Andrew,

We would like to nominate Dr Jonathan Craig to be a member of the Australian and New Zealand Paediatric Nephrology Association. Dr Craig has recently been appointed as a half time staff specialist in paediatric nephrology at the New Children's Hospital. We enclose a copy of his curriculum vitae.

With best wishes
Yours sincerely,

Dr Elisabeth Hodson
Head
Department of Nephrology

Dr John Knight
Staff Specialist - Paediatric Nephrology
Head - Centre for Kidney Research

Appx 3

ALLOCATION OF TRANSPLANT KIDNEYS

The case for giving preference to children.

BACKGROUND

The pertinent ethical issue is one of justice. What can be agreed upon as fair?

There are 2 predominant philosophical frameworks to consider:

1) A utilitarian view - if you have to ration medical care resources, the duty is to maximise the greatest happiness/benefit to the greatest number.

2) A rights based view - the duty is to optimise care such that those with similar need have equal access to scarce resources. Here, the emphasis is upon fairness being maximised rather than happiness.

Transplant allocation practice currently reflects the second of these principles.

The basis for decisions can be summarised under two variables:

a) Medical need - In Australia, this is assumed to be the same for all potential recipients except when life is threatened by permanent failure of dialysis access. This approach avoids the difficulty of judging relative medical need. It also means that a patient's quality of life is never considered or assessed in the allocation context.

b) Probability of a successful outcome - this arises from a duty to donors, the community and potential recipients not to waste scarce resources. This has meant that certain "medical" factors are taken into account, including HLA matching,risk of disease recurrence and probability of non-compliance. These are ostensibly objective criteria but it has been argued that they may, at times have masked unacceptable subjective prejudice on the part of doctors, e.g.on personal grounds or social worth criteria.

It is almost certainly true that on occasion individual patients may have a demonstrably greater "medical need" than others, though generally this kind of judgement is clearly problematic. To define a class of patients deserving of preference would seem similarly difficult but I believe that as a group, children do carry burdens not experienced by adults which, taken together, constitute a significantly greater need. My argument follows.

The burdens experienced by dialysis patients awaiting a transplant (physical, psychological and social) are substantial for all sufferers, though the same symptom or disability may carry quite different significance for each individual. However, children suffer an impact

on maturational processes that clearly cannot be experienced by adults with ESRF. These may include effects on growth, psychomotor and social development as well as educational opportunity. They may lead to permanent disability or limit potential in later life.

Adults with ESRF will never be left with short stature, or failure of vocational fulfillment after educational deficiencies, or problems with lasting personal relationships from social immaturity. Their renal failure may cause problems in relationships or employment but at least adults have had the opportunity of achieving their potential, of establishing their vocation and of forming lasting relationships before the onset of their disease.

THE EVIDENCE

The rehabilitation of adult graduates of paediatric ESRF programmes is deficient. The above-mentioned problems are well descibed in patients treated in the 1970's and 1980's the UK and the US (Morel 1991, Henning 1988, Reynolds 1993). Since the advent of growth hormone final adult height is likely to improve but at the expense of a further increase in treatment burden for children and their families.

The long-term follow-up data from a range of sources reflect a consistent pattern in the rehabilitation of sufferers of paediatric ESRF:

Employment rates - Comparable to the general population and healthy controls. Results in the US are better than in the UK.

Education - relatively low achievement in standards achieved, the data suggesting that patients are not fulfilling their potential rather than individuals lacking that potential.

Independent living - the majority of young adults are still living with their parents at 25 years of age (e.g.67% vs. 30% of controls).

Relationships - significantly fewer are married or have a stable relationship (e.g.27% vs. 51% of controls).

Most investigators have shown a correlation between poorer rehabilitation (with respect to the above features) and earlier onset of disease and length on dialysis. The latter is reflected chiefly in the differences between the US and the UK where length on dialysis is clearly greater.

Data from Reynolds 1993 (UK), Morel 1991 (US), Henning 1988 (UK), Potter 1991 (US) and European Working Group on Psychosocial Aspects of Children with Chronic Renal Failure 1994.

SUMMARY

The described disadvantages experienced by children with ESRF which are not encountered by adults, favour them (as a group) when considering allocation of transplant kidneys. The weight of these disadvantages has particular moral significance because of its effect on lifelong potential.

This view is based upon greater need and reflects a rights-based philosophical framework. It is not "ageist" and does not consider any of the "social worth" criteria that can be applied e.g. greater potential in terms of length of survival or commercial value to the community.

CONCLUSION

While there is no direct evidence that transplanting paediatric patients earlier to minimise their time on dialysis will alleviate the problems they encounter in adult life, it seems likely that such an approach would assist significantly. Clearly, short-term rehabilitation is improved by transplantation over dialysis and cross-sectional comparisons strongly support the superiority of transplantation with respect to psychosocial and functional rehabilitation (Brownbridge and Fielding,1991). It is also of note that long-term studies show significantly better results in the US than those in the UK and Japan. The only notable difference in this data is the tendency for longer dialysis periods in the latter countries.

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Dr Johnathan Craig	Ph: (02) 9351 4823 Fax (02) 9351 7420
Dr Charles Crompton Department of Nephrology Princess Margaret Hospital for Children Roberts Road PO Box D184 Subiaco, WA 6008 Perth WA 6001	Ph: (08) 9340 8354 Switch (08) 9340 8222 Fax: (08) 9340 8301 Mob: 0418 917 733
Dr M Falk Princess Alexandra Hospital & District Health Service Ipswich Road Woolloongabba, QLD 4102	Ph: (07) 3240 5080 (0419) 641449 Fax: (07) 3240 5480 email: klaf@extro.ucc.su.oz.au
Dr Paul Henning Department of Nephrology Adelaide Women's & Children's Hospital North Adelaide, SA 5006	Ph: (08) 8204 7000
Dr Ian Hewitt Princess Margaret Hospital for Children Roberts Road GPO Box D184 Subiaco, WA 6008 Perth WA 6001	Ph: (08) 9340 8354 Ph: (08) 9340 8222 (Hosp switch) Fax: (08) 9340 8301 Mob: 0418 928 983 email: Ian.Hewitt@health.wa.gov.au
Dr Elisabeth Hodson The New Children's Hospital PO Box 3515 Parramatta, NSW 2124	Ph: (02) 9845 3430 Fax: (02) 9845 3432
Dr Lilian Johnstone Paediatric Nephrology Unit Paediatric Section Monash Medical Centre Clayton Road Clayton, VIC	Ph: (03) 9550 4209 (03) 9550 4176 Pager: (03) 9387 1000 Fax: (03) 9550 6909
Dr Colin Jones Director Department of Nephrology Royal Children's Hospital Flemington Road Parkville VIC 3052	Ph: (03) 9345 5054 Fax: (03) 9345 5611 email: cjones@cryptic.rch.unimelb.edu.au

Dr KF Jureidini Department of Nephrology Adelaide Women's & Children's Hospital North Adelaide, SA 5006	Ph: (08) 8204 7000/(08) 8267 7303 Fax (08) 8204 6048
Dr Gad Kanier Department of Nephrology Children's Hospital Prince of Wales Hospital Randwick, NSW 2031	Ph: (02) 9382 1111 Fax: (02) 9388 3311
Dr John Knight The New Children's Hospital PO Box 3515 Parramatta, NSW 2124	Ph: (02) 9845 3431 Fax (02) 9845 3489
Dr Debra Lewis The New Children's Hospital PO Box 3515 Parramatta, NSW 2124	Ph: (02) 9845 3431 Fax (02) 9845 3489
Dr David Lines Flinders Medical Centre Flinders Drive Bedford Park SA 5042	Ph: (08) 8204 5511 Fax: (08) 8204 5450
Dr David McCredie Department of Nephrology Royal Children's Hospital Flemington Road Parkville VIC 3052	Ph: (03) 9345 5612 Fax: (03) 9345 5611
Dr Max Morris University of Auckland, Department of Paediatrics School of Medicine Private Bag Auckland, NZ	Ph: 0011-649-3074921 Fax 00156-649-3074913
Dr Harley Powell Department of Nephrology Royal Children's Hospital Flemington Road Parkville VIC 3052	Ph: (03) 9345 5766 Fax: (03) 9345 5611
Dr Andrew Rosenberg Department of Nephrology Children's Hospital Prince of Wales Hospital Randwick, NSW 2031	Ph: (02) 9382 1111 Fax (02) 9388 3311

Dr Paul Roy The New Children's Hospital PO Box 3515 Parramatta, NSW 2124	Ph: (02) 9845 3431 Fax (02) 9845 3489
Dr P Tomlinson	
Dr Amanda Walker Paediatric Nephrology Unit Paediatric Section Monash Medical Centre Clayton, VIC	Ph: (03) 9550 4209 (03) 9550 4176 Pager: (03) 9387 1000 Fax: (03) 9550 6909
A/Professor Rowan Walker Department of Nephrology Royal Children's Hospital Flemington Road Parkville VIC 3052	Ph: (03) 9345 5054 Ph: (03) 9342 7053 Royal Melb. Hosp. Fax: (03) 9345 5611
Dr W Wong University of Auckland Department of Paediatrics School of Medicine Private Bag, Auckland, NZ	Ph: 0011-649-3074921 Fax 0015-649-3074913 email: wmwong@nznet.gen.nz

CALL FOR NOMINATIONS

Nominations for the position of

Deputy Chair and Secretary/Treasurer are called for.

The attached form needs to be completed and returned to Colin Jones, Chairman, ANZPNA, by 31st August 1997. A postal vote will then take place to determine these positions.

Att.

NOMINATION FORM

POSITION NOMINATED FOR:

DEPUTY CHAIR _____

SECRETARY/TREASURER _____

PROPOSERS _____

_____

SECONDER _____

_____

SIGNATURE OF NOMINEE _____

Return to: *Dr C Jones, Chairman, ANZPNA, Department of Nephrology*
Royal Children's Hospital, Flemington Road, Parkville 3052

CALL FOR INTERNAL BIDS : HOST CITY FOR IPNA, 2004

The ANZPNA meeting resolved that ANZPNA bid for the IPNA congress in 2004.

(i) only one centre should bid from Australasia and that all members would support the chosen city.

(ii) satellite symposia be held in association with the meeting. These could include the Renal Developmental Workshop and the Paediatric Transplantation Meeting.

(iii) some significant members of the various committees be composed of ANZPNA members outside the host city where appropriate (eg. scientific, continuing education, Advisory Committee).

There was discussion on the proposed:

(i) terms of a bid. Some numbers felt that if funding were not sought and obtained from IPNA their bid would not proceed. J Burke, as IPNA Councillor, was asked to report on the financial aspects of hosting IPNA from discussions with the organisers of next year's congress in London.

(ii) Australian city that should make the bid.

(iii) structure of the organisation committee.

The members from Melbourne and Brisbane have decided not to bid. Active interest was shown by Sydney and Adelaide members. New Zealand was not represented.

A submission to IPNA council would be needed in 18 months' time. One year would seem a minimal time to finalise the submission and lobby IPNA council. Thus, I propose to implement the meeting's motion by asking for internal bids by end of January 1998 with the following information to be circulated in the Journal then:

1. Bid City
2. Executive
   - President
   - Vice-president
   - Members
3. Committee Chairs
   - Scientific
   - Finance
   - Publication
   - Publicity
   - Satellites
   - Continuing education
   - Social
4. ANZPNA Advisory Committee

COLIN JONES
CHAIRMAN
ANZPNA

The New Children's Hospital
Royal Alexandra Hospital for Children

Dr Elisabeth Hodson MB BS FRACP
Consultant Physician
Paediatric Nephrology
Telephone: 61 2 9845.3430 Fax: 61 2 9845.3432
Provider no: 29665AH

11th July, 1997

Dr Burke
Department of Nephrology
Princess Alexandra Hospital
Ipswich Road
WOOLLOONGABBA QLD 4102

Dear John,

We would like to nominate Dr Colin Jones to be the next Convenor of the Australian and New Zealand Paediatric Nephrology Association.

With best wishes
Yours sincerely,

Dr E Hodson *Dr LP Roy* *Dr D Lewis* *Dr J Knight*

faxed

ANDREW R. ROSENBERG, MB BS, FRACP
Paediatric Nephrologist
Provider No: 409051X

PHONE: 02 - 9382 1646
FAX: 02 - 9382 1580
Email: A.Rosenberg@UNSW.edu.au

SYDNEY CHILDREN'S HOSPITAL

High Street, Randwick NSW 2031
Telephone: 02 9382 1111

1. LPR to do constitution
2. 3 man executive
3. Proxies from LPR, etc
4. BA to talk to Colin

Monday, 23 June, 1997.

Donors – evidence Adelaide do well
evidence not extra workforce
Other countries' policies
Evidence that donors are coming from PICUs.
Permission to harvest + use locally
5 yrs on dialysis + opportunities for growth.

TO: **ALL MEMBERS OF ANZPNA**

FROM: **ANDREW ROSENBERG**

I apologise for the fact that I will not be able to attend the meeting in Melbourne.

I herewith call for nominations to replace me as Convenor of the Association. Please address your nominations to John Burke.

Andrew R. Rosenberg

ANZPNA MEETING

To be held on 20th July, 1997

TIME: **12 Midday**

VENUE: **Washington Rooms 3 & 4**
Carlton Crest Hotel
65 Queens Road
Melbourne
Telephone: (03) 9529 4300

AGENDA

1. Apologies

2. Minutes of Meeting of October, 1996

3. Membership:
   - 3.1 List of members
   - 3.2 Application for Membership (F. Willis)
   - 3.3 Constitution of the Australasian Paediatric Endocrine Group (for information)
   - 3.4 Rules of the British Association for Paediatric Nephrology (for information)

4. International Paediatric Nephrology Association - J Burke to report

5. Drugs
   - 5.1 Nifedipine - ANZPNA Position Statement
     - Letter from ADEC
   - 5.2 Growth Hormone - ANZPNA Position Statement
     - Letter from PBAC
   - 5.3 Dexsal and Acid Liquid (C. Jones to report)
   - 5.4 Cyclosporin for nephrotic syndrome (E.Hodson). A draft letter from E. Hodson is enclosed together with references. It is suggested that the case for cyclosporin would be stronger if all Units in Australia pooled their patient numbers.
   - 5.5 Mycophenolate

6. ANZDATA - review of paediatric component (foreshadowed at last meeting)

AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

MINUTES OF MEETING

AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

SYDNEY 11 OCTOBER, 1996

ATTENDANCE: A Rosenberg, P Roy, I Hewitt, G Kainer, A Walker, C Jones, E Hodson, K Jureidini, W Wong, M Morris, M Falk, C Crompton, J Burke

APOLOGIES: P Henning, H Powell, D McCredie, R Walker, L Johnstone, D Lewis, J Knight

SANDOZ: The chairman thanked Sandoz for their generosity in providing $6,000.00 for the travel costs associated with this Meeting.

MEMBERSHIP: Eligibility for membership of ANZPNA requires
1) that the applicants have substantial involvement with paediatric nephrology.
2) a proposer and seconder and
3) a vote by the membership.

Following extensive discussion about physicians who have/had significant involvement with paediatric nephrology it was decided that D Lines and R Bailey are to be approached as to their desire to join the Association. G Kainer agreed to prepare a membership application form.

TRAINEES IN PAEDIATRIC NEPHROLOGY:
F Willis, J Craig, S Alexander, F Mackie, M Tilley

IPNA: J Burke (IPNA Representative) discussed major items from the recent IPNA Council Meeting.
1) The process of appointing the new editors for the Journal was discussed.
2) There was discussion as to whether Australia should make a representation in the future for the IPNA Scientific Meeting to be held in Australia. It was noted that the meeting in 2001 will be held in North America and it is likely that the meeting in 2004 will take place in

(PBAC) and the Australian and New Zealand Society for Nephrology (ANZSN).

DEXSAL ANTACID LIQUID:

C Jones reported that this preparation, which could be used as a phosphate binder, contains aluminium trisilicate as a suspending agent. It was decided that Reckitt & Coleman be asked to reformulate and develop this medication without aluminium trisilicate. C Jones undertook to discuss the matter with the Company.

CYCLOSPORIN:

It was noted that cyclosporin is not listed under Section 100 for children with steroid dependent and resistant nephrotic syndrome, although it is listed for several other conditions. It was unaminously moved that an application for listing of cyclosporin for children with the above forms of nephrotic syndrome be made under Section 100. E Hodson undertook to further look at this matter.

ANZDATA:

It was noted that R Walker and I Hewitt are members of an ANZSN Committee which analyses ANZDATA. It was agreed that, at a future meeting of ANZPNA in 1997, there should be a review of the paediatric component of ANZDATA.

PRIORITY TRANSPLANTATION FOR CHILDREN:

There was considerable discussion about whether children should receive any priority with regard to allocation of cadaveric kidneys. At present this is a State matter and there is wide variation in the methods of allocation of kidneys between States. It was noted that in Queensland, uniquely, children are given priority rating.

At the Dialysis and Transplant Workshop at the Blue Mountains in 1994 a recommendation had been passed that children receive priority. J Burke will make inquiry as regarding the fate of this recommendation.
A motion was then passed, unaminously, supporting the development of a priority system for allocation of cadaveric transplants to children. K Jureidini undertook to ask P Henning to prepare a Position Statement.

COLLABORATIVE RESEARCH:

At present no multicentre study is being carried out by ANZPNA. It was suggested that each Unit send a summary of their ongoing research studies to A Rosenberg for listing.

ANZPNA MEMBERSHIP

J. BURKE
C. CROMPTON
M. FALK
P. HENNING
I. HEWITT
E. HODSON
L. JOHNSTONE
C. JONES
K.F. JUREDINI
G. KAINER
J. KNIGHT
D. LEWIS
D. LINES
M. MORRIS
D. McCREDIE
H.R. POWELL
A.R. ROSENBERG
L.P. ROY
P. TOMLINSON
A. WALKER
R. WALKER
W. WONG

A N Z P N A

MEETING FRIDAY 11/10/96

TIME: 10.00 am

VENUE: SENIOR STAFF ROOM
LEVEL O
SYDNEY CHILDREN'S HOSPITAL
HIGH STREET, RANDWICK

A G E N D A

1.	Apologies	
2.	Membership	Attachment 1
3.	IPNA	Attachment 2
4.	Pharmaceutical	
	4.1 Growth hormone	to be tabled
	4.2 Nifedipine capsules	Attachment 3
	4.3 Kindergen Prod	Attachment 4
	4.4 Dexsal antacid liquid	
	4.5 Cyclosporin	
5.	Allocation of kidneys to children	Attachment 5
6.	ANZDATA registry	
7.	Training in paediatric nephrology	
8.	Collaborative research	
9.	Other business	
10.	Date of next meeting	

Andrew R .Rosenberg

Attachment 2

QUEENSLAND HEALTH

BRISBANE SOUTH REGION
NORTH-WESTERN SECTOR

PRINCESS ALEXANDRA HOSPITAL

Ipswich Road
Woolloongabba
Brisbane Qld Australia 4102
Telephone (07) 3240 2111
Facsimile (07) 3240 5577

ENQUIRIES RENAL UNIT
PHONE 61 7 3240 5080
FAX 61 7 3240 5480
OUR REF JB:mbk
YOUR REF

DIC: 17 September 1996
TYP: 18 September 1996

Dr A Rosenberg
Nephrologist
Prince of Wales Children's Hospital
High Street
RANDWICK 2031

Dear Andrew

I am writing concerning Agenda for the Meeting on 11 October. I would like to speak to the Meeting concerning the last IPNA Council Meeting. Enclosed are the major agenda items discussed at that Meeting and I will bring a copy for each person attending.

Specific issues for our group, is whether we should have some official involvement and assistance to undeveloped countries in our region such as New Guinea and Fiji. Are there people in these countries who could be receiving the Journal subsidised by IPNA. We should also discuss our Association with the IPNA Council, particularly as the Asian's have become an official Sub-Committee.

As a separate agenda item we need to discuss the activity of our Group and the possibility of more multicentre studies. I look forward to seeing you in Sydney.

Yours sincerely

JOHN BURKE

PEDIATRIC NEPHROLOGY JOURNAL

There continues to be a distribution from IPNA to under developed countries such as China.

The Editors will appreciate any comment concerning the content of the Journal.

INTERNATIONAL SOCIETY OF GENETIC RENAL DISEASE

Study involving Bartter's and Gillterman's Syndrome is now in its first draft. There have been considerable problems with this study.

HUS IN JAPAN

The Japanese representatives discussed the recent outbreak of HUS involving 150 cases in Japan. Many of these children have been cared for by adult Nephrologist who have been recommending plasmaphoresis. In Argentina there are approximately 400 cases a year.

RUSSIAN SOCIETY OF PEDIATRIC NEPHROLOGY

A Congress has been held in September 1996. There has been active support for training in pediatric nephrology for Russian pediatricians by IPNA. Two members are being sent to Siberia later in the year to participate in a course in Nephrology.

ASIAN SOCIETY OF PEDIATRIC NEPHROLOGY

This Society was recently formed and involves 10 countries including China, Hong Kong, Indonesia and the Philippines. This Society has become an official Sub-Committee of IPNA.

IPNA MEETING NORTH AMERICA 2001

A delegate from Seatle, Chicago, and New York attended the Meeting to present a case for that Meeting to be held in their city. A vote for the venue will be taken by Council at their next meeting in May 1997.

Attachment 1

ANZPNA MEMBERSHIP

J. Burke
C. Crompton
M. Falk
P. Henning
I. Hewitt
E. Hodson
L. Johnstone
C. Jones
K.F. Juredini
G. Kainer
J. Knight
D. Lewis
M. Morris
D. McCredie
H.R. Powell
A.R. Rosenberg
L.P. Roy
R. Walker
M. Walker
W. Wong

AUSTRALIA AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION
October 11, 1996

Proposal for requesting listing of cyclosporin under Section 100 for use in frequently relapsing and steroid dependent nephrotic syndrome

Dr Elisabeth Hodson
New Children's Hospital

In 1991 the Commonwealth Government agreed to fund certain highly specialised and expensive drugs that were required for ongoing care of patients after discharge from hospital under Section 100. These drugs must be prescribed by specialists and dispensed in a public hospital pharmacy. The Highly Specialised Drugs Working Party of the Commonwealth Department of Health is responsible for selecting drugs proposed for inclusion under Section 100 arrangements according to a number of criteria.

Cyclosporin is available under Section 100 for use in transplantation. It is proposed that a request be made for cyclosporin (Neoral) to be made available under Section 100 for children with steroid dependent or frequently relapsing nephrotic syndrome. Cyclosporin has been shown to be effective in these conditions with 60-80% children maintaining remission when corticosteriod therapy is ceased[1,2]. Most children relapse when cyclosporin in withdrawn. This is in contrast to the results following treatment with 8 or 12 weeks of cyclophosphamide or chlorambucil where 40-60% remain in remission for 2 years or more[3,4,5]. However in those children who relapse, second and subsequent courses of cyclophosphamide or chlorambucil are generally contraindicated because of the risk of gonadal toxicity especially in boys[6]. Cyclosporin is of particular value in this group of children. Cyclosporin is also of value in children with frequently relapsing or steriod dependent nephrotic syndrome where cyclophosphamide or chlorambucil are considered to be contraindicated because of the risk of haemorrhagic varicella or other viral diseases in non immune children. Available data on glomerular filtration rates[7] indicate that it can be used safely for long periods when administered in a dose of 5-6 mg/kg/day though tubulointerstitial lesions may be seen on serial renal biopsies[8]. Cyclosporin for this indication satisfies the criteria for selection of highly specialised drugs for Section 100 listing.

There should be discussion as to whether cyclosporin should also be listed under Section 100 for use in children with steroid resistant nephrotic syndrome since it appears to be much less valuable in that situation.

1. Niaudet P et al. Clinical Nephrology (1991) 35: S.31-36
2. Hulton S-A et al. Pediatr Nephrol (1994) 8: 401-403
3. Arbeitsgemeinschaft fur Paediatrische Nephrologie. New Engl J Med (1982) 306: 451-454
4. Ibid. Arch Dis Childh (1987) 62: 1102-1106
5. Niaudet P and the French Society of Paediatric Nephrology. Pediatr Nephrol (1992) 6: 1-3
6. Watson AR. Brit Med J (1985) 291: 1457-1460
7. Hulton S-A et al. Pediatr Nephrol (1994) 8: 404-407
8. Habib R and Niaudet P. Clinical Nephrology (1994) 42: 141-146

AUSTRALIA AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION
October 11, 1996

Dr Elisabeth Hodson
New Children's Hospital

The following principles of care for children with renal failure are included in the Draft Report of the Review of Maintenance Dialysis Services in NSW. It is proposed that these should be accepted by the Australia and New Zealand Paediatric Nephrology Association. If these principles are accepted, the National Health and Medical Research Council and the Australia and New Zealand Society of Nephrology should be asked to endorse them.

1. Children with chronic renal insufficiency (defined as a calculated or measured glomerular filtration rate less than 30ml/min/1.73m^2) should always be managed in consultation with a recognised paediatric nephrology service.

2. Children with renal failure (defined as requiring acute or chronic dialysis or a renal transplant) should always be managed by a recognised paediatric nephrology service.

AUSTRALIA AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION
October 11,1996

Dr Elisabeth Hodson
New Children's Hospital

Issue: Health Care Card Eligibility for patients with a chronic illness requiring multiple medications.

Background: At present a Health Care Card is only available with a Child Disability Allowance or with the family's Social Security Benefits. With a Health Care Card patients can obtain medications for $2.70 per prescription and pay a maximum of $140 per calendar year. Without a Health Care Card patients pay up to $16.80 per prescription to a maximum of $600 per calendar year. Once they have reached this threshold, they become eligible for a Safety Net Concession Card which entitles them to pay only $2.70 per prescription. Following renal transplantation children require two or more immunosuppressive medications, as long as they have a functioning transplant, and in addition may require antihypertensive and other medications. The nineteen children with renal transplants currently followed at the New Children's Hospital require between 2 and 6 medications each. Most children following successful renal transplants do not need to continue on Child Disability Allowances. However, since remaining on the allowance is the only way that most of these children can have Health Care Cards, great efforts are made to maintain the allowance. When these patients reach 16 years or complete full time schooling, they have to be on Social Security Benefits to be eligible for reduced prescription costs. Some adolescents have been encouraged by the Department of Social Security to go on a disability pension because this the only way that their medication costs can be reduced.

Possible Solution: Patients of all ages with chronic illness requiring multiple medications should be eligible without a means test for a Health Care Card. This solution was suggested in a Review conducted by the Commonwealth Department of Health in 1994 but was not implemented. If post transplant paediatric patients received these cards without Child Disability Allowances, the cost of the allowances and of administering the two year reviews would be saved.

AUSTRALIA AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION
October 11,1996

Dr Elisabeth Hodson
New Children's Hospital

Issue: Travel costs for outpatients from rural areas

Background: Unlike adults with renal failure who can receive treatment locally, the majority of infants with advanced chronic renal failure and all children with endstage renal failure, who are on dialysis or who have received renal transplants, need to be reviewed at monthly or two monthly intervals by their paediatric nephrologist in Sydney. If they live less than 200 km from Sydney, they receive no monetary help with transport. If they live more than 200 km from Sydney, they are entitled to receive help from the Isolated Patients' Travel and Accommodation Assistance Scheme (IPTAAS). However the latter is insufficient for many families as they have to pay the first $40 of an IPTAAS claim and they can only claim $20 for additional transport costs in Sydney such as transport from the airport. The AAC bus service, the cheapest available service from the airport to the New Children's Hospital, costs $60 round trip for a child and a parent while a taxi costs $100. Thus rural families attending the New Children's Hospital for monthly appointments can anticipate an annual cost after IPTAAS subsidy of $960.00. In addition most families have to pay for their travel and then claim reimbursement. Some families are not able to pay these charges and may miss appointments.

Possible solution: Money from the IPTAAS Scheme should be easily available to families before they travel. Needy families from rural areas, who have children with chronic disease and have to come to Sydney for frequent outpatient follow up, should have their travel costs provided so that they can attend their specialists.

AUSTRALIA AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION
October 11, 1996

Dr Elisabeth Hodson
New Children's Hospital

Issue: Costs of special feeds and supplies for nasogastric and gastrostomy feeds

Background: Children with advanced chronic renal failure (GFR below 30ml/min/1.73m^2) and endstage renal failure frequently suffer from malnutrition and retarded growth. Our own studies and those from other centres indicate that growth rates can be considerably improved by adequate nutrition alone. In addition adequate nutrition appears to be essential for an optimal response to Synthetic Growth Hormone, when this is employed in uraemic children. Most uraemic children only achieve satisfactory nutrition when they are fed overnight by nasogastric tube or gastrostomy using specialised formulae with calorie supplements. Unless the children are eligible for PADP assistance in their Area Health Service, the families have to pay for the Kangaroo pump supplies for overnight feeds. In addition they have to pay for Polyjoule supplements and for the special feeds; these are not available through PADP even if the family is eligible for PADP. Kangaroo pump bags cost approximately $32 per month depending on how long each bag lasts; nasogastric tubes cost $17 each and can last up to a month but may require replacement earlier. The Polyjoule supplement costs $10/kg, which lasts 1-3 weeks depending on the size of the child. The monthly charge at the New Children's Hospital for special feeds, where the child is taking some normal food as well, varies between $40 and $70 depending on the age of the child and is based on the normal cost of feeding a well child. The New Children's Hospital subsidises the costs of any special formulae. In hospitals where such subsidies are not provided the family may not be able to afford the most appropriate formula for their child's condition and may go without nutritional support.

The mother, of a 3 year old child with chronic renal failure who is fed via gastrostomy, has estimated that the cost of feeding her child, using a standard milk formula from the supermarket (5-6 cans of NAN at $11/can), Polyjoule (3-4 kg at $10/kg) and four Kangaroo pump bags is $127.00 per month or $1524.00 per annum.

Possible Solutions: When special formulae for children with renal disease are available (e.g. Kindergen Prod, Nepro), these should be provided on Pharmaceutical Benefits. The PADP Scheme should be extended to supplement the cost of feeds for needy families. The costs of Kangaroo or other pump supplies and of nasogastric tubes should be provided to all children with renal disease regardless of the family's income.

AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

c/- Dr Andrew R Rosenberg
Department of Nephrology
The Prince of Wales Children's Hospital
High Street, Randwick NSW 2031
Phone: (02) 3821646
Fax: (02) 3995414
Email: A.Rosenberg@UNSW.edu.au

Friday, 24 January, 1997.

TO: Members of ANZPNA

FROM: Andrew R. Rosenberg

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1. Unconfirmed minutes of meeting of 11/10/96 attached.

2. Establishment of ANZPNA as a Regional Society of IPNA:= letter from Ira Greifer attached.

3. *Nifedipine capsules* - letter from Michael Falk and Position Statement attached.

   Also attached are letters from Bayer and from ADEC confirming withdrawal of the capsules from the market.

   I would be very grateful for any advice as to what more ANZPNA can do.

4. The cost of the meeting in October was $4651.64. I have written to Sandoz expressing our gratitude and asking if they would be willing to donate more money this year.

5. I attach a letter from Dr. Paul Tomlinson asking to be a member of the Association. If people do not contact me by mid February I will assume that this is OK.

Andrew R. Rosenberg

AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

MINUTES OF MEETING

AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

SYDNEY 11 OCTOBER, 1996

ATTENDANCE: A Rosenberg, P Roy, I Hewitt, G Kainer, A Walker, C Jones, E Hodson, K Jureidini, W Wong, M Morris, M Falk, C Crompton, J Burke

APOLOGIES: P Henning, H Powell, D McCredie, R Walker, L Johnstone, D Lewis, J Knight

SANDOZ: The chairman thanked Sandoz for their generosity in providing $6,000.00 for the travel costs associated with this Meeting.

MEMBERSHIP: Eligibility for membership of ANZPNA requires
1) that the applicants have substantial involvement with paediatric nephrology.
2) a proposer and seconder and
3) a vote by the membership.

Following extensive discussion about physicians who have/had significant involvement with paediatric nephrology it was decided that D Lines and R Bailey are to be approached as to their desire to join the Association. G Kainer agreed to prepare a membership application form.

TRAINEES IN PAEDIATRIC NEPHROLOGY:
F Willis, J Craig, S Alexander, F Mackie, M Tilley

IPNA: J Burke (IPNA Representative) discussed major items from the recent IPNA Council Meeting.
1) The process of appointing the new editors for the Journal was discussed.
2) There was discussion as to whether Australia should make a representation in the future for the IPNA Scientific Meeting to be held in Australia. It was noted that the meeting in 2001 will be held in North America and it is likely that the meeting in 2004 will take place in

Europe.

3) It was reported that the Asian Paediatric Nephrology Society has recently affiliated with IPNA. Further, it was noted that ANZPNA is not currently affiliated with IPNA. After discussion it was decided that ANZPNA, through J Burke, should begin discussion with IPNA concerning affiliation (proposed K Jureidini, seconded E Hodson).

4) Articles of association will be required. P Roy, J Burke and A Rosenberg agreed to prepare this document.

5) It was reported that in 1997 the North American Paediatric Nephrology Association Meeting will be held at the end of April in Washington DC and the European Society for Paediatric Nephrology will meet in Athens at the end of September.

NIFEDIPINE:

It was reported that Nifedipine capsules are to be withdrawn from the Australian market because they have not had a listing for the management of acute hypertension and because of concern about adverse affects in adults. Unfortunately, despite the widespread use of Nifedipine capsules in the management of childhood hypertension, there are very few reports in the literature and there have been no randomised clinical trials. ADEC have been approached by this association to review the decision to withdraw Nifedipine capsules. A submission by Bayer would be required but is unlikely to be forthcoming.

It was unaminously decided that ANZPNA should continue its attempts to have Nifedipine capsules registered by the TGA for the treatment of childhood hypertension (proposed P Roy, seconded E Hodson).

It was further moved that ANZPNA support the treatment of hypertensive emergencies in children by Nifedipine capsules *under supervision by a paediatrician* (proposed G Kainer, seconded K Jureidini).

It was pointed out that the medication could be imported to Australia under Section 19 through an application to TGA. This would require a Position Statement; A Walker and C Jones undertook to prepare such a statement.

Informal attempts will be made to seek an extension of the use of Nifedipine for childhood hypertensive emergencies for at least another 12 months.

ENTERAL FEEDS:

E Hodson discussed the costs involved with feeds such as Kindergen Prod. This is a State issue and no action can be taken by this Association.

GROWTH HORMONE:

A Position Statement concerning growth hormone for children with chronic renal failure was approved and is to be sent to the Pharmaceutical Benefits Advisory Committee

(PBAC) and the Australian and New Zealand Society for Nephrology (ANZSN).

DEXSAL ANTACID LIQUID:

C Jones reported that this preparation, which could be used as a phosphate binder, contains aluminium trisilicate as a suspending agent. It was decided that Reckitt & Coleman be asked to reformulate and develop this medication without aluminium trisilicate. C Jones undertook to discuss the matter with the Company.

CYCLOSPORIN:

It was noted that cyclosporin is not listed under Section 100 for children with steroid dependent and resistant nephrotic syndrome, although it is listed for several other conditions. It was unaminously moved that an application for listing of cyclosporin for children with the above forms of nephrotic syndrome be made under Section 100. E Hodson undertook to further look at this matter.

ANZDATA:

It was noted that R Walker and I Hewitt are members of an ANZSN Committee which analyses ANZDATA. It was agreed that, at a future meeting of ANZPNA in 1997, there should be a review of the paediatric component of ANZDATA.

PRIORITY TRANSPLANTATION FOR CHILDREN:

There was considerable discussion about whether children should receive any priority with regard to allocation of cadaveric kidneys. At present this is a State matter and there is wide variation in the methods of allocation of kidneys between States. It was noted that in Queensland, uniquely, children are given priority rating.

At the Dialysis and Transplant Workshop at the Blue Mountains in 1994 a recommendation had been passed that children receive priority. J Burke will make inquiry as regarding the fate of this recommendation.
A motion was then passed, unaminously, supporting the development of a priority system for allocation of cadaveric transplants to children. K Jureidini undertook to ask P Henning to prepare a Position Statement.

COLLABORATIVE RESEARCH:

At present no multicentre study is being carried out by ANZPNA. It was suggested that each Unit send a summary of their ongoing research studies to A Rosenberg for listing.

CLINICAL PRACTICE GUIDELINES:

The following clinical indicators were fully supported:-

1. EPO in anaemia of chronic renal failure in children.
2. Management of first episode of nephrotic syndrome.
3. Management of acute renal failure in HUS.

GUIDELINES FOR CARE OF CHILDREN WITH CHRONIC RENAL FAILURE:

The following guidelines were unanimously supported:-

1. Children with chronic renal insufficiency (defined as a calculated or measured glomerular filtration rate $<30ml/min \times 1.73m^2$) should always be managed in consultation with a recognised paediatric nephrology service.

2. Children with chronic renal failure (defined as requiring acute or chronic dialysis or a renal transplant) should always be managed by a recognised paediatric nephrology service.

These guidelines will be forwarded to the National Health and Medical Research Council and the Australian and New Zealand Society of Nephrology.

MINIMAL STANDARDS FOR PAEDIATRIC RENAL UNITS:

K Juredini undertook preparation of a Position Statement.

HEALTH CARE ELIGIBILITY FOR CHILDREN WITH CHRONIC RENAL DISEASE:

Travel costs for Outpatients from rural areas in New South Wales were noted. Discussion ensued as to whether the development of new guidelines for the Child Disability Allowance may disadvantage children with chronic renal disease. No action to be taken at present.

Andrew R. Rosenberg
Convenor

INTERNATIONAL PEDIATRIC NEPHROLOGY ASSOCIATION

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Membership & Subscription Dept.
IPNA - P.O. Box 412
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November 14, 1996

Andrew Rosenberg, M.D.
Prince of Wales Children's Hosp.
Dept. of Nephrology
High Street Randwick
Sydney NSW 2031
Australia

Dear Andrew:

I hope all is going well with you, and your family are all in good health.

The International Society of Nephrology meeting in Sidney is fast approaching and I am wondering whether there has been any pediatric participation or a pediatric program planned around that time.

I saw John Burke in London and he informed me that you all met in Australia-New Zealand to discuss whether to establish a regional society to fully represent your goals and aspirations. He explained the possible establishment of the **Australia-New Zealand Pediatric Nephrology Association (ANZPNA).**

As I mentioned to him, if you decide to do so, I am sure the IPNA Council would readily accept you as a regional society and that your chief executive officer would become an Assistant Secretary to IPNA.

In the meantime, I wish you and your family good health and success.

With kindest personal regards and in fondest friendship.

Sincerely,

Ira Greifer, M.D.
Professor of Pediatrics
Albert Einstein College of Medicine

IG:eg

QUEENSLAND HEALTH

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23 October 1996

Dr Andrew Rosenberg
Nephrologist
Prince of Wales Children's Hospital
High Street
RANDWICK 2031

Dear Andrew

re: ANZPNA MEETING 11.10.1996

Thank you for organising the 1996 ANZPNA Meeting which I felt was a great success. It was an important opportunity to get Paediatric Nephrologists from throughout Australia and New Zealand to discuss policy and also to steer towards establishing guidelines in the formation of ANZPNA.

As part of my brief from the Meeting I was asked to discuss with Sue Pond the problems with licensing Adalat Capsules 5mg for the use of hypertension in children. As you are aware she is the Chairman of ADEC and was quite sympathetic to our position. She felt that ADEC would be an appropriate body to pursue our submissions for the licensing of this medication in children, and again recommended that this be done in conjunction with the Company (Bayer) and Louis Landau. Sue was of the opinion that ADEC was out best opportunity and that further the TGA would be advised by ADEC rather than the other way round. I had subsequent discussions with Tim Mathew, who is a member of TGA, and his opinion was that since the FDA has banned the use of Nifedipine in the United States any further progress in this area would be problematical. Nonetheless I was encouraged by Sue's opinion and believe it is still possible to mount a last minute assault on the various regulatory bodies.

Professor Pond was certainly in favour of us using Section 19 to bypass the Australian regulatory system but thought that asking for an extension of further time, whilst ingenious may be difficult to achieve.

Please find enclosed copies of my expenditures in attending this meeting and I am most thankful for Sandoz's participation in reimbursing these costs.

With warm wishes.

Yours sincerely

Michael

MICHAEL FALK
STAFF NEPHROLOGIST

From: "Paul Tomlinson" <paultom@southnet.co.nz>
To: "Dr Andrew Rosenberg" <a.rosenberg@unsw.edu.au>
Subject: Australian Paedaitric Nephrology Group
Date: Mon, 16 Dec 1996 20:34:02 +1300
X-MSMail-Priority: Normal

Dear Dr Rosenberg

I became aware of your e-mail address form the MOPS handbook, and I am taking the liberty of writing to you following conversations I have had with Max Morris and William Wong.

I understand that you are the chairman of the Australian Paediatric Nephrology Group. I wrote earlier this year to Dr John Burke to enquire about the membership of this group. I did this having been circulated a statement via Dr Burke to the effect that all members of the International Pediatric Nephrology Association (IPNA) would hopefully be members of their local associations. I gather that the membership criteria were discussed at a recent meeting and I have had some informal feedback following that meeting.

I wish to make the following points:-

1. I am a General Paediatrician with special interests in Nephrology and Endocrinology, and I see a lot of children with renal disease, including a few with chronic renal failure and transplants.

2. I undertook 2 years of research (also renal clinics and on-call) and almost 1 year full-time as a Senior Registrar in Paediatric Nephrology at Guy's Hospital in London from 1987-1990.

3. I became a member of IPNA following a presentation by me at the Toronto scientific meeting.

4. I was recently awarded the degree of "Doctor of Medicine" through the University of Auckland for my thesis entitled "The Use of Low Molecular Weight Proteins in the Diagnosis of Renal Tubular Dysfunction in Children".

5. I am still publishing papers from my research in London and I have some new renal research beginning this year.

6. I have refereed 11 papers for "Pediatric Nephrology" over the last 5 years, since being in my current post in Invercargill.

7. New Zealand has only two "Paediatric Nephrologists", both of whom are in the same institution. Apart from dialysis and transplantation, they see only a small proportion of children with renal disease nationally.

8. I received personal invitations from both Sir Cyril Chantler and Martin Barratt to attend the next IPNA meeting in London when I was at the last meeting in Chile.

I have been told that only full-time Paediatric Nephrologists are invited to join your group. I have no desire to be the only member of a group of renal doctors who is not practising in a transplant unit, but I reacted with some disappointment to the information I received regarding the outcome of your meeting. New Zealand has a number of Paediatricians who provide renal services by way of a special interest, including George Abbott, who has published a number of papers in Nephrology. He has expressed an interest in the past in participating in some form of local continuing medical education forum in renal disease. In New Zealand, and in Australia, the Endocrinology group are very good at arranging meetings, and the national collective knowledge base is rising as a consequence of this. I would very much like to see a similar arrangement in Paediatric

Nephrology which might involve interested parties on both sides of the Tasman, especially since MOPS points need to be collected.

