Chair's Report 2021

In my last year's report, I expressed the hope that by now, we will be able to meet face-to-face and enjoy our social interactions. Sadly, it's still not possible, and many people, especially in New South Wales and Victoria, remain under the lockdowns. COVID-19 is still spreading through the world and claiming lives. The future remains uncertain, but there is a hope that with vaccinating most of the population in our countries, we will be able to travel and meet again. The members of ANZPNA have been instrumental in promoting COVID vaccination. We have engaged with the local health care providers in our states and territories and supported/promoted the vaccination of our most vulnerable patients, especially those living with kidney transplants and those receiving dialysis.

ANZPNA remains active in representing our society on multiple committees and working groups of other organisations.

The closest ties are with ANZSN, with our representation on almost all standing committees and the task or time-limited working groups. The ANZPNA Chair remains the only non-voting attendee of the ANZSN Council by invitation of the Council. These arrangements have been successful in sharing the information between our societies and in promoting ANZPNA in a wider nephrology community. Good examples of this collaboration are successful paediatric nephrology sessions at the ANZSN annual scientific meeting and the update courses, and the establishment of the paediatric research award at the annual scientific meeting.

ANZPNA has strong ties with TSANZ, where our members actively and successfully advocate on behalf of paediatric patients. This has been reflected on the recent changes in paediatric kidneys allocation system and the activities of COVID task force, specifically development of information and advice on school attendance of children and adolescents with kidney transplants during the COVID-19 pandemic.

ANZDATA Paediatric Working Group continues to play an important role in generating ANZDATA annual reports and the dissemination of paediatric ANZDATA-based research studies, both in reviewing the proposals for research but also actively participating in research studies.

The collaboration between ANZPNA and RACP is another important area, with our members actively involved in creating and maintaining the Advanced Training in Nephrology Program, which is being evaluated biennially by the Advanced Trainee Committee (Australia) and the Aotearoa New Zealand Advanced Trainee Committee (NZ), both of which have ANZPNA representation. This arrangement ensures that the paediatric nephrology area is included in the training curriculum that it is in line with up-to-date educational best practice. Model of Collaboration between ANZPNA and RACP that was developed in 2016 recognises the relationship between ANZPNA and RACP and documents a meaningful collaboration, particularly in areas of common interest, such as education and training and delivery of CPD. The Model is being currently reviewed and updated to make sure it remains current and fit for purpose.

On an international level, our members play an active role in multiple IPNA committees, including the Executive Committee, Sister Centers Committee, Communication Committee,

Juniors Committee, and others. ANZPNA also does essential work helping with resources in low-income countries in the Pacific region.

Moving into the future, our Association will continue to promote the changes that have emerged as important themes in our society. We will continue to advocate for providing a **culturally appropriate and safe care** for our patients and their families, especially addressing one of the most urgent issues – closing the gap in health and education opportunities and outcomes between Indigenous and non-Indigenous people. We will continue to support and strengthen the principles of **equity, diversity and inclusion** among the members of our Association. It has been pleasing to see the incremental involvement and acknowledgement of our young female members on a national and international level. The other area worth exploring by ANZPNA is the provision of **environmentally sustainable health care**, especially dialysis. Our adult colleagues are developing environmental practice guidelines focused on measures that dialysis units can implement locally. We can also look at how we can minimise our environmental footprint regarding electricity and water consumption or waste.

This is my last Chair's report because at this year's Annual General Meeting, we will be voting in a new executive team. I want to thank the leaving members of the "pandemic or virtual" executive team for their contributions to the Association. Josh Kausman as the Chair and immediate past Chair for his vision and guidance, Siah Kim, the retiring Treasurer for keeping our Association in a financially safe position, and Nick Larkins, the retiring Secretary for sending around the endless emails and thus keeping our members engaged. I have enjoyed working with you all. I wish the new members of the executive team success in their roles, and I look forward to working with the new Chair, the Treasurer and the Secretary in the next three years.

Peter Trnka ANZPNA Chair

ANZPNA Treasurer's Report for 2020-2021 Financial Year

The Association's financial position remains stable and a surplus of \$ 1515 was recorded for the financial year 2020/2021. We remain in a strong financial position with recent growth in membership.

Currently 45 members are up to date with subscription payments, with 38 members opting for joint IPNA membership. Four trainees have also opted for joint ANZPNA/IPNA.

Mr. Barry Hodson has produced the auditor's report and it and the financial statement are prepared for approval at the 2020 AGM. Reports are attached for members to review.



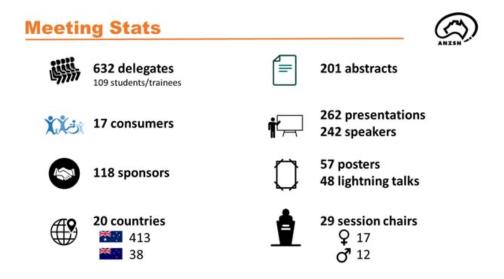
Siah Kim Honorary Treasurer ANZPNA Sept 6 2021

2021 ANZPNA Research Report

ANZSN ASM

Excellent bench to bedside paeds/genetics session "From genetics to gene therapy"

Update course- paeds session on apheresis, home dialysis and parenthood planning



New Awards

The Tonya Kara award started last year in honour of our dear colleague Dr Tonya Kara who was passionate about collaboration and undertaking quality research whilst building strong friendships and having lots of fun. Dr Tom Forbes was the winner of the 2020 award. There were no applicants for the award this year despite 3 paeds abstracts presented- please apply for the award next year!

Research activity (a very incomplete list)

Basic Science

Tom Forbes: organoid research into novel gene discovery for steroid resistant nephrotic syndrome

New clinical trials/ cohort studies

- BEST PARENT- starting 2021/2022: assessment of novel immunological risk profile to establish the most suitable parental donor for kidney transplantation

INCEPTION—commenced 2021: immunological assessment to improve paediatric kidney transplantation outcomes

- NAVKIDS2 –commenced 2020, active at Westmead, SCH, RCH, Perth, QLD: an RCT of a patient navigator to improve self-rated health and family care satisfaction in children with CKD
- Validation of fingerprick measurements of Tac and MPA (David Metz)
- Research genomics group: Cathy Quinlan, Tom Forbes
- Hyperoxaluria trial: Tom Forbes

- Habit Trial- Josh Kausman: providing HLA matched red blood cell transfusions to prospective transplant recipients

PhD 2020 - 2021

Tom Forbes

David Metz

Grants/ Fellowships/Awards

GlomCon Fellowship: Rachael Kermond

Jacquot PhD scholarship: Rowena Lalji

RACP establishment scholarship: Anna Francis

IPNA Report

Fiona Mackie

- The next IPNA scientific meeting will be 7-11 September 2022 in Calgary. This will be a
 hybrid meeting of face-face and remote conferencing as it is acknowledged that some
 countries are likely to still have travel restrictions.
- The Pediatric Nephrology Journal has gone from strength to strength under the stewardship of Joseph Flynn and the impact factor has increased from 2.8 to 3.7.
- An exciting new addition to the social media profile of IPNA has been the creation of the IPNA live twitter journal club started in July. A lot of useful snippets of paediatric nephrology or recent or seminal articles are appearing there. Check out the twitter handle at IPNAJC@ipnajc
- For trainees there are some good webinars on the IPNA site and live case presentations with the Grand Rounds in Pediatric Nephrology sister centres collaboration with ISN. The next is on October 1 and the case/discussion will be on Neonatal AKI and the risk of CKD.

IPTA Report

ANZPNA

Website

Currently SA Sec/Treas DH Council and Membership Committee, FM Committee Chair

ASM in Prague possibly in person and virtual. March 26-29, 2022
Details at https://ipta2022.org/
Abstracts due soon
Also nominations for awards

2023 in USA either New Orleans

Fellows Symposium Virtual: Friday 22nd October Details to follow Likely a Sat session with better hours for ANZ.

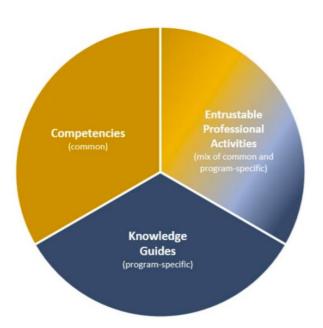
COVID has delayed a bid for IPTA to come to ANZ (?2025 or 2027).