I would be interested in any comments you may have in response to this letter.

Yours sincerely,

Paul Tomlinson
Consultant Paediatrician

POSITION STATEMENT

THE USE OF SHORT ACTING NIFEDIPINE CAPSULES FOR HYPERTENSIVE EMERGENCIES IN CHILDREN

(C. Jones, A. Walker and A.R. Rosenberg on behalf of the Australian and New Zealand Paediatric Nephrology Association).

Introduction

The Australian Drug Evaluation Committee (ADEC) has resolved that Nifedipine capsules be withdrawn from the Australian market because recently published case reports have linked short acting calcium channel blockers, in particular Nifedipine, when used for the management of angina and myocardial ischaemia, to an increased risk of myocardial infarction. The members of the Australian and New Zealand Paediatric Nephrology Association (ANZPNA) have unanimously expressed support for the continued used of Nifedipine capsules in the treatment of severe hypertension in paediatric patients by Specialist Physicians.

This position statement summarises concerns regarding the use of Nifedipine for the treatment of hypertension, the effectiveness of Nifedipine in the acute treatment of hypertension in children, the safety of treatment in acute hypertension, and whether severe hypertension should be treated with rapidly acting anti-hypertensive agents.

Concerns regarding the use of Nifedipine in severe hypertension

The approved registered indication for the use of Nifedipine in Australia is the management of angina pectoris due to coronary heart disease. It has not been registered for use in hypertension, although its use in paediatric hypertension is widespread.

Grossman et. al.[1] recently reviewed nine reports describing adverse reactions in 15 patients (33 - 79 years of age) and in one foetus whose mother was given Nifedipine during pregnancy. Episodes of cerebral ischaemia, stroke, syncope, hypotension and myocardial infarction were described. However, as the authors themselves noted, these adverse effects "had been observed with other interventions that precipitously lower arterial pressure" and are not specific for the rapidly acting form of Nifedipine.

There are no randomised controlled trials of Nifedipine in paediatric hypertension. It is argued, therefore, that in view of the reported complications in adults, Nifedipine should not be used in children.

Effectiveness of Nifedipine in the acute treatment of hypertension

The published experience [2, 3] and the experience of members of ANZPNA has been that

Nifedipine is effective at lowering blood pressure. Indeed, despite their suggestion that Nifedipine not be used, Grossman et. al [1] have not claimed that it is ineffective.

Safety of using Nifedipine in the acute treatment of hypertension in children

Serious complications resulting from the use of Nifedipine have been described in adults[1]. However, these complications are attributable to sudden lowering of blood pressure and are not attributable to Nifedipine per se. In case reports concerning adults Nifedipine has been found to be safe [4-8]. Serious complications resulting from Nifedipine use in children have not been reported.

In a recent survey of 66 paediatric nephrologists (from the United States, Canada, Australia, South Africa, the Czech Republic, Germany and Turkey) 65 reported that they use Nifedipine capsules as the drug of choice for severe paediatric hypertension[9]. With the exception of one infant who developed mild, reversible evidence of hepatocellular injury, the only complications encountered were attributable to the lowering of blood pressure and not to Nifedipine itself. None encountered an irreversible complication associated with the use of Nifedipine.

The comparative safety of Nifedipine versus other anti-hypertensive treatments is a critical issue. No drug administered orally for the rapid lowering of blood pressure has an exactly predictable duration and extent of activity. Except for the continuous intravenous administration of sodium nitroprusside or intravenous labetalol by small boluses, the extent of the hypotensive response in the acute treatment of severe hypertension is uncontrollable. The use of sodium nitroprusside and labetalol in these ways demands an intensive level of care that can be provided by expert staff available in tertiary referral centres, but not in primary and secondary centres of paediatric care. It has to be understood that the goal of treatment in most situations is to lower blood pressure to prevent a hypertensive emergency from developing, rather than to treat an established case of malignant hypertension.

What are the indications for rapidly acting antihypertensive agents in children with asymptomatic severe hypertension?

The data to answer this question are not available. In the survey of paediatric nephrologists[9] 56 of the 66 nephrologists considered seizures the most likely complication in an untreated asymptomatic patient with severe acute hypertension, 3 considered stroke and 4 considered congestive heart failure the most likely complication. The members of ANZPNA believe that blood pressure should be lowered quickly when it is severely elevated in a patient who was previously healthy, e.g. in a patient with acute post streptococcal glomerulonephritis, or a patient who has multi-system disease of recent onset such as haemolytic uraemic syndrome or vasculitis. ANZPNA members also believe that the blood pressure of a child with renal failure needs rapid lowering when it is much higher than usual for that patient. For all but two of the paediatric nephrologists in the international survey, Nifedipine in the rapidly short acting form is currently the drug of choice in such situations[9].

Conclusion:

ANZPNA recognises the potential risks of rapid reduction of blood pressure while noting that these complications have been rarely, recorded in children. The retrospective analysis of complications of Nifedipine in adults are insufficient to recommend its withdrawal for the treatment of hypertension in children. Paediatric nephrologists world wide regard the use of Nifedipine in the rapid lowering of blood pressure as a major advance because of its safety, ease of administration and effectiveness. Indeed the most recent report of the National High Blood Pressure Education Program Working Group on Hypertension Control in Children and Adolescents[10] in the United States lists Nifedipine among the drugs recommended for the treatment of hypertensive emergencies.

Members of ANZPNA therefore support the continued use and availability of rapidly acting Nifedipine capsules for the treatment of hypertensive emergencies in children by Specialist Physicians.

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Bayer

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Dr Andrew Rosenberg
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No. of pages (including this page): 2

J Phone

Reference	Your Contact	Direct Tel.	Direct Fax	Date
RA.5899	David Tsui	(02) 9391-6148	(02) 9391-6107	20-Dec-96

Dear Andrew,

Re: ADEC Resolution on Adalat Capsules

I am sending you a copy of the ADEC resolution pertaining to ADEC's deliberation on Adalat capsules at their recent meeting.

As you can see from the resolution, having considered the position statements put foward by your association (and the Council of the Australasia Society for the Study of Hypertension), ADEC is of the view that there are still insufficient grounds for the continued availability of Adalat capsules in Australia.

Accordingly, we will cease the distribution of Adalat 5 mg capsules as of 1 May 1997.

Kind regards,

David Tsui

attach.

cc. JJH

AUSTRALIAN DRUG EVALUATION COMMITTEE

PO Box 100
WODEN ACT 2606
Telephone: (06) 289 7260
Telex: 62149 Fax: (06) 289 8103

All correspondence to be addressed to THE SECRETARY

In reply please quote:
File No: 96/21583
Clin:

The Medical Director
Bayer Australia LImited
PO Box 903
PYMBLE NSW 2073

Dear Sir/Madam

SUBJECT: NIFEDIPINE / ADALAT Capsules

At its meeting on 5-6 December 1996 the Australian Drug Evaluation Committee made the following recommendation to the Minister and the Secretary:

RESOLUTION NO 7129

THE ADEC HAS NOTED THE CORRESPONDENCE FROM BAYER AUSTRALIA LIMITED REGARDING THE COMPANY'S INTENTION TO DISCONTINUE THE MARKETING OF ADALAT CAPSULES (NIFEDIPINE - 5 MG) AS OF 1 MAY 1997. THIS DISCONTINUATION HAS RESULTED FROM A COMPANY DECISION NOT TO MAKE A SUBMISSION TO THE TGA FOR REGISTRATION OF THOSE CURRENTLY UNAPPROVED INDICATIONS REFERRED TO IN ADEC RES NO'S 5924 AND 5969.

THE POSITION STATEMENTS FROM THE AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION AND THE COUNCIL OF THE AUSTRALASIAN SOCIETY FOR THE STUDY OF HYPERTENSION IN PREGNANCY SUPPORTING THE CONTINUED USE AND AVAILABILITY OF NIFEDIPINE CAPSULES DID NOT PROVIDE SUFFICIENT GROUNDS FOR RECONSIDERATION OF ADEC RES NO 5857 WHICH HAD RECOMMENDED WITHDRAWAL OF THE CAPSULES FROM THE MARKET.

It is expected that this recommendation will be confirmed at the next meeting, on 6-7 February 1997

Yours faithfully

Beverley David
Secretary
Australian Drug Evaluation Committee
17 December 1996

December 30, 1996

Dr David Graham
Chairperson, Highly Specialised Drugs Working Party
Commonwealth Department of Health and Family Services
GPO Box 9848
Canberra
ACT 2601

Dear Dr Graham

On behalf of the Australia and New Zealand Paediatric Nephrology Association, I would like to request that cyclosporin for use in children with steroid dependent, frequently relapsing or steroid resistant nephrotic syndrome be made available under Section 100 of the Pharmaceutical Benefits Scheme.

Cyclosporin is already funded under Section 100 of the Pharmaceutical Benefits Scheme for organ or tissue transplant recipients, for severe psoriasis and severe active rheumatoid arthritis. Cyclosporin has been approved for use in nephrotic syndrome in children and in adults but to date has not been funded under Section 100 for this use. The use of cyclosporin in childhood nephrotic syndrome would satisfy the criteria for the selection of highly specialised drugs for S100 funding. Cyclosporin treatment is initiated and supervised by paediatric nephrologists for the long term outpatient management of a readily identified patient group. Cyclosporin is a highly specialised drug with a high unit cost. Relatively few children require this treatment. Currently only ten children with nephrotic syndrome, whose care is supervised by paediatric nephrologists at the New Children's Hospital, Westmead, receive cyclosporin.

Most children with the nephrotic syndrome go into remission when treated with corticosteriods. However approximately 30% of these children relapse when corticosteriods are ceased (frequent relapsers) or relapse while receiving daily or alternate day corticosteriods (steroid dependent). A high proportion of these children develop signficant steroid side effects, with growth retardation being the most serious of these. These children require alternative therapies to achieve and maintain prolonged remissions without serious steroid related side effects. Treatment with 8-12 weeks of cyclophosphamide or chlorambucil result in 40-60% of children with frequently relapsing or steriod dependent nephrotic syndrome remaining in remission for 2 years or more. However, where children subsequently relapse, second courses of

INTERNATIONAL PEDIATRIC NEPHROLOGY ASSOCIATION
COUNCIL MEETING - WASHINGTON DC
30 APRIL - 1 MAY, 1997

MAJOR AGENDA ITEMS:

Financial Report: There is both a European and American account. Present cash on deposit is $199,000.00. A payment of $138,000.00 for the Journal is to made in the near future.

Pediatriac Nephrology Journal: Dr R Chesney and Dr Michelle Broyer, who are now the new Editors, gave a report. The citation rate will increase if there are more original articles than case reports. Discussion took place concerning an increase in urological articles. There is a 10% royalty for the journals sold to institutions. A new agreement with Springer-Vrlag is required in 2002.

XI Congress - London 1998: Martin Barrett and Cyril Chantler gave a progress report. Corporate sponsorship is likely to be between £150,000.00 and £200,000.00. A major sponsor donates £15,000.00, and Sandoz has given £30,000.00. The conference should meet expenses with a sponsorship of £100,000.00 and 750 registrants paying approximately $600.00.

XI Congress 2001: Seattle, USA, has been selected after a vote for this meeting.

Congress 2004: Applications for this meeting may be made by Australia, Asia and Europe.

Secretary General Position: Professor Ira Griefer has held this position since 1983 and at this stage intends to retire in 2001. A committee is to be formed to make recommendations to Council as to how his successor is appointed. It is likely that the successor will have had a previous term on Council. Issues that would need to be discussed include job description, tenure of appointment and renewal.

Affiliation of Australian & New Zealand Paediatric Nephrology Association with IPNA:
A formal application had been made by the Australian and New Zealand Paediatric Nephrology Association in 1996 to affiliate with IPNA. After discussion a unanimous vote was taken for this Association to become an official Society of IPNA. There are now six official societies, - America, South America, Europe, Asia, Japan and Australia & New Zealand. Africa does not have a representative on Council and the possibility of having representatives from North Africa, Central Africa and South Africa was discussed.

Executive Committee of IPNA Council: Discussion took place as to whether two full Council Meetings a year was necessary with the added cost involved. It is likely that there will be one full Council Meeting a year and the second meeting will consist of an Executive Committee, and other members on special committees. It is likely that the Executive Committee will comprise the Secretary General, a Regional Secretary for each of the six affiliated regional societies, and the two Editors of Pediatric Nephrology.

Reports of Special Societies: Subsequent Council Meetings will now require a report from the Australian & New Zealand Paediatric Nephrology Association.

AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

MINUTES OF MEETING

AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

SYDNEY 11 OCTOBER, 1996

ATTENDANCE: A Rosenberg, P Roy, I Hewitt, G Kainer, A Walker, C Jones, E Hodson, K Jureidini, W Wong, M Morris, M Falk, C Crompton, J Burke

APOLOGIES: P Henning, H Powell, D McCredie, R Walker, L Johnstone, D Lewis, J Knight

SANDOZ: The chairman thanked Sandoz for their generosity in providing $6,000.00 for the travel costs associated with this Meeting.

MEMBERSHIP: Eligibility for membership of ANZPNA requires
1) that the applicants have substantial involvement with paediatric nephrology.
2) a proposer and seconder and
3) a vote by the membership.

Following extensive discussion about physicians who have/had significant involvement with paediatric nephrology it was decided that D Lines and R Bailey are to be approached as to their desire to join the Association. G Kainer agreed to prepare a membership application form.

TRAINEES IN PAEDIATRIC NEPHROLOGY: F Willis, J Craig, S Alexander, F Mackie, M Tilley

IPNA: J Burke (IPNA Representative) discussed major items from the recent IPNA Council Meeting.
1) The process of appointing the new editors for the Journal was discussed.
2) There was discussion as to whether Australia should make a representation in the future for the IPNA Scientific Meeting to be held in Australia. It was noted that the meeting in 2001 will be held in North America and it is likely that the meeting in 2004 will take place in

(PBAC) and the Australian and New Zealand Society for Nephrology (ANZSN).

DEXSAL ANTACID LIQUID:

C Jones reported that this preparation, which could be used as a phosphate binder, contains aluminium trisilicate as a suspending agent. It was decided that Reckitt & Coleman be asked to reformulate and develop this medication without aluminium trisilicate. C Jones undertook to discuss the matter with the Company.

CYCLOSPORIN:

It was noted that cyclosporin is not listed under Section 100 for children with steroid dependent and resistant nephrotic syndrome, although it is listed for several other conditions. It was unaminously moved that an application for listing of cyclosporin for children with the above forms of nephrotic syndrome be made under Section 100. E Hodson undertook to further look at this matter.

ANZDATA:

It was noted that R Walker and I Hewitt are members of an ANZSN Committee which analyses ANZDATA. It was agreed that, at a future meeting of ANZPNA in 1997, there should be a review of the paediatric component of ANZDATA.

PRIORITY TRANSPLANTATION FOR CHILDREN:

There was considerable discussion about whether children should receive any priority with regard to allocation of cadaveric kidneys. At present this is a State matter and there is wide variation in the methods of allocation of kidneys between States. It was noted that in Queensland, uniquely, children are given priority rating.

At the Dialysis and Transplant Workshop at the Blue Mountains in 1994 a recommendation had been passed that children receive priority. J Burke will make inquiry as regarding the fate of this recommendation.
A motion was then passed, unaminously, supporting the development of a priority system for allocation of cadaveric transplants to children. K Jureidini undertook to ask P Henning to prepare a Position Statement.

COLLABORATIVE RESEARCH:

At present no multicentre study is being carried out by ANZPNA. It was suggested that each Unit send a summary of their ongoing research studies to A Rosenberg for listing.

EDITORIAL COMMENT

1. Why have a Journal?

The Association is getting bigger, some members have not met each other, some are unable to get to our annual meeting, and we wish to do collaborative things. As an effective Association, we need to have a memory of the decisions and arguments that have been made and put forth respectively. As an active organisation we need to have a means of co-ordinating our activities.

2. Publication

Anything a member likes can be submitted for publication and, as long as it is not too long (a cost issue), it will be published. Please submit things by email (my email is on page 13) or disk (IMB or MAC) to help my secretary. I am happy to have documents that are printed on A4 paper photostated into the Journal.

3. Finance

The Association needs money for (i) incorporation costs, pending Paul Roy's work in this are, (ii) formation of a Web site page, pending Michael Falk's work, (iii) a hurdle for admission to the Association. We need a bank account for banking existing Association monies (present with Andrew Rosenberg at Sydney Children's Hospital), banking membership subscriptions, banking corporate donations and drawing money.

The Membership has not given their authorisation for any monies to be spent as yet. I propose to use the Journal to seek approval for the use of money where appropriate.

At this stage while the Assocation is unincorporated the monies of the Association will be managed in the following manner, and following incorporation, with the election of a Secretary/Treasurer, these arrangements may need to be changed. I have set up a business banking account with the Commonwealth Bank. The two signatories are Colin Jones and Rowan Walker and both are needed to withdraw funds. The current balance is $0 but the monies from Andrew Rosenberg's tenure as Chairman will be deposited. The Association does not have a tax file number and the bank will withdraw tax from interest payments at a rate of 49%. The bank charges an account maintenace fee of $5 per month. A charge of 30 cents is applied to transactions if more than 15 are used per month (nothing less than 15 which is what I would assume with our Association). Thus, with a balance of $3,000, an interest rate of around 2.5%, no transaction charges, the account will generate around $15 per year before tax. A quarterly report will be in the Journal.

Following incorporation and the election of a Secretary/Treasurer the mechanics of the account may change, formal auditing requirements would exist, I would plan to keep quarterly reporting of the balance and transactions, and, as Chairman I would approve all withdrawals of money.

4. Next Meeting

The Baxter Peritoneal Dialysis Conference next year will be at Royal Pines Resort, on the Gold Coast, from July 17-19. It would be possible for us to hold our meeting at the Resort on the 19th and to have another one day clinical meeting on the 20th. Baxter management has yet to finalise its budget for next year. Plans for the meeting and the clinical day cannot be finalised, in this context, until around November 1997.

5. Future Additions Of The Journal

The plans are at this stage for the next Journal to be the preceedings of the Paediatric End-Stage Failure Symposium held on July 21st 1997. This will be bound by Baxter.

Thereafter, Steven Garchow (Business Unit Manager, Renal Therapy, Baxter) has offered to take the Journal, bind it and distribute it. This would clearly cut down costs of distribution. I do not believe it would compromise what we could put in the Journal.

6. ANZPNA Representation On The Council Of ANZSN

Andrew Rosenberg thought this would be worth persuing. This needs to be approached with some tact to be successful as there could be a number of subgroupings of the ANZSN that may feel they need representation. The best way may be to obtain an invitation from the Council to be represented, rather than to actively seek representation (at lest in the first instance). I would be interested in member's ideas. In June 1996 (last list I have) four ANZPNA members were on 6 of 12 committees of the Council.

7. Sister Centres Working Party

Again, Andrew raised this with me. Gavan Becker and Michael Field have been working on sister centres with the aim of forming a working party. A paediatric representative on this would be worthwhile. I have written to Michael Field.

COLIN JONES
CHAIRMAN
ANZPNA

JOURNAL OF AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

VOLUME 1, NO. 2 JANZPNA, pages 25 - 27

9 September 1997

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ELECTION OF EXECUTIVE

The Minutes of the ANZPNA meeting on Sunday 20th July 1997 have been disputed. Instead of proposing a Chair, Deputy Chair and Treasurer/Secretary, the mover of the motion claimed the second sentence should read "it was proposed that the Executive consist of a Chair, a Secretary and Treasurer". In that case the Secretary would be the Chair in the Chair's absence.

In view of this error the nomination form (page 17) is also incorrectly drawn up.

To correct these misunderstandings a new motion has formally been proposed by Harley Powell, and seconded by Rowan Walker, consistent with the original motion proposed by John Knight and Michael Falk. A majority of votes for or against the motion will determine the nature of the Executive. If the new motion is passed then I will call for nominations for the positions of Secretary and Treasurer. Then a postal ballot for those positions will be held. Your vote for the amended motion should reach me by Friday 26th September 1997 in the envelope provided. I will count the votes with two other members of ANZPNA. If the motion is carried I would hope to have the call for nominations and then the election of the Executive complete by the end of October.

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22 October 1997

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CONTENTS 28

NIFEDIPINE

Previous References

JANZPNA 1:20
JANZPNA 1:4

Current Situation

The next five pages contain correspondence relating to Nifedipine including the ANZPNA position statement drawn up at the end of 1996.

As agreed at the July 1997 meeting, Paul Henning explored the possibility of importing Nifedipine for registered users. Following his work and discussions with him it appears the simplest way to proceed will be for Paul to complete and application under Section 19.5 of the TGA act to allow nominated specialists within his institution to prescribe Nifedipine using a written protocol. Paul will submit this application. If he is successful he will give us the application to modify for our own institutions and, with precedent on our side, we will hopefully be successful also. In that situation it would be up to each centre to arrange application for provincial centres within their State (New Zealand is not affected by this problem).

The possibility of orphan Australia taking over sponsorship of Nifedipine is another option. However, the process suggested by Alastair Young in his letter sounds bureaucratic and time consuming. If Paul's approach fails then I would be happy for another member to persue this or other strategy.

POSITION STATEMENT

THE USE OF SHORT ACTING NIFEDIPINE CAPSULES FOR HYPERTENSIVE EMERGENCIES IN CHILDREN

(C. Jones, A. Walker and A.R. Rosenberg on behalf of the Australian and New Zealand Paediatric Nephrology Association).

Introduction

The Australian Drug Evaluation Committee (ADEC) has resolved that Nifedipine capsules be withdrawn from the Australian market because recently published case reports have linked short acting calcium channel blockers, in particular Nifedipine, when used for the management of angina and myocardial ischaemia, to an increased risk of myocardial infarction. The members of the Australian and New Zealand Paediatric Nephrology Association (ANZPNA) have unanimously expressed support for the continued used of Nifedipine capsules in the treatment of severe hypertension in paediatric patients by Specialist Physicians.

This position statement summarises concerns regarding the use of Nifedipine for the treatment of hypertension, the effectiveness of Nifedipine in the acute treatment of hypertension in children, the safety of treatment in acute hypertension, and whether severe hypertension should be treated with rapidly acting anti-hypertensive agents.

Concerns regarding the use of Nifedipine in severe hypertension

The approved registered indication for the use of Nifedipine in Australia is the management of angina pectoris due to coronary heart disease. It has not been registered for use in hypertension, although its use in paediatric hypertension is widespread.

Grossman et. al.[1] recently reviewed nine reports describing adverse reactions in 15 patients (33 - 79 years of age) and in one foetus whose mother was given Nifedipine during pregnancy. Episodes of cerebral ischaemia, stroke, syncope, hypotension and myocardial infarction were described. However, as the authors themselves noted, these adverse effects "had been observed with other interventions that precipitously lower arterial pressure" and are not specific for the rapidly acting form of Nifedipine.

There are no randomised controlled trials of Nifedipine in paediatric hypertension. It is argued, therefore, that in view of the reported complications in adults, Nifedipine should not be used in children.

Effectiveness of Nifedipine in the acute treatment of hypertension

The published experience [2, 3] and the experience of members of ANZPNA has been that

Conclusion:

ANZPNA recognises the potential risks of rapid reduction of blood pressure while noting that these complications have been rarely, recorded in children. The retrospective analysis of complications of Nifedipine in adults are insufficient to recommend its withdrawal for the treatment of hypertension in children. Paediatric nephrologists world wide regard the use of Nifedipine in the rapid lowering of blood pressure as a major advance because of its safety, ease of administration and effectiveness. Indeed the most recent report of the National High Blood Pressure Education Program Working Group on Hypertension Control in Children and Adolescents[10] in the United States lists Nifedipine among the drugs recommended for the treatment of hypertensive emergencies.

Members of ANZPNA therefore support the continued use and availability of rapidly acting Nifedipine capsules for the treatment of hypertensive emergencies in children by Specialist Physicians.

Women's and Children's Hospital
ADELAIDE

72 King William Road
North Adelaide
South Australia 5006
Telephone (08) 8204 7000
Facsimile (08) 8204 7459

25th August, 1997

Dr Colin Jones
Department of NephrologRoyal Children's Hospital
Flemington Road Parkville 3052

Dear Colin,

re: ANZPNA MEETING 20/7/97

Thank you for your note of 31st July. I enclose the abstract for my case report presented at the meeting. With the respect to the Nifedipine issue, I have discovered that Bayer are continuing to make the capsules (Australia is the only country to ban them sofar). The company have had discussions with the TGA and it is clear that the latter will not view an SAS application favourably, but may be sympathetic to an application under section 19.5 of the TGA Act. This allows nominated specialists within an institution to prescibe an unregistered "off label" drug using a written protocol. The protocol would have to be submitted to the TGA with the application. The company would supply the drug in this arrangement and so we would avoid the need to become importers ourselves. I plan to write a draft protocol in the coming weeks and would be happy for you to circulate this to members for comment and modification as necessary. I should add that members would have to apply individually to the TGA for their own use of the drug, though I would be happy to test the water first.

Regards

Paul

Paul Henning (WCH)

- Nifedipine application under Paul to complete section 19.5 of TGA Act to allow

ORPHAN AUSTRALIA

YOUR AUSTRALASIAN LINK TO
orphan disease know how
orphan drug marketing
orphan drug r&d

TELEFAX

To: Dr Doug Brown
Of: Spinal Unit, Austin Hospital
No: 03 9496 3626
cc:
From: Alastair Young, Managing Director
Re: Nifedipine Capsules
Date: July 25th 1997 No of pages including this page: 2

Dear Dr Brown,

Thanks for your enquiry about our interest in Nifedipine.

As discussed, we are interested in considering the option of taking over the sponsorship of Nifedipine Capsules in Australia & New Zealand. To do this we would need the agreement and support of Bayer, the TGA and the specialist medical societies we discussed this morning.

We have worked with the TGA on several products and have a good on-going relationship. Recently we worked with Janssen-Cilag and the TGA on the process of taking over the sponsorship of Antabuse®. We are also working with the Gastroenterological Society to improve access to a couple of orphan products in their area of speciality.

We are happy to approach Bayer and the TGA about this product. However, our experience has shown us that the chances of success are improved if the specialist medical societies take the lead in suggesting the transfer of sponsorship with both the TGA and the relevant pharmaceutical company. Therefore, I suggest that you approach The Managing Director, Bayer Australia Ltd, Health Care Business Group, 875-893 Pacific Highway, Pymble, NSW 2073, Tel 02 9391 6000; Fax 02 9391 6107, and Dr Susan Alder, Director, Drug Safety & Evaluation Branch, Therapeutic Goods Administration, PO Box 100, Woden, ACT 2606, Tel 06 232 8100; Fax 06 232 8140. We would be happy to negotiate with both parties.

May I also suggest that you may wish to copy your letters to the TGA and Bayer to a representative of the other interested specialist medical societies, together with a copy of this fax.

For your information, I have attached a recent press release regarding a new program for orphan drugs in Australia. We have worked for nearly two years to have such a program introduced. There is to be an announcement on August 12th regarding the actual implementation plan. I will be at the official function in Canberra, which will also be attended by the Head of the Office of Orphan Drug Development at the FDA in the USA.

Please contact me if you have any questions or if I can be of further immediate assistance.

Kind regards,

Alastair Young

Orphan Australia Pty Ltd
A.C.N. 067 189 342
e-mail: orphan@netspace.net.au

Address:
12 Langmore Lane
Berwick, Victoria 3806
Australia

Telephone:
+61 3 9769 5744
Telefax:
+61 3 9769 5944

MONASH MEDICAL CENTRE

A hospital of the Southern Health Care Network

DW L/C

4 August 1997

Dr Amanda Walker
Unit Head
Paediatric Nephrology
Monash Medical Centre

Dear Mandy

Re: Discontinuation of Nifedipine Capsules by Bayer

To continue the saga of discontinuation of Nifedipine Capsules I have continued to try to find another supplier and I have been speaking with Alistair Young of Orphan Pharmaceuticals. He says he is willing to approach the TGA to request importation of Nifedipine Capsules as long as he has the support in his submission to TGA of appropriate medical consultants. He has had discussion with Dr Brown/Spinal Unit Austin/Repat as attached and with O&G consultants. You may like to contact him directly or via your Paediatric Nephrology Group. His address is 12 Langmore Lane, Berwick, 3806, Telephone 9769 5744, Fax 9769 5944.

I still have stock of Adalat 5mg Capsules Expiry date is September 1998, but because of the TGA withdrawal a single patient use request with referral to the Therapeutics Committee and SAS Category A form would be required. Patient consent would be required as for other non registered products.

Thank you

Regards

Liz Creber
Deputy Manager of Pharmaceutical Services

ANZPNA Constitution and Incorporation

Previous reference JANZPNA 1:3

Paul Roy agreed to draft an Articles of Association or Constitution for the Group. He also agreed to investigate and arrange Incorporation of the Group. I understand it will be easier to incorporate with a constitution, so this will be done first. I have asked Paul to aim for around February 1998.

Sister Centre's Working Party

Previous reference JANZPNA 1:24

Professor Michael Field (President) ANZSN asked me to join the Sister Centre's Working Party which had its initial meeting in Launceston at the Dialysis and Transplant Workshop. The idea of the Sister Centre's Working Party was discussed in the ANZSN newsletter and this meeting will basically deal with financial arrangements, possible programs and funded activities and a relationship to ISN programs.

Michael Field said around $500,000 from the profit of the ICN Sydney conference would be invested to provide $30-40,000 per year for support of sister centres. Sister centres would be supported if they were established under the ISN guide lines between Australia-New Zealand and Asia-Pacific. Details on how the money will be spent have yet to be organised. professor Gavin Becker will prepare a draft paper taking into account of range of ideas.

Web page for ANZPNA

Reference JANZPNA 1:7,10.4

Michael Falk is organising to set up a web site under the site of the RACP. This will not cost the Association. Michael plans to send a scheme of the web page and his proposed contents to me for distribution in the Journal.

Collaborative Research in Progress

1. VUR trial (see JANZPNA 1:39)

2. Growth Hormone Data in Chronic Renal Failure

   Dr Deborah Lewis and Dr Elisabeth Hodson are organising this and will be seeking details about patients from specific centres.

3. Results of Paediatric Transplantation in Australia

   Michael Falk and Rowan Walker are working on this.

Secretary and Treasurer

Only 1 nomination for secretary was received and none for treasurer (despite multiple indications of interest from members). Dr Lilian Johnstone has been elected secretary. ***STOP PRESS:*** Late nominations for treasurer were received following a reminder, and a ballot will be held.

PRIORITY TRANSPLANTATION
Reference JANZPNA 1:5,10,21

1. The ANZPNA meeting in July 1997 moved that the decision recommending children be given priority for renal transplantation reached at the Dialysis and Transplantation Workshop held in Leura in 1995 be distributed to various administrative bodies including the NH&MRC, the ANZSN, the TSANZ and the Dialysis and Transplantation Workshop. Unfortunately, the Dialysis and Transplantation Workshop has no memory (there are no proceedings or records made of recommendations). Thus there is no official recording of the recommendation passed.

2. It was stated at the ANZPNA meeting that the UN had a policy providing for priority treatment of children. I read the United Nations Charter contained in the publication "The State of the World's Children 1991" edited by James P Grant, Executive Director of United Nations Children's Fund (UNICEF) Oxford University Press, Oxford, UK, 1991. The convention on the Rights of the Child and the World Declaration on the survival, protection and development of children includes extensive references to children's health but contained no statement that children have priority for medical care in the presence of limited resources. The closest the convention comes in Article 23 and 24 where the rights of the child for primary health care services are acknowledged. Thus, I cannot find any information that the United Nations have recommended children having priority in the presence of limited medical resources.

3. The issue was discussed at the Interstate Organ Sharing Committee which includes Michael Falk and Rowan Walker as members and Graeme Russ as chairman. Michael Falk put forward the proposition that children be given preferential allocation for well matched kidneys. There were objections to this approach by some members of the Committee and the alternative, which we have discussed at our meeting, that children and adults receive a waiting for allocation for a kidney depending on the proportion of their life they have spent on the registry as an available recipient. The latter received a more favourable response from the Committee. The Committee felt that issue was one for each State.

4. The issue was discussed at the Dialysis and Transplant Workshop in Launceston in October. In a session chaired by A/Prof Rowan Walker, Dr Graeme Russ (Chairman of the Interstate Organ Sharing Committee) briefly addressed the issue. The meeting was asked whether there was support for priority allocation of kidneys to children. There was almost unanimous agreement for this. There was some discussion of the means by which priority allocation could take place but no firm agreement was reached. The two principle means of allocating kidneys that were discussed were:

1. That children who satisfied criteria of a certain age and duration on the dialysis waiting list be promoted to the top of the list for well matched grafts. It would be up to each State to work out the details of this mechanism.

2. That children and adults receive a weighting for allocation for a kidney depending on the proportion of their life they have spent of the waiting list as an available recipient.

I have asked Rowan Walker as chairman of that session to summarise the discussions and conclusion so that there is a document we can reference. This document would be sent to the TSANZ and the ANZSN. I have asked Dr Graeme Russ as Chairman of the Interstate Organ Sharing Committee to write to me acknowledging the discussion and the discussion within their Committee.

It would be up to each State's paediatric nephrologists to follow through on these recommendations.

At our next annual meeting I will prepare a proposal to be forwarded to the NH&MRC which could be asked to set a national standard.

MINUTES OF THE FIRST MEETING

OF THE

AUSTRALASIAN PAEDIATRIC NEPHROLOGY ASSOCIATION

Held in Toronto, Canada

on Tuesday, August 29th. 1989

Attendance: P. ROY, E. HODSON, A. ROSENBURG, M. MORRIS, H. POWELL, D. LEWIS, R. WALKER, K. JUREIDINI, P. HENNING, I. HEWITT, J. BURKE.

Apologies: D. McCREDIE, J. KNIGHT.

Title of Group: AUSTRALASIAN PAEDIATRIC NEPHROLOGY ASSOCIATION

Aims: Ensure a high standard of clinical management, teaching and research in Paediatric Nephrology.

Membership: A person is entitled to membership if a substantial amount of his or her work is involved in Paediatric Nephrology.

Election of Office Bearers: A Chairman and Vice-Chairman will be elected each two years. For the period 1989 - 1991 J. Burke is the Chairman and M. Morris is the Vice-Chairman.

Subscription: At this stage no subscription will be levied, but this will be kept under review as future needs arise.

Multi-Centre Trials: Dr. R. Hogg from Dallas, U.S.A. addressed the Meeting concerning South West American Paediatric Nephrology Group. Their group covers fifteen to twenty percent of the American population. Their collaborative studies are simply defined and approximately eighty to ninety percent of members wish to participate in a project. The studies should be potentially publishable. Greater interest may arise if the study involves a disease peculiar to that area. Pathologists are important in their studies. The group started with nine members and a separate day meeting is held with a National Meeting. Some money has been obtained from the Texas Kidney Foundation. The spirit in the group is important, and a separate dinner is held at each meeting.

Discussion then took place concerning the possibility of collaborative studies in Australia and New Zealand. All members are asked to consider projects that may be suitable, and then to send a protocol of the study to J. Burke in Brisbane who will then send a copy of the protocol to each member of the Association for their comments. If there is sufficient response for collaborative studies then a full-day meeting

will be held in Brisbane on Tuesday, March 13th., prior to the A.S.N. Meeting which is to be held in Brisbane from the 14th. to 16th. March, 1990. A dinner will be organised that night.

A.S.N. Registry:

Paul Roy brought to the attention of the Meeting that bone age and pubertal status were not being adequately entered on to the sheets for the Registry. All members agreed that this should be improved.

Future Meetings:

It is hoped that an Annual Meeting will be held at the A.S.N. or A.P.A. Meetings, possibly on an alternative basis. It is not envisaged that any Papers would be presented at any business meeting.

MINUTES OF AUSTRALASIAN PAEDIATRIC NEPHROLOGY ASSOCIATION

MEETING held in BRISBANE 15th MARCH 1990

ATTENDANCE:
P. ROY
A. ROSENBURG
K. JUREIDINI
I. HEWITT
J. BURKE
M. MC IVOR
G. KAINER

APOLOGIES:
D. MC CREDIE
J. KNIGHT
M. MORRIS
E. HODSON
R. WALKER

NEW MEMBERS:
M. MC IVOR
G. KAINER
N. THOMPSON

MULTI-CENTRE TRIAL:

Discussion took place concerning a national trial with subcutaneous erythropoietin. J. Burke is to draw up a protocol to be forwarded to all Members of the Association.

Points to be discussed:- Children to be included with chronic renal failure, peritoneal and haemodialysis with a haemoglobin 7.5 or less. The length of the trial would be 12 months, with a target haemoglobin between 9 - 11.

Is a bone marrow to measure iron stores necessary before commencement of erythropoietin! Studies will include P.T.H., aluminium, growth, bone age, and blood transfusion requirement. A funding for this study will be necessary and applications to NHMRC and AKF will be considered.

GROWTH HORMONE:

A discussion took place concerning growth hormone for short children with chronic renal failure. Dr. G. Kainer is to draw up recommendations for those children who may be helped with growth hormone. A national trial is not being recommended at the present time, as some Units have already commenced studies.

NATIONAL DATA BASE:

There will be obvious advantages in having a data base for paediatric kidney diseases. Discussion took place concerning computer discs, but as yet no final recommendation is being made.

FUTURE MEETING:

The next Meeting is planned for the ASN Meeting in Christchurch, in February 1991.

MINUTES OF AUSTRALASIAN PAEDIATRIC NEPHROLOGY ASSOCIATION MEETING HELD IN CHRISTCHURCH 28 FEBRUARY 1991

PRESENT: M Morris, P Roy, E Hodson, A Rosenberg, K Jureidini, P Hanning, I Hewitt, G Kainer, C Jones, J Burke

INATTENDANCE: M Falk, R Hogg, P Duwan.

The minutes of the previous meeting, 15 March 1990, were confirmed by P Roy and I Hewitt.

ERYTHROPOITIN TRIAL

The psychological tests require further clarification as the Wechsler test is only suitable for children between eight and sixteen years and it has been suggested that the Stanford Binet Intelligence Test be performed between two and eight years. It was suggested that more accurate memory and concentration tests were required for suitable analysis. Dr J Burke is to liaise with Ms J Stephens (psychologist) in Brisbane to draw up the psychological tests and circulate to all members. Ms Stephens will then be the co-ordinating psychologist and psychologists in other States can contact her if further information is required. Her address and telephone no will be stated in the circular.

STATISTICS

If a significant rise in the haemoglobin is to be estimated then approximately 20-30 cases will be required.

SITE OF INJECTION

There was a suggestion that the rate of absorption of erythropoietin could vary with the site of injection. Some children have already been commenced with the injection given in the thigh and others in the abdomen. It is to be left to the clinician to decide on the site of injection, but this should be recorded.

DATA COLLECTION

Elizabeth Hodson has agreed too act as a co-ordinator for the data. The data sheets have already been forwarded to members and the sheets will full information should be sent to Dr Hodson each three months. This data will then be computerised.

GROWTH HORMONE

A letter has been sent to the Australian Growth Hormone Committee asking that children with chronic renal failure be considered for medication when their height has fallen to the 25th percentile instead of below the 3rd percentile. The growth velocity will be less than 25% for bone age and the observation period would be a minimum of twelve months. This committee has approved this

.../2

recommendation and the request has now been forwarded to the PBA Committee. The Council of the Australian and New Zealand Nephrology Society has also approved this recommendation and Dr Paul Roy, who is the secretary of the Association will also be writing to the PBA Committee.

NATIONAL DATA BASE

Some Nephrology Units are using ICD9 to record their primary diagnosis of renal conditions. It was suggested that other units who are considering computerisation consider this data base. Paul Roy is to discuss this in detail at the next meeting in 1992.

IDIOPATHIC HYPERCALCIURIA

Elizabeth Hodson has circulated a protocol to look at the incidence of hypercalciuria presenting as haematuria. There was general agreement for co-operation to this study. Most of the investigations were part of the normal investigation for haematuria. It was considered that a fasting calcium creatinine ratio, afternoon calcium creatinine ratio and a 24 hour urine calcium (if toilet trained) should be included.

There was a shortage of time for discussion on management. All members are requested to write to Elizabeth Hodson stating their intention as to enter the study and also their views on potential management. Some members considered that no treatment may be required, while others discussed a low protein, low calcium, low sodium diet for a period.

DINNER

The next meeting is to be held in 1992, at the Australian and New Zealand Nephrology Association meeting in February. A two hour meeting on the first day following the AGM is planned. A dinner for members at a nearby restaurant will then follow. (Melbourne).

HOSPITAL ADDRESSES, PHONE NO AND FAX NO

J Burke is to write to all members for this information and then to send this information to all members.

MINUTES OF AUSTRALASIAN PAEDIATRIC NEPHROLOGY ASSOCIATION

MEETING - HELD IN MELBOURNE 25.2.92

PRESENT:

J. Knight, M. Falk, A. Rosenberg, G. Kainer, D. McCredie, H. Powell, C. Jones, M. McIvor, D. Lewis, P. Henning, M. Morris, J. Burke.

APOLOGIES:

N. Thomson, R. Walker, E. Hodson, K. Jureidini, P. Roy.

MINUTES OF PREVIOUS MEETING:

28.2.91 - were confirmed by A. Rosenberg and C. Jones.

ERYTHROPOIETIN TRIAL:

Twenty-four patients have now been entered into the trial and a decision was made not to enter any new patients. Elizabeth Hodson was to have assisted in the computerisation of the results, but now Janssen-Cilag have agreed to perform the computerisation. A photocopy of the present data on all patients should be sent to J. Burke and this will be forwarded to Janssen-Cilag. It would be easier to now start entering the data rather than wait until patients have finished the trial. J. Burke will then liaise with some of the Sydney members to discuss the data and write a draft paper. A paper could initially be prepared for "Paediatric Nephrology" and the Journal of Paediatrics and Child Health.

Some Melbourne members have been performing the aluminium levels only at each six months as the Government rebate is only at this period. Storage for Erythropoietin antibodies if not taken regularly during the trial should be taken at the end of the trial.

IDIOPATHIC HYPERCALCIURIA:

Elizabeth Hodson is preparing a standard report sheet for the data. Harley Powell said there may be some problems in giving no treatment for a period of 12 months.

GROWTH HORMONE:

A letter was received from Ms. R. Snow, Pharmacist-in-Charge, Growth Hormone Programme concerning our comments on the availability of growth hormone for children with renal disease.

She asked that the following questions be addressed:

1. Would it be reasonable to expect growth hormone treatment to induce catch-up growth in these children with chronic renal failure, or would it merely stop growth velocity falling away from the normal percentiles.

2. How might the committee assess the growth of these children post-renal transplant when steroid dosage is high? Would it be reasonable to continue growth hormone therapy until the dose of steroid drops to a relatively low maintenance level.

There was general agreement to the first question; that there was evidence for catch-up growth and that after two years of growth hormone the dosage may need to be increased.

There were different opinions expressed for the second question. Most members agreed that growth hormone could be ceased for 9-12 months following transplantation and then reassessment made. Some members expressed a strong view that if the child was below the third percentile and/or approaching puberty then the growth hormone should be continued. One member expressed the theoretical risk of rejection because of T-cell stimulation in vitro.

Paul Henning is to discuss with Alex Disney the present ANZDATA concerning growth following transplantation. J. Burke, G. Kainer and J. Knight are to compile a letter in reply to R. Snow.

PARTICIPATION OF SPORT FOR CHILDREN WITH MEDICAL CONDITIONS:

A letter was received from Dr. E. Welch concerning the participation of contact sport in patients with renal disorders. A list of medical conditions has been compiled based on information published by the Sports Medicine Committee of the American Academy of Paediatrics. The Social Issues Committee of The Royal Australasian College of Physicians is currently drafting a document and Dr. Welch is the representative of the Australian College of Paediatrics.

A number of renal conditions were listed, but did not include renal transplants. There was not general agreement among members concerning the risks of certain contact sports. In general support for the present document was given with the suggested inclusion on renal transplants.

RENAL RESOURCE CENTRE (SYDNEY DIALYSIS CENTRE):

A letter has been sent by Dr. John Mahony to individual members of our group concerning the relative lack of information for families regarding paediatric kidney disease. Elizabeth Hodson is to be approached as to whether she would serve on this committee, and Margo McIvor would also be willing to participate. Elizabeth would be asked to review the present education material available in Australia from individual hospitals and the Australian Kidney Foundation. There is material already available at the Royal Children's Hospital, Melbourne, and at the Children's Hospital, Adelaide. It is hoped that the Renal Resource Centre could then make material available for paediatric units in Australia and New Zealand.

PAEDIATRIC NEPHROLOGY TRAINEES:

Discussion took place as to the relationship of this committee to new trainees. There was general agreement that minutes of the meeting should not be forwarded to the trainees. However, they would be welcome to become new members after taking a position in Australia and New Zealand.

CHAIRMAN:

A call was made for a new Chairman to replace J. Burke, and he was asked to remain in Office for a further 12 months. Max Morris, who is at present Vice Chairman said that he would have difficulties in taking the position as Chairman. Andrew Rosenberg then accepted the position as Vice Chairman and will take the position of Chairman in 12 months.

IPNA:

Andrew Rosenberg is to inform IPNA of our Association and aims.

CHANGE OF NAME FOR AUSTRALASIAN PAEDIATRIC ASSOCIATION:

A motion was moved by Max Morris and seconded by G. Kainer, that the name of this Association be changed to "Australian and New Zealand Paediatric Nephrology Association". This was accepted by all members.

Writing paper with the official title is to be made for correspondence. Various bodies are to be informed of our Association - Australian Kidney Foundation, Australian College of Paediatrics, New Zealand Paediatric Society, The Royal Australian College of Physicians, Dialysis Society of Australia.

MEMBERSHIP FROM COUNTRIES OUTSIDE AUSTRALIA AND NEW ZEALAND:

Discussion took place as to whether Singapore members should be invited to join this Association. Members considered that there may be problems if Indonesian members were not included. There is no further action to be taken.

F.R.A.C.P. EXAMINATION QUESTIONS:

Andrew Rosenberg has again asked that members submit questions for the F.R.A.C.P. paper examination.

The half day meeting and the dinner that evening were considered to be successful, and is again planned for the afternoon preceding the Australian & New Zealand Society of Nephrology meeting in Hobart in February 1993. A short meeting will most likely be held for those members attending the Jerusalem meeting in September and will be chaired by Andrew Rosenberg.

J. BURKE
31.3.92

Dr. J. Burke
Renal Unit
(07) 240 5480

6 April 1993

MINUTES OF THE AUSTRALIAN & NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION MEETING - HELD IN HOBART 2.3.93.

Present:
K. Jureidini
E. Hodson
M. McIvor
M. Falk
J. Burke

In Attendance:
U. Wong.

Apologies:
A. Rosenberg
D. Lewis
I. Hewitt
P. Roy
J. Knight
R. Walker
P. Henning
C. Jones

Minutes of previous meeting on 25.2.93

Minutes were confirmed by M. McIvor.

Erythropoietin trial

Approximately 24 patients have now completed the trial. The data has been sent to Janssen-Cilag for computerisation. Dr. J. Adams was contacted one week prior to the meeting and entry of the data had not been commenced.

Idiopathic hypercalciuria

Elizabeth Hodson reported that there was a difficulty with the protocol in that three urines had to be collected for calcium/creatinine ratio. The protocol is to be re-written and it is only necessary for patients to be entered in this study if the calcium/creatinine ratio is elevated in two random urines. It is hoped that 200-300 children will enter the study.

Ken Jureidini reported that he had data on the calcium/creatinine ratio on a large number of normal kindergarten children in Adelaide, and this could possibly be used as control values. An amended protocol will be sent by Elizabeth Hodson to all members.

Henoch-Schonlein Purpura

Ken Jureidini discussed the possibility of a study looking at the use of steroids in the nephritis of Henoch-Schonlein Purpura. He will consider drawing up a protocol and forwarding a draft to members for comment.

Growth Hormone

A letter in reply to Ms R. Snow from our Association was tabled concerning our recommendations for growth hormone for children with renal disease. These guidelines were discussed at the 1992 meeting.

Renal Resource Centre

Elizabeth Hodson is a member of this group that is preparing literature for Australian patients with renal disease. At present pamphlets are being prepared by Margo McIvor on cystic disease, and nephrotic syndrome by J. Burke. A pamphlet has already been prepared in South Australia for children with end stage renal failure. It is intended that draft copies of these pamphlets be sent to all members for comment.

If there are any further topics on which a pamphlet should be prepared please contact Elizabeth Hodson.

IPNA

A letter was received from Andrew Rosenberg concerning the possibility of IPNA being held in Australia in 2001. The 1995 meeting is to be held in Chile, and in 1998 will be held in Europe.

There was some positive interest expressed by some members. Further discussion over the next two years is to continue. A program committee would need to be formed some years beforehand to obtain ideas from other meetings. Reservation was expressed concerning the work load of the present nephrologists and therefore limited time for the organisation of a meeting of this size. Another major problem is the organisation of a budget to run the meeting.

Single Paediatric Transplantation Service for Australia and New Zealand

A letter was received from Paul Roy concerning a single transplant unit for Australia and New Zealand. The letter had been circulated to all members prior to the meeting. Replies from C. Jones, H. Powell, R. Walker, and D. Lewis were tabled.

There was no general support for the proposal mainly for geographical reasons and disruption to famlies. It was considered that the results of transplantation in older children were satisfactory. However, each individual unit could consider transferring their very small children if full expertise was not available. Suggestions were made that paediatric transplantation should only be performed in centres with full paediatric facilities, including intensive care and nuclear medicine, and a single unit may be sufficient in each city.

Dialysis and Transplantation Workshop October 1993

A sympsoium "Kids Grow Up" will be held. Professor Glen Bowes (Adolescent Medicine from Melbourne) will be the invited speaker. Other speakers will include John Knight and an adult nephrologist. Issues to be discussed will possibly include a single transition clinic, growth, nutrition, puberty, sexuality, contraception, pregnancy, education, job opportunity, separation from a paediatric hospital. At the end of the symposium there should be some definite recommendations.

New Members

Charles Crompton is now working as a paediatric nephrologist in Perth. Mandy Johnson is a trainee at Monash.

JB. 6.4.93

AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION
C/- The Prince of Wales Children's Hospital
High Street, Randwick NSW 2031
Phone: (02) 399 4538
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1 August 1994

TO: MEMBERS OF ANZPNA

FROM: ANDREW R. ROSENBERG

RE: ANNUAL MEETING (SOMEWHAT DELAYED)

Agenda:

1. EPO Study - Janssen-Cilag has agreed to the payment of $6000 for the data to be computerised and analysed at the Department of Surgery at the Princess Alexandra Hospital. John Burke expects the data analysis to be completed in the next few weeks. Provided the data is satisfactory he intends to submit an abstract on behalf of ANZPNA to the IPNA meeting in Chile next year. He will send a copy of the abstract, for comment, to each member who submitted patients.

2. Hypercalciuria Study - Elisabeth Hodson reports very poor progress, despite the fact that we all agreed to take part in this study. The patient numbers are inadequate for any data analysis at this stage. Elisabeth would be very grateful if people would enter more patients and make the study viable.

3. ANZDATA Registry Committee - Rowan Walker reports that the Committee are genuinely sympathetic to whatever subdivision of "paediatric" age groups we would like. The intention at this stage is to run the 3 previous age groups:

   0-4 years
   5-9 years
   10-14 years

   and to run a subdivision of the 15-24 year old group which will consist of 15-19 years.

   Rowan and Ian Hewitt took the view that preserving the previous age group ranges would be useful for historical comparisons. Hopefully the addition of the 15-19 age group will satisfy our needs in the adolescent area.

   Rowan would also like members of the ANZPNA to give consideration to what aspect of the database they would like to see presented in the

"Paediatric Report" section of the next Registry report. Ideas could be forwarded to Alex Disney or to Rowan. The ANZDATA Registry are very anxious that they provide in the report the information that paediatricians actually want to see.

4. Care of children with renal failure - At a recent meeting of the Sydney Paediatric Nephrology Group it was agreed that the following recommendations should be put to members of ANZPNA for their approval:

> that the Association recommends that all children of school age or younger with chronic renal failure be cared for in consultation with a recognised paediatric nephrology service and
>
> that the Association recommends that all children school age or younger with endstage renal failure be cared for only by a recognised paediatric nephrology service.

If these recommendations are accepted by ANZPNA, I would seek your agreement to put them up for adoption by the Australian and New Zealand Society of Nephrology, the Australian College of Paediatrics, the Royal Australasian College of Physicians and the National Health and Medical Research Council.

5. Scientific Meeting of the Paediatric Research Society of Australia and the Australian College of Paediatrics - I would like to remind you that the next meeting is in Adelaide commencing May 9, 1995. Ulf Jodal from Sweden, well known to most of us, will be guest speaker. The PRSA is anxious to support subspecialty paediatric research groups and hope to have a specific theme at each annual meeting which would rotate through the subspecialties. Ulf's visit next year should lead to increased emphasis on nephrology.

6. IPNA Council Member - My term on IPNA Council will conclude next year. I would like members of ANZPNA to consider how my successor might be chosen. One suggestion is that I should call for nominations from members, followed by a postal vote. As our membership is small it should not be necessary for the person nominating to have a nominator and seconder.

I would like to receive formal support from all members for the recommendations in Item 4 and I would also seek your guidance as to how we should proceed to choose our next IPNA Council member.

Andrew R. Rosenberg

Proceedings

of

THE FIRST PAEDIATRIC END-STAGE RENAL FAILURE SYMPOSIUM

Melbourne, July 1997

Edited by:

COLIN L JONES

FOREWORD

The first meeting of the Australasian Paediatric Nephrology Association (forerunner of the Australian and New Zealand Paediatric Nephrology Association) was held in Toronto, Canada on 29 August 1989. The one aim of the Association on its inaugural meeting was to ensure a high standard of clinical management, teaching and research in paediatric nephrology. The Association has tried to fill the void between paediatrics and adult nephrology, a void that has grown with the advent of successful end-stage renal failure programs and methodologies for children with renal disease. By its nature, a small group, the Association has never been able to hold a clinically distinct meeting that gathered the nursing, dietary, social work, psychiatric, teaching, pharmacological and medical personnel to form the basis of nephrology programs for children together for a clinical meeting. This symposium, kindly and generously sponsored by Baxter Healthcare, has enabled the convening of such a meeting. In this, the proceedings of the symposium, are chapters based upon the lectures, short papers and peer group sessions. The scientific organising committee attempted to emphasise clinical aspects of paediatric nephrology in the developmental setting of paediatric nephrology and the multi-disciplinary care that is the background of the discipline. The collection of papers in this book provides stimulation to improve the care of children with renal disease and provide a continuing effort to achieve the aim of the Australasian Paediatric Nephrology Association at its inaugural meeting.

Colin L Jones
Melbourne, 1997.

THE FIRST PAEDIATRIC END-STAGE RENAL FAILURE SYMPOSIUM

Organising Committee

Ms Jane Goller, Royal Melbourne Hospital, Victoria
Dr Colin Jones, Royal Children's Hospital, Victoria
Ms Yogi Jeyakumar, Monash Medical Centre, Victoria
Ms Maree Nugent, Royal Children's Hospital, Victoria
Dr Amanda Walker, Monash Medical Centre, Victoria
A/Prof Rowan Walker, Royal Children's Hospital, Victoria

Conference Convenor

Ms Michell Duddington, Baxter Healthcare

Contributors

Prof B Adler, Royal Children's Hospital, Parkville, Victoria
Ms A Bigham, Department of Microbiology, Royal Children's Hospital, Parkville, Victoria
Dr J Burke, Princess Alexandra Hospital, Brisbane, Queensland
Dr C Crompton, Princess Margaret Hospital, Perth, Western Australia
Dr M Falk, Renal Physician, Princess Alexandra Hospital, Brisbane, Queensland
Ms J Farquhar, The New Children's Hospital, Westmead, New South Wales
Ms J Goller, Royal Melbourne Hospital, Parkville, Victoria
Dr I Hewitt, Princess Margaret Hospital, Perth, Western Australia
Dr E Hodson, The New Children's Hospital, Westmead, New South Wales
Ms Y Jeyakumar, Monash Medical Centre, Clayton, Victoria
Dr L Johnstone, Monash Medical Centre, Clayton, Victoria
Dr C Jones, Royal Children's Hospital, Parkville, Victoria
Dr K Juriedini, Women's & Children's Medical Centre, Adelaide, South Australia
Dr J Knight, The New Children's Hospital, Westmead, New South Wales
Ms K Latage, Social Worker, Monash Medical Centre, Clayton, Victoria
Ms J Lawton, Women's & Children's Medical Centre, Adelaide, South Australia
Mr J McCormack, Royal Children's Hospital, Parkville, Victoria
Ms M Nugent, Royal Children's Hospital, Parkville, Victoria
Ms D Palmer, Women's & Children's Medical Centre, Adelaide, South Australia
Dr H Powell, Royal Children's Hospital, Parkville, Victoria
Ms R Tulip, Royal Children's Hospital, Parkville, Victoria

Dr A Walker, Monash Medical Centre, Clayton, Victoria
A/Prof R Walker, Royal Children's Hospital, Parkville, Victoria

ACKNOWLEDGEMENTS

The kind and generous support of Baxter Healthcare enabled the Paediatric End-Stage Renal Failure Symposium to be held and the foresight, care and diligence of their staff, particularly Ms Michelle Duddington and Mr Steve Garchow are appreciated by the Organising Committee.

The efforts of Ms Kerrin Groves and Baxter Healthcare are acknowledged in the production of this book.

CONTENTS

1. GROWTH AND DEVELOPMENT : LESSONS FROM THE REGISTRY

ROWAN G. WALKER
The Royal Children's Hospital, Melbourne

INTRODUCTION

The unique collection of end stage renal failure (ESRF) data contained in the Australian and New Zealand Dialysis and Transplant Registry (ANZDATA Registry) is highly acclaimed and the ANZDATA Registry itself enjoys an enviable position amongst the organ registries around the world. There is no doubt that the Registry's success can be largely attributed to the cooperative nature under which the various ESRF services in Australia and New Zealand work. Because of this cooperation, it has been possible to compile a complete collection of data on all patients placed on ESRF care programs in Australia and New Zealand since the inception of such programs in Australia in the early 1960's - the completeness of the data is the feature of the ANZDATA Registry which makes it unique.

As is the experience elsewhere in the world, the ANZDATA Registry has demonstrated that the historical incidence of ESRF amongst children (patients < 15 years of age) in Australia and New Zealand remains relatively constant but low compared with adult populations (see Figure 1). It is has therefore been useful for paediatricians to examine the whole Australian and New Zealand experience in order to obtain meaningful information about children with ESRF disease. This has allowed paediatricians an opportunity to make more informed decisions about future management and improvement in the quality of ESRF care offered to children and importantly maximising every prospect for growth and development. It has therefore perhaps been even more essential that those clinicians involved in the paediatric ESRF services in Australia and New Zealand work cooperatively to maintain the high quality of the data collected by the ANZDATA Registry.

INCIDENCE OF END STAGE RENAL FAILURE IN CHILDREN

The overall incidence of ESRF amongst children (<15 years of age) indicates that approximately 1-2 paediatric patients per million of population present annually with end stage renal disease. The incidence of ESRF for the various paediatric age groups is shown in Figure 1.

For children <5 years of age, the overall annual incidence of ESRF is approximately 3 per million of population (age adjusted). The annual incidence of renal failure for all children 5-14 years of age is approximately 9 per million of population (age adjusted). A similar number of adolescents (aged 15 - 19 years), many of whom of course are not looked after in paediatric institutions present annually with ESRF (Figure 2)

Figure 1: Incidence of end-stage renal failure in paediatric patients (Australia 1983-1995)

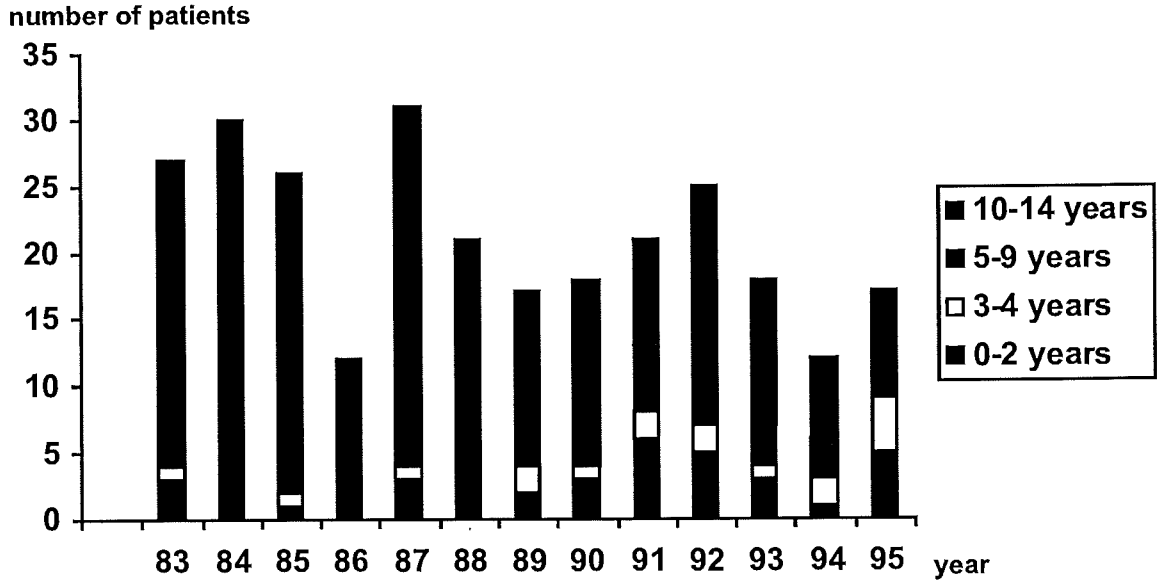
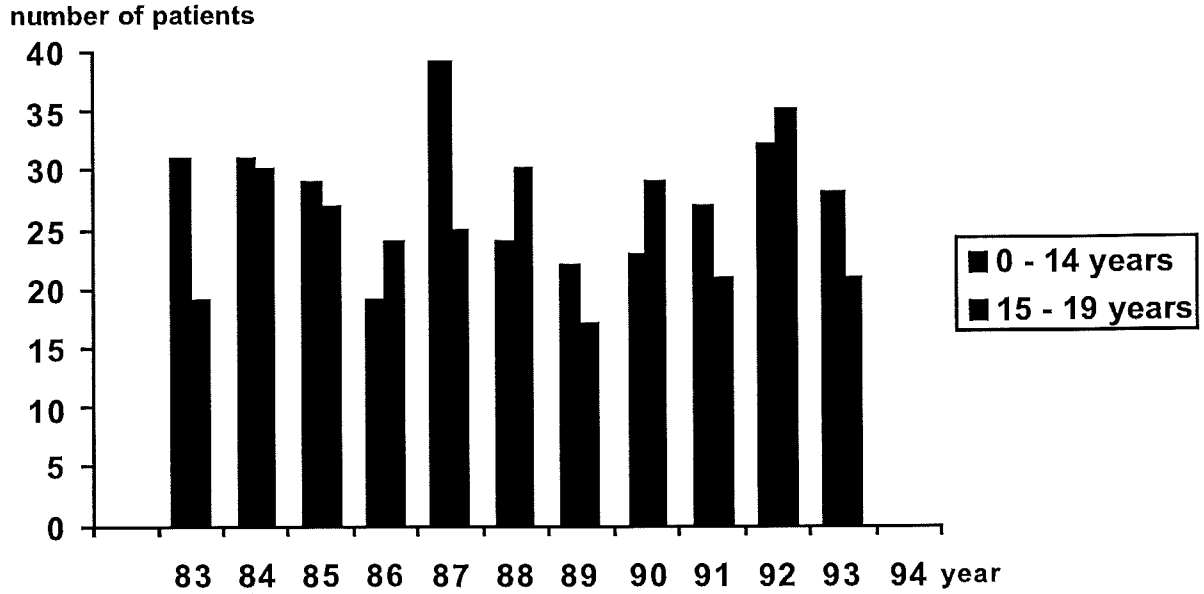


Figure 2: Incidence of end-stage renal failure in paediatric and adolescent patients (Australia & New Zealand 1983-1993)



In both Australia and New Zealand, the number of children <4 years of age accepted onto ESRF programs virtually doubled in the six inclusive years from 1989 to 1994 compared to the acceptance rate for this age group in the six years up to the end of 1988. Given that this trend may be maintained, there are potentially very significant implications for "growth and development" of these infants and very small children - very likely to be different to those issues of growth and development experienced in middle childhood and adolescence.

MODE OF TREATMENT

1. Mode of first treatment

Between 1983 and 1993, the mode of first treatment for children (<15 years of age) and adolescents (age 15 to 19 years) is shown in Figure 3 and Figure 4. Comparing the paediatric age group with the adolescent age group, the mode of dialysis chosen as the first line of therapy is clearly quite different. Of paediatric patients who received dialysis as first line therapy, 84% (Australia) and 77% (New Zealand) are commenced on some form of peritoneal dialysis. For the adolescent age group, only 34% (Australia) and 35% (New Zealand) are commenced on peritoneal dialysis. Of small children treated initially by dialysis, 91% (Australia) and 100% (New Zealand) are treated with some form of peritoneal dialysis. There is a preference for automated forms of peritoneal dialysis (IPD) as the treatment of first choice for infants and small children.

Figure 3: Mode of first treatment of end-stage renal failure in paediatric patients (Australia & New Zealand 1983-1993)

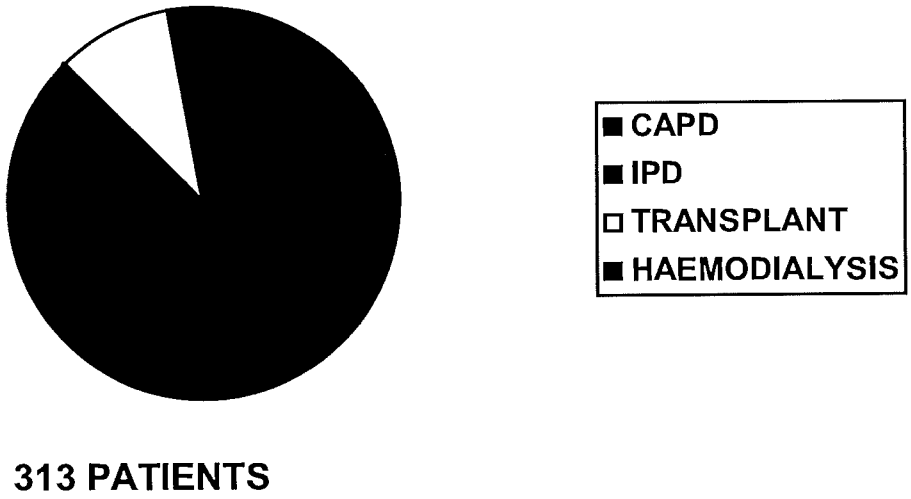
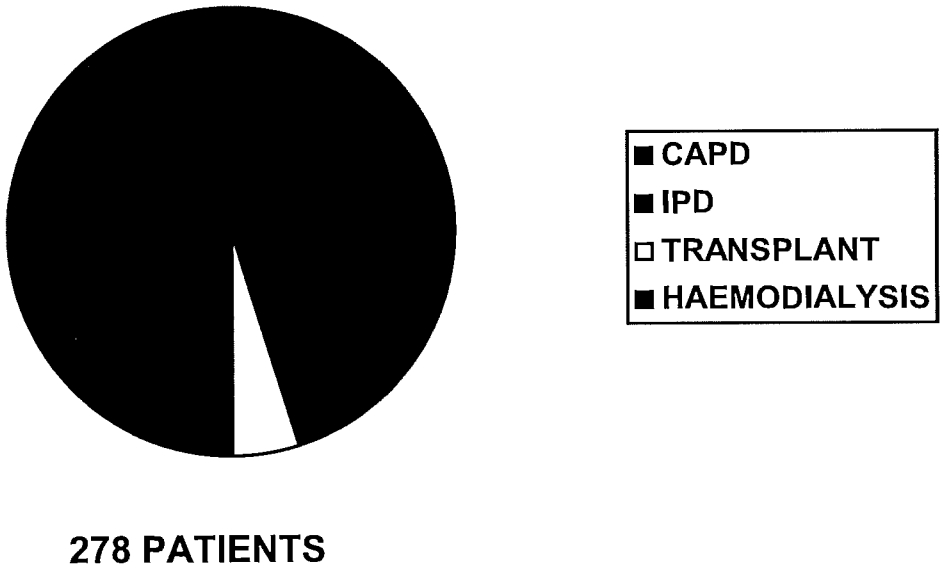


Figure 4: Mode of first treatment of end-stage renal failure in adolescent patients (Australia & New Zealand 1983-1993)



Increasingly, particularly in children, transplantation (live donor transplantation) prior to any form of dialysis therapy is being performed in a number of patients. There appears to be a clear desire, wherever possible, to limit the amount of time that paediatric patients spend on dialysis - transplantation is much preferred perhaps explaining at least in part, the high proportion of children receiving live-related compared to cadaveric transplants (Table 1). There is a perception, that the quality of life for a child with ESRF, and the prospects for growth and development are superior with a successful renal transplant compared to a life on regular dialysis.

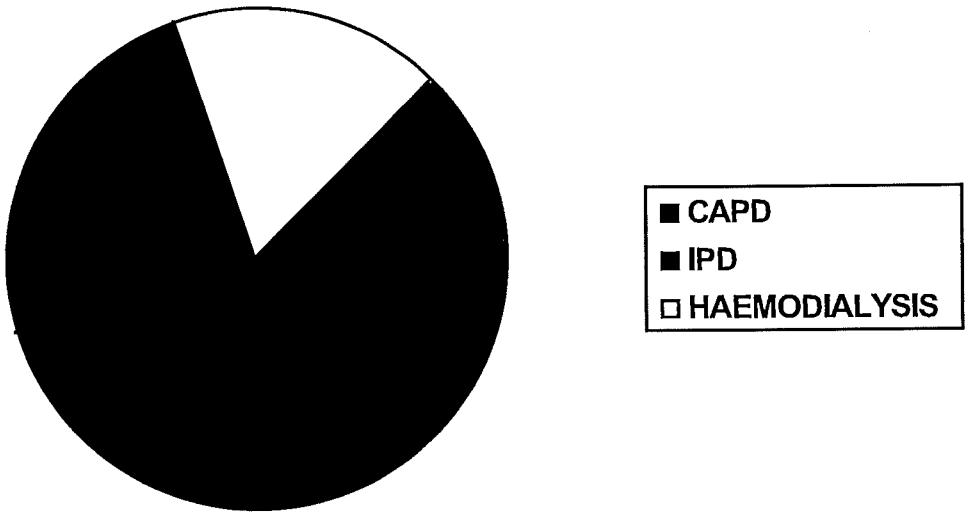
2. Mode of current treatment related to age

Analysis of the relatively small numbers of patients in both Australia and New Zealand, being treated with dialysis at the beginning of 1994 (<15 years of age, n=40: 15-19 years of age, n=54) shows a similar high proportion - 83% (Australia and New Zealand combined) of children being treated with peritoneal dialysis (see Figure 5) and indeed 40% of adolescents being treated with this form of dialysis. As at the 31st of March 1995, there were only five children (0-4 years of age) in Australia and 0 children in New Zealand receiving maintenance dialysis. As at the 31 st of March 1994, there were no children in New Zealand receiving haemodialysis. There were 85 children being followed in both countries < 15 years of age (70 of these were in Australia) with functioning renal transplants.

Table 1 : Primary transplants related to age and donor source (Australia 1983-1993)

AGE AT TRANSPLANT	CADAVER	LIVE DONOR	(% LIVE DONORS)
0 - 4 YEARS	16	14	(47%)
5 - 9 YEARS	28	23	(45%)
10 - 14 YEARS	60	54	(47%)
15 - 19 YEARS	130	51	(28%)
20 - 55 YEARS	2552	337	(12%)
56 + YEARS	720	24	(3%)

Figure 5: Mode of current dialysis treatment of paediatric patients (Australia & New Zealand : 31st March 1994)



40 PATIENTS

RENAL TRANSPLANTATION

In the area of transplantation, there are salutary lessons to be learned from the early experience (1963 to 1982) prior to the introduction of cyclosporin A. Dramatic improvement in patients and grafts survival has occurred in most age groups since the introduction of cyclosporin (1983 to 1995). The early experience in renal transplantation, particularly in very small children was characterised by a number of technical difficulties that have largely been overcome. We are now seeing quite outstanding results in paediatric patients receiving allografts (both living related and cadaveric) (Table 2 and Figure 6). The most striking improvement is seen in the graft outcome of very young children where since 1983 there have been no patients die and only one graft loss in the living related recipient group. By contrast, adolescents have experienced no significant improvement in graft outcome (note particularly cadaveric renal transplantation) in the cyclosporin era (Figure 7).

Table 2: Primary graft (%) survival in patients < 15 years of age analysed by era of transplantation (Australia 1963 - 1995)

		1 YEAR	3 YEAR	5 YEAR	10 YEAR
CADAVERIC	1963 - 1982	65	41	36	23
	1983 - 1995	80	70	61	40
LIVE DONOR	1963 - 1982	84	70	59	43
	1983 - 1995	95	85	80	63

Figure 6 : Primary allograft survival related to era of transplantation Paediatric patients < 4 years of age (Australia 1963-1994)

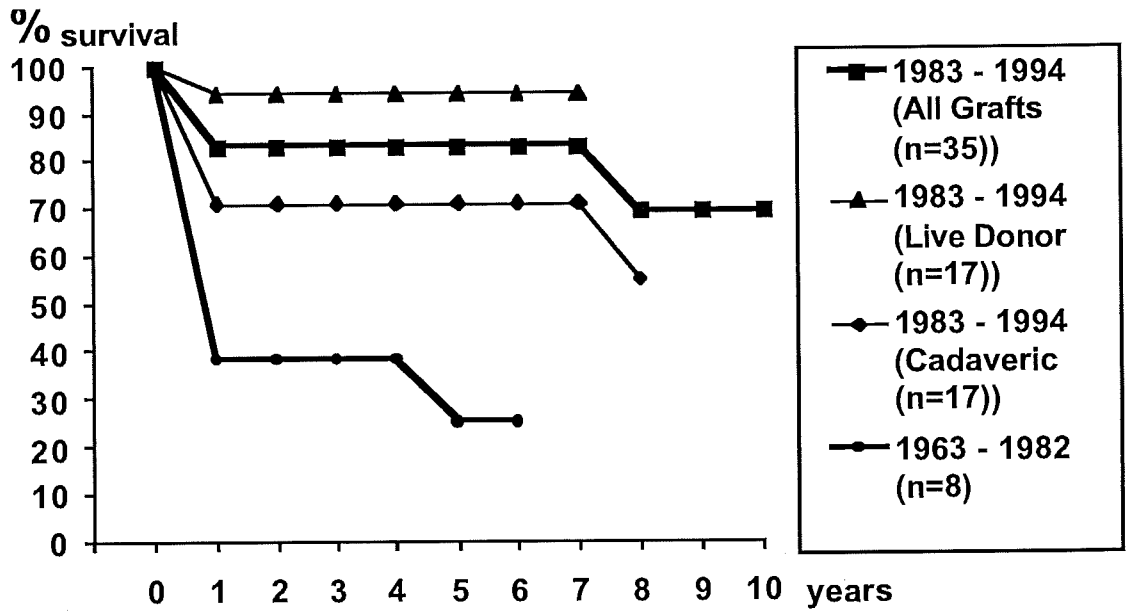
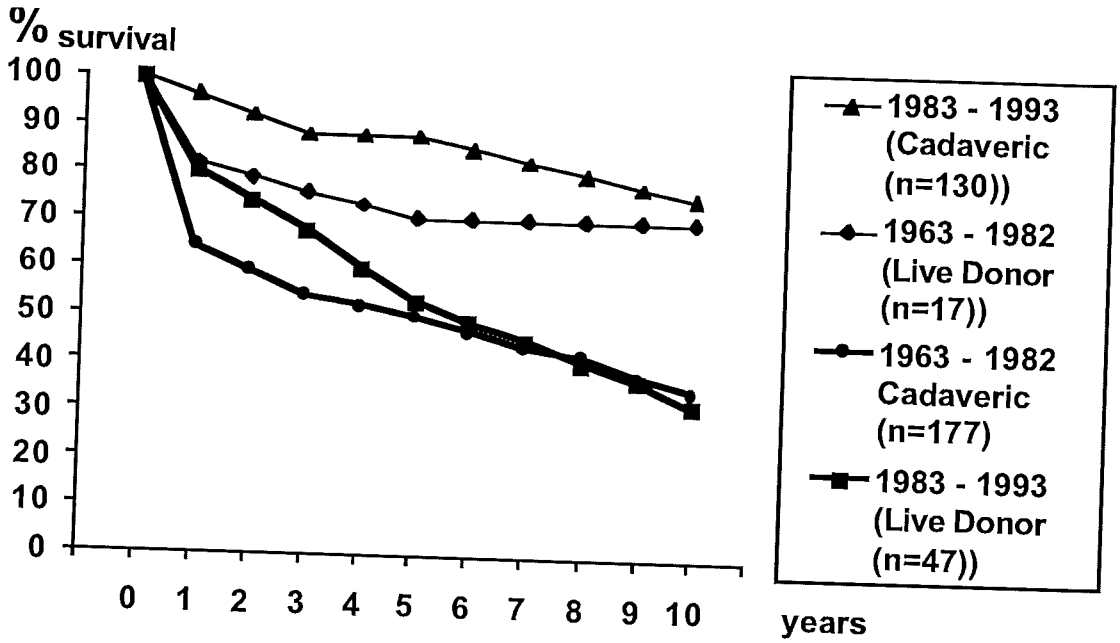


Figure 7 : Primary allograft survival related to era of transplantation Adolescent patients (Australia 1963-1993)



This is a probably a potent reminder of the need to focus on all aspects of our patients' care including dealing with the enormous difficulties of compliance - a particular problem amongst teenagers and young adults. An ANDATA Registry analysis of the causes of graft loss, analysed by age of transplants, shows that at only **2.6%** of children (<15 years of age) but as many as **10%** of adolescents (aged 15-19 years) have ***'non-compliance'*** recorded as the cause of the graft loss. It seems likely that these figures represent the "minimum" as doubtless amongst the many cases of ***'chronic rejection recorded'*** - there are a considerable number where the graft loss is likely to be due at least in part to non-compliance.

GROWTH

The issue of achieving satisfactory growth in paediatric patients with renal impairment both prior to the commencement of dialysis, whilst on dialysis and post renal transplant, remains of critical importance to the paediatric nephrologist. Recombinant human Growth Hormone (rHGH) has provided a major opportunity to substantially alter the growth potential of children with renal impairment at all stages of pre-ESRF and ESRF (dialysis and post-renal transplantation). This of course does not diminish the importance of other factors such as optimal nutrition, corticosteroid effects and preservation of renal function (the latter 2 being important in the post transplant setting).

Table 3 shows not surprisingly that the mean height-SDS (SDS is defined by the formula

$$\frac{\text{Actual height - Mean height for Age}}{\text{Standard deviation for that Age}}$$

for Australian children on rHGH is lower than for children not on rHGH. This almost certainly relates, at least in part, to strict Health Department qualifying criteria for the use of rHGH.

Table 3: Height standard deviation scores for children 2 to 18 years of age and use of growth hormone at any time

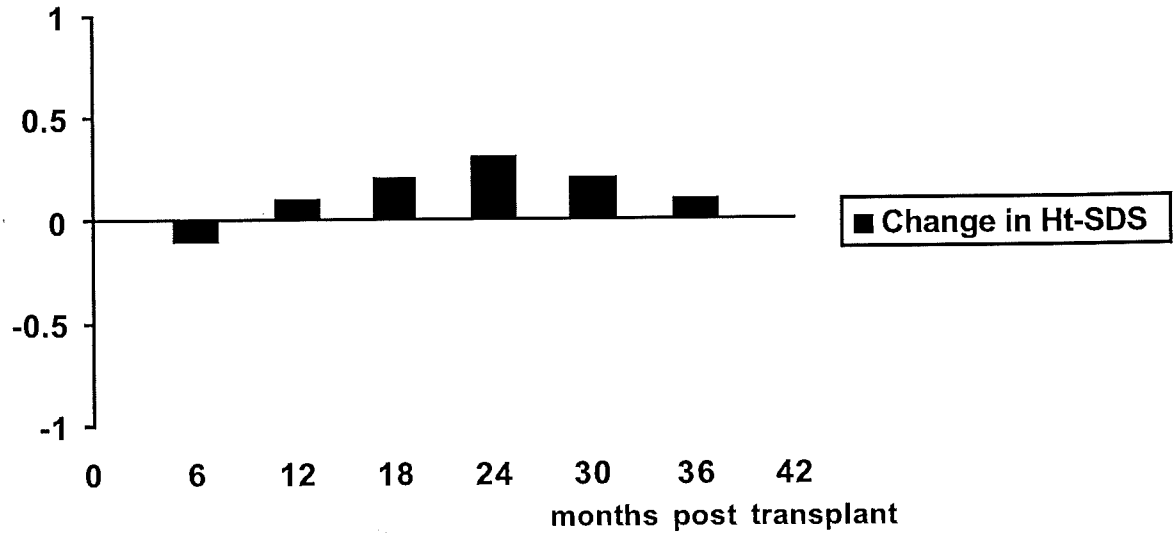
rHGH use	TREATMENT	MEAN SDS	MINIMUM SDS	MAXIMUM SDS
rHGH	DIALYSIS (n=10)	-2.2	-3.9	-0.3
	TRANSPLANT (n=15)	-2.6	-4.8	-0.9
No rHGH	DIALYSIS (n=43)	-1.7	-5.1	+1.3
	TRANSPLANT (n=96)	-1.7	-7.2	+2.1
TOTAL	(n=164)	-1.8	-7.2	+2.1

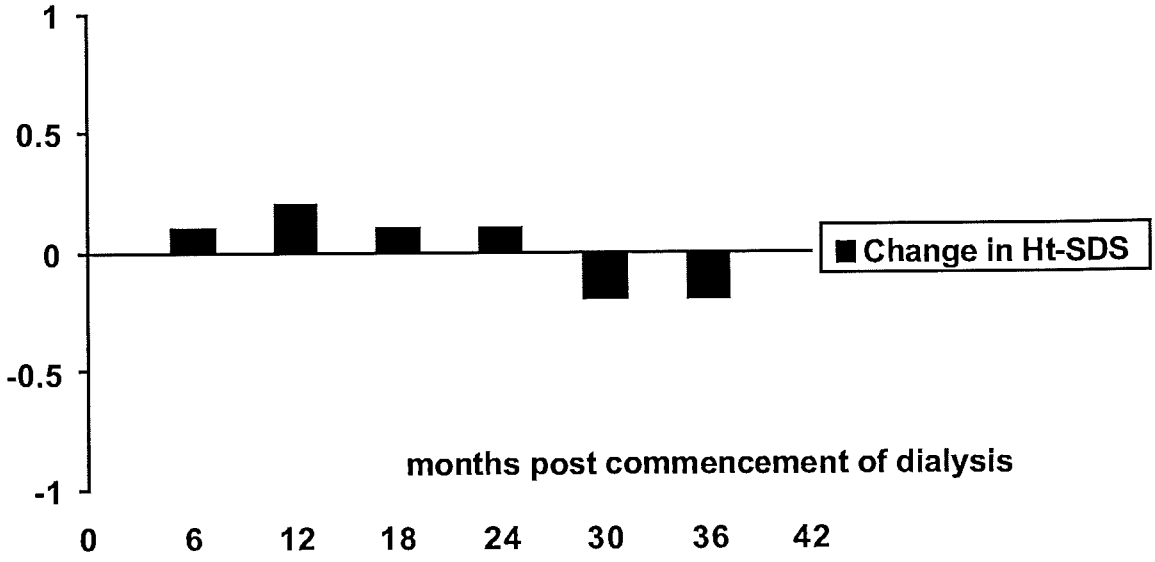
Observations both after commencement of dialysis and for children with renal transplants shows that the median SDS over time is remarkably stable. This indicates that the '***catch up***' growth is not a prominent feature. The children are however maintaining (on average) normal growth velocities. There is no clear indication from the ANZDATA Registry that rHGH is influencing catch up growth. However the number of children in whom rHGH has been used and the data adequately collected remains relatively small.

In general, growth velocities appear to be well maintained post transplant. Perhaps there is a very slight suggestion that a very small improvement in median height SDS at 18 and 24 months (a mean change in the median height SDS of +0.2 to +0.3 has occurred at these intervals for more than 130 observations) irrespective of whether the patients were taking rHGH. However, marked catchup growth is certainly not obvious. The possible benefits of rHGH may be better studied in the subsequent growth of a small selected cohort of individuals in whom very poor pretreatment growth was a feature prior to the introduction of the rHGH (Figure 8)

There seems to be a general impression that growth is being well maintained in dialysis/transplant patients but substantive catchup growth of the whole population is difficult to detect.

Figure 8: Changes in height standard deviation scores of 162 paediatric patients (aged 2 - 18 years) following renal transplantation (upper panel) and 155 paediatric patients after commencement of dialysis (lower panel)





REHABILITATION

The following Tables (Tables 5 and 6) show the Rehabilitation Status of children and adolescents with ESRF on maintenance dialysis or with a functioning renal transplant. Table 5 compares the survey results of 1988 with 1994 for children of school age in Australia and New Zealand and Table 6 is the first survey of its type for adolescents in both countries.