Twitter handle @iptapedstx

Steve Alexander 8/9/2021

RACP ATC

The ATC has busy over the past year, with curricula review processes beginning among RACP ATC as part of the shift from time-based to competency-based training. Rob MacGinley is leading this and open to our input on how paediatrics best be incorporated into the broader nephrology advanced training curriculum, working with a curriculum review group to which Matt Sypek has also kindly been co-opted. At present it is envisaged the curriculum will be delivered in a modular format with MCQ, as opposed to an exit exam. Regardless, it is clear the existing time-based system did not satisfy Australian Medical Council expectations that trainees' knowledge be specifically evaluated to ensure they meet a minimum standard by completion of the program.



Core competencies and entrustable professional activities are being developed, with the development of knowledge guides being next. The paediatric curriculum will be an adapted version of that for adult trainees (i.e. omissions and additions to the standard program).

ANZSN ETC

It has been a challenging year for the ETC, attempting to deliver courses in an online environment. The basic course was delivered over two days, in May and June. Feedback from attendees was positive, although presenters noted that the additional time required to prepare and then attend a live session. The HD Academy is scheduled for November this year and the Advanced course will be run in 2022.

TSANZ

The new kidney allocation system was introduced in May, with the following aims:

- Adjust PRA thresholds to meet the standard practice of solid phase assays rather the cytotoxic PRA.
- b) Improve the access of younger patients to well matched organs through national allocation. The previous system prioritising the shipping of zero mismatched organs to recipients regardless of expected survival. The new system prioritises shipping of well-matched organs (favouring class II matching) to recipients likely to realise that benefit (younger recipients). Paediatric priority is retained at each level.
- c) A more uniform state-based allocation system. Previously there was wide variation in the allocation system between states. This did not meet community expectations and was highlighted in the recent EY review. The new system introduced survival matching by prioritising allocation based on HLA-matching to younger recipients. However, thus far most state-based allocation have been based on waiting time. Within the waiting time strata, the paediatric bonus means paediatric recipients will be the first to receive potential offers.

There was a bolus of highly sensitised patients transplanted shortly following implantation of the new algorithm. The number of patients matched at this level is

expected to reduce with time. There remain groups disadvantaged within the new allocation system, including those with rare alleles, of whom First Nationals peoples are overrepresented. Further changes to the allocation system are anticipated, based on the performance of the changes instituted thus far. The experience overseas has been that similar changes can have unintended consequences for some groups., including children. RTAC are cognisant of this and monitoring the number of kidneys allocated by state and age-group, and remain open to making adjustments as required to ensure an efficient and equitable system.

Appendix C

Kidney allocation algorithms

National Allocation formula

Match level	Description Very Highly sensitised	Crit	eria	Base score	
1		1a	mPRA ≥99.7	99 700 000	
	ABO Compatible	1b	mPRA ≥99	99 000 000	
		1c	mPRA ≥98	98 000 000	
		1d	mPRA ≥97	97 000 000	
		1e	mPRA ≥96	96 000 000	
		1f	mPRA ≥95	95 000 000	
National Urgent	ABO Compatible	Rec	cipient National urgency >0	90 000 000	
2	EPTS restriction HLA matching	2a	0 mismatches HLA-A or HLA-B and EPTS ≤25	89 000 000	
	Prioritises Low EPTS recipients Matched at HLA DRB1 ABO Matched	2b	1 mismatch HLA-A or HLA-B and EPTS ≤25	88 000 000	
			2 mismatch HLA -A or HLA-B and EPTS ≤25	87 000 000	
	KDPI max value is applied from this level down	2d	0 mismatches HLA -A or HLA-B and EPTS ≤60	86 000 000	
3	HLA matching Highly Sensitised	За	0 mismatch at HLA A or HLA B or HLA DRB1 and mPRA >80	79 000 000	
		3b	1 mismatch at HLA A or HLA B or HLA DRB1 and mPRA >80	78 000 000	
		3с	2 mismatches at HLA A or HLA B or HLA DRB1 and mPRA >80	77 000 000	
	HLA Matching	3d Matched at HLA DRB1		76 000 000	
	Centre credit difference		1 mismatch HLA A or HLA B And mPRA ≤80 And Centre credit difference ≤-3		
		Зе	Matched at HLA DRB1 2 mismatch HLA A or HLA B And mPRA ≤80 Centre credit difference ≤-6	75 000 000	
		3f	mPRA >80 Centre credit difference ≤-9	74 000 000	
		3g	Centre credit difference <-20	73 000 000	