Table 5 & Table 6: Rehabilitation status of children (school - age) and adolescents (Australia and New Zealand 1988 - 1994)

TABLE 5

STATUS	MARCH 1988		MARCH 1994	
	n	%	n	%
SCHOOL (AGE APPROPRIATE)	129	72	90	72
SCHOOL (DIALYSIS LIMITED)	5	3	1	1
SCHOOL (AGE BELOW)	23	13	6	5
SCHOOL (PHYSICALLY HANDICAPPED)	3	2	2	2
SCHOOL (DEVELOPMENTALLY HANDICAPPED)	6	3	2	2
MEDICALLY UNFIT	2	1	2	2
PRE-SCHOOL	10	6	22	17

TABLE 6

STATUS	MARCH 1994	
	n	%
WORK (FULL TIME)	29	39
WORK (PART-TIME)	15	20
ABLE TO WORK (NO JOB)	15	20
ABLE TO WORK (DIALYSIS LIMITED)	3	4
ABLE TO WORK (DISINCLINED)	11	15
MEDICALLY UNFIT	2	2

Perhaps the most important observation from these data is the fact that the rehabilitation status of paediatric patients has tended to improve since 1988. The current analysis indicates that 87% of school children (Australia = 89%; New Zealand = 80%) are attending school in a class appropriate for age. Disappointingly, the adolescents who are not attending school, are only finding employment (either full-time or part-time) at a rate of 59% (Australia) or 55% (New Zealand) - a statistic not helped by high unemployment rates for youth in both countries.

CONCLUDING REMARKS

It is critical in a period where cadaveric renal transplantation is increasingly difficult to achieve (due to relative shortages of suitable donors) that a great deal of attention is paid to the details of dialysis care thus ensuring adequate nutrition and providing the best prospects for growth and development for children with ESRF. The advent of rHGH for the treatment of growth retardation associated with chronic renal impairment and for recombinant human Erythropoietin (for the treatment of anaemia of chronic renal failure) also has the potential to make a very significant impact on the growth and development and self esteem of young patients with ESRF.

The prospects for a favourable outcome following renal transplantation have clearly improved for most paediatric age-groups - virtually all the technical and most of the immunological problems of this procedure in the paediatric setting have been solved. Thus many more children will progress to adulthood with a functioning transplant. It therefore will become mandatory that increasing focus be placed on assessments of intellectual capabilities, growth and psycho-social development so that these young patients are appropriately equipped for the future that lies ahead of them.

There is no doubt that ANZDATA Registry will continue to give us an excellent opportunity to study many of these things. It is an enviable and irreplaceable resource that we should continue to nourish and expand with the aim of using the data to enhance our capabilities in caring for these young patients.

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2. DIETARY MANAGEMENT OF CHRONIC RENAL FAILURE

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Following animal data suggesting that excess dietary protein and phosphate accelerate deterioration of severe chronic renal failure (CRF), we performed a five year study of ten children with CRF who had been on moderate protein and phosphate restriction for two years. The alterations in management during the study period included normalisation of parathyroid hormone (PTH) levels and further restrictions of protein intake. Compared with the control period, there was significant improvement of growth, control of PTH, rate of deterioration of renal function, lipids and wellbeing.

Subsequently we have derived three diets for children with CRF. Those with renal function <33% are managed with strict phosphate and protein reduction. Those 33%-66% have moderate restrictions and those >66% are advised how to avoid excesses of protein and phosphate. All groups are advised to maintain adequate energy intake, with supplements often required and tube feeding sometimes indicated.

3. RECOMBINANT HUMAN GROWTH HORMONE USE IN CHILDREN WITH RENAL DISEASE

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Recombinant human growth hormone (rhGH) has been used for the last decade to treat growth failure associated with renal disease. Many studies report satisfactory short term improvement in growth velocity, but long term data are lacking, particularly with respect to final adult height.

The ANZDATA Registry has included a full analysis of growth and the effects of human growth hormone in its annual report since 1995. However data on the use of rhGH has been collected for new patients since 1991. The 1996 report indicates that although growth velocity is maintained in children treated with rhGH, catch-up growth is not regularly observed. However interpretation of ANZDATA is limited by incomplete data sets on individual patients, and small numbers of patients with complete data. There is an obvious need for ongoing accurate and complete data collection.

The impact on linear growth of the child with renal disease on linear growth can be assessed by reviewing the final adult height. A report from the EDTA last decade assessed final adult height in 276 young adults, 21 years or older, who had commenced dialysis before 15 years of age. 50% had reached a final adult height of less than the 3rd centile. It is on a background of such data that short term studies on the use of rhGH appeared. A recent study by Richard Fine et al (Kidney Int 49:781-785,1996) is one of only a few studies reporting five year treatment data. The report relates to the treatment arm of a multi centre, randomised, placebo controlled study looking at growth hormone treatment for five years in a group of 20 children with chronic renal insufficiency. The mean height SDS score increased from -.26 at base line to -0.7 after five years of treatment, with the maximum growth velocity being reported in the first year, with a mean of 12.2 + -2.8cms per year.

Reviewing available ANZDATA on the use of rhGH in Australian and New Zealand children, a somewhat less dramatic response in the clinical, non-study setting. Catch-up growth was not a prominent feature, with the median height SDS being relatively steady over time, with children maintaining relatively normal growth velocities.

A source of potentially more useful and complete data is the OZGROW Data Base which is an Australia wide data collection for all children treated with growth hormone. This data base is located in the New Children's Hospital, Westmead and has complete data sets on all patients, however there is no regular reporting or analysis of data. Data from West Australian children treated with rhGH between 1989 and 1996. There were 16 patients treated in that time, 12 male and four female, ranging in age from 2 - 16.7 years. Six had renal transplants with good function, four were on dialysis, five chronic renal failure with a FGR of 40 - 60 mls per minute with 1.73m squared and one had normal renal function (distal renal tubular acidosis). The height SDS at base line ranged from -5.74 to -1.71. The mean change in height SDS was 0.7. The height SDS improved in six, remained the same in six, and deteriorated in four. The best response was an average of 7cms per year for four years in one child. The cost of rhGH treatment for this group of patients was approximately $1,000,000.00.

In conclusion, it appears that better long term data are needed to assess the response to rhGH in the clinical non-study setting. It is planned to analyse the Australia wide data on rhGH use, using the OZGROW Data Base.

4. SETTING SOLUTE TARGETS FOR DIALYSIS IN CHILDREN: THE ROLE OF UREA KINETIC MODELLING

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Introduction

Early dialysis prescription was based on subjective data, which postulated that thrice weekly haemodialysis was better than twice weekly because patients reported that they felt better (Acciardo, 1994). There was no consensus as to how much dialysis provided optimal well being and prevented uraemic complications (Heimburger, 1996). Indeed dialysis schedules have been largely based on intuition, trial and error, and with the exception of paediatrics, there has been little regard for individual differences in patient size, age, metabolic rate, or nutritional status (Farrell, 1983). Even so, paediatric dialysis prescription has concentrated on the technical aspects of performing procedures on small patients, such as achieving and maintaining vascular and peritoneal access, and modifying equipment to accommodate small circulating blood volumes and body surface areas (Alexander, 1989). Over the past decade, advancements in dialysis equipment, infection control, and treatment survival have occurred, and as a result, adult renal units have redirected their attention towards assessment of dialysis adequacy and optimal dialysis prescription.

The Effect of Too Little Dialysis

The adverse effects of underdialysis on nutritional status, overall well being, and survival rates have been well documented by adult renal units. Burkart (1993) reported that inadequate dialysis dose contributed to the high mortality rates frequently observed in ESRF patients. This assertion has been reflected by a number of careful multicentre studies such as the American National Co-operative Dialysis Study (NCDS), which reported a direct correlation between urea kinetics and morbidity of dialysis patients (Van Holder, Smit, Hsu, Vopleare & Ringoir, 1994). Increased awareness of the importance of dialysis adequacy has culminated in the development of quantitative indicators of dialysis prescription. Thus, the indices urea kinetic modelling and creatinine clearance calculations provide an objective way to measure dialysis efficiency (Mendley, Umans, & Majkowski, 1993). Whilst it is recognised that paediatric dialysis prescription warrants a similar precise approach to that now afforded adult patients, relatively few studies of paediatric dialysis adequacy have been conducted.

Urea Kinetic Modelling

Dialysis adequacy has become a key issue of the 1990's in respect to patient care and quality assurance. Dialysis kinetic modelling began in the 1970's when Gotch & Sargent introduced kinetic equations to quantify haemodialysis efficiency. They stated that in a steady state, the concentration of urea in the body results from the balance between the generation or input rate and its removal rate. This principle was applied to dialysis urea removal in 1985 when Gotch & Sargent presented their formula KT/V (K = urea clearance of the dialysis membrane, T = time and V = volume of urea distribution which is equivalent to the patient's total body water content). It is only recently however, that dialysis adequacy testing has been seriously considered important in the overall dialysis prescription. Original models speculated uraemic toxins to be the intermediate molecular weight metabolites (Acchiardo, 1994). this hypothesis was founded on observations of a crippling neuropathy which developed in haemodialysis patients despite control of measurable metabolic abnormalities (Harmon & Grupe, 1984). The supposition was not proven, leaving individual uraemic toxins evasive, and the pathophysiology of uraemic manifestations not entirely understood. Consequently, rather than measure middle molecule clearance, urea was adopted as a marker of dialysis adequacy because it is the most abundant organic solute to accumulate in renal failure (Depner, 1994). Urea is a readily diffusible molecule, evenly dissolved in total body water, and therefore relatively easy to measure (Vanholder, et al, 1994). Whilst it is acknowledged that accumulation of both large and small molecules are responsible for the toxic effects of the uraemic syndrome, it is now widely accepted that small molecular weight toxins are the most significant. Hence, the basis of dialysis prescription in the 1990's is small toxin removal, represented by urea kinetic modelling

which quantifies protein intake and excretion (Daugirdas, 1994). Target KT/V values of between 1.2 to 1.5 per dialysis session have been set for adult haemodialysis patients. These values are assumed to be equivalent to 10% of the normal glomerular filtration rate.

Urea clearance per total body water (Kt/V) is widely considered the best method of haemodialysis adequacy assessment, however, the optimal technique for peritoneal dialysis assessment is less definite, with both weekly urea clearance, and weekly creatinine clearance per 1.73 m^2 body surface area suggested standards for peritoneal adequacy evaluation (Diaz-Buxo, 1994). Recent clearance targets for peritoneal patients proposed by the Canada-USA (CANUSA) Ad Hoc Committee on Peritoneal Dialysis Adequacy were KT/V 2.3, and creatinine clearance 60 litres per week (Blake, 1996).

Paediatric Dialysis Prescription

Generally paediatric dialysis is considered an interim treatment until a renal transplant is possible, and deemed successful when children have no obvious signs of uraemia such as high blood urea, normal blood pressure, reasonable weight and height gain, and favourable reports of dietary intake and overall well being. However, the waiting time for transplantation is becoming longer, and with improved patient survival rates, increasing numbers of children return to dialysis following failed transplants. Since more children are requiring dialysis for longer periods of time, dialysis personnel must be concerned with providing nutritional intake for growth while simultaneously removing the end products of its metabolism by dialysis (Harmon, 1994). At the present time there have been no dialysis solute clearance targets set for children on haemodialysis or peritoneal dialysis (Warady, 1997), and there have been no formal dialysis adequacy studies of Australian children reported. In general, paediatric dialysis in Australia is still prescribed and assessed according to inspection of blood biochemistry, and subjective data is unreliable when applied to dialysis prescription, since the manifestations of inadequate dialysis are generally slow to evolve (Farrell, 1983), and once established are not easily reversible despite corrections to the dialysis prescription (Warady, 1997). Khanna, et al. (1993) warned against relying solely on blood urea levels as indicator of dialysis adequacy because of the significant influence of dietary protein intake on serum urea. It is now understood that inadequate dialysis, with accompanying anorexia and malnutrition can present deceptively low levels of blood urea, leading to further underdialysis. Therefore, a low serum urea level in a dialysis patient most likely indicates protein malnutrition rather than efficient dialysis, since malnourished patients have uraemic symptoms which are disproportionate to their plasma urea levels (Acchiardo, 1994). In addition to serum urea, suggested indices of adequate dialysis are: normal scrum albumin and pre albumin; normal serum electrolytes; stable nerve conduction studies; weight and height progression between the 25th and 50th percentiles; achievement of normal developmental milestones; regular school attendance and normal academic progress; participation in play and sport.

Peritoneal Dialysis Adequacy Assessment at Royal Alexandra Hospital for Children (RAHC)

In the past peritoneal dialysis at RAHC has been prescribed using a standard 3 or 4 daily CAPD exchanges of 50 ml per kilogram, and in more recent years, 5 or 6 overnight CCPD cycles. Dialysis cycle numbers and volume have been adjusted by trial and error according to the need for increased ultrafiltration or urea clearance. However, in view of reports such as the CANUSA study associating better patient survival and improved nutrition with increased dialysis small solute clearance, the renal unit at RAHC has incorporated dialysis adequacy assessment into routine patient management. A formal study began in September 1996.

Patients and Methods

Fourteen weekly KT/V and creatinine clearance studies have been performed in 11 children (4 girls and 7 boys) on chronic peritoneal dialysis, ranging in age from 1 to 17 years. In the absence of clear guidelines for paediatric goals, solute clearance target rates were set at a higher level than the CANUSA report: 2.5 weekly KT/V; 80 litres weekly creatinine clearance. Testing was performed one month after commencing peritoneal dialysis and then every six months. Studies were delayed for one month if peritonitis occurred. Since our objective was to associate dialysis adequacy with nutritional status, nutritional and body composition assessment

included: plasma albumin and pre albumin levels; a three day food diary; Dual Energy X-Ray Absorptiometry (DEXA); Total Body Nitrogen (TBN) assessment; indirect calorimetry, 24 hour urine and dialysate collections measuring volume, urea, creatinine, glucose, and protein were performed the day prior to the child's monthly clinic visit. A blood sample measuring sodium, urea, creatinine, glucose, protein, albumin and pre albumin was drawn on the morning of the clinic. The Biochemistry department were contacted to ensure that the Jaffe correction (0.0053) was used to prevent overestimation of creatinine by glucose interference.

The following formulas were used to calculate total weekly KT/V_{urea} and total weekly creatinine clearance:

1. Weekly KT/V = dialysate KT/V + urinary KT/V

- Dialysate KT/V = 24 hour D/P_{urea} (24 hour drain volume (L)) (days per week dialysed)/Volume of distribution of urea
- Residual renal KT/V = 24 hour urine volume (ml) X U urea (mmol/l)/Volume of distribution of urea

2. Weekly creatinine clearance (Ccr) = dialysate Ccr + urinary Ccr. Weekly Ccr results were divided by body surface area, and normalised to a surface area of $1.73m^2$.

- Residual renal Ccr = 24 h urine volume (ml) X urine creatinine (mmol/L)/Serum creatinine
- Residual renal Ccr in Litres/week = renal Ccr (ml/min) X days/week dialysed/1000ml
- Dialysate Ccr (Litres per week) = 24 hour D/P creatinine X 24 hour volume X days dialysed
- To normalise Ccr to $1.73m^2$\body surface area (BSA) = Ccr (L/week) X $1.73m^2$BSA/child's BSA

Two of the greatest sources of error in dialysis kinetic modelling are miscalculation of total body water (V) and accurate 24 hour urine collection (Tzamaloukas, 1996). There are no recommendations for estimating V in paediatric dialysis adequacy studies. A number of nomograms such as Friis-Hansen and Mellit and Cheek are available to estimate total body water (Mendley, Schoeller & Majkowski, 1996). Based on the Friis-Hansen nomogram, RAHC estimated V to be 60 ml per kilogram of euvolaemic body weight (Low, et al, 1996). To improve compliance, it is preferable to collect the 24 hour urine on a day that the child is not at school. Adhesive urine collection bags are recommended for infants and young children who are not toilet trained.

Results

In order to investigate the relationship between peritoneal dialysis adequacy, nutritional status and clinical outcome, weekly KT/V, and weekly creatinine clearance has been studied in 11 paediatric peritoneal dialysis patients between age 1 year and 17 years. Their mean creatinine clearance was 68.5 litres per week (range 26.4-102.1), and mean KT/V was 2.6 (range 1.8-4.4). The study is higher dialysis solute clearance and better nutrition with positive correlation of total body nitrogen composition and higher levels of KT/V and creatinine clearance.

Children with poor dialysis adequacy

Making changes to the peritoneal dialysis prescription is not as easy as for haemodialysis, were the dialysis capacity of the dialysis membrane is known, and it is possible to simply change dialysers should the one being used have inadequate solute clearance. The dialysis capacity of the peritoneum is unknown, and it is impossible to substitute the peritoneal membrane if dialysis capacity is inefficient (Twardowski, et al, 1987). The only way to alter the dialysis dose is to manipulate the dwell time, volume, or number of exchanges performed each day (Burkhart, 1994). Baseline assessments of individual peritoneal membrane transport characteristics have been suggested to be the optimal way to guide preliminary and subsequent alterations of peritoneal dialysis prescription. Twardowski, et al. presented the peritoneal equilibration test (PET) in 1987 as a method of characterising the transport performance of the peritoneal equilibration test (PET) in 1987 as a method of characterising the transport

performance of the peritoneal membrane in adult peritoneal dialysis patients (Burkhart, 1995). Since then, several other formulas and computer programmes have been developed to assess the peritoneum, and provide a dialysis prescription that best suits individual patient peritoneal transport characteristics. A RAHC, children found to have inadequate dialysis weekly Kt/V or creatinine clearance have further investigation of their peritoneal membrane transport characteristics utilising a computer program.

Conclusions and Recommendations

An hypothesis exists that infants and small children have a more efficient peritoneal membrane compared with older children and adults. Therefore dialysate to plasma equilibration of glucose is rapid, making satisfactory ultrafiltration difficult to achieve as a result of a diminished trans peritoneal osmotic gradient (Mendley & Majkowski, 1995). In view of this there has been a trend towards continuous cycling peritoneal dialysis with short dwell times for young paediatric patients. Whether this theory is valid or not, the following questions arise: exactly how long dwell times should be?; how many cycles should be performed to achieve solute and water clearance in this age group?. The approach to these questions appears subject to much trial and error, thus, formal assessment of dialysis adequacy takes the guesswork out of dialysis prescription, and may improve dialysis solute clearance because dialysis is prescribed according to the patient's peritoneal membrane characteristics.

A number of small studies using PET to assess the peritoneal membrane characteristics of children have been reported. However the results are difficult to interpret since there has been o standardisation in the Paediatric PET protocol to ensure consistency in the dialysis dose delivered, with dialysate volumes ranging from either 30-50 ml per kilogram of body weight, or between 900 and 1200 ml/m^2. A recent recommendation by Warady (1997) is 110 ml/m^2.

Since PET has not been endorsed for paediatric use, RAIIC has chosen to assess the peritoneal membrane characteristics of children with inadequate total weekly Kt/V_{urea} and total weekly creatinine clearance with a computer program reported to be suitable for paediatric use. The computer program provides the following information: renal and dialysis Kt/V_{urea} and total weekly creatinine clearance; the effective peritoneal dialysis membrane area; the unrestricted pore surface area exchange, and hydraulic conductance (ultrafiltration capacity); the amount of reabsorption from the abdominal cavity into the blood; large pore flow, which estimates protein loss via the peritoneum; lymphatic drainage; nutritional information (protein catabolic rate, protein nitrogen appearance, caloric requirements, calories provided by dialysate glucose) (Broms, 1994).

Once the initial peritoneal membrane characteristics have been calculated by whatever computer program is used, dialysis personnel are able to provide the computer with treatment suggestions, such as cycle numbers, cycle volumes, dwell times, glucose concentration, day time dwells, CAPD versus CCPD, prior to making a decision as to which dialysis program best suits the individual child, and their lifestyle. Dialysis adequacy testing also entails assessment of the total nitrogen appearance and protein catabolic rate, therefore providing an estimation of the child's nutritional status and compliance with enteral feeding regimes. Information regarding peritoneal protein losses allows for replacement to be incorporated into the child's dietary intake.

Since the residual renal contribution to overall solute clearance and patient well being is significant, it is important to detect declining residual renal function so that dialysis may be increased to compensate. Regular formal dialysis adequacy assessment should ensure that dialysis personnel increase dialysis solute clearance when residual renal function diminishes. Better dialysis should achieve better patient well being and treatment survival, and may perhaps even prolong the benefit of residual renal function. Feber, et al. (1994) suggested that residual renal function may be maintained longer on peritoneal dialysis than on haemodialysis because patients are not exposed to artificial dialysis membranes which generate potentially nephrotoxic inflammatory mediators. An additional advantage of peritoneal dialysis is that patients rarely experience the severe hypotensive episodes leading to ischaemia of the remaining renal tissue that may occur during haemodialysis.

In conclusion, on the assumption that improved dialysis small solute clearance has the potential to improve nutrition, and overall patient well being, RAHC have introduced six monthly dialysis adequacy assessment into routine patient management. using a computer program as a tool to formally assess Kt/V_{urea} and weekly creatinine clearance, we hope to take some of the guesswork out of dialysis prescription. Individual peritoneal dialysis regimes aim for 80 litres weekly creatinine clearance, and 2.5 weekly Kt/V_{urea}. Dialysis regimens are simulated on the computer prior to trying them on patients. Adult dialysis centres report that better nutrition, and treatment survival is achieved by regular assessment of dialysis solute clearance, and individualisation of peritoneal dialysis prescription to achieve set targets. Surely children deserve a similar precise approach to treatment.

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5. NUTRITIONAL MANAGEMENT OF END STAGE RENAL FAILURE

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This presentation will cover aspects of nutritional management of Peritoneal Dialysis, Haemodialysis and Post Renal Transplantation in the paediatric patient. The role as the Renal Dietitian at the Children's Hospital is one that is extremely challenging but also rewarding.

The frustrating hours spent doing potassium education with non-compliant teenagers are soon forgotten when I receive phone calls as I did last week from an excited mother. She had just been to the Maternal and Child Health Nurse and had rung me immediately to share the good news that her baby had gained 160g. This was not much compared to the other babies at the centre who drink formula from bottles and eat solids three times a day, but for this baby a weight gain of 160g was a great achievement that hadn't been reached for months.

The Dietitian's perspective of the typical child in end stage renal failure, is one of a little person who is:

falling off the growth charts,
eats very little, in a grazing style,
refuses to eat family food,
will not sit at the table with the family,
vomits or gags at the thought of food being forced upon them,
sleeps for much of the day.

As you can imagine this results in very stressed and anxious parents. They find it difficult not to compare their child with renal failure to other children, they are unsure whether they should discipline the child for bad eating behaviour, and they are concerned about what effect all this will have on other children in the family.

The solution of how to manage a situation like this is one that is very complex. On one hand we want to encourage good behavioural habits, but yet on the other we want this child to be adequately nourished.

NUTRITIONAL ASSESSMENT

A Dietitian's role usually begins with a nutritional assessment. A thorough dietary history is often not a difficult task for the mother, because the child often does not eat a large selection of foods. A history of serial weights and heights is also essential to form a picture of the current nutritional status. To complete the assessment and to aid in making recommendations details of biochemical parameters, bowel habits, fluid balance, current medications and dialysis treatment need to be taken into consideration.

The opinion of the whole renal team is vital when making a nutritional assessment and formulating plans. Nutritional goals need to fit into the overall management plan.

PERITONEAL DIALYSIS

From my experience, children on Peritoneal Dialysis tend to be better nourished than their counterparts on Haemodialysis. I attribute this to two points. Firstly the continual removal of waste products, without peaks and troughs, from their systems reduces the feeling of nausea and anorexia. Secondly the absorption of glucose from the PD fluid provides the child with a constant source of energy. This energy absorbed would vary from child to child depending on membrane permeability and dialysis regimen, but it has been reported as being in the order of 8 kcal/kg/day.

With younger children on PD who still have problems with poor growth and poor appetite, I have found it necessary to continue to supplement their diet with energy. I do this with additional fats and simple carbohydrates which can be easily added to the foods already being consumed. This can be done with using products already found in the home such as margarine or sugar, or with commercial products such as polyjoule and calogen.

It is known that significant amounts of protein are lost during the process of PD, these have been found to be greater in the younger children due to their proportionally larger peritoneal surface area. Research on protein requirements whilst on PD has been done primarily in adults, the recommendations are based on the recommended daily intake (RDI) plus and additional allowance to replace loses. This is felt an important issue in adults because a protein deficiency can result in muscle wastage, decreased serum protein levels, increased susceptibility to infection and delayed wound healing. In children we not only have these issues but also the additional consideration of the role of protein in growth. Therefore ensuring that the growing child on PD has adequate dietary protein is vital.

I follow the recommendations of the American Dietetic Association, which depending on age suggests an intake of 1.5 - 4.0 g/kg/day.

Getting adequate protein into the diet of a fluid restricted formula fed infant is difficult. I have found that in order to meet protein requirements whilst restricting other dietary components I have to add a dietary protein supplement to formula. At the Children's we use Maxipro which contains 80% high biological value protein.

Current paediatric recommendations for supplementation of Vitamins B6, C and folate are based on data of loses in adults. Vitamin supplementation in children with renal failure is an area which Janet Coleman from Nottingham in the UK has done a considerable amount of research. She has recommended that children on PD should receive a supplemental dose of 60mg Vitamin C, 0.4mg Vitamin B6 and 500micrograms of Folate. The risk of overdose of any of these three vitamins is not an issue, so when searching for an appropriate vitamin supplement these amounts should be treated as a minimum requirement. What does need to be taken into consideration is the electrolyte and vitamin E content of the supplement. There have been several reports in the literature of vitamin E toxicity in renal patients.

In Australia our selection of vitamin supplements is quite poor compared to other countries such as the UK and the USA, where several suitable single dose vitamin preparations are available. With Ketovite tablets now unavailable to us, I am currently recommending a combination of one Multi B Forte and 500 micrograms of Folic Acid per day. This is not an ideal solution but seems to be one that is readily available and suits our needs. SHS recently released a supplement called Paediatric Renal Seravit which has a high content of vitamin A, therefore it has not been routinely prescribed to our patients.

Potassium is often not restricted in children on PD due to serum levels not exceeding the normal reference range. Only when serum levels are consistently exceeding the upper limit of the reference range would a dietary intake of Potassium be limited.

The need for serum phosphate control continues in children on PD. Dietary intakes may be slightly higher due to a higher protein intake. Education on making low phosphate choices ie white bread instead of wholemeal bread, as well as teaching children when to take phosphate binders is important.

When fluid intake is restricted it can have a significant impact on providing a nutritionally adequate diet. Fluid can be the most significant source of nutrition in an infant or enterally fed child.

HAEMODIALYSIS

In theory the energy requirements of a child on Haemodialysis are similar to those during predialysis. This is most often quoted as being RDI for height age. However in practice we find a huge amount of variety and each child needs to be individually assessed. In our Haemodialysis unit at the Children's we have some children who need little attention paid to any part of their diet, and others who need attention paid to every aspect of their diet. For those who require energy supplementation I usually increase fats and simple carbohydrates, which can be easily incorporated into their current dietary intake.

There are several commercial products available such as Nepro, but I generally find that these are not as well accepted due to their sweet taste and thick mouth feel. More than often I resort back to items already found in the home. Adding margarine to vegetables and frying meats are more acceptable to the child, and cheaper for the family to purchase.

Non-compliance with fluid restrictions is one of the touchiest topics in our unit. We have had several adolescents who repeatedly come in grossly overloaded at each session. The resulting confrontation usually ends up with angry nursing staff, an upset patient and a dietitian who feels like a complete failure. Time and time again we go through making daily plans, contracts and giving all the usual helpful hints to next to no avail.

I recently attended a workshop on patient compliance, one of the most important messages that I got from attending the workshop was that; aiming for perfection is being totally unrealistic form my part, and that it isn't lack of knowledge that is causing our patients to have these problems with compliance but many other interfering issues. Our adolescents are not only trying to cope with their chronic disease with very little family support, but also going through all the same adolescent issues that their peers are also experiencing.

Once again phosphorus continues to be an issue. Low phosphorus foods should continue to be selected and phosphate binders should be distributed so that they are taken with food which contains large amounts of phosphorus.

Potassium is often a problem, children who consistently have elevated serum levels will need to follow a dietary restriction. This is often no easy task because some of kids favourite foods include: chocolate, chips, pizza, and spaghetti bolognaise, all high potassium foods. Sometimes the desire to eat what all the other kids eat is much stronger than the knowledge of what hyperkalaemia could do to them.

ENTERAL FEEDING

Enteral feeding, either via nasogastric or gastrostomy, has been an invaluable part of nutritional management in most of our younger children and babies in end stage renal failure. Their poor growth and poor oral intake has both short and long term implications which contribute to the child's poor health and the parents stress levels.

Selecting a suitable formula usually requires assessing the childÕs individual nutritional requirements and then modifying on the many commercially available formula available.

We generally find that the decision to enterally feed a child either partially of in full, takes a great pressure away from the parents. Rates and times of the feed delivery can be manipulated to suit the needs of the child and family. Oral feeding can at long last turn into an enjoyable and happy occasion, rather than being a never ending struggle. At the end of the day we usually see improved growth, relaxed parents and a happier home environment.

TRANSPLANTATION

The dietitian has a very different role after transplantation. The previous dietary restrictions need to be abandoned, and the previous encouragement of fats and sugars now need to be discouraged and replaced with a healthy well balanced diet that fits in with the rest of the family.

Anti-rejection medications which the child is on after transplantation have many side effects, which includes weight gain and increased appetite. If this new found appetite is satisfied with the previously consumed high calorie foods, the resultant weight gain has the potential to become a long lasting problem.

Dietary education tends to follow the guidelines which we would recommend to all healthy children. The Diet Pyramid is used as a guide to teach eating: less fats, especially saturated fats, less sugars, moderate amounts of meats and dairy products, and more fruits vegetables and cereals. Voracious appetites should be satisfied by selecting foods from the bottom of the pyramid.

CONCLUSION

To conclude a paediatric renal dietitian needs to show flexibility when making goals and plans. Children are always undergoing change, and we must ensure that our plans are as accommodating as possible.

We should expect some degree of poor compliance because we are dealing with people who will have food fads, tantrums, frequent illnesses and have parents who hate to see their children miss out on anything. We're also dealing with teenagers who in addition to their renal failure are going through adolescence.

6. PROSPECTIVE STUDY OF CMV INFECTION IN CMV NEGATIVE RECIPIENTS OF CMV POSITIVE GRAFTS

K Heathershaw, CL Jones, H Powell, R Walker. Royal Children's Hospital, Parkville.

CMV infection is an important cause of morbidity in sero-negative renal transplant recipients who receive a kidney from a sero-positive donor. The NH&MRC had a protocol for the use of CMV hyperimmune globulin in a prophylactic manner for these patients. This study was designed to determine the nature of CMV infection in this patient group. CMV hyperimmune globulin was administered 5 days prior to transplantation, the day before transplantation, the day of transplantation and weekly for 8 weeks in a dose of 30 mg/kg body weight to living related kidney recipients (LRRT) and, for cadaveric recipients (CRT), the same regime was used omitting the pretransplant doses. Acyclovir was given to all patients during the duration of the immune treatment. The CMV serology (CMV IgG and IgM by enzyme immuno assay), shell vial culture of leucocytes and urine, and CMV polymerase chain reaction (PCR) of leucocyte DNA were performed at 2 weekly intervals over the 1st 3 months and then up to 2 monthly in seronegative patients and testing was stopped following serum IgM detection. 9 patients were studied, median age 8 y (range 3-27), M:F ratio 8:1, 8 LRRT, 1 CRT. 5 underwent seroconversion. The time to IgM seroconversion post-transplant was 57 to 129 days. All patients who became seropositive had CMV DNA detected in leucocytes by PCR, and this preceded the detection of CMV IgM in serum in 4 patients by 6 to 24 days and the detection occurred simultaneously in 1 patient. In 3 of these patients CMV was detected by PCR prior to the cessation of the CMV hyperimmune globulin. The remaining 4 patients were seronegative for CMV at 3, 11, 18 and 24 months post transplant respectively. 1 child had transient mild graft dysfunction (Cr increased from 0.06mmol/l to 0.08mmol/l) and a sub clinical hepatitis, another developed mild cough and transient graft dysfunction (Cr 0.06 to 0.10mmol/l). In both cases symptoms occurred at the time of IgM CMV seroconversion. 2 of the adults developed fevers, malaise, muscle aches, cough that responded to ganciclovir 1 at the time of and the other 4 weeks after IgM seroconversion. In summary, PCR detected CMV prior to illness and preceded IgM seroconversion and CMV infection occurred in some patients while on immune prophylaxis.

7. SUCCESSFUL RENAL TRANSPLANTATION IN JEUNE'S SYNDROME.

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Jeune syndrome (asphyxiating thoracic dystrophy) is an autosomal skeletal dysplasia with multisystem involvement. Associated abnormalities include renal failure due to tubulointerstitial nephritis, glomerular cysts, hepatic fibrosis, pancreatic cysts and dysfunction, ocular abnormalities and cardiomyopathy. We describe a 4 year old girl with Jeune syndrome who presented at 2.5 years of age with endstage renal failure who is now well 18 months following cadaveric renal transplantation. She was admitted ICU at 2.5 years with cardiac failure and respiratory distress precipitated by influenza B infection. On admission she was found to be hypertensive (160/100). Laboratory investigations revealed renal failure (creatinine: 223 umol/l, urea: 26.3 mmol/l. Urinalysis was negative. She had been seen previously by a paediatrician at 12 months due to concerns about poor growth with no cause found. She has a twin brother who is well and thriving. The children are the result of an IVF pregnancy using parental gametes. She had minor dysmorphic features and a small thoracic cage. Both height and weight were below the third centile. Skeletal survey revealed cone shaped phalangeal epiphyses but no other bony abnormalities. Renal biopsy revealed glomerular sclerosis, periglomerular fibrosis and severe interstitial sclerosis. Karyotype was normal. Peritoneal dialysis was commenced. At 3 years a cadaveric renal transplant was performed without complication. Antihypertensive therapy is ongoing. Apart from myopia, no ocular, hepatic or pancreatic abnormalities are evident. The ANZDATA Registry records 2 other children with Juene's syndrome who commenced peritoneal dialysis in their third year. Both children died prior to transplantation. There is one reported case in the literature of a child with Juene's syndrome undergoing renal transplantation. We report the first child in Australia with Jeune syndrome to have a renal transplant, and draw attention to this rare but important cause of renal failure in early childhood. The chromosomal abnormality is not het known, and the inheritance is thought to be autosomal recessive or autosomal dominant with variable penetrance. Antenatal ultrasound can be diagnostic.

8. HIGH DOSE CYCLOSPORINE THERAPY FOR CHILDREN WITH STEROID RESISTANT NEPHROTIC SYNDROME

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The aim of high dose Cyclosporin (CyA) therapy is to improve the renal outcome for children with nephrotic syndrome who are unresponsive to other forms of therapy, including standard dose CyA. Cyclosporin in doses of 5-10 mg/kg/day have been shown to be effective in preventing relapses of steroid responsive nephrotic syndrome and reducing proteinuria in many children resistant to other forms of therapy.

Recent studies have suggested that elevated serum cholesterol may be a predictor of CyA non-responsiveness, and isolated reports have demonstrated the potential benefit of using high dose CyA.

The protocol consists of treating children with steroid resistant nephrotic syndrome commencing CyA at 10 mg/kg/day with weekly increments of 5 mg/kg to a maximum of 35 mg/kg daily. Should creatinine increase more than 50% above baseline or a remission is reduced then dosage of CyA is reduced. Weekly urea/elect/creat, HPLC CyA trough levels, lipids, liver function tests, total protein, albumin weekly 24 hr urinary protein and daily urine albustix were measured.

The results of the first 4 pts studied will be presented. One patient achieved a remission, one patient did not tolerate doses above 20 mg/kg/day, and the remaining 2 patients achieved maximal dose of CyA without a remission achieved.

9. PROTEOLIPID IN PERITONEAL EFFLUENT OF CAPD PATIENTS

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Proteolipid in the form of surfactant proteins "B & C" are known to have a major role in the function of surface - active phospholipid (SAPL) by activating the rate of absorption of SAPL.

We analysed the effluent dialysate for proteolipid and phospholipid using standard methods with time on dialysis. Forty-five patients aged between 26-72 years (59 ± 25) were studied. Period of CAPD ranged from 1 to 75 months (25 ± 22). Dialysate contained both proteolipid (mean 1.205 ± 0.747 μg BSA equiv/ml) and phospholipid (mean 20.558 ± 9.583 DPPC equiv/ml). The ratio of proteolipid to phospholipid ranged from 0.0158 to 0.1618 (mean 0.066 ± 0.0391). Concentration of phospholipid decreased with time on CAPD ($p<0.05$) and proteolipid showed no significant correlation with time on CAPD. There was no correlation of proteolipid or phospholipid with episodes of peritonitis and peritoneal equilibration test.
We conclude that peritoneal effluent contains proteolipid and the concentration does not change significantly with time on CAPD in patients who have no major loss of ultrafiltration ability.

10. MATERNAL DEPRIVATION ACCOMPANYING ESRF IN INFANCY

Christine Fischer, Peritoneal Dialysis Training and Education Centre, Royal Melbourne Hospital

In April 1997, a two year old boy received a living-related transplant from his paternal grandfather. At six months of age, he developed severe haemolytic uraemic syndrome that quickly progressed to ESRF requiring peritoneal dialysis. Adequate growth was identified as a problem and a gastrostomy was required for total nutritional intake. His dialysis program was also changed from CAPD to CCPD. This boy's mother was his chief caregiver. She had to balance pump feeding with medication administration and twelve hours of CCPD per night, seven days a week. Due to the task orientated and time consuming nature of care for an infant with ESRF, his mother expressed that she felt more like his nurse than his mother and deprived of a normal mother and infant relationship. As health care professionals, we often become too engrossed with the clinical aspects of care required by these infants and spend too little time on the psychological and emotional needs of the child and their families who are most often their carers. We need to ensure that families receive and feel as though they are receiving adequate support from the unit, and are made aware of available support services and programs such as Linkages, Making a Difference and the Family Choice Program. Programs such as these aim to support parents with the technical and financial aspects of their child's care, therefore allowing them the time to interact with the child and feel as though they are experiencing the child's development and forming a more balanced parent/child relationship.

11. ABSENCE OF NEW RENAL SCARS AFTER URINARY INFECTION IN INFANTS

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Studies based on intravenous urography have suggested that children with urinary infection (UTI) are at risk of developing new renal scars. However intravenous urography is not sensitive enough to detect small scars in the first year of life so that the apparent appearance of new scars could, in fact, be due to previously undetected scars becoming more obvious with renal growth. 99m Technetium dimercaptosuccinic acid (DMSA) scintiography can detect defects in very young infants so we conducted a prospective study in a group of children who had a DMSA scan at the time of their first identified UTI and again 2 years later to determine the likelihood of new DMSA defects occurring during follow-up after UTI.
As subsequent UTI's have potential to cause transient DMSA defects for a few months after infection, we ensured that no follow-up DMSA scans were done within 6 months of a UTI, thereby enabling determination of the true incidence of persistent scars at follow-up.
The study group comprised 150 children aged up to 5 years followed for 2 years after their first detected culture-proven UTI. The initial UTI's were treated and then, if vesico-ureteric reflux (VUR) was present, prophylactic antibiotics were given until night-time continence was achieved. Subsequently, patients were treated only for identified UTI. The mean age at presentation was 1.47 years (range 0.1- 5 years) and 88 (58%) were girls. VUR was detected in 36% (54 of 150) and initial DMSA scans demonstrated cortical defects in 63% (95 of 150).
During 2 years of follow-up, 15 of the 150 children had further UTI. A subsequent DMSA scan was performed at a mean interval 2.3 years after the initial UTI episode. DMSA defects resolved in 68 of the 95 children with initial defects and persistent defects were present in 27 children. None of the 150 children developed any new defects.

This study suggests that in children receiving prophylactic treatment for VUR after initial UTI, despite recurrent episodes of infection, there is no risk of additional scarring during subsequent UTI.

12. PHARMACOKINETICS OF CYCLOSPORIN NEORAL IN CHILDREN WITH STABLE RENAL Transplantation

JC Tam, JW Earl*, CE Nath* JF Knight, EM Hodson. Centre for Kidney Research, Royal Alexandra Hospital for Children, *Department of Biochemistry, Royal Alexandra Hospital for Children

Clinical monitoring of cyclosporin remains a difficult task and few pharmacokinetic studies have been performed in children. We have adapted a previously reported pharmacokinetics program[1] to investigate the pharmacokinetics of cyclosporin in children with stable renal transplantation.

Fourteen children, aged 5 to 17 years, average body weight 38.6 kg (range 15.7 - 67.6), taking cyclosporin 12 hourly since their transplant 1.5 to 9 years previously and with stable renal function and stable trough levels were studied. Average dose was 6.4 mg/kg/day (range 4.4 - 8.4) of the microemulsion preparation (Neoral). Blood was collected at 0, 20, 40 mins and at 1, $1^1/_2$, 2, $2^1/_2$, 3 4 6 8 hrs following the morning dose, and analysed by Abbott monoclonal TDX immunoassay.

The data was consistent with a 2-compartment model with first order absorption. The delay time in absorption varied from 24 to 96 minutes resulting in a similarly variable appearance of the peak plasma level (Tmax) of 60 -144 minutes. Tmax was related to the age of the patient (Tmax=0.027 age + 1.41, r^2=0.56, $p<0.005$). The AUC correlated well with peak levels (Cmax) (r^2=0.064), but not with trough levels (r^2=0.03).

Peak level appears to be a more suitable measure of exposure to cyclosporin than trough level. Prediction of Tmax based on the age of the child may help to overcome the problem of when to collect blood for peak levels.

Reference

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13. RECURRENT HAEMOLYTIC URAEMIC SYNDROME

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A previously healthy 13 month old caucasian boy presented to the Alice Springs Hospital with a haemolytic uraemic syndrome (HUS) following a 5 day prodrome of mild diarrhoea. Faecal cultures later confirmed salmonella enteritis. He was transfused and immediately transferred to the Women's and Children's Hospital in Adelaide. He required haemodialysis for two weeks and was given a course of plasma exchange (x7). His progress was complicated by severe hypertension and respiratory failure secondary to pneumonia. He appeared to make a full recovery and anti-hypertensive therapy was progressively withdrawn. At 21 months of age he re-presented with HUS without a prodrome. Faecal cultures were negative and Shiga-like toxins were not identified. He appeared to respond to plasma exchange and prostacyclin infusion but has been left with a residual impairment of renal function and persistent hypertension (well controlled). He has an estimated GFR of 78 ml/min/.1.73m^2 and has not relapsed for the past 9 months.

This patient has a recurrent form of HUS that is not familial and has not been associated with drug exposure. The condition appears to respond to plasma exchange and/or prostacyclin in a manner similar to that described in anecdotal case reports and personal communications. Prognosis is generally viewed as poor but prompt management may allow preservation of life and renal function.

14. CONGENITAL NEPHROTIC SYNDROME, FANCONI SYNDROME AND TOO MANY NEPHRONS

S Gulati, C Cooke-Yarborough, M Cahill, J. Bertram, H Powell, R Walker, C Jones.

This case report describes a child who presented at 3 months of age with the previously unreported association of congenital nephrotic syndrome (CNS) and a Fanconi syndrome of proximal tubular malabsorption. Culture of the baby's urine was positive for cytomegalovirus

(CMV) and IgM anti-CMV antibodies were detected, but there were no stigmata of intrauterine CMV infection. Medical treatment was not successful in controlling the protein and electrolyte losses. The baby underwent bilateral nephrectomies and dialysis, but died of septic complications at 32 weeks of age. Pathological examination and the quantitation of an extraordinary number of glomeruli in the kidney (1.26×10^6) suggested that Finnish microcystic disease may have been the cause of this clinical picture but perinatal CMV infection or a unique disease could not be excluded.

15. RECURRENT SEVERE CEREBRAL SYNDROMES ASSOCIATED WITH THE USE OF OKT_3

R Walker, H Powell and C Jones

The benefit of murine monoclonal antibody (OKT_3) for effective prevention or reversal of allograft rejection is a widely accepted therapy. Since its introduction in 1981, many side effects have been reported. Besides predictable, self-limited and common first dose reactions (the so-called cytokine release syndrome) which manifests as flu-like symptoms including fever, headache, malaise and joint pains, OKT_3 is associated with a number of other adverse events.

Centre nerve system (CNS) side effects are amongst the rare but more severe adverse reactions associated with OKT_3 therapy. The most frequent reported CNS side effects include seizures, encephalopathy and aseptic meningitis. Rarely, have there been reported cases of recurrent episodes of the symptoms.

An 8-year-old lad, with ESRF secondary to medullary cystic kidney disease received his first cadaveric allograft in 1989. The graft functioned well but he developed a severe rejection episode eighteen months later. He was treated initially with corticosteroids but subsequently received a course of OKT_3 (2.5 mg for 3 days) during which he developed high fever, neck stiffness and photophobia. A lumbar puncture yielded a clear cerebrospinal fluid. The cell count was 511 (509 polymorphs, 2 lymphocytes). Subsequent cultures were negative. Five days later the symptoms of "aseptic meningitis" disappeared without sequelae. The OKT_3 had been ceased on the third day of the symptoms.

During his second renal transplant (1991), he had further rejection episodes. Most of these of episodes were reversed successfully with corticosteroids but during one episode he received the second course of OKT_3 (2.5 mg daily for 12 days). There were no adverse cerebral consequences. In the course of this allograft, he received the second course of OKT_3 (2.5 mg for 10 days). This was associated with high fever and hypotension but successful reversal of the allograft rejection and no cerebral consequences.

His third transplant occurred in 1997 at the age of 17 years. OKT_3 was given prophylactically because of high panel-reactive antibodies (PRA>50%). Within 24 hours of initiating OKT_3 he developed high fever, hypertension and subsequently hypotension. On the second post-operative day, OKT_3 was suspended for 24 hours but represcribed on the third post-operative day after which he developed an altered conscious state, blurred vision, dizziness, drowsiness and hallucinations. Lumbar puncture yielded clear cerebrospinal fluid, the CSF cell count was 207 WBCs (120 polymorphs, 78 lymphocytes). An EGG was compatible with severe encephalopathy. OKT_3 was ceased and he recovered, 8 days later he was prescribed Atgam for 10 days and he remained well without any adverse CNS consequences.

16. MUCOSAL IMMUNE DEFECT IN PATIENTS WITH IgA NEPHROPATHY

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IgA nephropathy (IgAN) is characterised by the deposition of IgA in the glomerular mesangium. Mesangial IgA derives from bone marrow plasma cells suggesting that a primary abnormality within the mucosal immune system may underlie the pathogenesis of IgAN. Studies of mice in which the genes for the γδ T-cell receptor have been deleted have shown that the mucosal IgA production in these animals is significantly reduced. This study has analysed the T cell receptor variable region expression by γδ T cells in the intestinal mucosa of patients with IgAN using our previously described methods[1,2]. Small bowel biopsies of 11 patients

with IgAN were compared to those of 11 matched control individuals. γδ T cells in normal gut predominantly express Vγ3, Vδ3, Vγ3 gene expression was significantly decreased in IgAN gut compared to control gut (P=0.023) and a significant decrease in Vγ3 gene expression gut (P=0.043). These findings indicate that a subpopulation of γδ T cells which represent the majority of γδ T cells in normal gut mucosa are significantly diminished in the gut of patients with IgAN. This suggests that a "hole" in the mucosal γδ T cell repertoire may play a fundamental role in contributing to the pathogensis of IgAN.

1. Falk MC et al. Clin Exp Immunol 1994 98:78-82
2. Olive C, Nicol D, Falk MC. Cancer Immunol Immunotherapy 1997;44:27-34

17. CHRONIC RENAL DISEASE IN CHILDHOOD: DOUBTS, HOPES AND EXPECTATIONS

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ABSTRACT

The outlook for patients with chronic renal disease has altered dramatically with the technological advances of the past 25 years. The implications for children with end-stage renal disease and their families are explored in the light of the available literature and the author's clinical experience.

The impact on the patient of major technological advances in the treatment of end-stage renal disease has been compared with rebirth: 'an awakening from the dead'. Instead of facing certain death, children and their families now have to confront the possibility of continued life with all the doubts, hopes and expectations that accompany a treatment which is lifesaving but is not a cure. Even after successful transplantation, complications of immunosuppressant therapy, fear of rejection causing death or a return to haemodialysis persist. One author has suggested that 'this fear of death, coupled with a fear of life, is the dilemma of the patient with chronic renal failure'[1].

In the child, growth retardation which accompanies end-stage renal disease may not be reversed following transplantation. Schooling is disrupted by repeated hospitalisation and doubts about the future may lead to persistent underachievement even after a return to regular schooling is possible. Emotionally, the child who has a chronic illness may be forced into prolonged dependency at a time when the normally developing child is moving away from the earlier dependent relationships with his parents.

In a review of the psychological reactions to renal transplantation in adult donors and recipients, Abram suggested that the psychiatric complications of dialysis are greater than those of transplantation[2]. He pointed out the dependent relationship which frequently develops between dialysis patients and the machine and staff. This dependency is often characterised by intense ambivalence and marked episodes of depression, but recipients may unrealistically view transplantation as a solution to all of their problems. The depression and anxiety recur readily, especially at times of threatened rejection of the kidney. It has been suggested that the transplanted kidney goes through 'stages of internalisation' from the 'foreign body stage' through the 'stage of partial incorporation' to the 'state of complete incorporation'[3].

The recipient frequently identifies with the donor (especially in the case of living related donors) and is described as taking on many of the personality characteristics of the donor. This may pose a particular problem in the case of a donor of the opposite sex. The donor, despite being motivated by altruistic motives, may experience some resentment towards the recipient, especially as the time of the operation approaches.

The literature on the psychological implications of the chronic renal disease and its treatment in children is not extensive. Fine *et al*[4] in a report on 69 children who had transplantation commented upon marked growth retardation, especially in pre-pubertal children. They also reported a significant deviation in social adapation and a high incidence of lowered self-esteem. Of particular concern was non-compliance with immunosuppressant medication leading to irreversible reduction in graft function. This was documented in 14 cases, most of whom were

adolescent girls, and contributed to loss of transplanted kidney in eight. It was suggested this was due to adolescent rebellion and self-consciousness about their cushingoid appearance. Drotar and Ganofsky[5] have pointed out that the normal child's increasing ego control is threatened by severe illness and enforced passivity. In the case of haemodialysis this threat takes on a unique form when the child is attached to, and dependent for his life upon a machine to which he is 'linked by a veritable umbilical cord'. The parents frequently experience considerable guilt and their parenting relationship with the child is affected by the presence of the 'wire mother' machine[6].

CASE STUDIES

Case 1: A young adolescent girl was noted for her difficult behaviour in an adult renal unit, consisting of persistent demands on staff and continual complaints of bone pain and problems with her shunt. She had had an unsuccessful renal transplant which had been rejected despite massive corticosteroid therapy. The latter had left her severely cushingoid in appearance and had aggravated her renal osteodystrophy, causing destruction of both hip joints. Her behaviour can be understood as an expression of her depression, her anxiety about the future and her anger at her continued ill-health despite multiple painful procedures. In an adult hospital her behaviour was not understood and provoked anger.

She finally died, aged 16 years, having had not only two unsuccessful renal transplants but also total replacements of both hip joints and one knee joint.

The Royal Alexandra Hospital for Children in Sydney has had a renal unit for five years. During this time seven children have received transplants. Four (all cadaver donors) have died. Three (all living related donors) are alive 1-3 years after transplantation. At present there are six children aged 5-16 years on dialysis.

Case 2: A 10 year-old boy had a successful renal transplant performed two years earlier. His father was the donor, after his mother was found to be incompatible. he was referred because of aggressive behaviour and poor school achievement. The only serious medical problem was failure to grow. His father, a truck driver, had been out of work for all but three months of the past two years. He denied any emotional sequelae of donation, but said he had not been able to cope with the physical demands of truck driving since the operation. His mother found it difficult to request help for herself although she could acknowledge that she was depressed. She was used to putting on a brave front and helping others and felt guilty and responsible for her son's illness. The patient, a small boy, was very articulate and expressed concern about his small size as his ambition was to be a truck driver like his father. His aggression appeared to be partly an attempt to compensate for his small stature and a denial of his depression about the future.

Case 3: A boy aged 9.5 years had been on haemodialysis in an adult unit for nine months. He was referred because of his aggressive behaviour, sexual curiosity, and underachievement at school.

During sessions with an occupational therapist his drawings clearly expressed anger at his helplessness and fears of dialysis. His ambivalence towards the dialysis machine which he named 'ambulance' was expressed in drawings of 'a monster trying to eat a little boy on the top of a building' and 'a monster breathing fire on a baby monster'.

At the time of referral he was about to commence home dialysis training, a situation which caused anxiety to both him and his mother. This was expressed in a drawing of himself on the dialysis machine which had caught fire: the staff had left him in this situation and his mother could not take him off the machine.

His mother was in her late forties and expressed considerable guilt about her son's illness. She had been unsure about having a second child so late in life. He had been premature and there had been major feeding difficulties for which she had repeatedly sought medical attention. When he finally became ill, at five years, it confirmed her worst fears. It was this guilt which

made it impossible for her to set realistic limits on her son so she allowed him to tyrannise her. Although she had offered herself as donor she proved to be incompatible. It seemed that she had made the decision to exclude her 22 year old son and her husband from consideration.

DISCUSSION

These three cases illustrate a number of problems facing children with end-stage renal disease and their parents.

In recent years enormous technical developments have taken place in the field of transplant surgery. Much less progress has been made in understanding the emotional significance of such losses of parts of 'the self' and how to help patients cope with these losses. Consideration about quality of life must be given if a rational decision about continuation of treatment is to be reached. How can one decide to withhold or withdraw treatment when this inevitable means death for the patient? Schowalter[7] has discussed the importance of the adolescent's feeling about continued treatment or its termination and the impact of such a decision on a unit committed to treatment.

Most people are at least intellectually aware that they will die some time. For the child with chronic renal disease death, instead of being a remote possibility becomes a personal reality. This is also true for his family. If the child is to continue a satisfactory life both he and his family must come to terms with this reality. Otherwise the doubts about the future will cause all to ask 'what's the point?' repeatedly. This fear of life may manifest itself in underachievement at school and in parents' difficulties in setting realistic limits on their 'sick' child's behaviour. Medical setbacks will inevitably arouse anxiety and reawaken fears of death, regardless of how well these have been worked through.

Despite the low incidence of overt psychiatric problems reported by some authors[8]. there seems to be ample grounds to justify assessment of all families at the time of diagnosis of the disease. This assessment should be aimed at discovering the family's habitual methods of coping with stress and identifying premorbid psychopathology. The psychiatrist may then be helpful to the family in the crises they will have to face.

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18. DON'T LOOK AT ME WITH PITY - I NEED YOUR STRENGTH
Educational Issues Relating to a Student with End Stage Renal Failure

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Over the past several years there has been a growing recognition that a more cooperative relationship is needed between the disciplines of special education and paediatrics to optimise the academic experience for students with specialised medical and educational needs.

Although most children with a chronic illness such as End Stage Renal Failure do not need specific special education placement, they require coordinated school interventions to maximise school attendance and facilitate educational and social growth. The process of integrating the child or adolescent into school is arduous and requires cooperative efforts among the health care providers, the school, the family, and the child or adolescent.

Impact of End Stage Renal Failure on Schooling:

Certainly End Stage Renal Failure has a major impact on the overall adaptation of afflicted children and adolescents. These problems are reflected in the psychological well-being of the child, in integration with peers, and in school performance. Behavioural problems, academic failure, and school absenteeism may be the outcome. Because the child's ability to attend school, relate to peers, and achieve academically are integral parts of optimal overall adaptation to such an illness/impairment, effective management of school programming is imperative. Successful integration requires consistent, prospective identification and management of problems with school attendance and obstacles to attendance.

School Attendance:
Surveys of school attendance in general have shown that children and adolescents with chronic illness exhibit more absenteeism than do their healthy peers.

School Performance:
Some children with End Stage Renal Failure will experience diagnosable learning disorders. Mediating variables such as anxiety, absenteeism, attention problems, or subtle learning disorders, may account for some academic difficulties. If the child has a prior history of learning problems, the illness may simply exacerbate the situation, necessitating some form of program modification or support service when the child is at school or during hospitalisation.

Obstacles to School Participation:

School attendance is an ongoing problem for the child with End Stage Renal Failure, for the family, and for the school. Parents of children and adolescents with acquired impairment report three major causes for school absenteeism:

- minor illnesses;
- direct effects of the End Stage Renal Failure itself; and
- scheduled hospital / clinic visits

Yet, factors that may influence school performance seem much more complex than suggested by these overt reasons and include:

1. factors associated with the condition and its treatment;
2. child variables, such as the individual response to the illness, academic impairment, and social dysfunction;
3. attitudinal issues of the various significant adults, including parents, school personnel, and health care providers; and

4. the availability of educational and health care resources within the child's school system.

The importance of schooling for the End Stage Renal Failure child or adolescent cannot be over-emphasised. It is critical for his or her social survival as effective medical or surgical treatment is for the child's physical survival.

The school milieu for growing and developing children or adolescents provides students with opportunities to learn, socialise with peers, experience success, and develop increased independence and control over their environment (Davis, 1989). Children who are physically unable to attend a full school program may feel devalued, experience a decrease in self-esteem, and become even more fearful that they may be dying, alone and isolated from peers (Davis, 1989). Therefore, full integration of the child with such a chronic illness into the school setting should be as much a part of the overall management of the illness as the more medically oriented interventions.

Illness and Treatment Effects:

Specific aspects of the illness or the treatment regimen may make it difficult for the child or adolescent to attend school on a regular basis or full time. Problems due to the therapy prescribed for the illness such as regular haemodialysis may increase the child's vulnerability to school integration problems.
Although some children with End Stage renal Failure may be more vulnerable to disruptive schooling due to related minor health issues, an exaggerated response to symptoms of minor illness by an overprotective family or an overconcerned teacher may further exacerbate school absence. The illness requires medical management through health care visits of varying frequencies. Medically necessitated absences may also hinder academic functioning in some children, further compromising their comfort in attending school.

Child Variables:

Social/Emotional Difficulties:
Reichwald-Klugger, Weck, Korn, and Bonzel (1986) found that, for most individuals, the psychological aspects of renal failure seemed to be more difficult to handle than the somatic problems. Because haemodialysis treatment has been scheduled during school hours, absenteeism from school has been an additional stressor for school-age children. These absences from school jeopardise school achievement, the child's opportunity to develop peer relationships, and the formation of school and life goals. Failure to maintain work levels and disrupted contact with peers contribute to feelings of isolation and inferiority. Absences with little contact with peers may hamper social interaction and make it more difficult for the child or adolescent with End Stage Renal Failure to participate fully in school. In fact, the immediate outcome of limited participation may seem positive to the resistant child but may also be viewed as a message confirming the perceived hopelessness of the situation, further complicating the emotional issues involved in school integration.

Anxiety over attending school results when a child or adolescent is confronted with physical changes. Any physical change threatens the student's body image and, ultimately, self-esteem, potentially causing discomfort in peer interactions. Physical limitations may contribute to the child's difficulties in interacting with peers and ultimately hamper school attendance of participation in the full school program. School provides the child with the opportunity to engage in team sports and physical activities that can enhance feelings of personal competence and help provide a place of status in the peer group. Adolescents, in particular, express specific worries about the changes in their appearance, fears of peer ridicule or teasing, and discomfort talking about the illness to schoolmates and teachers. Chekryn, Deegan, and Reid (1986) also reported that the students' fear of peer rejection, often couched in fears about physical differences or the inability to communicate with their peers, frequently makes schooling formidable. Interestingly, while the fear of peer rejection is paramount prior to the school intervention, most children and adolescents ultimately find that the fundamental emotional

support for their educational involvement comes from classmates who have been educated about their illness.

Academic Difficulties:
Children and adolescents with chronic illness may experience academic difficulties. Despite the fact that the majority of students with chronic illness are normally intelligent, many, in the absence of known cognitive impairment, fail to achieve to their potential in comparison to their physically healthy peers (Dworkin, 1989).

Some children with chronic illness will experience diagnosable learning disorders. Rutter, Tizard, and Whitmore (1970), in the classic Isle of Wight community survey, found an increased incidence as compared to healthy controls (4.5%) of severe reading problems in children with chronic illness (14%), despite the absence of diagnosed neurological disorder. This would indicate that mediating co-morbid variables, may account for some academic difficulties.

Multiple factors may be involved in the aetiology of the academic difficulties experienced by children and adolescents with End Stage Renal Failure. Prolonged absence or multiple, brief absences from school may contribute significantly to school performance. Children who were marginally successful prior to the onset of the illness may be more vulnerable to the educational difficulties from intermittent school absences. Additionally, educational deficits are most likely to be manifested in school subjects that build on previous knowledge. For many children, falling behind and needing to catch up on missed work will result in anxiety, which may further interfere with their cognitive skills and their ability to concentrate.

Children with diagnosable learning problems, either preexisting or subsequent to the onset of the illness, may be at greater risk for schooling problems. Documented learning difficulties may require placement in the least restrictive educational environment in which the child may most optimally function or enable them to access integration support supplied through the school.

Some children with End Stage Renal Failure also experience more subtle academic difficulties. Teachers may erroneously attribute these subtle problems to the reactive effects of the illness, tolerate the impaired learning, and refrain from making referrals to the educational psychologist or special education consultant for follow-up. If the school-age child is unable to attend a regular school full time, arrangements must be made to bring education to the child. Children on haemodialysis can do schoolwork with a teacher during the dialysis treatment. Educational sessions offered during the haemodialysis treatment are not optimal for a number of reasons. Generally speaking each patient will only receive 1 to 1.5 hours of instruction per session, which limits the amount of material that can be covered. Beeping machines and noise from hospital staff and other patients adds unwelcome distractions to the learning atmosphere.

Attitudinal Issues in Significant Adults

School issues may be compromised by caregiver attitudes in the child's environment - at home, at school, and in the health care setting.

Parental Attitudes:
The attitude of the child or adolescent's parent(s) is critical to successful school programming. The process of the child's schooling often adds additional stress to the already overwhelming situations in which the child and family find themselves. Parents may feel that the emotional, and sometimes physical, effort needed to maximise educational experiences is excessive. Frequent outpatient medical visits that necessitate school absence may reinforce this feeling of futility in the parents. Absenteeism may be fostered more overtly by parental overprotectiveness, which expresses itself in constant surveillance. Additionally, some parents do not recognise that school attendance is vital. Typically, parents focus on the academic benefits of school rather than the social and developmental aspects.

Attitudes of School Personnel:
The successful integration of the child or adolescent into the school setting is dependent on the attitudes and preparedness of the teachers and other school personnel. Teachers who are unaware of their students' potential problems will be at a disadvantage in meeting the needs of these children with End Stage Renal Failure. For most teachers, dealing with the schooling of a child with a serious or chronic illness is a new experience. They often harbour a mixture of emotions similar to those that have been experienced by the child's friends and family since the time of diagnosis. Limited knowledge about particular diseases, preconceived ideas about certain disorders developed through negative experiences, and the vulnerability communicated by changes in the child's health or energy level may cause teachers to be overly sympathetic. Teachers may feel overwhelmed, unsure of how to approach the child, uncomfortable seeking information from the already stressed parents, and unable to deal with their own feelings about the situation. Lacking the knowledge about how to relate, teachers may overidentify with the child with a chronic illness, frequently exhibiting a reluctance to challenge the student to his or her potential. On the other hand, teachers may be unable to recognise true limitations and exert unrealistic expectations, which may lead to frustration and discouragement. Occasionally, the tendency of the teacher to minimise the child's problems may alter the teacher's ability to accurately report the child's behaviour or performance.

Teachers may also worry that they will be unable to handle medical issues that may arise, whether they involve emergency measures or protecting the child from injury or infection. These fears may cause the teacher to be even more protective - overreacting to even minor complaints, which isolates the child and further hampers his or her normalisation process, decreases the child's self-confidence, and limits peer acceptance. Teachers are often concerned about how the presence of a child with End Stage Renal Failure in the classroom will affect their other students. They may feel unprepared to handle the reactions of the other children. Inadequate information and preparation make it almost impossible for teachers to facilitate acceptance of children with such illness by their healthy peers. Additionally, teachers may be concerned that an ill child will require too much personal attention and limit their ability to meet the needs of the other children in the class. The teacher may feel caught between the seemingly conflicting demands of caring for the individual child and continuing to meet the needs of the remainder of the class.

Attitudes of the Health Care Team:
Failure to communicate with the school compromises the coordinated care of the child. Lack of adequate medical information concerning the child's special needs limits the school's ability to meet the needs of the child with a chronic illness.

Successful School Integration Plan

Although no single intervention plan can be applied to all situations, the investigations have nonetheless identified four guidelines that have proven useful in facilitating school acceptance:

- preparation of the child and family,
- preparation of the school personnel,
- preparation of the class, and
- continued follow-up of the child at school.

Preparing the Child and Family:
It is imperative that school programming be discussed almost immediately from the time of diagnosis. The health care team should clearly communicate to the family that education is an essential component of the child's overall treatment plan. Schooling is particularly significant because it gives the child the symbolic message of normality.

Specific issues need to be addressed with children faced with schooling after the diagnosis of an illness such as End Stage Renal Failure. Adequate information about the condition, as well as an awareness of what questions might be asked by peers and teachers and what responses may be given in return, help prepare the child for this often stressful process. The child is also taught coping strategies to deal with possible peer interaction difficulties such as teasing.

Practise in question-answer sessions has proved to be particularly beneficial. Sometimes, classmates who visit the child in the hospital or home while undergoing treatment become allies and facilitate the school program.

Preparing the Teacher:
Even if it is not possible at the time to include the parents, the team member and school personnel should initiate the development of a school plan. It is important to designate one teacher, counsellor, administrator, or Welfare Co-ordinator who will act as a liaison among the school, family and medical team. It is critical that this individual have the time and inclination to undertake the responsibility of keeping all the child's teachers, informed and updated. During this initial planning phase, information is provided to school personnel regarding the nature of the child's illness or any impairments. The child's teacher is an important ally and can make a significant contribution to promoting normalcy. Information that a teacher requires is outlined in the following:

Informational Needs of Teachers:

- Nature of the child's illness, prognosis, and how it is being treated
- Specific treatment side effects
- Specific physical capabilities or limitations
- What the child knows about or calls the illness
- What the parents want the class and other school personnel to know
- What the child would like peers to know about End Stage Renal Failure
- Schedule of upcoming medical appointments

Sometimes it is also beneficial for the teacher to share their concerns with the child's physician or team member. This will assist the teacher in establishing realistic goals for the child. Teachers should be encouraged to maintain appropriate expectations of behaviour and achievement, despite the illness. It is critical that the medical information provided to the teacher be child specific and education related. Often, informal achievement testing will assist the teacher in determining the child's level of functioning at the time of schooling and assist with educational planning. General teaching approaches that might be incorporated with children evidencing learning and behavioural difficulties are outlined in the following:

General Teaching Techniques:

- Avoid teaching at a frustration level. Teach at a level that is easy but challenging for the child. Careful evaluation of his or her current level is critical.
- Help the child to structure tasks so that he or she can proceed step by step.
- Be firm. Do not allow the child to escape a task he or she is currently capable of doing. Be consistent.
- When necessary, teach global organisational techniques.

Preparing the Class:
From the time of initial diagnosis, classmates should be encouraged to be actively involved with the child who is ill. If the child is hospitalised for any period of time classroom contacts help bridge the gap between school and the hospital, making children who are chronically ill feel that they are not forgotten and that their return to the classroom is expected.

Follow-Up:
The importance of follow-up is frequently underestimated in the overall plan. However, this is a crucial component, because complications with the illness and the process are likely to occur over subsequent months and even years. Follow-up should include both support for the child and family and continued contact with the teacher. Follow-up with the school will need to occur in order to induct new staff and acknowledge difficulties that have arisen.

CONCLUSION:

Successful school integration must be a dynamic, ongoing process requiring continuous cooperation and commitment among the home, medical team, and school. Failure to prioritize education on the part of the family, school, or medical team compromises successful school integration and ultimately the child's educational progress.

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19. TRANSITIONAL CARE FOR THE YOUNG ADULT WITH END STAGE RENAL FAILURE

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Why do we need transition programmes?

The survival of increasing numbers of children with chronic diseases or disabilities into adult life has highlighted the need to transfer these young people from paediatric to adult services. There is a consensus among adolescent health clinicians that young adults should receive their care in adult services[1,2]. In Australia that policy is supported by state and national health policies[3]. Data suggest that young people with chronic disease or disability experience difficulties in making the transfer from the holistic care in paediatric services to the disease-centre care in adult services and that some patients may opt out of regular medical care to the detriment of their health[2]. There are considerable obstacles[2,4] to successful transfer to adult services. These arise from the patients, their families, paediatric caregivers and the adult team and some are listed below:

1. The patients: Dependent behaviour, immaturity (cognitive, emotional, social), severe or unstable illness or disability, lack of support systems, feeling of abandonment by paediatric caregivers, lack of confidence in adult caregivers, poor compliance.

2. The families: Emotional dependency, need for control, overprotection, lack of trust in caregivers, lack of parental consultation in adult environment, lack of focus on future.

3. The paediatric clinicians: Emotional bonds with patient and family, Ignorance of adult health care system, concerns about ability of adult caregiver to provide equivalent level of care, ambivalence to transfer of care resulting in insufficient preparation of the patient and family.

4. The adult clinicians: Lack of resources to provide interdisciplinary care, ignorance of disease process and developmental tasks of adolescence, perception of excessive care demands.

Transition of Transfer?

Discussion began more than ten years ago about how young people could move successfully to adult services and the concepts of transition and transition services were developed. Transition has been defined as "the purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-orientated health care systems"[1]. The purpose of transition is to provide uninterrupted and coordinated health care so that the young person maintains health status and copes with and feels comfortable in the adult health care system. Transition is a process which involves the whole family and paediatric team[5]. Planning for it should begin early in a child's illness and the process continues after the young adult has moved to an adult service[5]. The actual transfer to an adult programme is simply an event in transition. Several models[2,5] of transition programmes have been identified:

1. Disease specific models in which the young adult moves from the paediatric service to a transition team utilising paediatric and adult clinicians and finally to the adult system. Within this model certain clinicians (frequently nurses and/or social workers) provide continuity across the settings.

2. Generic models where the patient moves from paediatric to adolescent to adult services with co-ordination by general paediatricians or adolescent physicians and with adult and paediatric specialists acting as consultants.

3. Primary care models where the care co-ordinator is the general practitioner and where paediatric and adult specialists act as consultants.

Whichever model of transition is used, several factors[2,4,5] are considered important in the establishment of a transition programme. These are:

1. Perception that there is a need for a transition process.
2. Commitment by the paediatric team to the process.
3. Perception that the programme should address social, emotional, vocational, sexual and general health needs as well as the specific disease concerns.
4. Perception that the young adult and the family are transferring.
5. Acknowledgement that the time for the transfer cannot be fixed.
6. Identification of adult clinicians prepared to pursue the task.
7. A co-ordinated approach with formal and informal communication to foster the development of trust between the teams in preparation for the physical move.
8. Institutional support and resources.

Do transition programmes exist and do they work?

Despite the development of the concept of transition and the increasing numbers of young people requiring treatment in adult facilities, few transition programmes[2] exist in Australia or in other countries. Most young people are transferred to the adult system "in a very *ad hoc* fashion" while others remain in or return to paediatric service is available for them[2]. Though it is presumed that transfer may result in deterioration in health status, there are few data available to confirm this. In addition to date there are few data showing improved health status because of a transition programme. Studies of young adults with cystic fibrosis[6], rheumatoid diseases[7] and diabetes mellitus[8] suggest that formal transition programmes are more likely than *ad hoc* transfer to result in the young person continuing his or her care in the institution to which they were transferred.

What information is there about transition of renal patients?

Most children with ESRF now survive into adult life. In Australia the 10 year survival rate of patients transplanted before 15 years of age 85%[9]. ESRF is not a "new" problem for adult services and facilities to care for adult patients with ESRF are well developed with widespread availability. These facilities deal with large numbers of older patients and the small numbers of young people transferred annually from paediatric services are diluted in the much larger population of adult patients. In 1995 in Australia[9] there were 396 young adults with ESRF aged 15-24 years, which covers the age for transfer, in an ESRF population of over 8530. Resources are stretched in adult services restricting the access of patients to the range of services generally available in a paediatric service. These factors could militate against the successful transfer of a young person from the cosy protected paediatric service to the unfamiliar and comparatively unfriendly adult health service unless a transition process has been put in place. Cadaveric graft survival in adolescents aged 15-19 years has not improved with the advent of cyclosporin and there is a higher documented rate of non-compliance causing graft loss in this age group[10]. It is possible that transfer to an adult service could contribute to this.

Transition has rarely been addressed in the nephrological literature. Professor J Stewart Cameron[11] points out that the biggest danger is loss to follow up and the biggest problem is the physical and emotional gap between paediatric and adult services. This problem is particularly great when the paediatric renal service is sited in a separate paediatric facility. Patients and families quickly sense the degree of rapport between the two services. The effect on the transferring adolescent and his/her family is likely to be great if advice in the new facility conflicts with that previously adhered to. Professor Cameron urges careful planning of the transfer with both sets of staff recognising the size of the problem and their need to compromise their behaviour and attitudes when dealing with transferring patients. Paediatric nephrologists need to plan for long term survival when considering such things as cytotoxic therapy, nephrectomy, protection of vascular access and growth and adult nephrologists need to be aware of long term problems in diseases such as cystinosis. In concluding Professor Cameron argues that training programmes for both paediatric and adult nephrologists should include some training in the other service.

How are young people with ESRF transferred to adult services in Australia?

We received a 100% response rate to a questionnaire on transition sent to twenty one paediatric nephrologists in Australia. One physician does not transfer his patients. Most physicians transferred their patients when the physician (14; 70%) considered the patient ready and/or the patient (15; 75%) felt ready. Though 16 (80%) physicians considered the patients underwent transition and 20 (100%) prepared their patients for transfer, only 2 (10%) began the process more than 2 years before transfer. Of 19 responses, only 3 (16%) indicated that there was no introduction by a paediatric clinician to the adult team. Nurses (12; 63%) and doctors (10; 53%) were most likely to perform the introduction with both involved in 7 (37%) responses. Ten (53%) physicians indicated that they formally reviewed their patients at least once during or after transfer; in 6 of these responses young adults were seen effectively in the same institution. Four respondents reported that clinical deterioration occurred in a total of 10 patients; 8 were non compliant with follow up or treatment post transplant. In conclusion, paediatric nephrologists consider that they prepare their patients for transfer but some patients suffer clinical deterioration following transfer. It is possible that this deterioration could have been prevented by greater attention to the transition process.

How should the transition of young people with ESRF take place in Australia?

The following ideas have developed during the preparation of this paper and have not been tested. We believe that the transition process should be considered in four phases - preparation, assessment of readiness, transfer and follow up.

1. Preparation

This should begin many years before transfer and probably at diagnosis and should involve the patient, the family and all members of the paediatric team. The first aim of the preparation phase is to enable the young person to manage in the adult environment. The young person needs to achieve control over the management of his/her disease. He/she should develop the sense that he/she is an effective person with the ability to perform things necessary for managing his/her life. The development of this self-efficacy has been shown to result in improved compliance[12]. This could be achieved through a programme for all adolescents with chronic diseases or disabilities and could be run in groups by or with input from the adolescent service. The Cystic Fibrosis management team at the Hospital for Sick Children, Toronto has described a programme to encourage self management[13]. The goals for each age group are set in terms of the behavioural, emotional and cognitive developmental milestones expected. The goal of the programme is to have the young person totally self-managing by the age of 16 years. The second aim of the preparation phase is to provide the young person with accurate information about the adult system. This requires that the paediatric team learn themselves about the differences between adult and paediatric systems and find out how the adult teams perceive the differences and how they perceive that transition process. The third aim is to prepare the families for the move emphasising that the young person has a future.

2. Assessment of readiness to transfer

Currently, judging by the results of the questionnaire, physicians decide with our without the young adult's input when that person should transfer. It is not clear what criteria we use to determine "readiness". We need to determine what we mean by "readiness" and we need to monitor how young people are progressing towards it. One way could be to develop a check list of "transfer competencies" for the disease, including such things as knowledge about disease and medications, and for adult life, including their general problem solving ability.

3. Physical transfer

Because of the small number of young people involved and multiple adult units, transition clinics as such are not cost effective. Each person will be transferred as an individual. While it

is ideal to transfer a young person to a unit where the adult team has a commitment to transition and is well known to and trusted by the paediatric clinicians, this may not be possible. Ideally one person on the paediatric team should be identified as the transfer co-ordinator. The transfer co-ordinator would get to know the appropriate adult clinicians, introduce the young adult to these people in either the paediatric or adult facility and show him/her the adult facility. For dialysis patients, the most obvious person to co-ordinate the transfer is a senior renal nurse since most dialysis care is co-ordinated by renal nurses. For transplant patients, it is less clear who the co-ordinator should be. A young adult could be transferred to a transplant clinic or to see a renal physician privately. However standard outpatient clinics where waiting times are prolonged and where a patient may see a different physician on each visit are poorly tolerated by adolescents, who value continuity of medical care, short waiting times and an informal atmosphere[8]. Many adult clinics do not have a system in place for following up non-attenders. In conventional adult diabetic clinics, it is reported that 20% of young adults gave up attending the clinic at all[8]. While transfer to clinic or private rooms will differ from centre to centre, we favour transferring care of a transplant patient to private rooms to ensure continuity of medical care. However a senior paediatric renal nurse remains the best transfer co-ordinator to ensure that the patient becomes known to a senior transplant nurse to provide an additional and more easily available resource person for the young person. Again a check list of things to be attended to at transfer may prove useful. While a senior renal nurse is the co-ordinator for the young person, the social worker may perform that role for the family. In cases where the adolescent and/or family have special needs, a case conference may be required.

4. Follow up

We believe that the young adult and their family should be followed up in person orby telephone after physical transfer and that the transfer co-ordinator and social worker should be available as contact people. There should be at least one formal post transfer visit to the paediatric team. Where paediatric and adult facilities are in separate institutions, paediatric clinicians will have no authority in the young person's care once that person has transferred to the adult service making formal follow up by the transfer co-ordinator and the paediatric team difficult unless agreed to by the adult team and authorised by paediatric and adult institutions. This will need to be organised before transfer.

CONCLUSION

We believe that young people with ESRF and their families should be involved in a transition process. The views on transition provided above are largely personal and untested by us. Part of the process involves a better knowledge and understanding of the paediatric or adult service by the other. To this end we would endorse Professor Cameron's view that adult and paediatric nephrologists should receive some training in the other service to increase the understanding of both groups of issues relating to transition. We would argue that this should be extended to other clinicians, particularly nurses and social workers. Finally paediatric nephrology clinicians should consider obtaining retrospective data on the outcome of transfer to assist in planning transition processes and to provide data against which to measure the outcome of such processes.

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20. REQUIREMENTS FOR PAEDIATRIC END-STAGE RENAL FAILURE PROGRAMS IN AUSTRALIA

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ABSTRACT

The minimal requirements for a paediatric end-stage renal failure (ESRF) program have been determined from the context of achieving the two goals of ESRF management. These goals are the provision of optimal care for children with ESRF and the care of the body of knowledge unique to this area of paediatric nephrology. The requirements include (i) diagnostic facilities including imaging, renal biopsy and interpretation, urodynamics and urological investigations under anaesthesia, (ii) treatment services including acute and chronic haemodialysis, haemofiltration, dialysis access surgery, renal transplantation, (iii) training facilities for home peritoneal dialysis, and the administration of erythropoietin and growth hormone, (iv) facilities for hospitalisation and ambulatory consultation, and (v) staffing with medical, nursing, dietetic, social work, psychiatric, and other supporting staff. The organisation of these requirements for the ESRF program will vary depending upon the geography, population density and culture of the communities served by the program. In each case the organisation of these elements must solve equity issues and place the service in a paediatric environment. Achieving a critical amount of patient related activity and enough staff number is central to achieving the aims of the paediatric ESRF program. Overall this seems to be occurring in Australia through a greater number of ESRF treatments per patient and higher numbers of staff. The extension of paediatric ESRF programs to long term patients of the service to the age of around 21 years, the adoption of a "one team, multiple site, different practice" approach or the amalgamation of centres will allow critical mass to be achieve. Organisation failure, attributable to geographic isolation and small population density and physician/paediatrician autocracy, result in a significant segment of the Australian population not receiving appropriate minimal ESRF care.

INTRODUCTION

The minimal requirements for a paediatric end-stage renal failure (ESRF) program vary between communities because of differences in resources, willingness to spend those resources on ESRF, and a community's cultural values. Comparing individual cases the differences in requirements are more marked. For instance, the decision to place a child with congenital nephrotic syndrome or severe ESRF in early infancy on the ESRF program requires more resources than the decision to not place the child on the ESRF program. The author has evaluated the minimal requirements from his background in a large metropolitan paediatric teaching hospital providing care in a developed nation with, largely, Western values.

From the authors view, the aims of ESRF treatment should determine the minimal requirements for an ESRF program. Thus, the author has chosen to consider the following points:

1. An overview of paediatric ESRF in Australia.

2. The aims of a paediatric ESRF program.

3. The methods of achieving these aims encompassing both the physical requirements and the staff work required.

4. The organisation by which the methods may be employed and by which the economic costs are considered.

5. Means of developing of higher standards for paediatric ESRF programs.

1. OVERVIEW OF PAEDIATRIC ESRF PROGRAMS IN AUSTRALIA

Demographic data on the population in Australia are shown in Table 1 with emphasis on the number of children and projections of changes over the next two decades.

A decreasing birth rate and a lower immigration rate has seen the number of children in Australia remain relatively constant over the last two decades (Table 1)[1,2]. The number of new patients (0-14 years old) with ESRF has remained steady from the years of 1987-1995 (Table 2)[3].

However an analysis of further data in Table 2 shows that paediatric ESRF program activity has increased significantly in the 1990's. The number of new patients on haemodialysis (1. NEW HD, Table 2)in the age group 0-14 has increased since 1993 and there has been a smaller increase in the age group 15-24. In contrast the number of new patients on CAPD (NEW CAPD, Table 2) has tended to decrease in the age group of 0-14 and remain the same in the age group 15-24 over the years since 1986-1996. When both forms of dialysis are considered (ALL DIAL, Table 2)together there has been only a small increase in the number of patients on dialysis in the age group of 0-14 and a moderate increase in the number of patients aged 15-24. The transplantation data prior to 1990 has been coded in age groups of 0-9 and 10-19 in the ANZDATA registry. Thus, the author has only considered the transplantation data from 1990 because this is comparable with the data for dialysis in that both data sets are for the ages 0-14 and 15-24. The transplantation data shows a tendency for an increase in the number of transplants done in the later years compared to the earlier years in the 0-4 year age group but no change in the number of transplants done in the 15-24 age group. However, when the activity of new patients on haemodialysis, peritoneal dialysis and transplantation is summed, as displayed in the fields for total activity in Table 2, it is clear that there is an increase since 1990 in the number of new patients entering any modality of treatment.

In the context of a stable patient population base, no increase in the number of ESRF patients (Table 2), the finding of increased total activity seems to relate to underlying changes in the major units in Australia. In the lower half of Table 2 the number of paediatric nephrologists in each centre has been listed by year and an estimate made of the number of effective full-time nephrologists is below that. These numbers have increased since 1990. The number of nephrologists has increased since 1990. Major changes in treatment occurred around 1989-1991 with the introduction of erythropoietin and recombinant human growth hormone. The relocation of all clinical services (transplantation and haemodialysis) from the Royal Melbourne Hospital site to the Royal Children's Hospital site occurred in 1994, and the amalgamation of the Westmead Unit with the Camperdown Unit on a stand alone paediatric site occurred in late 1995 with the introduction of transplantation and haemodialysis in the paediatric hospital. In 1995 the Perth Unit lost the paediatric haemodialysis stand alone unit.

How do these changes described relate to the minimal requirements for paediatric ESRF programs? These data indicate that the resources consumed in paediatric ESRF programs have increased and the activity of the two largest units now takes place entirely within paediatric environment. The writer concludes that the resources consumed by paediatric ESRF programs have increased over the last decade.

2. AIMS OF PAEDIATRIC ESRF PROGRAMS AND MEASUREMENT OF SUCCESS IN ACHIEVING THOSE AIMS

The aims of a paediatric ESRF program are to care for children with renal failure and to care for the knowledge unique to paediatric nephrology. It follows that the minimum requirements of an ESRF program relate to requirements to achieve both these aims.