May 2021 version 1.6 129

Bonus points added
250 000
50
1000 + recipient centre credit
500 000 (except level 3G)
Number of months x 1

State Allocation

- Allocation initially matched with restriction applied (EPTS-KDPI <=50) then unrestricted matching is applied
- KPDI max at clinician's discretion.

Level	Description	De	etails	Base Score	
State Urgent	State Urgency Index >0	Ur	gency index added to	60 000 000	
Level	Description	De	etails	Restricted base score	Unrestricted base score
State HLA	HLA mismatches	1a	000	49 000 000	39 000 000
	A/B/DRB1	1b	100 or 010	48 000 000	38 000 000
		10	: 110	47 000 000	37 000 000
		10	001	46 000 000	36 000 000
		16	200 or 020	45 000 000	35 000 000
		1f	1 0 1 or 0 1 1	44 000 000	34 000 000
		10	210 or 120	43 000 000	33 000 000
State Waiting	Months on dialysis	Νι	umber of months x 1	40 000 000	30 000 000

Additional scores

- Paediatric bonus of 100 000 for restricted algorithms state HLA and state waiting
- Recipient and donor are HLA DRB1 homozygous bonus 500 000 to state HLA matching algorithms only.

In the event that a more than one patient has the same score, the ranking is randomised.

Interstate Utilisation Algorithm

In rare situations there may not be enough patients in a given state to be able to accept the available kidneys. Most often this occurs if the donor has a rarer blood group, such as AB. If there are not enough patients to receive the kidneys locally, a national interstate Utilisation t is run. This list incorporates patients from across the country, to ensure that the kidneys do not go to waste.

Level	Description	Details	Restricted base score	Unrestricted base score
State HLA	HLA mismatches	1a 000	19 000 000	9 000 000
	A/B/DRB1	1b 100 or 010	18 000 000	8 000 000
		1c 110	17 000 000	7 000 000
		1d 001	16 000 000	6 000 000
		1e 200 or 020	15 000 000	5 000 000
		1f 101 or 011	14 000 000	4 000 000
			13 000 000	3 000 000
State Waiting	Months on dialysis	Number of months x 1	10 000 000	0

May 2021 version 1.6 130

Other work within TSANZ includes new deceased donor guidelines, which are being prepared based upon previous reviews, including the National Review of Paediatric Kidney Transplantation, chaired by Fiona Mackie. The TSANZ also moved to swiftly establish and continues the COVD-19 Taskforce. This group meets fortnightly, with minutes broadly disseminated per the following example. It has proved an important tool for communication across state and national boundaries, between organ groups, and between transplantation sectors.

COVID-19 - Australian Transplantation and Donation Rapid Response Taskforce Communique No.44 – 31 August 2021

• Transplantation update in Australia:

- o Nationally, the total number of COVID-19 cases since February 2020 is 56,212.
- ANZDATA has reported the following COVID-19 cases among dialysis patients and kidney transplant recipients; 52 (26 recoveries, 12 active cases and 14 deaths): 27 kidney transplant patients (20 recoveries, 4 active case and 3 deaths) and 25 dialysis patients (6 recoveries, 8 active cases and 11 deaths).
- o There are 951 COVID-19 patients in hospital with 172 patients in ICU with 75 being ventilated.
- Donation and Transplantation teams are having to manage logistical issues with both intrastate
 and interstate retrievals and shipping due to the availability of commercial flights, border
 closures/restrictions and quarantine requirements due to COVID-19.
- On 6 August 2021, AHPPC members reconfirmed the decision from April 2020 that organ and tissue donation, retrieval and transplantation should not be impeded by COVID-19 restrictions, including teams not being restricted or quarantined due to regional or interstate travel.
- o There are currently no issues with ICU capacity and ARCBS Lab staff have no issues to report.