Care for the paediatric patient with renal failure is meant to be applied in a broad sense. It not only concerns the choice and provision of appropriate physical therapy (drugs, diet, dialysis, transplantation) but also the evaluation of the appropriateness of that treatment in an individual

case and the psycho/social approach adopted with that person and their family. The measurements of the success of this care are include patient and graft survival rates, length of time on dialysis, height and weight outcome, developmental assessment outcome, and ultimately the number of patients maintaining gainful employment and leading independent lives compared to the number of patients dying early through preventable cardiac disease and suicide. The success achieved by paediatric ESRF programs has made such factors as one and five year graft survival times, and patient survival times to 10 years meaningless indicators of the success of programs because they are all too short in time span to judge the effectiveness of a paediatric treatment program. With cadaveric mean survival times of 7.5 years and one halpotype living-related renal transplants having a median survival of at least 15 years it seems that many of these parameters will only be judged historically. The challenge is to find meaningful measurements that enable a current patient treatment group to be assessed in a shorter period of time.

The knowledge base of paediatric nephrology is the raison d'etre for paediatric ESRF program. This knowledge base differentiates the paediatric nephrologist from the paediatrician and from the adult nephrologist, the nephrology nurse is the succour of the child with renal failure and their family because of this knowledge, and the worthiness of the work of the renal dietitian, play specialist, urologist, and other members of the paediatric ESRF team is related to the knowledge of this speciality. A minimum requirement is the preservation of existing knowledge and the acquisition of new knowledge. A corollary of this is the education of the public which includes arguing against the misinformation and ignorance of our colleagues and other professionals. This knowledge gives the confidence and obligation to argue for the best practice standards. Thus, care for the knowledge base involves teaching and research.

3. METHODS OF ACHIEVING THESE AIMS

The writer has drawn much of the data for the components of a paediatric ESRF program from the report of a working party of the British Association for Paediatric Nephrology (BAPN) entitled "The provision of services in the United Kingdom for children and adolescents with renal disease" (published in March 1995)[4].

1. Paediatric Environment

Children need to be managed in developmentally appropriate environment. This is an accepted principal of paediatric care, yet it is notable that it has often been observed in the most minimal sense in a majority of paediatric ESRF programs in Australia (as well as in Britain) over the last decade with regard to haemodialysis and transplantation in particular. The counter argument has been that these treatment modalities cannot be justified due to the low numbers of patients requiring them and that facilities should be integrated in the adult site. The BAPN recommendation, with which the writer agrees, is that haemodialysis should be staffed on the one-to-one patient to nurse ratio and that schooling or play workers be available for the session. The economic justification for use of adult facilities has involved not having a one-to-one nursing requirement and not having a school or play therapist and not having the close supervision of a paediatric consultant (which is part of the consultant driven approach of paediatrics as opposed to Hospital Medical Officer driven approach of adult medicine). Currently haemodialysis is established at home on a daily basis in adult medicine, and dialysis technician transport machines anywhere to establish dialysis, so the off-paediatric site for haemodialysis reflects lack of imagination and poor organisation in the paediatric ESRF program. Similarly, in transplantation rather than the patient move to the adult hospital the transplant surgeon should move to the paediatric institution.

2. Diagnostic Facilities

The following need to be available:

(i) A renal biopsy service. The histopathology need not be performed on site and there would be advantages to having a common city wide pathology centre staffed by a specialist renal histopathologist who was familiar with disease in children.

(ii) Radiology and ultrasonography including nuclear imaging, arteriography and facilities for performing antegrade pyelograms.

(iii) Urodynamics. The minimum required is the ability to measure pressure and volume relationships in the bladder.

(iv) Specialist biochemistry, microbiology and haematology.

(v) Facilities for 24 hour ambulatory blood pressure monitoring are desirable.

3. Treatment Services

(i) Acute renal failure: peritoneal dialysis, haemodialysis and haemofiltration.

(ii) Plasma exchange is optional depending on treatment protocols.

(iii) Facilities for continuous ambulatory peritoneal dialysis, continuous cycling peritoneal dialysis and haemodialysis.

(iv) Urological, and dialysis access surgery.

(v) Renal transplantation.

4. Staffing

(i) Consultant medical staff
As in most areas of paediatrics, consultant medical staff play an active hands-on role. The paediatric ESRF program should be located within a paediatric hospital with other paediatric subspecialists available. From what has been discussed, all consultant medical staff need proficiency in the diagnostic and treatment modalities. A background in adult renal medicine can be seen as an advantage in providing greater experience in diagnosis and treatment methods.

The BAPN working report suggests that a minimum of four consultants each devoting not less than eight notional half days per week to nephrology should be available in every comprehensive centre providing a service for a population of 3-5 million. The writer is of the opinion that a paediatric ESRF program should be available to initiate major treatment changes or perform transplantation at any time. This means that there is no place for a service where general paediatricians cover for nephrologists to provide services. This implies there is no place for a single paediatric nephrologist working in isolation (ie. without, at least, adult nephrologist cover).

(ii) Junior Medical Staff. The paediatric ESRF program will have junior medical staff comprising of specialist trainees rotating through the program for variable periods of time. It is not necessary that any of these be specifically training for paediatric nephrology. It is desirable if these trainees spend greater than three months in their term with the program so that they can contribute something to the running of the program.

(iii) Nursing Staff. The minimal requirement for the paediatric ESRF program is a nurse recognised as the leader of the nephrology nursing staff and a staff that can provide dialysis any time of their working week. The "charge" nurse needs to have the equivalent of the Post-Graduate Diploma in Advanced Clinical Nursing - renal stream. They need to have experience in haemodialysis, peritoneal dialysis and renal transplantation. It needs to be realised that adult training may be an advantage in enabling a nurse to obtain sufficient throughput of experience

to be able to obtain such training and the required degree of proficiency within a few years. The charge nurse needs to be able to maintain nursing standards throughout the group of nurses and needs sufficient nurses to be able to organise the program so that cover is available at all times. At the RCH, Melbourne, the maintenance of peritoneal dialysis capacity results in 18 nurses needing to be trained at anytime in peritoneal dialysis, and to maintain haemodialysis for up to 5-6 patients requires 12 nursing staff being trained each year to maintain a competent group of about 6-8 nurses.

The nursing staff levels recommended by the BAPN working party report are as follows[4]:

a. Haemodialysis service for end-stage renal failure 5 years and under 1:1 for patients aged more than 5 years 1:2

b. Ward nurse staffing. A ratio of 1:3 staff:patient ratio is desirable with 1:4 being the minimum acceptable for safety. Transplant recipients require 1:1 nursing for 48 hours post-operatively and up to 72 hours in children less than 5 years old.

c. Peritoneal dialysis for end-stage renal failure requires at least one nurse available for CAPD training, outpatient reviewing continuing care. Cover must be provided in the absence of the CAPD nurse.

d. Community liaison, ambulatory clinics, urodynamics, and transplantation require designated nurses.

(iv) Dietitians. The BAPN working party report estimates one working time equivalent for every 3 million total population served[4].

(v) Psychiatric and psychologist. A family orientated service and adequate psychosocial support for patients in the paediatric ESRF program requires the ready availability of these staff.

(vi) Social Workers. The BAPN working report suggests one working time equivalent is required for every 3 million total population served[4].

(vii) Play Workers and Play Therapists and School Teachers. Prolonged hospitalisation is uncommon. Facilities should be available for the child who is hospital for a prolonged period of time.

The child in need of these workers is the child on haemodialysis. Haemodialysis takes time from school. Paradoxically, the author has observed that the school achievement of patients on haemodialysis has been accelerated when they had commenced haemodialysis compared to prior to haemodialysis. This is not related to an improvement in their level of well being on haemodialysis but more to the 1:1 interaction that takes place between play workers and school teachers. Thus, the presumed loss of school and the child's school environment must be balanced against the increased attention the child receives while on treatment in an effective paediatric ESRF haemodialysis centre. The activity of the child during haemodialysis is in marked contrast to the adult who puts out his arm and goes to sleep, and is an argument for use of central venous access rather than AV fistula access.

(viii) The renal office secretary/manager. An effective and competent receptionist/secretary/office manager is necessary for the paediatric ESRF program. This person acts to field calls from anxious and confused parents, passes on messages to harassed doctors, organises appointments in a timely fashion and is able to sort out sick patients from patients who can wait longer to be seen. This person becomes a disseminator of results and a confidant to the parents who work through her to liaise with the medical and nursing staff. The resources used on maintaining a good office are well spent.

5. Quality Assessment

The BAPN suggests service audits that should be initiated and maintained which seemed reasonable[4]. These include the equivalent of:

(i) ANZDATA registry material such as new patients and stock of patients on ESRF management[3].

(ii) Workload data for specific renal services.

(iii) Confidential enquiry into any child dying from acute or chronic renal failure to identify preventable factors.

(iv) Development of protocols and management guidelines on routine program work.

(v) To these could be added procedures to ensure that treatment ordered is delivered (drugs and drug doses in the Ward etc), patients with potential progressive renal problems followed if they miss appointments, and participation in hospital quality assurance programs.

6. Education

Paediatric ESRF program must have education commitments. This will be directed towards:

(i) Staff in Unit.

(ii) Junior and Hospital Resident Staff.

(iii) University students.

(iv) Community interested participants (eg. maternal and child health nurses).

It is desirable that the program establish a set of formal lectures so that the dissemination of subspecialist knowledge can be facilitated.

7. Research

The paediatric ESRF program must be involved in research.

1. Local and specific - this may involve laboratory based research or clinical based research

2. Collaborative research. Each paediatric ESRF program has a duty to participate and co-operate with other programs in furthering the knowledge of the subspecialty.

4. ORGANISATION OF THE RESOURCES OF THE PAEDIATRIC ESRF PROGRAM

The organisation of a particular paediatric ESRF program will be dependent upon on the geography, population density, ethnic culture(s) and funding available in the community served. The organisation must be developed to solve the equity issues so that everyone has access to appropriate treatment. The organisation of the "bits and pieces" discussed under Methods is the way in which apparently scarce resources can be made to provide an effective service or which abundantly sources may be wasted to provide a second-rate service.

The organisation possible depends to a large extent on the way in which State health funding is handled. The Victorian program which was initiated in 1994 provides a particularly innovative method of funding that enables adult and paediatric units to develop their own services in their

own way[5]. Under the Victorian Maintenance Dialysis Program a unit cost for a year of service in providing dialysis to a patient is provided to the ESRF program that cares for that patient. In addition there is a service fee for each episode of treatment that is paid to the hospital or service that provides that particular service. For example, a parent unit caring for a patient on haemodialysis receives around $34,000 per year for providing for that patient's service. If a patient requires recurrent admission to hospital, or dialysis centre for treatment and additional $17,000 can be claimed per patient per year. The first payment, the program grant, pays for the turnover of dialysis machines, the training of staff, the running of the infrastructure to support the patient (eg. dialysis fluid). The second payment pays for the staff to do a particular treatment (eg a 4 hour haemodialysis treatment with a dialysis nurse).

The program has the disadvantage that if a program is successful at transplanting all dialysis patients then the funding decreases to zero unless those patients are replaced with new ones. This is a particular problem with paediatric units that require support to maintain facilities when patient numbers may be lower. The administration of a hospital may not pass on funding to the paediatric ESRF program.

Privatisation of services in Victoria has enabled the paediatric ESRF program at RCH Melbourne to develop somewhat independently from the Hospital because less that 50% of the funding for the program's activities comes from the traditional Hospital budget. This has been particularly important in the development of Victorian ESRF programs where paediatric leadership and hospital rivalry undermined development of paediatric ESRF programs.

An overview of the organisation of services in Victoria is shown in Figure 1. A "one-team, multiple site and different practice method" approach is a goal; one group of consultants who have respect for each other and communicate on a weekly basis; multiple site acknowledging the historical development of two separate paediatric ESRF program infrastructures; and different practice methods recognising that there are different ways to manage a patient with ESRF with the equivalent end results, that patients need a choice of physician and method (to what extent that is possible), and that Australian practice is isolated and risks becoming idiosyncratic in a particular case.

5. THE DEVELOPMENT OF HIGHER STANDARDS

The weakest aspect of the Australian paediatric ESRF program is the time available for education and research. This comment could be made about most aspects of medical practice in Australia. From a practice point of view greater numbers of patients would be a help for most programs. The achievement of greater resources, uncommitted time and higher practice throughput could all be achieved by:

(i) increasing the age at which treatment is delivered. The long term patient of the paediatric ESRF program could be maintained in the program to a later age, say 21 years, if ESRF treatment activity was likely before that age. Table 1 shows that the 15-24 year age group activity is two to three times that of the activity between 0-14 years age group. Most paediatric hospitals have developed adolescent programs with inpatient facilities. The paediatric ESRF patient often has developmental and intellectual problems and transfer to an adult program is often in the patient's interests if performed later.

(ii) amalgamation of units. The amalgamation of Westmead and Camperdown program seems to have resulted in a bigger, more productive program to the author.

(iii) acquisition of more resources - unlikely in the present environment.

A process of formal audit of a particular program by an "Audit Committee" of the ANZPNA may be useful to that program by providing an opinion, for example, that a certain service was needed by that program. Such an audit process may put some pressure on a recalcitrant hospital administration.

There are not children denied ESRF activity in Victorian because of lack of resources or staff (the same may not be the case in other States). Any potential new medical staff should need to jump a higher hurdle to be practicing in the State.

Development of practice clinics in outlying areas help both paediatricians and patients.

There are areas where there is impractical access to the paediatric ESRF program (eg. Tasmania, Northern Territory, Northern Queensland). Audiovisual communication links may help, but appropriate funding for these time consuming interviews needs to be found for their widespread use. In the author's experience children in these areas are often managed with adult nephrologists with little paediatric input. The regular, even if infrequent, regional clinic where the paediatric nephrologist reviewing the patient in the general paediatricians rooms, preferably with the paediatrician, is beneficial for paediatrician and child in organising treatment including diet, growth hormone, erythropoietin, angiotensin converting enzyme inhibitor therapy, dialysis and transplantation. Early transplantation programs may help, the author has found that general paediatrician liaison with the adult unit is often ineffective and attempts to engage the adult nephrologist in paediatric aspects of care may be politely ignored but should be tried.

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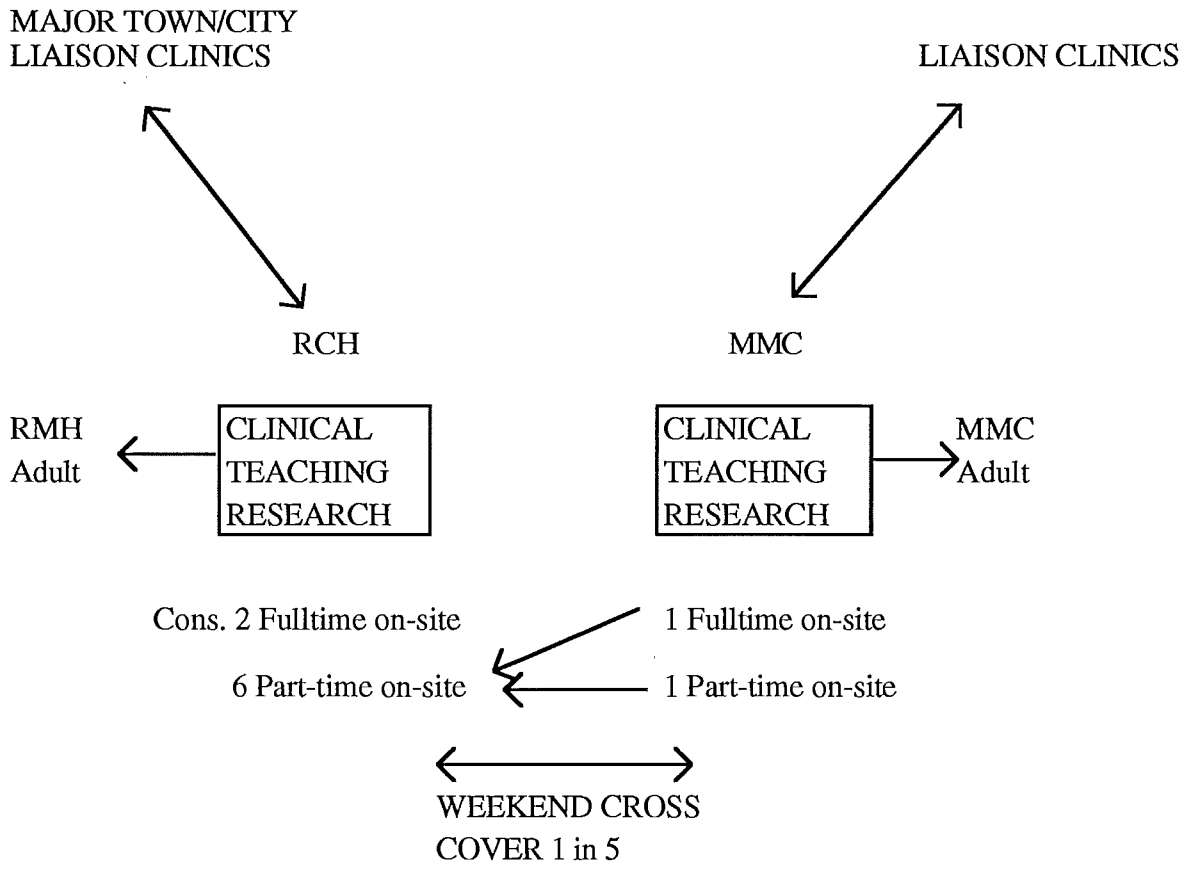

Figure 1 Overview of organisation of paediatric ESRF services in Victoria. Limited application of "one-team, multiple site, different (individualised) approaches to treatment" concept.

Table 2

		Year									
	Age	1986	1987	1988	1989	1990	1991	1992	1993	1994	1995
New ESRF Patients	0-4	-	4	4	4	4	8	7	4	4	12
	5-14	12	27	17	13	14	13	18	15	24	20
	15-24					60	59	62	55	65	64
NEW HD	0-14	10	4	9	9	9	5	6	5	11	12
	15-24	44	48	53	48	57	53	62	50	60	58
NEW CAPD	0-14	9	20	16	13	10	11	11	14	15	11
	15-24	19	23	26	19	20	29	21	26	24	23
ALL DIAL	0-14	19	24	25	22	19	16	17	19	26	23
	15-24	63	71	79	67	77	82	83	76	84	80
TSP	0-4 CAD					2	0	4	2	1	1
	LRT					1	1	3	3	2	5
	5-14 CAD					3	8	4	5	3	7
	LRT					3	8	11	6	8	13
	15-24 CAD					14	44	31	35	27	30
	LRT					7	23	14	10	20	17
TOTAL	0-14					28	33	39	35	40	49
ACTIVITY	15-24					98	149	128	121	131	127
No. of PAED NEPHROL'S (EFT)											
VIC		2.5	2.5	3.5	3.5	3.5	3.5	3.5	3.5	3.5	3.5
NSW		4	4	4	4.5	4.5	4.5	5	5	5	5
QLD		1	1	1	1	1	1	1	1	1	1
SA		2	2	2	2	2	2	2	2	2	2
WA		1	1	1	1	1	1	1.5	1.5	1.5	1.5
TOTAL		10.5	10.5	11.5	12.0	12.0	12.0	13.0	13.0	13.0	13.0

Table 2 Dialysis and Transplantation activity in Australia from 1986 to 1995[3]. See text for description. The number of paediatric nephrologists in each State has been crudely estimated from paediatric nephrologist's memories.

21. INTEGRATION OF THE PAEDIATRIC RENAL UNIT

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This presentation will to focus on the nursing issues related to the expansion and integration of the Paediatric Renal Unit at the Royal Children's Hospital (RCH), Melbourne.

The Royal Children's Hospital is a 300 bed general and acute paediatric teaching hospital. The hospital is part of the Women's and Children's Health Care Network. It is situated close to the central business district of Melbourne. The Victorian Paediatric Renal Service (VPRS) currently manages approximately 25% of the children in Australia with end-stage renal failure (ESRF).

Victorian Paediatric Renal Service - History

When the Service was introduced the needs of the children were very different to the needs of today. Prior to 1994, the end-stage renal failure program was limited and reliant of the nearby Royal Melbourne Hospital adult renal unit. Peritoneal dialysis was the only form of dialysis offered and the transplantation services was supported again by the adult hospital. The adult hospital performs the transplants on all children greater than 15 kg. In the middle of 1994 the need for expansion within the RCH was identified. This need for expansion involved a need to incorporate all facets of end-stage renal failure care within the paediatric environment. The expansion of the Renal Unit involved the transfer of the renal ward from a general medical ward to the previously existing specialist cardiac unit. Thus the integration of the Cardiac/Renal Unit began.

Victorian Paediatric Renal Service - Why Expand?

The first reason why it was necessary to expand the renal service within the paediatric environment, was because of the special needs of children. Children with end-stage renal failure have complex and specific needs, and it is important to nurse them in an environment appropriate for children. The paediatric hospital incorporates a comprehensive practice including physiological, psychological and social needs. The increased need to provide comprehensive service for end-stage renal failure at RCH, became more necessary as the advances in dialysis and renal transplant technology and treatment options allowed treatment possible for smaller and more complex children. As the Royal Children's Hospital is a major paediatric hospital with access to a wide variety of resources, expanding the Service allowed for a greater utilisation of available resources and ensured that all forms of renal replacement therapy were available, on one site, if needed.

RCH Cardiac Nurses

The nursing staff of 7 West Cardiac Unit were those who had the overwhelming and challenging task of learning the new specialty of nephrology nursing. There was a very large number of nurses, the majority of whom had very little prior renal nursing knowledge or experiences. Nephrology nursing is studied within the Nursing Diploma and Bachelor of Nursing, but since graduation the nurses have only utilised this knowledge to a very small extent. Despite their overall lack of nephrology experience, the nurses were very knowledgeable and confident within their chosen specialty of Cardiac nursing, and a high standard of nursing care was delivered within the Cardiac Unit. The nurses were experienced paediatric nurses with well developed acute and chronic paediatric nursing skills along with a high level of surgical and technological skills. The nurses had been working together, in some cases for many years, and therefore had developed a strong support network within the unit. This high standard of nursing staff, and made it easier to implement new nursing skills. It was extremely difficult for otherwise experienced nurses to be placed in frequent unknown clinical

situations. This problem was enhanced by the fact that they were already so highly specialised and knowledgable within their chosen specialty.

The Role of the Renal Co-ordinator - 1994

The role of the Renal Co-ordinator was a newly created position, beginning in 1994, primarily to support the expansion of the new unit. The first task for the Renal Co-ordinator was that of education. This involved education for the nursing staff, parents and the children within the Renal Unit. The education of the nursing staff, was the main focus in the beginning. The position also entailed that of a resource person and support person.

Development of the Independent Haemodialysis Unit.

In order to prepare for haemodialysis nursing, six senior Registered Nurse's were selected and attended a series of lectures, at the RMH. Following this, they each worked for one week in the adult in-centre haemodialysis unit (at RMH), in order to gain practical experience. Following this, one 3 year old child commenced haemodialysis and was stabilised at the Royal Melbourne Hospital. Fortunately, he had extremely reliable arterio-venous access via a dual lumen "Perm-cath". Once this child was stabilised, the one new machine and the one stabilised child were then transferred to the Royal Children's Hospital. The machine was placed in the corner of an otherwise six bed area within the ward. In the beginning, this was a supported environment, with one child and one machine. The Renal Co-ordinator was always present and able to provide total supervision for the nurses at all times. Time was available to develop comprehensive policies and procedure manuals, which were then able to be used as a reference.

Haemodialysis Problems

The nursing problems that were experienced, related to the development of the dialysis unit, were largely related to lack of prior nursing expertise. This was due to lack of prior knowledge and experience. This problem was enhanced by the fact that there was infrequent experience within the paediatric environment. In the beginning, there were six nurses performing haemodialysis and only one patient having twice weekly haemodialysis. The nurses experienced feelings of isolation, as they were used to working as part of a team and needed to adjust to working independently in the dialysis unit. There was a rapid increase in patient numbers, making it necessary to expand the number of machines. This increase in patient numbers, and their dialysis related problems was not predicted. We also experienced technical and plumbing problems related to the increase in number of machines and this significantly added to the stress experienced by both the Renal Co-ordinator and the new dialysis nurses.

Peritoneal Dialysis Nursing Skills

The introduction of peritoneal dialysis (PD) was stressful and difficult to control. This was probably for two main reasons. Firstly, patients arriving unexpectedly and requiring 24 hour dialysis care and secondly, the reality that in the paediatric environment admissions for PD were very infrequent.
20 senior ward nurses completed a short PD training course, conducted at the PD Centre. This course incorporated basic principles of PD and practical procedures such as bag exchanges. Apart from this course, it was difficult to teach everyone at once. The time elapsed between the training course, and actually performing a bag exchange on the ward was often a few months. It was necessary to carry out further PD training sessions, and bag exchange practical assessments, for all permanent registered nurses. The difficulties that were experienced were further enhanced by the comments of anxious parents who were carrying out PD at home. These comments were possibly the cause for more stress, especially for nurses who are otherwise extremely knowledgeable and confident. The way in which the difficulties with PD education, and nursing confidence was overcome when one child required a regular weekly hospital admission for social reasons. This served as a weekly practical education session and in the long term proved to be extremely beneficial.

Renal Transplant Nursing

The implementation of renal transplant nursing was relatively smooth for transplant recipients. This was because of the nurses' past experience with nursing heart and heart lung transplants recipients. The nursing issues are similar for children undergoing renal transplantation as they are for undergoing other organ transplants.

The management of the living-related renal donor was a further challenge for the nurses, the majority of whom, had been practicing in the paediatric environment for many years. Nursing care for adult patients is different and it was necessary for the paediatric nurses to consider the different needs of adult patients. This was made slightly more difficult and therefore more stressful when considering the emotional ups and downs of a post-operative renal donor.

The Educational Program Devised

The education program devised for the nurses consisted of a series of general nephrology lectures. These general nephrology lectures were incorporated into the ward education calendar and all members of the multidisciplinary team were invited to participate. Training courses for dialysis (haemodialysis and peritoneal dialysis), and Renal Transplant nursing were conducted as mentioned earlier. A "doubling" system was carried out for haemodialysis nursing, therefore the nurses were supervised until confident and competent to work independently. Clinical supervision was encouraged on the ward, if necessary, especially during new procedures. A self-learning package for PD nurses was constructed and available for nurses to utilise. The time to develop detailed policies and procedures manuals was taken. These manuals served as a Reference.

Barriers to Implementing Renal Care

The barriers that were experienced in implementing renal care, into the cardiac unit, included the little opportunity for nursing practice in the paediatric environment. This is related to the fact that clinical situations are often once off and that there is limited opportunity for nurses to learn from the experiences of their peers. There was a large number of nursing staff employed in the unit (52 in total), 15 of whom were part-time. The rotating nature of nursing, incorporating rotating shift work including night duty and weekend shifts, contribute to the difficulty of implementing a change. This also made it difficult to provide continuity of education. The RCH has a reduced changeover time for nurses of only one hour, during the day. This one hour shift overlap time has limited the time for education considerably. The nurses experienced feelings of fear, anxiety and uncertainty. These feelings acted as a negative forces affecting their ability to carry out the renal care.

A further barrier to the implementation of renal nursing was the lack of time. The process of learning and changing takes time. It was difficult for the nurses to find time to include education, learning and practising new skills along with the demands of the regular working day. It is important to allocate time for learning and education away from the routines of daily work, and away from the bedside. Many half day study days were carried out so that nurses could concentrate on learning new skills without the added distractions of ward routines and time restrictions.

Integration: Recommendations for Nursing

The recommendations for nursing arising from the RCH experience of integration of the Renal and Cardiac wards will now be discussed. It is necessary to ensure support from both the Medical Staff and the Nursing Unit Manager. It is essential to ensure a commitment to education. This commitment is necessary from both the nurses and the nurse manager. Appropriate time for education must be ensured so that education can be provided away from the regular ward routines. The appointment of Renal Clinical Nurse Consultant or Renal Nurse Co-ordinator to provide support, act as a resource and ensure quality management procedures is important. This position is particularly important in the paediatric environment with the small

number of children and their complex needs. The Renal Clinical Nurse Consultant can provide support for the children and their families as well as the nursing staff. Detailed policies and procedure manuals are necessary and are needed as a reference on the Ward for all staff.

It is important to allow sufficient time for change. This often difficult and especially difficult in the RCH experience, as the Haemodialysis Unit expanded very quickly. Encouragement and peer support for nursing is useful, as the nurses can support each other and assist each other when carrying out new skills thus reducing the burden. It is important to have an input into decision making. It is important for the nurses to have input into their learning needs and their need for support and supervision.

Victorian Paediatric Renal Service - Overview

In 1996 there has been an increase in the number of children on dialysis and the number of renal transplants performed, as can be seen in the following table:

	1993	1996
Admissions	171	246
Transplants	2	7
PD (pt months)	68.5	37.6
HD (pt months)	0	55.4

There is increased support, from RCH, for the national annual Kidney Kids Camp. A 'parent support group' for parents of children with chronic renal failure, was introduced in 1996, and to date has been very successful. Support for the children of the South-East Asia region has been carried out, particularly those children requiring living-related renal transplants. 3 children from overseas have undergone living-related renal transplantation in the past 12 months.

Victorian Paediatric Renal Service - Future?

The future for the VPRS includes plans to continue and to expand the support for the children of South-East Asia region. It is planned to continue to encourage and strive for the goal of living-related renal transplantation for all children with end-stage renal failure. The RCH encourages visiting medical and nursing staff to the unit.

22. HOW DO WE MAINTAIN OUR DIALYSIS NURSING SKILLS IN THE PAEDIATRIC ENVIRONMENT.

YOGI JEYAKUMAR
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Paediatric nephrology has grown in recent years. Nurses caring for these children in End Stage Renal Failure(ESRF) requiring dialysis need special skills and knowledge. As you know, there are many aspects of general renal nursing that are similar between adults and children. But one must always remember that a child is NOT a small ADULT! Although paediatric numbers are low, nursing skill and knowledge of both dialysis modalities commensurate. Paediatric renal nurses often face the difficulty of maintaining dialysis nursing skills when patient numbers fall. So, what methods are used to maintain dialysis nursing skills? With this in mind, I conducted a simole survey of the 9 paediatric renal units in Australia and New Zealand.

Aim

A written survey of the 9 paediatric renal units in Australia and New Zealand was conducted to identify patient population, staffing, treatment modalities and unit characteristics.

Methods

The survey involved a simple questionnaire. 100% response was achieved.

Results

Findings revealed that two units were stand alone units and seven were integrated within a specialty ward. Specialties varied between Cardiology, Cardio-thoracics, Medical, Surgical, Neurology, Neuro-surgery and transplantation. All units provided peritoneal dialysis. (PD). PD modalities included Continuous Ambulatory Peritoneal Dialysis (CAPD) and Continuous Cycling Peritoneal Dialysis (CCPD). Home training was provided by all units except one where training was done in the adult training centre. Four units provided both PD and Haemodialysis (HD). Two of these are stand alone units and two were integrated into a paediatric ward. Three units offer HD in an ICU/ Adult setting only. Two units did not offer HD as a treatment option. Although, one unit responded that there was a future outlook for HD to be offered as a treatment option in the next five years. Patient numbers were small in all units and ranged from 2-5 on HD and 1-10 on PD. Similarly, numbers of qualified nursing stsff were small ranging between 1-5. Qualified nursing staff are those who had completed a Graduate Certificate or a Graduate Diploma in Nephrology Nursing. The unit with five qualified nursing staff also provided other services such as plasma exchange, haemodiafiltration, cyclophosphamide infusions, albumin infusions, post-transplant follow up care and outpatients clinic.

Units integrated into a paediatric ward, generally rotated their staff into the dialysis unit and had 1-2 dedicated specialised renal nurses. Training programmes were provided by dedicated specialty nurses through short courses and inservice education programmes. Length of these courses ranged from 2-6 weeks. None of the units rotated staff to Adult services for hands on training The overall low numbers of children on dialysis can be attributed to the low incidence of ESRF, promotion of transplantation and progression onto Adult Units. From the numbers surveyed, PD appeared to be the most used treatment modality.

Further, advances in Cycler technology with automated machines like the Baxter Homechoice and the Gambro 100, has simplified usage and teaching. From a nursing point of view, the PD nursing skills are easily taught and generally well retained. Chronic HD on the other hand, although technically challenging, is a safe and viable treatment. It can be used as a primary treatment or as an alternative treatment when PD has failed or is not an option. With the advent of ultrafiltration controlled dialysis machines, paediatric lines and dialyzers many technical

problems have been reduced. However, nursing skills and knowledge are central to the successful management of these children.

Conclusion

In the light of these observations, I would like to stress that it is essential to have a paediatric renal nurse specialist liberated from the responsibilities of 'the ward' to provide ongoing education and training of ward staff. This, ensuring adequate back up support to provide the best possible care for these children. The qualified nurse specialist should also be encouraged to attend conferences, seminars and workshops to acquire and share knowledge with specialists from other units.

Through active participation in the Kidney Kids Camp, where children from various units are dialyzed together, it is an ideal situation for staff to discuss various issues pertaining to dialysis therapy. Support received from each other would no doubt be invaluable.

Rotation of qualified renal nurse specialists between units should also be encouraged in spite of the current economic and work commitment constraints. Rotation between paediatric units within the state and interstate should be considered. Rotation through adult units should also be an option especially if there is an adult unit within the institution.

I would like to conclude by saying that caring for these children offers a demanding but none the less a rewarding experience for me the renal nurse.

OPTIMISING CARE OF THE CHILD WITH ESRF/THERAPY SELECTION

Chair Persons: **A/Prof R Walker**
Ms M Nugent

Nephrology Peer Panel:

Dr M Falk
Ms A Bigham
Ms J Lawton
Ms K Latage

CASE 1.

28 y.o. mother of three healthy children in her fourth pregnancy. This pregnancy:

- *oligohydramnios*
- *18/40 ultrasound*
  - minimal liquor volume
  - no kidneys identified

Diagnosis: renal agenesis/Potter's syndrome

Family counselled
re: Dismal prognosis
re: Management options : *termination of pregnancy*
: *progress* (but expect neonatal death due to pulmonary hypoplasia and renal failure)

Subsequent Events

Family very upset: Father wants everything to be done, Mother overwhelmed but happy to go along with husband's decisions
Via Internet: Family locate USA doctor who recommends amniotic fluid infusions and neonatal dialysis (both techniques available in Australia)
Family Reaction: Contact media and Health Minister for financial help to go to USA.

The Chair directed discussion towards the following issues:

1. Should amnio-infusion and neo-natal dialysis be offered? Can it be refused?

2. What advice is given to families regarding Internet use and interpretation of what is contained on the Internet?

DISCUSSION BY MEMBERS OF PEER PANEL

Ms Kathleen Latage

The pertinent concerns for the family at this point of the pregnancy are issues around grief and loss in relation to the 'death' of a potentially healthy baby which is now replaced by an infant this is potentially and terminally impaired. With this pregnancy comes the loss of the family's dreams and hopes.

Whatever the parents decide, the difficulty is two fold during this very complex and difficult time. If a decision is made to terminate at this gestation there are not only issues of grief and loss but also often feelings of responsibility and potential conflict between the couple in relation to the decision. If is common for couples to experience high levels of confusion and distress

during this time which often leaves them feeling powerlessness in the face of this very difficult situation.

Exploring alternatives in relation to treatment and seeking second opinions during this period is something that parents feel is absolutely necessary in terms of exploring what in the baby's best interest and it can also often feel like the only channel open to parents which gives them a sense of having some input in an attempt to make sense of a situation over which they reel very little control. Becoming very focused on the practical issues around management and treatment can also present a couple with one way of coping with their pain but it can also be seen as a way of distancing the parent from the grief that is being experienced.

During this time it is important to identify individual strengths and flexibility's within the couple, strengthening those adaptive behaviours that will support the couple during this time. Intensive work during this period is often useful for the couple, mindful of working at their own pace and with respect for their own meanings of what this pregnancy has created but at the same time gently challenging where appropriate, those strategies that disconnect the couple from this distressing process.

Dr Michael Falk

The institution of amnio-infusion and neonatal dialysis at this point in time for a foetus which has renal agenises/Potter's syndrome must be regarded as experimental since no successful outcomes have been reported in the scientific literature. As such, informed consent is difficult to obtain and certainly on behalf of the foetus impossible. One has been left with the basic principles of beneficence and non malfeasance. As there is no guarantee that the institution of this experimental therapy would be to the benefit of the child, it may be that this treatment is a process of prolonging death. In fact this may be an example of malfeasance in which painful therapies are instituted without a clear outcome. Experimental therapy need not be offered to patients, but if requested, could be considered. This case has political overtones and may be decided in that arena.

I believe that all members of the community, including patients and their relatives, should have full rights to information available from any source including the Internet. Interpretation of this information is however problematical since Internet information does not undergo a peer review or external review process, and may then contain inaccuracies which may not easily be discerned by non experts. My advice to families is to make available any resource they believe is helpful and then to discuss this with their guiding renal team. The example of Lorenzo's Oil was salutary.

Ms Jill Lawton

Certainly an emotive and morally difficult scenario.The discussion swayed more towards terminating the pregnancy with the majority of medical people agreeing that treatment was not an option. All agreed that counselling was vital for the parents and other family members regarding the outcomes for
the baby and themselves, as well as the problems with information accessed through Internet.

I personally found this a difficult situation to be confronted with. As a Renal Nurse I recognise the poor prognosis for the baby and the enormous strain on resources and the family if treatment were to be commenced. However I also can understand the need of the family to want to do everything possible - in particular the father, especially as it was revealed late in the discussion that the other children in the family were not his, it made his determination all that more understandable.

Ms Andrea Bigham

This case illustrates the extent a family will go to save their child once a light of hope is discovered. Unfortunately, they usually do not have the education to determine if it is a false

hope, as presented in this case. The family should always be encouraged to learn about the illness affecting their child and discuss this with their doctor to get a better understanding and to help interpret medical jargon. The Internet is just another source of information (a library on line). However, anyone can have a home page and information present is not reviewed by trained and knowledgeable peers. It is important to explain this to lay people and encourage them to discuss any information found with the family doctor to determine the scientific merits of the information. Maybe an independent doctor should be asked to consult with the family to eliminate bias.

The mother being happy to go along with the father's decision is a common but upsetting situation. The future of the child should be a mutual decision by both parents made on rational grounds but it is hard in some cases to rectify this. Also, maybe the father is in the wrong frame of mind or wrong stage of the grieving period to make such a decision regarding the life of the child. Once again, counselling and strong family support is required here from social workers etc.

Enormous pressure and strain would be placed on the family structure and especially the other three children during the rest of the pregnancy and during subsequent treatment of the baby, if tried. Once again strong family support is required here.

Medicine still has a long way to go in a number of fields and it is sad when false hope is given that can never be fulfilled. This leads to the point that the unit should not be forced to give treatment it feels Is experimental or for which it does not have the expertise and especially not forced by the Health Minister to give treatment based on political pressure.

Media involvement in any medical story can be dangerous depending on how they want the story presented. This is frustrating as they are the main liaison between the medical world and the general public and may often misrepresent a story to sell it.

Whether or not the pregnancy is terminated should be a personal family issue and also opens various ethical issues about the rights of the foetus and the right of the mother to see her child etc which are not relevant to this conference.

SUMMARY BY CHAIR PERSONS:

Ms Maree Nugent

Issues discussed:

- we need to remember **who is the patient?**
- consider will we do any **harm**
- consider if the treatment is **experimental?**
- Father wants everything done, but in reality it is often the mother performing the majority of the work.
- What **benefit** will be gained from this treatment in the long run? Who will gain this benefit?

- **equity:** The only reason that this became such an issue was because the parents had access to information via the internet. Not everyone has access to this level of technology.

- **internet:** Families are welcome to utilise other avenues to gain information, but should discuss new information found with their doctor, or health care team.

- The **health minister** contacted 4 paed nephrologists in Australia, each one gave a brief account of the advice they gave to the health minister.

A/Prof Rowan Walker

1. Extremely difficult nature of the underlying medical problem was acknowledged and the recognition of how difficult long term ESRF replacement therapy would be in such a case. It was generally acknowledged that the immediate and ongoing counselling of the parents was critical in the decision making progress. All of the special circumstances of the case (eg. the family dynamics, major area of the workload likely to be the mother and the particular desires of the father) needed to be taken into account and constantly worked over.

2. There was general agreement that patients (parents) should be encouraged to seek information from other sources (including the Internet). There was no particular need to "fear" information banks such as the Internet. Generally speaking, information was likely to be helpful.

3. The case highlighted the difficulties faced by clinicians and healthworkers when cases reach the media and involve politicians. Clinicians and healthworkers can only give the best advice for the care of the patient and the patient's family. Whether that advice is accepted by politicians is not something over which clinicians and healthworkers have much control. Clinicians and healthworkers have major responsibilities to patients.

4. Whether or not a particular treatment should be offered (particularly when it is experimental) provided a total dicotomy of view. Some felt that it was appropriate to offer the treatment, provided that the patient (parents) understood that in its nature it was experimental. Others felt that because it was experimental it was not essential to offer such treatment. There was a general view that the key to whether the treatment was offered/not offered lay in the appropriate counselling of parents (and patients) and working constantly through all the difficulties and stresses being raised.

CASE 2.

An 18 year old girl with ESRF on CCPD, changed to haemodialysis in an attempt to reduce persistently high serum phosphate levels. Social problems led this young girl to be non-compliant with her peritoneal dialysis regime and her intake of phosphate binders.

Past History

MPGN ⇒ ESRF
Hyperparathyroidism ⇒ Parathyroidectomy x 2 - 1990 & 1994.
Cadaveric Renal Transplant 1992 - - Failed 1993
Cardiomegaly -- ?secondary to poor nutrition and chronic fluid overload.
Hyperphosphataemia -- ?compliance to phosphate binders.
Renal osteodystrophy -- Biochemical and radiological evidence.

Current Blood Chemistry

Phosphate	3.51 mmol/L
Calcium	2.16 mmol/L
Parathyroid Hormone	62.0 mmol/L
Parathyroid Scan:	Difficult study because of previous surgery. *'Parathyroid likely to be within the mediastinum'*

The Chair directed discussion towards the following issues:

1. Serum phosphorous is a complex process, would a phosphorous educational program be effective?

2. Should a 3rd parathyroidectomy be performed?

DISCUSSION BY MEMBERS OF PEER PANEL

Ms Kathleen Latage

This case represents a very complex situation which poses many questions. Not only does this young woman's family of origin need to be explored with its perceived family problems but also her own issues around body image and self-esteem in relation to her long history of intrusive surgery and treatments needs to be explored in depth. A comprehensive psycho-social assessment needs to be carried out with close communication between all team players with view to working with this young woman over a prolonged period in order for any change to be realised. It is also important to remember that this young woman would also be potentially struggling with the normal developmental issues of adolescence and this needs to be unravelled with her in the context of the medicalisation of her young life.

Dr Michael Falk

I am most concerned that this young woman, who is poorly compliant and possibly nihilistic about her long term outcome with all the problems of her self image and emerging sexuality is doing so poorly. Her calcium/phosphate balance is at a level with which she will be depositing calcium and phosphate in her large and small vessels and, with an underlying cardiomegaly possibly due to poor nutrition or fluid overload, her life expectancy must be severely limited.

Her parathyroid bone disease may be easily controlled with pulse Calcitriol whilst on haemodialysis, although one should be careful with the ongoing high phosphate levels not to further worsen the calcium/phosphate product. Surgery would be difficult and I don't believe indicated at this point in time, including the inherent risks of rendering her hypoparathyroid with the resulting long term problems then of large oral doses of Calcium and Calcitriol to protect her against imminent cardiac dysrhythmias. I would suggest she be considered for urgent transplantation and am not entirely dissuaded by the argument that her non compliance would continue from dialysis to transplantation.

Ms Jill Lawton

One assumes that the young woman has had some prior education on dietary and medical management of her renal disease in order to achieve optimal health. Obviously she needs ongoing education sessions but I believe these should be on a one to one basis with a person that can offer ongoing support and counselling for the social problems. She needs time to work through problems and deal with them as they arise without falling back on her health requirements. A teenager's lot is a difficult one regardless of additional problems with illness, this young lady could benefit from self realization and developmental classes.

If a third parathyroidectomy ,whilst difficult, was attempted it could alleviate the present situation, but she must be made aware of the limitations and the need for ongoing compliance and attendance to
counselling/education sessions. Above all I believe that re-transplantation would be the most beneficial in this case.

Ms Andrea Bigham

This case concerns noncompliance which as mentioned during the course of the conference, is most common in this age group. The causes of noncompliance are too numerous to mention, but include a social peer pressure, self image, family structure and financial problems to name but a few. The main issue is to get to the bottom of the cause for noncompliance, which often involves extensive counselling and support. The two main areas to distinguish between are non compliance due to social problems or that the patient has given up. Social problems could be addressed as mentioned in the discussion of this case by changing the living environment, or by showing that these are problems any 18 year old female may encounter these problems whether

on dialysis or not. This often helps as chronic patients often associate everything with their illness. It was good to hear that this case was showing up for haemodialysis and thus still wanted to live. This raises the issue of the need to re-build the self-image of the patient which has been destroyed by their chronic illness. Unfortunately, sometimes the person has just had enough and is not reached in time.

SUMMARY BY CHAIR PERSONS:

Ms Maree Nugent

Issues discussed:

- **Educational aspects** of maintaining a normal serum phosphate.
- Decided that in this case it probably wasn't the child's knowledge that was causing a problem, but rather it was a **compliance issue.**
- It was suggested that **surgery was not the appropriate solution** for a non-compliance issue.
- Even if parathyroidectomy was performed, it would be highly likely to cause life-threatening problems with low serum Calcium.
- It was decided provide **support** and try to encourage compliance

A nephrologist stated that he has successfully treated a child with a phosphate of over 3, with 3 caltrate pre and post HD, and 10 Calcitriol twice weekly after HD. The phosphate has been reduced to 1.9. The administration of **Caltrate and Calcitriol** under the supervision of HD nursing staff can be a useful alternative.

A/Prof Rowan Walker

The case highlighted the problems of compliance in adolescence.

1. Again the case highlighted the need for very adequate communication between the patient and the clinicians and healthworkers.

2. Most Units are not providing formal phosphate educational programs but information concerning phosphate is being provided as part of the renal failure dietary educational program.

3. There was again a dicotomy of views as to whether the patient should be subjected to a third parathyroidectomy. Some felt that if the clinical situation suggested that a parathyroidectomy was likely to improve the underlying renal bone status, it should be undertaken. Others felt that surgery into the mediastinum was very significant and that every effort should be made to control the parathyroid status medically. There was a view that if a parathyroidectomy was undertaken it would do very little to control the phosphate.

4. There was general view that it was important to continue to work towards a good relationship between patient and clinician.

5. The overwhelming view was that the patient should be offered a further transplant - no particular conclusion should be drawn about compliance with the transplant and compliance with phosphate control and phosphate binders.

CASE 3.

A six year old boy received a cadaveric renal transplant (aet 5 years of age) after two years of peritoneal dialysis. Nutritional support was required in the form of gastrostomy feeds.

From birth to 8 months he revealed no developmental abnormality. At 8 months he presented with pneumococcal meningitis, sepsis and haemolytic uraemic syndrome which result in CRF and a subsequent developmental deficit. On reaching ESRF (aet 3 years) he was walking independently. However, no speech was evident, he avoided eye contact and he interacted minimally with family and others.

The decision to place him on maintenance dialysis (and the renal transplant program) rather than to opt for palliative treatment was ultimately made by family and the health care team. The decision was difficult as the child's father was quite adamant about ongoing ESRF care whereas the mother and some members of the health care team (because of the child's marked developmental deficit) had expressed serious misgivings at various stages before the final decision to dialyse and to progress to a transplant was based at least in on the hope that his development may improve with active treatment and reversal of uraemia. The treating hospital has a policy to offer renal transplants to all paediatric dialysis patients (ie if the patient is not to be offered a transplant then the patient is not offered dialysis).

One year after his transplant the child remains on gastrostomy feeds; he is clearly more alert and aware that his actions affect others. A symbolic play test (examining symbolic thinking) scored him at <12 months. Language skills have been assessed as lower.

The Chair directed discussion towards the following issues:

1. Cadaveric transplants are a scarce resource. Should we be allocating such a resource to a patient with this degree of disability. Who makes the decisions in these cases?

2. Conversely, even without ESRF, a child with this degree of disability places enormous demands on both family and community resources. In order to reduce this burden, could we argue for the child to be made a 'priority' for renal transplantation?

DISCUSSION BY MEMBERS OF PEER PANEL:

Ms Kathleen Latage

This case certainly represents one of the many ethical dilemmas and emotive issues that confront a team that are closely working with a family that are confronted with this overwhelming decision in relation to their child's treatment and management. This period of decision making often forces the family to relive the pain and grief that was experienced around diagnosis. It brings rise to question their own relationship with their child and with each other, and what they are being asked to do, in effect is to question what meaning their child has within their family.

In reading the case I was interested to note that the mother had expressed misgivings before a final decision had been reached. In working with families that are faced with these decisions it is not uncommon for one partner to express some of the ambivalence that may be being experienced by the family and the team. For team members, it can be demanding and difficult to sit with this level of confusion and pain experienced by the family and the challenge for the team is to allow the space that is needed for families to change their minds many times before reaching a clearer decision.

Dr Michael Falk

This is a case of pneumococcal associated neuramidase HUS where one should be very careful with infusions of blood products. Our policy is to allocate renal transplants on the basis of patient survival rather than quality of patient outcome. The latter is far too difficult to measure or predict and is difficult to predict from the bias of special interest groups. He fills our criteria for transplantation with a >80% five year survival rate, and <2% peri-operative mortality. The decision for transplantation clearly required informed consent on the part of the patient or legal guardians, and should be made in conjunction with the patient's treating team and regulatory authorities including those involved in decisions of allocation of scarce resources.

This child had been on dialysis for 40% of his life before receiving his renal transplant and it is clear that this will result in significant inhibition of growth and achievements of milestones. One could argue strongly that he should receive priority transplantation on that basis, with the proviso that the kidney that he receives has a high degree of matching and high probability of long term survival. With respect to financial considerations, it is far more cost effective to have this patient transplanted than maintained on dialysis.

Ms Jill Lawton

This case was not as contentious as the others. The general thought was that transplantation could not be refused. The child has shown some improvement since the transplant and time will tell if further improvements occur, but surely the transplant has eased a lot of the burden on the family's and hospital's resources. I don't believe that transplantation can be refused to anyone (ie.those not terminally ill) whatever their situation as one less problem would surely ease their situation.

Ms Andrea Bigham

Cadaveric transplants are a scare resource. The question "Should we be allocating such a resource to a patient with this degree of disability?" immediately opens the Pandora's box of defining degrees of disability. How disabled does a person have to be to be excluded? Can this be defined?

The decision to place the child on the program was made by the family and the health care team in the hope that his development may be improved and this is indicated in that he is now responsive to others, and to reduce the burden of looking after this child. But as transplants are selected from a national/state pool maybe the decision should have involved other renal units as they "lose" a kidney. Ultimately an ethical board would be the answer.

The concept of exclusion may be accepted by the general public until it is their child.

Priority cases due to the scarcity of transplants should be based on life-threatening medical reasons only. This also raises the dilemma of what is the definition of a burden case on families and the health care system?

Once again this case had a discrepancy between the mother and father's decision regarding the treatment of the child, illustrating the importance of family support and counselling by the medical team as these conflictions would create enormous pressure between the parents.

This case is actually sadder later in life as we have the technology to keep this child alive through to adulthood, but he will still be effectively a young infant.

SUMMARY BY CHAIR PERSONS:

Ms Maree Nugent

Issues discussed:

- We cannot make the decision that a child is not **worthy** of a cadaveric kidney transplant.
- Good to **decide the long term plans** before we even commence dialysis
- We should carry out treatment according to the **wishes of the parents**
- Acknowledged the **burden** of caring for a child like this on PD

A/Prof Rowan Walker

1. The consensus view was that if the parents had come to the conclusion that therapy should be offered for a subnormal individual, that the decision should be supported by the clinical team.

2. It was emphasised again how important the initial communication and ongoing communication was with the parents. There are no "right" and no "wrong" decisions in such cases.

3. There was animated debate about the "worthiness" of severely intellectually impaired individuals and the scarce cadaveric allograft resource. In relation to this there was considerable discussion about "equity". This was also discussed in the context of the fact that paediatric nephrologists are in unanimous agreement that there should be preferential allocation of cadaveric allograft resources towards children.

4. There was disagreement as to whether the patient should be accepted to the ESRF Programme (dialysis and transplantation) or to dialyse alone. It was suggested that there was an option of discontinuing treatment and that appropriate counselling of parents for this situation should be considered.

5. With respect to counselling of parents, it was again acknowledged how the major workload was likely to fall on the mother rather than the father.

CASE 4.

A 16 y.o. girl of mixed Aboriginal (mother)/Greek (father) background commenced maintenance peritoneal dialysis in July 1992. She had presented a few months previously with near end stage renal failure due to reflux nephropathy.

Progress on peritoneal dialysis was generally satisfactory but hypertension and compliance with medication proved to be problematical. She had a parathyroidectomy in 1996 following the development of pathological fractures.

She has been maintained on the cadaveric renal transplant waiting list over the past five years. Blood group and tissue typing and those of her parents are shown in the Table below.

	HLA			Blood Group	Serotype	Anti-A_1 Titre	
	A	B	DR			Saline	AHG
Patient	24,25	51,56	4,8	O	--	1:8	1:64
Mother	24,24	39,56	8,8	A	A_1	--	--
Father	26,?	51,?	4,?	A	A_1	--	--

She has an MPI (Matched Probability Index) of 1. She has a *current* PRA reading of 0% and a *peak* PRA reading of 4%. Her father is in relatively good health, but marginally overweight. Mother has a history of hypertension and has a BMI of approximately 30. She has two siblings 18 and 21. All other potential living related (and living unrelated) sources for a future live donor transplant have been exhausted.

The Chair directed discussion towards the following issues:

1. Is there a possibility of performing an ABO blood group incompatible transplant here? What pre-transplant preparation needs to be done? eg. splenectomy, immunosuppression etc. If not an ABO incompatible transplant, what are the options?

2. Based on the HLA-typing, should the mother be the preferred donor, even allowing for her mild obesity and mild hypertension?

DISCUSSION BY MEMBER OF PEER PANEL:

Ms Kathleen Latage

Careful psycho-social assessment needs to be carried out with all members of the family including the siblings aged 18 and 21 . This assessment needs to be carried out with close input from all team members to fully assess family situation. This assessment needs to include an exploration of this young girl's role and responsibility with her treatment program. Issues around what meaning 'compliance' has for her and her ability to cope with treatment at home also needs to be explored.

Dr Michael Falk

Three literature provided by Toma's group form Tokyo University suggests that blood group A1 donors donation to blood group O recipients is possible and that approximately 80% one year graft survival is possible with prior splenectomy but reduces to approximately 25% without splenectomy. Although Toma's group has provided a large series this was an environment in which cadaveric transplantation was not available and the only possibility for transplantation was live related which by definition had the ABO incompatibility barrier.

In Australia this young woman is likely to receive a cadaveric kidney and one should carefully examine whether it would be in her interests to foreshorten that process by receiving a live related transplant across the ABO barrier. Toma's paper suggested that the induction therapy

should include splenectomy, Azathioprine, Cyclosporine, Methylprednisolone, anti lymphocyte globulin, Deoxyspergaline with graft irradiation prior to transplantation. We now know that should a graft survive long enough that 100% of patients will develop carcinoma of one form and with this particular induction therapy one would be most concerned about future malignancies. Based on this I would not recommend that this young woman undergoes ABO incompatible blood group transplantation, and would recommend that given her particular situation including renal osteodystrophy, that she be considered for priority cadaveric transplantation.

It is now understood that live transplant donors with a BMI of 30 or greater, have a much higher incidence of post operative complications and this young woman's mother should be carefully considered on the basis of do no harm. Using Terisarki's data the degree of matching for live related and live unrelated appear to be of less importance than previously thought, and either her mother or father would be suitable as donor. A most interesting question would be whether she should receive a transplant from her siblings aged 18 and 21, with most Units considering that at this age informed consent is difficult.

Ms Jill Lawton

This girl has a serious need for a transplant. I'm unsure of the possibility of ABO blood group incompatible transplants and leave that concept to the medical specialists. It is obvious however that a transplant is needed urgently. I would be reluctant to use the mother for the donor due to the fact that she is Aboriginal ,hypertensive and mildly obese. This is an open invitation for her own renal problems in the future. This could probably be worked with proper counselling and medical management of the mother's problems in order to gain her co-operation in gaining optimal health with ongoing medical support following the transplant.

Ms Andrea Bigham

The main issue here is how does the side effects and treatment of an incompatible transplant compare to her staying on peritoneal dialysis and treating the hypertension and compliance problems? This is further complicated by her mother being Aboriginal and thus a high incidence group for diabetes and renal failure. Sometimes not having a transplant is better than complicating the situation further by trying to.

This case, at 16 years, is old enough to understand that sometimes things go wrong inn which case she would be putting her mother into her own shoes. This is quite a dilemma that can stop a transplant going ahead and thus create enormous pressure on the family. Strong family and medical support is required, as with any transplant.

SUMMARY BY CHAIR PERSONS:

Ms Maree Nugent

Issues discussed:

- It would be better <u>not</u> to transplant this child from one of her 2 ABO incompatible parents. ie. **ABO incompatible transplant not a good idea.**
- Harley Powell briefly explained some of the theory related to ABO incompatible transplantation, and its required immunosuppression
- **Mother is likely to be unsuitable** for renal donor nephrectomy due to her weight, BMI and hypertension.
- not a great idea to put this child on the emergency priority list for cadaveric donor, because she needs a good quality, long lasting kidney,
- consider the **siblings** as potential renal donors

- It was suggested that we place a reduced amount of importance on the tissue typing aspects of the **allocation of cadaver organs.** In experience with living un-related donors (with a lower level of match), the results have been comparable to well matched transplants.

A/Prof Rowan Walker

1. The majority view was that a "priority transplant' should be offered to a child with difficult tissue typing and no blood group compatible living related donor available rather than proceeding to an ABO incompatible blood transplant. Arguments against the ABO incompatible blood group largely centered around the likely amount of immunosuppression required.

2. The suitability of the potential live related donors was discussed. In particular, concerns were expressed about Aboriginality, hypertension, and obesity.

3. Disagreement existed as to whether individuals in the age range 18-21 (who are capable of providing legal consent) are appropriate to be considered as live donors.

The main issue here is how does the side effects and treatment of an incompatible transplant compare to her staying on peritoneal dialysis and treating the hypertension and compliance problems? This is further complicated by her mother being Aboriginal and thus a high incidence group for diabetes and renal failure. Sometimes not having a transplant is better than complicating the situation further by trying to.

This case, at 16 years, is old enough to understand that sometimes things go wrong in which case she would be putting her mother into her own shoes. This is quite a dilemma that can stop a transplant going ahead and thus create enormous pressure on the family. Strong family and medical support is required, as with any transplant.

Princess Margaret Hospital For Children
Perth. Western Australia

Refer Enquiries to:

Telephone:

PAEDIATRIC NEPHROLOGY SERVICES
Fax: (08) 9340 8301

Princess Margaret Hospital for Children

Roberts Road
Subiaco WA 6008
GPO Box D184
Perth WA 6001
Telephone (09) 340 8222
Facsimile (09) 340 8111
Facsimile (09) 340 8115

15 October 1997

Dr Colin Jones
Chairman, ANZPNA
Department of Nephrology
Royal Children's Hospital
Flemington Road
Parkville VIC 3052

Dear Colin

Re: Metalozone tablets (Diulo)

I have been informed that the manufacturers of Diulo are planning to discontinue the manufacture of this product, but whether that is only in Australia or worldwide, I am not clear, and am seeking further clarification of this.

Ian and I both use this medication occasionally but regularly for the management of resistant oedema in children, and in conjunction with Frusemide is particularly effective. It would therefore be a great loss if this product was not available.

I have written to the company product manager concerning this issue, and will let you know of her response. It will be useful to know the extent of use of Metalozone by Paediatric Nephrologists in Australia, and perhaps in a forthcoming newsletter you could address this issue.

Kind regards.

Yours sincerely

Dr Charles Crompton
PAEDIATRIC NEPHROLOGIST

Editorial Addition: Send following to Charlie by Fax

.....✂.....✂.....✂.....

Dr Charles Crompton
Paediatric Nephrology Services
Fax: 08 9340 8301

PLEASE NOTE

	Yes	No
I use Metalozone tablets		
I don't use Metalozone tablets		
I am keen to assist you		

Name: ELISABETH HUDSON

JOURNAL OF AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

VOLUME 1, NO. 4 JANZPNA, pages 133 - 167

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AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

SUCCEEDING DEVELOPMENTS TO THIS MEETING INCLUDED IN BRACKETS IN ITALICS FOR THE WRITER'S CONVENIENCE.

MINUTES OF THE MEETING OF THE EXECUTIVE ON THURSDAY 18TH DECEMBER 1997, TELECONFERENCE

COLIN JONES (CHAIRMAN)
PAUL HENNING
LIL JOHNSTONE

1. TREASURER:

Colin Jones congratulated Paul Henning on his election to the position of Treasurer.

2. PROJECTS:

2.1 ASPSU Study re Nephrotic Syndrome

Colin Jones indicated that he has spoken with Elisabeth Hodson and with Jonathan Craig concerning this study and had subsequently corresponded with Elisabeth Hodson. Andrew Rosenberg's letter was noted. The Executive noted that the study had been accepted by the APSU, and that it was very important that the ANZPNA support the study and complete the questionnaire. Colin Jones indicated that Elisabeth Hodson was still happy to receive input regarding the questionnaire and that it may be possible to make amendments to the questionnaire during the three year period of data collection.

[EH and JC have reviewed/changed the APSU questionnaire in response to comments received. The questionnaire will be again distributed to members and should be ready to start by midyear.]

2.2 Growth Hormone Project

A letter was recieved from Debbie Lewis noting that funding for this project was not received by the Westmead group. This project is now being co-ordinated by Charlie Crompton. The Executive felt that this study was very important as it may impact on Government planning concerning the further provision of growth hormone to children with renal failure. Lil Johnstone is to write to Charlie Crompton to determine what support he requires. The Executive felt that a brief summary every three months to be included in the ANZPNA Journal would be helpful to contributors to follow the progress of the study.

2.3 Reflux Trial

Again, the Executive felt it was important that a three monthly update concerning the progress of the study be included in the ANZPNA newsletter.

[PR - 32 patients in trial 6/2/98
- Shamistha De Sousa resigned and no new appointment for postion yet.]

2.4 Other Studies

The Executive was not aware of any other collaborative studies in progress. John Burke and Lil Johnstone have had preliminary correspondence concerning collection of lipid data and cardiovascular data through the ANZDATA registry. Lil Johnstone to correspond with other paediatric units to determine whether this data collection is feasible.

[MF - (Paediatric renal transplantation outcome) has discussed with RGW recently, but nothing written yet.]

3. ANZPNA MEETINGS:

3.1 A letter from John Burke was noted advocating twice yearly meetings. The Executive felt that it was appropriate to consider this plan at some stage, however, it was felt that currently it is too early in the existence of the ANZPNA as it needs to be established how effective the ANZPNA works as a research group and how active the ANZPNA becomes. Paul Henning raised the issue of consideration of the costs to individual units to fund a member to attend this meeting. It was felt with time it may be useful as a facilitating meeting, however, it was recognised that ultimately each individual member of the ANZPNA had to be involved in the discussions. It was felt that a meeting at the ANZSN would need a more formal structure to be effective.

3.2 The ANZPNA 1998 Meeting

Steve Garchow has indicated that Baxter may be happy to fly all medical staff to a meeting in 1998 but a large meeting as was held in 1997 would be unlikely to be funded. Colin Jones is to speak to speak with Steve Garchow. Colin Jones is to fax information concerning the costs and funding to Paul Henning.

[Steve Garchow - No final agreement from Baxter senior management 22/2/98. SG planning for Royal Pines, QLD on July 19, 1998 ANZPNA meeting and July 20 Baxter would like to conduct a workshop on surgical access with a paediatric workout session. Steve thinks we would be able to bring a nurse from each unit. I have asked Amanda Walker to liaise with Michelle Duddington and organise a session.]

3.3 IPNA Meeting in Australia

The Executive have not received any indications of an interest to bid for this meeting. It was noted that the deadline for bids was the end of January 1998 (page 18 ANZPNA Vol 1, No. 1) and the Executive has put this date back to the end of February. Colin Jones will raise this topic with Andrew Rosenberg, Paul Roy and John Burke. Paul Henning will discuss this with Fred Jureidini as Adelaide had previously indicated an interest.

[AR and PR have communicated that Sydney will not bid. FJ - Adelaide will put in a bid. Details in this edition.]

4. FINANCIAL STATUS:

4.1 Colin Jones will close the bank account in Melbourne and Paul Henning will establish a bank account in Adelaide. The current funds (approximately $1350) will be transferred to Adelaide. It was noted that the ANZPNA is not yet incorporated therefore 50% of any interest earned will be lost in tax. The current bank charges are $5/month.

[PH has expended energy setting this account up.]

4.2 Subscription

The Executive determined that Paul Henning should call for subscriptions for the calendar year 1998-1999. It had been decided at the meeting in July that the subscription rate should be $100 initially to provide sufficient funds to assist in the setting up of the ANZPNA, its Website, and its Incorporation. The Executive plan to review the subscription fee at the AGM in 1998.

5. CONSTITUTION:

Colin Jones has spoken with Paul Roy and the Constitution is currently being developed. It will be distributed for comment when available.

[PR - Took leave to do the Aricles. Paul's comments and document in this Edition.]

6. PAEDIATRIC TRANSPLANTATION PREFERENTIAL ALLOCATION, VICTORIA:

Colin Jones noted his letter concerning the preferential allocation of kidneys to children in Victoria and indicated that this system has been established to commence in 1998. It was understood that NSW is possibly putting a similar system forward. Paul Henning indicated that he has discussions with Graeme Russ and was hopeful that the Victorian (and ? NSW model could be used as a potential nationwide model).

7. BUSINESS:

7.1 Correspondence had been received from Peter Phelan, President of the Australian College of Paediatrics, concerning a task force review regarding manpower requirements.

7.2 PBS Scheme

Correspondence was noted from Elisabeth Hodson concerning the therapeutic group premiums policy. Further correspondence from Trish Wurth parliamentary secretary to the Minister for Health and Family Services indicating that Amlodipine and Lisinopril will still be available by indicating on the prescription or by getting an authority prescription.

The executive felt our group was too small to have influence in changing the policy which is being implemented at a national level.

8. NEXT MEETING:

February 1998.

9. CLOSURE:

Signed as a true and correct record.

.....

CHAIRMAN 26/2/98

METOLAZONE

Australian manufactured Metolazone has been discontinued but UK manufactured medication will be available through the SAS. Four paediatric nephrologists responded to Charlie's enquiry regarding the use of Metolazone, two indicating they use the medication.

LIPOSOMAL AMPHOTERICIN

Debbie Lewis writes asking if members have guidelines on the use of liposomal amphotericin in oncology patients with or without renal impairment. Westmead are tightening their guidlines because of severe budgetary problems and are interested in other approaches. Currently a small increase in creatinine is used to change from standard to liposomal preparation in their guidelines.

Please send your thoughts/protocols to Debbie.

ANZSN AUCKLAND MARCH 1998

The following members are going to Auckland -

Willy Wong (he suggests meeting on the Tuesday afternoon)
Gad Kainer
Paul Henning
Ian Hewitt
John Knight
Michael Falk
Max Morris

Those not going include Debbie Lewis, Elisabeth Hodson, Frank Willis, David Lines, Charlie Crompton, Colin Jones, Harley Powell, Rowan Walker, Lilian Johnstone, David McCredie, Amanda Walker, Jonathan Craig, Andrew Rosenberg, Ken Jureidini, Paul Tomlinson, Paul Roy.

Paul will arrange an informal meeting.

REGULATIONS FOR MANAGEMENT AND ARTICLES OF ASSOCIATION OF A COMPANY LIMITED BY GUARANTEE

Covering letter from Paul Roy (edited):

1. (The Regulations for management and Articles of Association of a Company Limited by guarantee form) a long document. It is intended to serve the association as it grows and becomes influential medically, scientifically andpolitically. Changes must be registered and a fee is payable.

2. Incorporation will cost $405. $115 of this goes to permission to omit the word Limited from the name of the association.

3. You will notice an Honorary Secretary and a Secretary appear. The latter is a Statutory requirement and must be defined. The Honorary Sec can perform any functions of the Company Secretary.

4. I used documents and suggested layouts from the ASC and the articles of the ACP.

5. It is not necessary to include provision for reimbursement of costs for Executive Members to attend meetings. This can be covered by resolution.

6. There must be at least 5 subscribers. The names etc of these their signatures and the names etc and signatures of witness is completed on the last page as I have indicated by example. If the document is approved the 3 current executive and 2 other members could be filled in as the subscribers and the document lodged with Form 201 and 305 together with a stat dec in relation to not using "limited", which I will send in the mail with a disk.

REGULATIONS FOR MANAGEMENT AND ARTICLES OF ASSOCIATION OF A COMPANY LIMITED BY GUARANTEE

THE AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

1. NAME:

The name of the Company is "The Australian and New Zealand Paediatric Nephrology Association" (hereinafter called "ANZPNA".

2. OBJECTIVES:

The objectives for which the ANZPNA is established are:

(a) To encourage promote foster and develop the study of paediatric nephrology in Australia and New Zealand.

(b) To promote and maintain the highest standards of diagnosis and managemant of disorders of the kidneys and urinary tract in infants, children and young people and advance the practice of paediatric nephrology in Australia and New Zealand and to encourage and stimulate research in paediatrics.

(c) To act as a consultant and advisory body on paediatric nephrology in Australia and New Zealand and elsewhere.

(d) To promote personal intercourse and friendship among persons engaged in paediatric nephrology in Australia and New Zealand and elsewhere.

(e) To become a member of subscribe to or affiliate with or to grant affiliation with it to any other organization whether incorporated or not having objects altogether or in part similar to those of the ANZPNA or having for its objects or one of its objects the promotion fostering or developing of paediatrics nephrology or allied sciences provided that the ANZPNA shall not subscribe to or support with its funds any organisation which does not prohibit the distribution of its income and property among its members to an extent at least as great as that imposed on the ANZPNA under and by virtue of Clause 4 of these Regulations.

(f) Subject to Section 383 of the Corporations Law to take over the property assets and effects and liabilities of the present unincorporated Association known as Australian and New Zealand Paediatric Nephrology Association and for that purpose to execute and carry into effect any contract deed or other instrument which may be necessary.

(g) To cultivate and maintain the highest principles of practice and ethics in persons engaged in paediatric nephrogy in Australia and New Zealand.

(h) To promote arrange and conduct conferences meetings lectures discussions and demonstrations on or concerning paediatric nephrology and to diffuse information concerning diseases of the kidneys and urinary tract in infants, children and young people and as to the causes and effects thereof and the prevention and cure of the same.

(i) In furtherance of these objects to consider originate and promote so far as relates to the objectives of the ANZPNA alterations and improvements in the law and to oppose or support alterations therein and for such purposes to petition Parliament and take such action or proceedings as may be deemed expedient.

(j) To acquire establish print and publish magazines periodicals journals transactions treatises leaflets papers or other literary or scientific works which the ANZPNA may think desirable in furtherance of these objects or any of them.

(k) To establish and maintain libraries of scientific works for the members of the ANZPNA and other engaged or interested in paediatric nephrology and the practice thereof.

(l) To make and grant awards or other benefactions and establish scholarships and prizes for or in connection with the study of and research in paediatric nephrology.

(m) To provide establish maintain and equip offices examination halls lecture rooms museums and other premises and conveniences for the purposes of the ANZPNA and the use of the members thereof and others.

(n) Subject to Section 383 of the Corporations Law, to accept any gift endowment or bequest made to the ANZPNA generally or for the purpose of any specific object and to carry out any trusts attached to any such gift endowment or bequest.

(o) To undertake and execute any trusts the undertaking whereof may be necessary or convenient for the carrying out of any of the objects of the ANZPNA.

(p) To procure the ANZPNA to be registered or recognized in any country or place outside the State of Victoria.

(q) Subject to any restrictions as may for the time being be imposed by law to purchase take on lease or in exchange hire or otherwise acquire any real and personal property wheresoever situate and any rights or privileges which the ANZPNA may think necessary or convenient for the purposes of the ANZPNA.

(r) To construct maintain and alter any buildings or works necessary or convenient for the purposes of the ANZPNA.

(s) To sell improve manage develop exchange lease mortgage dispose of turn to account or otherwise deal with all or any part of the property and rights of the ANZPNA.

(t) To borrow or raise or secure the payment of money in such manner as the ANZPNA shall think fit and in particular by the issue of debentures or debenture stock perpetual or otherwise charged upon all or any of the property of the ANZPNA both present and future and to purchase redeem or pay off any such securities.

(u) Subject to Section 383 of the Corporations Law to invest and deal with the moneys of the ANZPNA not immediately required in such manner as may from time to time be determined. Provided that such moneys shall be invested only in such forms of investment as may be permitted by law for the investment of trust funds.

(v) To draw make accept endorse discount execute and issue promissory notes bills of exchange warrants debentures and other negotiable or transferable instruments.

(w) From time to time to make rescind or alter such by-laws not being inconsistent with any Statute or with these objectives or with these regulations the ANZPNA for the time

being in force for the regulation of any of the affairs of the ANZPNA as may be deemed necessary or convenient.

(x) To do all such other things as are incidental or conducive to the attainment of the above objects or any of them.

The intention is that unless the context shall otherwise require the objects specified in each paragraph of this clause shall be independent main objects and shall be in no wise limited or restricted by reference to or inference from the terms of any other paragraph or the name of the ANZPNA. And it is hereby declared that in case the ANZPNA shall take or hold any property which may be subject to any trusts the ANZPNA shall only deal with the same in such manner as allowed by law having regard to such trusts.

3. INCOME AND PROPERTY:

The income and property of the ANZPNA from whatsoever source derived shall be applied solely towards the promotion of the objects of the ANZPNA as set forth in these regulations and no portion thereof shall be paid or transferred directly or indirectly by way of dividend bonus or otherwise howsoever by way of profit to members of the ANZPNA provided that nothing herein contained shall prevent the payment in good faith of reasonable and proper remuneration to any officers or servants of the ANZPNA or to any member of the ANZPNA in return for any services actually rendered to the ANZPNA nor prevent the payment of interest at a rate not exceeding the rate for the time being charged by bankers in Melbourne for overdrawn accounts on money borrowed from any member of the ANZPNA or reasonable and proper rent for premises demised or let by any member to the ANZPNA, but so that no member of the Council or Governing Body of the ANZPNA shall be appointed to any salaried office of the ANZPNA or any office of the ANZPNA paid by fees and that no remuneration or other benefit in money or money's worth shall be given by the ANZPNA to any member of such Council or Governing Body except repayment of out-of-pocket expenses and interest at the rate aforesaid on money lent or reasonable and proper rent for premises demised or let to the ANZPNA provided that the provision last aforesaid shall not apply to any payment to any Railway Gas Electric Lighting Water or Telephone company of which a member of the Council of Management or Governing Body may be a member or to any other company in which such member shall not hold more than a one-hundredth part of the capital and such member shall not be bound to account for any share of profits he may receive in respect of any such payment and that the said provision shall not apply to the payment in good faith of reasonable and proper remuneration and expenses in any one year to not more than one-third in number of the members of the Council of Management or Governing Body of the ANZPNA for their services as Examiners Lecturers or Demonstrators in connection with the teaching and examining work of the ANZPNA in which case when by reason of their ability or their ability and other reasons the Council or Governing Body is of the opinion that such services of such members are pre-eminently desirable in the interests of the Council.

4. ALTERATIONS:

No alteration addition or amendment shall be made to or in these regulations for the time being in force unless the same shall have been previously submitted to and approved by the Australian Securities Commission.

5. SECTION 383 AUSTRALIAN SECURITIES COMMISSION

The fourth and fifth paragraphs of these regulations contain conditions upon which a licence is granted by the Australian Securities Commission to the ANZPNA in pursuance of the provisions of Section 383 of the Corporations Law .

6. LIABILITY

The liability of the members is limited.

7. WINDING UP

(a) Every member of the ANZPNA undertakes to contribute to the assets of the ANZPNA in the event of its being wound up while he is a member or within one year afterwards for payment of the debts and liabilities of the ANZPNA contracted before the time at which he ceases to be a member and the costs charges and expenses of winding up and for the adjustment of the rights of contributories among themselves such amount as may be required not exceeding twenty dollars

(b) If upon the winding up or dissolution of the ANZPNA there remains after satisfaction of all its debts and liabilities any property whatsoever the same shall not be paid to or distributed amongst the members of the ANZPNA but shall be given or transferred to a corporation set up by Royal Charter or Act of Parliament having objects substantially similar to the objects of the ANZPNA or to some other institution or institutions having objects similar to the objects of the ANZPNA and which shall prohibit the distribution of its or their income and property among its or their members to an extent at least as great as is imposed on the ANZPNA under or by virtue of the fourth paragraph hereof such institution or institutions to be determined by the members of the ANZPNA at or before the time of dissolution and in default thereof by the Chief Judge in Equity of the Supreme Court of Victoria or such other Judge of that Court as may have or acquire jurisdiction in the matter, and if and so far as effect cannot be given to the aforesaid provision then to some charitable object.

8. ACCOUNTS:

True accounts shall be kept of the sums of money received and expended by the ANZPNA and the matters in respect of which such receipts and expenditure take place and of the property credits and liabilities of the ANZPNA and subject to any reasonable restrictions as to time and manner of inspecting the same that may be imposed in accordance with the regulations of the ANZPNA for the time being the same shall be open to the inspection of the members. Once at least in every year the accounts of the ANZPNA shall be examined and the correctness of the balance sheet ascertained by one or more properly qualified auditor or auditors.

ARTICLES OF ASSOCIATION

of

THE AUSTRALIAN AND NEW ZEALAND PAEDIATRIC NEPHROLOGY ASSOCIATION

Interpretation

1. In these articles of association unless the context otherwise requires -

"The ANZPNA" means the company registered as "The Australian and New Zealand Paediatric Nephrology Associatian ".

"Executive" means the governing body of the ANZPNA herein provided for.

"Member" means a member of the ANZPNA .

"General Meeting" means an annual general meeting or an extraordinary general meeting and any adjourned holding thereof.

"Annual Meeting" means the annual general meeting of Members .

"Office" means the registered office of the ANZPNA for the time being.

"The Chair, "The Honorary Secretary", and "The Honorary Treasurer", mean those respective officers for the time being of the ANZPNA and include any persons appointed to perform the duties of those respective officers temporarily.

"In writing" and "written" include typing, printing or lithographing and other modes of representing or reproducing words and figures in a visible form.

Words importing the singular number include the plural number, and words importing the plural number include the singular number.

Words importing the masculine gender shall include the feminine gender and vice versa.

Words importing persons shall include corporations and companies.

"Month" means calendar month.

"By-laws" means the by-laws of the ANZPNA passed pursuant to these articles of association.

"The Law " means the Corporations Law as amended from time to time.

Membership

2. The subscribers to the Articles of Association and such other persons as shall be admitted to membership in accordance with these articles of association and none others shall be members of the ANZPNA.

3. For the purposes of registration the ANZPNA is declared to consist of Twenty Two (22) Members but the Executive may from time to time register an increase in the number of Members.

Membership Requirements

4. Medical Practitioners who hold a medical qualification conferred by an institution recognised by the ANZPNA and have a substantial involvement in paediatric nephrology shall be eligible to be admitted to membership of the ANZPNA.

Every applicant for membership of the ANZPNA must be proposed and seconded by Members and he or she must sign and deliver to the Honorary Secretary not less than one month before a general meeting an application for membership framed in such terms as the Executive shall require.

Every applicant for membership of the ANZPNA shall in his application state his agreement to abide by the articles of association and by-laws of the ANZPNA and to pay his annual subscription so long as he shall remain a Member.

All valid applications will be submitted to the next general meeting .

Notification of Membership

5. When an applicant for membership of the ANZPNA has been admitted notice to that effect shall be sent to him by the Registrar together with a request for the payment of the annual subscription payable on his admission.

Subscription

6. No person shall be deemed to be a Member nor shall his admission to membership be effective until he shall have paid the annual subscription payable on his admission.

Membership Non-Transferable

7. The rights and privileges of a Member shall be to himself and shall not be transferable.

Membership Dues

8. There shall be payable to the ANZPNA by each Member (other than an Honorary Member) for each year during which he remains a Member an annual subscription which shall become payable in advance on the first day of January in each year. The annual subscription shall be such a range as the ANZPNA shall from time to time in general meeting determine. The Executive may in its absolute discretion reduce the subscription of any Member or class of Members to such an extent as the Executive shall determine.

Honorary Member

9. Honorary Members may be elected from medical practitioners who have rendered outstanding Service to paediatric nephrology in Australia and New Zealand for which the ANZPNA desires to confer honour. Honorary Members shall be elected by the Council. Honorary Members may enjoy all the privileges and benefits of membership of the ANZPNA.

Resignation of Member

10. Any Member may resign his membership on giving to the Council three months notice in writing of his intention to resign and his resignation shall take effect at the expiration of such notice provided that no resignation of a Member shall be accepted or take effect unless and until all arrears of subscription due by such Member to the ANZPNA have been paid.

Termination of Membership

11. The membership of any Member shall be terminated ipso facto in any of the following events.

(a) On his death.

(b) If he ceases to retain any of the qualifications rendering him eligible for admission to membership of the ANZPNA.

(c) If he be in arrear with his annual subscription for two years and if after that period he shall fail to pay such arrears within two months after application is made to him in writing by the Honorary Treasurer to pay the same.

(d) If he become or be made bankrupt or insolvent under any of the laws relating to bankruptcy or insolvency for the time being in force in Australia and New Zealand, but the Council shall have power to declare that the membership of a Member shall be deemed not to have been terminated by his bankruptcy or insolvency and thereupon the membership of such Member shall continue as though he had not become bankrupt or insolvent.

(e) If he becomes mentally ill.

(f) By expulsion from membership by the ANZPNA in general meeting on the ground that the conduct of the Member is or has been detrimental to the honour and/or interests of the medical profession or of the ANZPNA or is or has been calculated to bring the medical profession or the ANZPNA into disrepute or contempt or on the ground that he has wilfully and persistently refused to comply with or has committed a wilful breach of these articles of association or of any by-laws of the ANZPNA provided however that a Member shall not be expelled from the ANZPNA except upon a resolution of a majority of at least three-fourths of the Members present and voting at an extraordinary general meeting of the ANZPNA at which there shall be present at least one-half of the Members for the time being and of which meeting such Member shall have been given at least seven clear days' notice. The notice shall state the purpose of the meeting and what is alleged against the Member concerned and such Member shall be entitled to attend such meeting and be given the opportunity to be heard in his own defence and of stating his case to the meeting, but the Member concerned shall not be permitted to be present at the voting or permitted to otherwise take part in the proceedings of the meeting except as the meeting allows.

Continuing Membership

12. Every Member shall remain a Member until his membership is terminated in accordance with the provisions of these articles of association.

Arrears of Subscription

13. If any Member shall by any means cease to be a Member of the ANZPNA he shall nevertheless remain liable for and pay to the ANZPNA all moneys which at the time of his ceasing to be a Member may be due from him to the ANZPNA.

Readmission

14. No person who shall have been a Member and ceased to be such shall be eligible for readmission until he shall have paid all arrears of subscription, if any, due from him to the ANZPNA at the date when his former membership ceased.

Register of Members

15. There shall be a register of Members kept by the ANZPNA and there shall be entered in such register the full name and address and occupation of each Member and such other particulars as shall be by Statute required to be entered therein and such further particulars as the Council shall from time to time prescribe.

General Meetings

16. The first annual meeting of the ANZPNA shall be held at such time during the year One thousand nine hundred and ninety-nine and at such place as the Executive may determine.

Time of Annual Meeting

17 .Subsequent annual meetings of the ANZPNA shall be held once in every year at such time not being more than fifteen months after the holding of the last preceding annual meeting at a time and place as the Executive may determine.

Extraordinary Meeting

18 .The meetings referred to in the last preceding article shall be ordinary meetings; all other meetings shall be called extraordinary meetings.

19. The Executive may whenever it thinks fit convene an extraordinary meeting. Extraordinary meetings shall also be convened and held as provided for in the Law .

Notice of A.G.M.

20. Not less than five weeks notice of a general meeting specifying the place the day and the hour of meeting and in case of special business the general nature of such business shall be given to the Members in manner hereinafter mentioned or in such other manner (if any) as may be prescribed by the ANZPNA in general meeting but the non-receipt of such notice by any Member shall not invalidate the proceedings at any general meeting.

21. The accidental omission to give such notice of meeting to any of the Members shall not invalidate any resolution passed at any such meeting.

Proceedings at General Meetings

Business of A.G.M.

22. The business of an annual meeting shall be:

(a) To receive and consider the report of the Executive.

(b) To receive and consider the accounts of the ANZPNA for the past year.
(c) The Declaration by the Chair of the result of the election of members of the Executive.

(d) To admit persons as Members.

(e) To consider any motion of which at least twenty-eight days notice in writing shall have been given to the Honorary Secretary.

(f) Any other business which may be lawfully transacted at the annual meeting.

All other business transacted at the annual meeting and all business transacted at an extraordinary meeting shall be deemed special.

Quorum A.G.M.

23. No business shall be transacted at any general meeting unless a quorum of Members is present. Except as hereinafter provided ten percent of all Members personally present and entitled to vote shall be a quorum for a general meeting.

Quorum Not Present

24. If within one-half hour from the time appointed for meeting a quorum of Members is not present the meeting if convened upon the requisition of Members shall be dissolved. In any other case it shall stand adjourned until the following day at the same time and place and if at such adjourned meeting a quorum of Members is not present those Members who are present shall be a quorum and may transact the business for which the meeting was called.

Chairman A.G.M.

25. The Chair shall except as hereinafter provided preside as chairman at every general meeting of the ANZPNA.

Alternative Chairman A.G.M.

26. If at any meeting the Chair is not present within fifteen minutes after the time appointed for the holding of the same, or being present is unwilling or unable to act as chairman the members present shall elect one of their number to be the chairman of the meeting.

Adjournment of Meeting

27. The chairman may with the consent of the meeting adjourn any meeting from time to time and from place to place but no business shall be transacted at any adjourned meeting other than the business left unfinished at the meeting from which the adjournment took place.

Voting at Meeting

28. Every question submitted to a meeting shall be decided in the first instance by a show of hands and in the case of an equality of votes the chairman shall both on a show of hands and at a poll have a casting vote in addition to the vote to which he is entitled as a Member.

Record of Motions

29. At any general meeting unless a poll is demanded by the chairman or at least five members present a declaration by the chairman that a resolution has been carried or carried by a particular majority or lost or not carried by a particular majority and an entry to that effect in the book of proceedings of the ANZPNA shall be conclusive evidence of the fact without proof of the number or proportion of the votes recorded in favour of or against such resolution.

Governing Body - The Executive Committee

36. The affairs of the ANZPNA shall be managed and controlled by an Executive Committee which shall composed of Chair, Honorary Secretary and Honorary Treasurer.

The Honorary Officers

37. There shall be the following officers of the ANZPNA namely a Chair, a Vice Chair, the Honorary Secretary and an Honorary Treasurer who will be Members. The Officers will be elected by the Members at the Annual General Meeting will serve for two (2) years and will not be eligible for immediate re-election.

Term of Executive Committee

38. Subject as otherwise herein provided members of the Executive shall retain office until the conclusion of the Annual Meeting at which their successors are declared elected or assume office.

39. No member of the Executive shall receive any remuneration for his or her services in the capacity of a member of the Executive.

40.(a) **Powers of Incomplete Executive**
In default of and until the election of any member or members whereby the number of members of the Executive is incomplete all the powers conferred on the Executive shall belong to and may be exercised by such members of the Executive as shall then be in office.

(b) **Vacancy on Executive**

Provided that in the case of a vacancy in the Executive occasioned by failure to elect at an election, the Members of the Executive then in office may appoint a Member to fill the vacancy. Any casual vacancy in the Executive may be filled by the Executive. A Member so elected or appointed to fill a vacancy as aforesaid shall, subject to the provisions of Article 41, retain his office only until the conclusion of the next Annual Meeting at which the relevant Executive Member is to retire.

41. **Vacation of Office of Executive Members**

The office of a member of the Executive shall be vacated if the member:

(a) holds any office of profit under the ANZPNA.

(b) becomes bankrupt or makes any arrangement or composition with his creditors generally; or

(c) becomes prohibited from being a director of a company by reason of any order made under the Law ; or

(d) becomes of unsound mind or a person whose person or estate is liable to be dealt with in any way under the law relating to mental health; or

(e) resigns his office by notice in writing to the ANZPNA; or

(f) ceases to be a Member ; or

(g) ceases to be a member of the Executive by virtue of the Law : or

(h) for more than six months is absent without permission of the Executive from meetings of the Executive held during that period; or

(i) is directly or indirectly interested within the meaning of the Law in any contract with the ANZPNA or participates in the profits of any contract with the ANZPNA. Provided however that a member of the Executive shall not vacate his office by reason of his being a member of any corporation society or association which has entered into contracts with or done any work for the ANZPNA if such corporation society or association is among the class of companies referred to in the last proviso to Clause 4 of the Regulations of the ANZPNA and if he shall have declared the nature of his interest in manner required by the Law . A member of the Executive shall not vote in respect of any contract in which he is interested or any matter arising thereout and if he does so vote his vote shall not be counted.

Vacancy in Executive Offices

42. In the event of the death during his term of office or resignation of the Chair the Honorary Secretary shall discharge the duties of the Chair until the conclusion of the next Annual Meeting.

Honorary Secretary's Duties

43. The Honorary Secretary shall summon all meetings of the ANZPNA and of the Executive and be responsible for entering the minutes of meetings of the ANZPNA and of the Executive in the books to be provided for that purpose.

Treasurer's Duties

44. The Honorary Treasurer shall manage the financial affairs of the ANZPNA and present the annual accounts of the ANZPNA to the Executive.

Frequency of Executive Meetings

45. The Executive shall meet not less than twice in each year and one of such meetings shall be held as soon as practicable after the close of the Annual Meeting of the ANZPNA in each year and one of such meetings shall be held immediately before the Annual Meeting of the ANZPNA to be held in each year. For the purposes of this Article a year shall be the period commencing at the conclusion of an Annual Meeting and ending at the conclusion of the next succeeding Annual Meeting.

46. Subject to the provisions of Article 55 the Executive shall meet for the transaction of business at such times or places at it may from time to time by resolution determine or as the Honorary Secretary may direct.

Executive Quorum

47. No business shall be transacted at a meeting of the Executive unless a quorum of the members thereof is present. Unless otherwise determined two members personally present shall constitute a quorum.

Chairman of Executive Meeting

48. At every meeting of the Executive the Chair or in his absence the Honorary Secretary shall be chairman.

Executive Voting

49. Questions arising at any meeting of the Executive shall be decided by a majority of votes and each member present shall have one vote and in the case of an equality of votes the chairman of the meeting shall have a second or casting vote.

Written Resolution

50. A resolution in writing signed by all members of the Executive shall be as valid and effectual as if it had been passed at a meeting of the Executive duly convened and held and such resolution shall be entered by the Honorary Secretary in the Minute Book and ratified by the Executive at its next meeting.

Proxy at Executive Meetings

51. In the event of a member of the Executive being unable to attend any meeting of the Executive he may nominate another Member to act as his substitute or to be his proxy at such meeting. The nomination of a substitute or proxy shall be in writing and signed by the member of the Executive making the nomination and must be produced at the meeting of the Executive in respect of which it is made.

Powers of the Executive

Powers of Executive

52. The management and control of the business and affairs of the ANZPNA shall be vested in the Executive and the Executive may exercise all such powers and do all such acts and things as the ANZPNA is by its Regulations or otherwise authorised to exercise and do and are not hereby or by Statute directed or required to be exercised or done by the ANZPNA in general meeting but subject nevertheless to the provisions of the Regulations of any Statute or of these presents.

Delegation of Executive Power

53. The Executive may delegate any of its power to other Committees consisting of such member or members of its body as it shall think fit and may from time to time make such delegation. Any Committee so formed shall in exercise of its powers so delegated conform to any regulations that may from time to time be imposed upon it by the Executive.

Secretary

54. A Secretary shall in accordance with the Law be appointed by the Executive for the performance in relation to the ANZPNA of the statutory duties and functions required to be performed by the Secretary of a company at such remuneration and upon such conditions as the Executive shall deem advisable and any Secretary so appointed may be removed by the Executive and provided that any duty act or thing required by these Articles to be performed or done by the Honorary Secretary may if the Executive so directs be performed or done by the Secretary. Nothing herein shall prevent the Executive from appointing a Member as Honorary Secretary and any Member so appointed shall forthwith become an officer of the ANZPNA and if not already a Member of the Executive ex-officio a Member of the Executive and he shall be subject to Clause 4 of the Regulations.

Funds

55. The Treasurer shall receive all funds of the ANZPNA and disburse the same. Unless and until the Executive shall otherwise determine cheques shall be signed by the Honorary Treasurer and one of such other persons as shall be authorised for such purposes by the Executive.

Seal

56. The Executive shall provide for the safe custody of the Seal of the ANZPNA and the same shall never be used except by the authority of the Executive previously given and in the presence of at least two members of the Executive who shall sign every instrument to which the Seal is affixed and every instrument to which the Seal is affixed shall be countersigned by the Honorary Secretary or some other person appointed by the Executive for that purpose.

Accounts

57. The Executive shall cause proper accounts to be kept with respect to:

(a) All sums of money received and expended by the ANZPNA and the matters in respect of which the receipt and expenditure takes place.

(b) All sales and purchases of goods by the ANZPNA.

(c) The assets and liabilities of the ANZPNA.

Statements of Account

58. The Executive shall from time to time cause accounts to be kept as provided by Clause 8 of the Regulations and shall from time to time in accordance with the Law cause to be prepared and to be laid before the ANZPNA in general meeting such income and expenditure accounts balance sheets and reports as are required by the Law to be prepared and laid before the ANZPNA made up to a date not more than six months before the date of the meeting.

Distribution of Balance Sheet before A.G.M.

59. A copy of every balance sheet (including every document required by law to be annexed or attached thereto) which is to be laid before the ANZPNA in general meeting shall not less than fourteen days before the date of the meeting be sent to all persons entitled to receive notice of general meetings of the ANZPNA.

Auditors

60. Auditors shall be nominated and appointed and their duties regulated in accordance withthe Law and Clause 9 of the Regulations.

61. Every account of the Executive when audited and approved by a general meeting shall be conclusive except as regards any error discovered therein within three months next after the approval thereof. Whenever any such error is discovered within that period the account shall forthwith be corrected and thenceforth shall be conclusive provided that nothing in this article shall give a conclusive effect to any matter or thing arising out of or involving a breach of Clause 3 of the Regulations.

Notices

Notice to Members

62. A notice may be served by the ANZPNA upon any Member either personally or by sending it through the post in a prepaid envelope or wrapper addressed to such Member at his registered place or address.

63. Every Member whose registered place of address is not in Australia and New Zealand may from time to time notify in writing to the ANZPNA an address in Australia and New Zealand which shall be deemed his registered place of address within the meaning of the last preceding Article.

64. As regards those Members who have no registered place of address a notice posted up in the office of the ANZPNA shall be deemed to be well served on them at the expiration of twenty-four hours after it is so posted up.

Certification of Notice

65. Any notice sent by post shall be deemed to have been served on the day following that on which the envelope or wrapper containing the same is posted and in proving such service it shall be sufficient to prove that the envelope or wrapper containing the notice was properly addressed stamped and put in the post office and a certificate in writing signed by the Honorary Secretary or other officer of the ANZPNA that the envelope or wrapper containing the notice was so addressed and posted shall be prima facie evidence thereof.

Signature of Notice

66. The signature of any notice to be given by the ANZPNA may be written or printed.

Counting Days of Notice

67. Where a given number of days notice or notice extending over any other period is required to be given the day of service shall (unless it is otherwise provided) be counted in such number of days or other period.

Indemnity of Officers

Indemnity of ANZPNA Officers

68. Every member of the Executive, the Honorary Secretary, the Honorary Treasurer or other officer of the ANZPNA or Auditor of the ANZPNA shall be indemnified out of the funds of the ANZPNA against all liability incurred by him as such member, officer or auditor in defending proceedings whether civil or criminal in which judgement is given in his favour or in which he is acquitted or in connection with any application under the Law in which relief is granted to him by the Court.

By-Laws

Regulations or By-Laws/Amendment of Regulations or By-Law

69. Save in so far as otherwise determined by Statute or these articles the ANZPNA shall have full power to make regulations or by-laws not inconsistent with the Regulations or these articles on all matters relating to the affairs of the ANZPNA and the conduct or management of its business and of the business of all committees or otherwise for the purpose of carrying out its objects and also on all matters relating to ethics as concerning Members and the rights and obligations of Members and all regulations or

by-laws so made and for the time being in force shall be binding on the Members as if they formed part of these articles and shall have full effect accordingly. Provided that any regulation or by-law so made may be rescinded or amended by resolution of any general meeting of the ANZPNA.

We the several persons whose names and addresses are subscribed as desirous of being formed into a company in pursuance of these regulations.

Names, addresses and descriptions of subscribers	Witness
For Example	
JOHN CHARLES ADAMS Medical Practioner 300 Macquarie St SYDNEY NSW 2000	JUDITH CATHERINE JONES Personal Assistant 27 The Heights CASTLECRAG NSW 2068

Dated this day of 1998

WEBSITE FOR ANZPNA

Michael Falk writes:

I think we should go ahead with the webpage for the ANZPNA.

I have spoken to Allison Hill from the College (I worked with her to set up the Transplant Society Website with great success..... look up http://www.racp.edu.au/open/tsanz.htm) and she is happy to set up the page for us. The cost may be nothing or at worst $200-300 and on the basis of our conversation yesterday I will proceed.

We should think about designing a logo for ANZPNA. It could be used as the front page for the website, on our correspondence etc. It would of course have to be ratified by members but if there were any budding artists around it may be useful for them to start.

To design the website I'll need someone (probably you) to write a page or two on the history of the group, aims/directions ie a general introduction to ANZPNA. I will also need the newsletter in electronic form and we discussed this yesterday with the need to scan some documents etc...let me know how this is going...it may be possible to have a reduced newsletter in the first instance.

Michael

I have reprinted the website next two pages for members' interest.

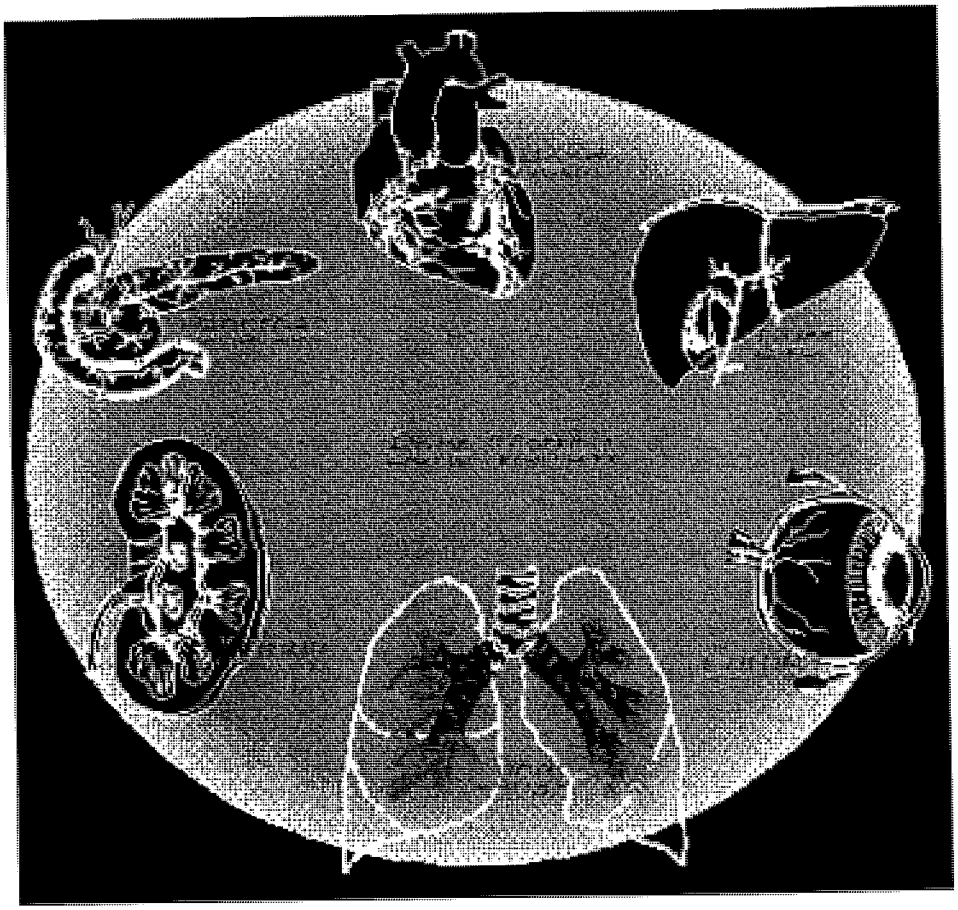
T · S · A · N · Z

The Transplantation Society of Australia and New Zealand Inc.

145 Macquarie Street
Sydney. NSW. 2000
Australia

Tel: (02) 9256 5461
Fax: (02) 9541 4083

The Transplantation Society of Australia and New Zealand has as members, scientists, doctors, transplant coordinators and research students with an interest in all forms of transplantation.

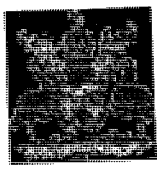


The Society logo symbolises:

- The three points represent the contribution of the donor, medicine and science to organ transplantation.
- The complexity of the process of organ transplantation is represented by the intertwining of the colours
- Australia and New Zealand are symbolised by their respective national colours: green, gold, black and white

For more information about our Society, please select a link below:

- *TSANZ Newsletter - January 1998 Issue Online!*
- *The Council*
- ***Sixteenth Annual Scientific Meeting 1998***
  (Information available soon!)
- ***Links of Interest***
  "The Renalnet Information Service" - Transplant Resources
  "Transplantation Resources on the Internet" - Transplant Centres



[RACP Website]

INTERNAL BID: HOST CITY FOR IPNA, 2004

As stated in the italicised notes accompanying the Minutes of the Teleconference on 18/12/97 of the Executive, Ken Juriedini has put together a bid to host IPNA, 2004. According to the resolution of the Annual Meeting, 1997, (JANZPNA, 1:1997;18) only one centre would bid from Australasia and all members would support the chosen city. As there is only one bid, it is up to the membership to accept that bid from Adelaide or to reject it. This is an onerous decision because the work involved in organising the IPNA meeting is beyond the capacity of the members in Adelaide without the active help of nearly all the rest of the members.

I have asked Ken to put the details of his bid on paper, and that follows. A main agenda item for our meeting in July will be the acceptance or rejection of that bid. Obviously, the details of the bid are fluid and Ken would be making changes as arrangements and details become available.

If the bid is accepted then it would be up to the members to begin lobbying for the IPNA Council to see the bid as an Australian one and a competitive one. We should attempt to make our desire to hold the IPNA conference widely known before and at the London conference this year.

Women's and Children's Hospital
ADELAIDE

72 King William Road
North Adelaide
South Australia 5006
Telephone (08) 8204 7000
Facsimile (08) 8204 7459

RENAL UNIT
Direct Dial (08) 8204 7303
Facsimile (08) 8204 6048
E-mail: jureidinik@wch.sa.gov.au

KEN JUREIDINI, FRACP
PAUL HENNING, FRACP
ANNE MARTIN, PhD

27 February 1998

Dr Colin Jones
Chairman
ANZPA

Dear Colin,

As you know, I have been a longstanding advocate for having the IPNA Congress in Australia/New Zealand and, specifically, if generally agreed, in Adelaide. I should like to unequivocally repeat that the first priority is an Australian and New Zealand meeting and that whichever city holds it, it should be seen as primarily representing the whole region.

Although I am awaiting more detailed information from various agencies, I am faxing with this what I believe is sufficient preliminary information to show that we have the capabilities to put on a top grade congress in Adelaide. The first attachment is from Hartley Management Group, headed by a most impressive Graham Teague, with whom I have had previous dealings. The second is from the Adelaide Convention and Tourism Authority (ACTA), who are very professional and extremely keen to assist in securing the meeting and arranging it. I shall be posting a more detailed blurb from them and from the Adelaide Convention Centre, whom are also busting to get the meeting. ACTA, as you will see, are used to sending out a regular mailout of appropriate messages and wine samples etc to the decision makers. Although my first reaction was a somewhat conservative shudder reflecting my age, it seems that this is the way it is done and they reassured me that it would be done *tastefully*.

Of interest, the Anzacs are bidding for the World Transplant Congress in Sydney from August 22-27, 2004. It would seem logical to bid for the IPNA from 29 August, 2004, which will no doubt assist in both bids. I have already discussed this with Randall Faull, one of the organisers of the Transplant bid. I have been in touch with Prof Gary Andrews, who organised the World Gerontology Conference in Adelaide for 1700 delegates and Adrian Porter, who is organising the ANZ Urology meeting here next year. Both are very willing to swap ideas and experience. Both Adrian and our Paediatric Urologists are keen to assist with giving a high profile of our meeting

to the international paediatric urology community and will consider an appropriate satellite meeting for Oz Urologists at least. I have also begun preliminary discussions with potential sponsors. As well as the usual international and national trade people, we are very confident of getting a number of local companies who wish to display their wares to the international visitors. I have contacts being established with politicians and other important people. Preliminary feedback establishes that the Adelaide psyche is to be very much behind such a venture, because it is very important for us to promote our state.

It is only worth the effort to put on such a meeting if the aim is to make it of superior standard. This will be very achievable if it has the goodwill of all the paediatric nephrology community of ANZ. It will be most important to spread the responsibility between representatives from the full area of ANZ. Clearly, someone has to take primary responsibility for ensuring that the highest standard is achieved. From a personal point of view, I have prevailed upon Paul Henning to take over the directorship of our renal unit for a number of reasons (the main one being that 20 years of administering a department is too long for me and the department). Thus, recognising that someone in Adelaide will need to be the primary coordinator, I shall be able to make sufficient time available. As is the case with the London meeting with Cyril and Martin, I believe that there should be two co-chairmen. I should be most appreciative if you could be co-chairman with me. I suggest that I head the local organising committee, arrange the venue and oversee the finance, sponsors, venue, social programme, publicity, satellites etc and that you oversee the scientific programme, continuing education and publication. I shall be in Melbourne at least four times in the next twelve months, and can meet with you each time. As we discussed, I can fund one visit for you via the hospital and at least one other through seeding funds for attempting to win the conference. Clearly, we shall only be able to achieve a successful meeting with strong cooperation from the members of the ANZSPA. I suggest that we ask the group as a whole to form the organising committee and to choose representatives to chair individual committees. Hopefully, appropriate people will volunteer for these. It would also be most helpful if members would lobby their individual regions for funding support.

I believe there it will be a major benefit to have David McCredie as president of the congress. I do not need to sell this to our members, but stress that as a founding member of IPNA, well known and respected in the world of paediatric nephrology and as the prime mover of the specialty in ANZ, I should personally consider it a great honour to have him. I have put it to David and he has agreed, subject to health. There is little risk of his health interfering, since the old buggar will probably outlive us all.

We have a viable local organising committee, comprising Paul Henning, Anne Martin, David Lines, Jill Lawton and Peter Wilby from our dialysis staff and Michelle Tilley who is presently a trainee. Adrian Porter from the ANZ Urology Society and Hilary Boucaut, Paediatric Urologist are also willing to take part. I believe the IPNA Council are keen for added input from the urologists. A representative from Adelaide's adult nephrogists would be desirable. We have Gay Simon, fulltime and Glenys Stoddard halftime secretaries, who with the Women's and Children's Hospital

promised support will be supplemented to provide clerical expertise. This will be further supported by ACTA and the Hartley Management Group.

As you will see from the accompanying brief documents, Adelaide has outstanding facilities and expertise to produce a state of the art congress. Day trips for accompanying people include the Barossa Valley, Southern Vales, Clare Valley winery districts, the Murray Mouth and Coorong, bushwalks and bus trips to the Adelaide Hills including Cleland Reserve (Koalas and Kangaroos in the wild) and Warrawong Sanctuary. Pre and post tours within South Australia include Kangaroo Island, extended winery tours and the Flinders Ranges. A major attraction of Adelaide is that it provides excellent facilities all close together at a cost well below most other venues.

Although I believe the format of the meeting should be decided by the group as a whole, the following are some suggestions for consideration:

A major session arranged by Paul Henning on ethical matters, perhaps concentrating on allocation of resources in differing communities and/or quality of life.

All of us seek younger people, beginning to make their mark in the world, who will still be fresh and original in 2004 as major speakers.

Ensure that the programme is relevant to third world delegates.

Lobby neighbouring countries to attend en masse.

The Adelaide Festival Centre is next door and could be considered for a major musical event.

In summary, Adelaide provides the venue and expertise for an excellent congress. I am confident that we can find more than adequate sponsorship to ensure that the meeting can be run at a profit at a very low cost to the delegates. We have an enthusiastic and talented local team, experienced in arranging major congresses and loads of talent among our own members to ensure success.

Regards Ted.

Hartley Management Group Pty Ltd

ACN 050 294 614

20 February, 1998

Report prepared for Fred Jureidini re International Pediatric Nephrology Association Conference

Proposed timeframe
Year 2004
Either September in keeping with previous conferences or March to tap into the Adelaide Festival of Arts

Expected attendance
1,000

Venue
The Adelaide Convention Centre is in the heart of the business district of Adelaide and is an ideal venue for a conference of this size.

It has 5 halls with tiered seating (capacities from 1100 to 400 individually and upwards of this number if combined) and 11 meeting rooms (capacities of 30 to 100 individually up to 200 combined) with flat floor seating. These halls and meeting rooms allow for a varied scientific program.

The Adelaide Convention Centre provides the latest in technology, with video-conferencing, internet connection and data projection presentations, audience-response devices and interpreting services all readily available.

Adjacent the Convention Centre is the Exhibition Hall which is currently 3000 sq m in area (comfortably accommodates 150 3m x 3m exhibition booths) and is soon to be doubled in size.

Accommodation
Within a 5 minute walk of the Convention Centre there are 2000 beds in hotels ranging from the 5 star Hyatt Regency to a number of 3 and 4 star properties.

Adelaide
Adelaide has hosted events such as the World Gerontology Conference and the Asian Retailers Association Conference for 1700 and 2200 delegates respectively, so it has a proven ability to handle events of significant size.

The major selling points of Adelaide as a convention city are its safety and convenience. Not only is the accommodation within a few hundred metres of the convention centre, so too are the cultural and shopping precincts.

Street address: 81 Sydenham Road Norwood SA 5067 - Postal address: PO Box 20 Kent Town SA 5071
Telephone (08) 8363 4399 - Facsimile (08) 8363 4577 - Email sgt@ozemail.com.au

Financial
Adelaide is noted as a value for money conference city. As a ballpark figure, a typical 4 day conference at the Adelaide Convention Centre, including catering and social functions, would cost of the order of AUD$500.

Five star hotel rooms of the Hyatt Regency sell to delegates for $200 per night and within walking distance are rooms of varying standard down to $70 per night.

Services
All the required conference services - exhibition hire, audio-visual hire, graphic design and printing, professional conference management, transport, touring, interpreting services etc - are available and are of world class quality and at prices which represent exceptional value.

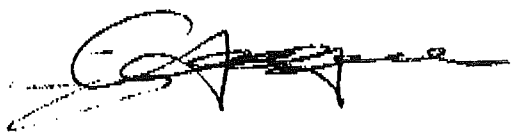
Tours
South Australia is noted for its high quality wine regions - the Barossa and Clare Valleys and the Southern Vales - and for the remarkable scenery of Kangaroo Island and the Flinders Ranges. Delegates will be given opportunities to visit regions of their choice either as pre- or post-conference tour options.

Professional Conference Management
Hartley Management Group has a strong record of successfully managing Adelaide based conferences. It has the resources and experience to support a small committee in all aspects of managing an international conference, from establishing budgets and timelines through to marketing the conference, liaising with speakers, sponsors, exhibitors and delegates, and managing all the contractors required.

Hartley Management Group knows Adelaide has the capacity to conduct an exciting and highly professional event and would be pleased to work with the Australian Organising Committee to compile a bid to bring the International Pediatric Nephrology Conference to Adelaide in the year 2004.

If the Australian Association is supportive of the concept of an Adelaide conference, the next step is to ask the Adelaide Convention and Tourism Authority to assist in putting together a bid document. The bid will include letters of support from local dignitaries, budgets, details of sources of seed funding and promotional materials including vidoes and give-aways.

I trust this information provides a useful background. Please feel free to call if you have any further queries.



Graham Teague
Managing Director

ADELAIDE
Convention & Tourism Authority
AUSTRALIA

Fax To :- **Dr Ken Jureidini - Department of Nephrology**
Adelaide Womens & Childrens Hospital

From :- **Catherine Leonard - Adelaide Convention & Tourism Authority**

Date :- **27 February, 1998**

Total Pages :- **3**

Dear Dr Jureidini,

Re: 13th Congress of the International Paediatric Nephrology Association - 2004

With reference to our meeting of Wednesday 25th February, please find enclosed an outline of the services and assistance the 'Adelaide Convention & Tourism Authority' can provide in the lead up to attract the above conference to Adelaide, South Australia in August 2004.

Additionally a brief summary is enclosed highlighting Adelaide as a 'User Friendly' city for conventions explaining the close proximity of the major city hotels to the Adelaide Convention Centre.

As outlined to you in our meeting, A.C.T.A can install a 'delegate teaser programme' targeted at the Board Members of the International Association to raise awareness of South Australia's desire to host this congress. If you agree with this campaign, could you please forward a copy of the current Board Members to me as soon as convenient.

A.C.T.A is very enthusiastic to work closely with yourself and Dr Colin Jones to ensure Adelaide is voted as the chosen host city but to also facilitate and ensure the congress is successful.

Kind regards,

Catherine Leonard
Business Development

Adelaide Convention and Tourism Authority
Level 3, 60 Waymouth Street Adelaide SA 5000
GPO Box 331 Adelaide SA 5001
Telephone +61 8 8212 4794 Facsimile +61 8 8231 9224 Email: mice@acta.sa.com.au

ADELAIDE

THE USER - FRIENDLY CITY

Adelaide's convention plant is the envy of many larger cities with major accommodation houses and meeting venues within walking distance of each other.

In the heart of the city, on the banks of the lovely River Torrens, is the first purpose-built Convention Centre in Australia. Completed in June 1987, the Adelaide Convention Centre caters for meetings up to 3,500 delegates and for banquets up to 2,000. Besides the major plenary hall, there are numerous break out rooms of varying sizes housing the latest audio-visual, translating and technical equipment. The Centre also includes a 3260 square metre exhibition hall which can accommodate 175 booths. Adjacent, the Adelaide Festival Centre is less than one minute's walk from the Hyatt Regency Hotel and the Adelaide Casino, which is proclaimed as the most luxurious in Australia.

Immediately across the road is the Grosvenor Vista Hotel, Stamford Plaza and opening in April 1998 the Playford Hotel. Transportation costs are therefore reduced due to the close proximity to the Adelaide Convention Centre.

All three properties are located on North Terrace within walking distance of the Adelaide Festival Centre, the Art Gallery, Museum and Botanic Gardens.

One block away from this convention hub is Rundle Mall - the major shopping area and the nightlife and restaurant precinct of Rundle Street.

Other styles of accommodation located in the heart of the city include a variety of standard to 5 star hotels, luxury self contained apartments and unique bed and breakfast style accommodation.

ADELAIDE CONVENTION & TOURISM AUTHORITY

Who we are and what we do ..

The 'Adelaide Convention & Tourism Authority' (A.C.T.A) is a private non-profit destinational marketing organisation. Our role is to promote South Australia as a prime convention, incentive & exhibition destination. Additionally A.C.T.A is dedicated to working together with you and the people who will make your event a success.

More than 500 professional businesses are members of A.C.T.A, covering every aspect of the meeting, exhibition, incentive and travel industries - and all the necessary services required 'behind the scenes'.

A.C.T.A can assist the Paediatric Nephrology Association by providing assistance and guidance with the following:

* arrangement of 'Adelaide' familiarisations
* programme planning advice
* venue and facilities guides
* brochures for satchels
* destination video tapes
* interactive, destinational multi media programme
* product referrals, contact and advice
* delegate boosting activities
* access to financial support schemes

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MINUTES OF THE MEETING OF THE EXECUTIVE BY TELECONFERENCE ON THURSDAY APRIL 2, 1998.

PRESENT: **Colin Jones (Chairman)**
Lilian Johnstone
Paul Henning

1. CHAIRMAN'S REPORT

1.1 ANZPNA Journal

The most recent addition of the Journal includes the proposed Articles of Association as prepared by Paul Roy. CJ is keen for any thoughts or comments concerning the Articles to be relayed back to him. He is hopeful that the next edition of the Journal will be distributed by mid-April.

1.2 IPNA 2004 Bid

Adelaide have submitted a bid for the IPNA meeting in 2004. The outline of this bid was included in the last edition of the Journal. PH and Fred Jureidini would obviously require near unanimous court of the ANZPNA membership for the bid to go ahead. A resolution will be put at the next AGM concerning the bid, in terms of acceptance and support of the bid, to be voted on by the membership. Prior to the meeting, comments from the membership will be sought concerning the thoughts about the bid. It was felt that the ANZPNA membership would be unlikely to put up a subsequent bid again for 2008 if the bid was not successful in 2004. CJ also noted that should the bid be accepted by the membership it will be necessary to provide some advertising for the London meeting to promote the Adelaide bid. It appears that other bids are likely from Hungary and the Philippines. PH reported that the meeting of the members of the ANZPNA who attended the Australian and New Zealand Society of Nephrology meeting in Auckland had extensive discussion about the proposal to host IPNA in 2004. It would appear that there were some disquiet amongst those members who are unable to attend the AGM in July 1997 that they had not been fully involved in the discussion about a bid. It would also appear that no other centre wishes to put forward a bid. A letter will be distributed to all ANZPNA members requesting comments and is to be returned to CJ. PH raised the possibility of a satellite meeting being conducted in Sydney which would be helpful in co-ordinating flights through Sydney to Adelaide.

1.3 Annual General Meeting 1998

The date of the AGM will be Sunday July 19. The meeting will be held at the Royal Pines Resort on the Gold Coast and again will be sponsored by Baxter. A meeting is planned on Monday July 20 with its major focus being surgical access and therefore will have predominately adult flavour. Baxter would encourage the ANZPNA membership to attend the morning session which would be followed by a break out session, with members returning to their home states in the afternoon. Mandy Walker is working with Michelle Duddington and others on an agenda. CJ is hopeful that a publication will be achieved as occurred last year. Baxter is prepared to sponsor ANZPNA members and also plans to invite surgeons and the chief dialysis nurse from each Unit.

2. TREASURER'S REPORT

2.1 Financial Status

The bank account has been set up in Adelaide through the National Australia Bank for the ANZPNA. CJ is to transfer funds from Melbourne to the Adelaide accounts once CJ and LJ are

registered as signatories to the account. *LJ and CJ to contact Gary Marsland, NAB, Adelaide, 08 8239 2004 re ANZPNA account.*

2.2 Subscriptions

Following the establishment of the account, PH will send subscription notices for the current year.

3. SECRETARY'S REPORT

Correspondence has been received and tabled and is included in the current issue of this Journal.

4. BUSINESS ARISING FROM THE MINUTES

4.1 Projects

4.1.1 APSU Study/Nephrotic Syndrome

The letter from Elisabeth Hodson was noted. This should have been received by all members of the ANZPNA. Please respond to EH as the planned commencement date of the study is June.

4.1.2 Growth Hormone Project

The letter and questionnaire from Charlie Crompton was tabled. PH noted that he had not received the questionnaire. Please communicate with Charlie directly about the study.

4.1.3 Reflux Trial

Enrolments are continuing.

The Executive are very keen to encourage the collaborative studies underway and to promote further collaborative studies. It was felt that it was very important that the ANZPNA could function as a collaborative group.

4.1.4 Others

CJ mentioned briefly that he and Harley Powell are putting together a proposal concerning treatment of FSGS.

4.2 Meetings

4.2.1 ANZPNA 1998

Will be held on July 19 at the Royal Pines Resort, Gold Coast, Queensland.

4.2.2 ANZSN Meeting Auckland 1998

PH reported that the meeting was very worthwhile. The ANZPNA members present there discussed the IPNA bid as mentioned above, and the preferential allocation of kidneys to paediatric patients. Gad Kainer indicated that in New South Wales children were having preferential allocations as the time on dialysis is a percentage of the child's age was being considered in the allocation of organs. He plans to review the previous year's history of organ allocation using

the new model to see what change if would make and whether it results in preferential allocation of organs to children. It was noted that the Interstate Organ Exchange does consider preferential allocation to children, however, the only kidneys transported interstate now are those with a 5-6 antigen match and therefore are of very limited numbers. The Executive was pleased to note that members of the ANZPNA had promoted preferential allocation to children in Queensland, New South Wales and Victoria and are hopeful that this will flow on to other states.

4.3 Constitution

As mentioned above, the Articles of Association have been distributed and are open for discussion, comment and change. Thanks are expressed to Paul Roy for his efforts in producing the Articles of Association. It was felt that the definition of a quorum for the passage of resolutions may have to be redefined as ten percent of membership may only be two members.

5. OTHER BUSINESS

5.1 Sincere apologies were expressed to Margo McIver who had not been included on the initial membership list. A copy of the Journal will be sent to her with this current edition

5.2 Nifedipine capsules.

PH has received a letter from the TGA which has refused his and Fred's application for Nifedipine capsules to be used by specifically defined prescribers. PH is keen to know what other people are doing with respect to treatment of hypertension and whether they have residual stores of Nifedipine capsules and requested that this be included as an Agenda item for July.

5.3 Gad Kainer has written to PH concerning the potential availability of liquid calcitriol which is apparently available in New Zealand. The paediatric endocrine group are currently approaching Roche, and PH will write on behalf of the ANZPNA to Roche to assess its availability in Australia.

6. NEXT MEETING

IPNA Council Meeting

28-29 February 1998
FLORIDA USA

GRANTS

ESPN - £10,000
American Paediatric Nephrology Society $5,000

FINANCIAL REPORT –

European Account $40,000: American Account $63,000.

Approximate cost to administer IPNA is $220,000 per year. A discussion took place concerning a protocol for raising money from major international companies involved in dialysis and transplantation. Doctors Harman, Stapleton and Barratt are asked to produce a report.

PAEDIACTRIC NEPHROLOGY JOURNAL

The number of issues is being increased from 6 to 9 per year. There has been some change in format commencing January 1998. Very good articles can be published within three months of acceptance. The normal review time is less than three months then a six month wait till publication. Some members felt this interval was too long and the editors will try to reduce this time to three months. An increased link with Urologists was discussed.

CONFERENCE

Molecular basis of normal bone growth and turnover and their dysregulation in Children with Chronic Kidney Disease – will be held in New York, March 11 – 13, 1999. There is expected to be approximately 200 –300 participants. Organisers are R. Kaskel and B. Tonshoff.

IPNA CONFERENCE – LONDON, SEPTEMBER 1998

Approximately £179,000 was raised from Corporate sponsorship. The congress Presidents, Professor Barratt and Chantler, are happy with their present planning and expect a good attendance.

DEVELOPMENTAL NEPHROLOGY CONFERENCE - STOCKHOLME, 1998

This meeting is being held prior to the London meeting. The timing of this meeting in 2001 with the Congress in Seattle will be reviewed.

SECRETARY-GENERAL POSITION

Professor Greifer expects to retire in 2001. The position will then be for a term of 6 years. A nominating committee from the IPNA Council will be formed to recommend a short list to Council for an election by Council . It is expected that the new Secretary -General will have an elect period of three years on the Council.

IPNA CONGRESS 2001

Preliminary planning is proceeding very well. This meeting is being organised by Bruder Stapleton and Sandra Watkins. The conference will be held at a major hotel and it is expected that hotel rooms can be obtained at that venue for approximately $125. If 400 rooms are rented and the banquet is at that hotel then the rental space for congress will be free.

IPNA CONGRESS 2004

Expressions of interest at this stage have been received from the Philippines and Budapest in Hungary. A decision for the venue for that Congress will be made in 1999.

INTERNATIONAL CHILDREN'S KIDNEY FUND

A special fund with tax exemption is being planned. The council members will act as Directors. A fundraiser would be employed and hopefully would raise approximately $1,000,000 a year with some money arising from bequests. Money from this fund would assist in developing teaching programmes in undeveloped countries.

Dear

Re: Study of Growth Hormone Use in Children with Renal Disease

Deborah Lewis wrote to you in November 1997 concerning a project to analyze Australian and New Zealand growth data for children with renal disease treated with Growth Hormone.

Coincidentally, at the same time that a hospital fellowship was being sought by an Endocrinology Registrar at the New Children's Hospital, funds had been applied for and obtained in Perth for this same project. As the New Children's Hospital Fellowship application was unsuccessful, it was agreed that I would analyse the growth hormone data in conjunction with Dr Geoff Byrne, paediatric endocrinologist in Perth, primarily using the OZGROW Database, with individual data supplied by New Zealand paediatric nephrologists. Any publication that might arise from this work would include members of ANZPNA as authors (all members listed as a footnote).

The aim of the study is to determine the effectiveness of recombinant Human Growth Hormone on growth in children with renal disease, and to investigate possible causes of poor response. This is to be achieved by analysing the OZGROW data (and data from New Zealand) in conjunction with clinical data provided by individual clinicians.

The study cannot be undertaken without your assistance in information gathering. The accompanying questionnaire may seem a burden to complete but shouldn't be more onerous than the ANZDATA forms.

Any comments or criticisms would be welcomed.

Thanking you in anticipation of your help.

Yours sincerely

Dr Charles Crompton
Paediatric Nephrologist

Growth Hormone in Paediatric Renal Disease

Questionnaire

SURNAME MEDICAL RECORD NO

CHRISTIAN NAMES

DATE OF BIRTH: SEX

(Use sticker if available)

1. **PRIMARY RENAL DIAGNOSIS**
(Please give details)

_____

_____

2. **RENAL FUNCTION**

a) **Chronic renal insufficiency (not on dialysis)**
Serum creatinine _____
GFR (if known) _____
Calculation of GFR (Schwartz) _____

b) **Dialysis**
When started _____
Haemodialysis or peritoneal dialysis _____
Date started: (month and year) _____

c) **Transplant** _____
Date of transplant (month and year) _____
Current transplant function (GFR or creatinine) _____

3. **NUTRITIONAL STATUS**

a) Tube feeding YES/NO
b) Serum albumin _____
c) Urea _____
d) Body mass index _____
e) Clinical assesment Well nourished / undernournished

4. **PUBERTAL STATUS - Tanner Staging** _____

5. **BIOCHEMISTRY**

a) Calcium _____
b) Phosphate _____
c) PTH _____
d) Albumin _____
e) Urea _____
f) Creatinine _____
g) Thyroid function _____

6. **MEDICATIONS**

a) Antihypertensives _____
b) Corticosteroids _____
c) Thyroxine _____
d) Testosterone _____
e) Vitamin D _____
f) Calcium _____
g) Phosphate binders _____

IPNA 2004

Adelaide Bid

The process of accepting the bid is a formal vote at the next AGM of ANZPNA on July 19, 1998.

Prior to this the Executive would like feedback from the membership regarding the following:

1. Have you read the proposal? Yes ☐ No ☐

2. Are you prepared (in general, subject perhaps to minor reservation) to support the bid? Yes ☐ No ☐

3. Are you prepared to be involved in the planning process bearing mind this may take time? Yes ☐ No ☐

4. What are your reservations, concerns and comments?

_____

_____

_____

_____

_____

5. Are you planning for a last minute, alternative bid? Yes ☐ No ☐

If yes, some details please:

_____

_____

FAX RETURN TO: ***DR COLIN JONES***
03 9345 5611

C:\My Documents\ANZPNA\IPNA 2004.doc