• Immunisation status in Australia:

Currently 46% of Australians have been vaccinated with 27% having received both doses.

Vaccination, research and trials:

- In relation to a 3rd (booster) dose of vaccine, further research is required to fully understand the
 risks and benefits of COVID vaccination for transplant recipients and such a strategy in Australia
 requires more data and improved supply of vaccine.
- The Taskforce supports the strategy that patients on the waiting list should be vaccinated where possible due to the risk of developing COVID-19 and we will continue to advocate for vaccination access for transplant recipients and the prioritisation for "ring" vaccination of those close to all recipients (e.g., family members or others who reside with the recipient); and vaccination for all prospective living donors.
- There is a shortage of PCR tests that provide a quick (less than 4 hours) and robust result.
- On 20 August 2021, the Therapeutic Goods Administration (TGA), granted <u>provisional approval</u> to GSK for its COVID-19 monoclonal antibody treatment – SOTROVIMAB (XEVUDY) - making it the second COVID-19 treatment to receive regulatory approval in Australia. Australia is the first OECD country to issue a formal regulatory approval for sotrovimab (XEVUDY).

Data:

- COVID-19 epidemiological data was provided and is available here. Australia recorded 1,220 new cases in the last 24 hours, with 1,118 of those cases being in NSW.
- Internationally, there have been 4.57 million new cases reported globally in the past week and more than 69,000 deaths. Infection rates are continuing to increase in the USA, UK, Philippines, Vietnam and Israel.
- Some of the countries with the highest reported vaccination rates include: UAE 84.9% (74.2% fully vaccinated), Iceland 81.2% (76.7%), Malta 80.3% (80.08%), Singapore 78% (75%), Spain 78% (70%), Uruguay 76.4% (72%), Denmark 75.7% (71.7%) and Chile 74.9% (70%).

A/Professor Helen Pilmore Co-Chair of Taskforce Professor Steve Chadban Co-Chair of Taskforce

PAEDIATRIC WORKING GROUP ACTIVITY REPORT



Reported by: Amelia Le Page Date: 8/9/2021

Members: Amelia Le Page (Convenor), Amanda Walker, Hugh McCarthy, Swasti Chaturvedi, Anne Durkan, Sean Kennedy, Chanel Prestige

Convenor Summary (key highlights in past 12 months)

- 1 working group project published in this time frame.
- Currently exploring consistency of Echo investigation, reporting in paediatric ESKD in ANZ (lit review and unit survey planned). Is it useful/feasible to include this as part of paediatric collection?
- Currently refining pediatric data collection schooling question. Noted that paper forms were different to electronic forms – ANZDATA to fix this
- Continuing to work on recommendations for consistent use of the "other" primary ESKD disease diagnostic column (e.g. genetic details)
- Past consideration of paediatric ESKD palliation "registry" put on hold. Concerns with data completeness due to non-nephrologist involvement. Other avenues of data collection reviewed (APSU) cost impediments. Past estimates of palliation from ESKD in kids suggest the frequency of this is low at around 6-7 patients between 0-19 years in Australia over 5 years.

Projects in Progress:

4+ non paediatric specific projects5 paediatric specific projects2 paediatric transplant donor projects

Publications 2021:

- 1. Chaturvedi et al. Rising incidence of End Stage Kidney Disease and Poorer Access to Kidney Transplant among Australian Aboriginal and Torres Strait Islander children and young adults. Kidney International Reports. 2021
- 2. Sypek et al. Paediatric deceased donor kidney transplant in Australia: A 30-year review-What have paediatric bonuses achieved and where to from here. Pediatric Transplantation 2021
- 3. Francis et al. Impact of initial steroid response on transplant outcomes in children with steroid resistant nephrotic syndrome francis et al. 2021. Pediatric Nephrology 2021 (linkage project)
- 4. Larkins NG, Wong G, Alexander SI, McDonald S, Prestidge C, Francis A, Le Page AK, Lim WH. Survival and transplant outcomes among young children requiring kidney replacement therapy. Pediatr Nephrol. 2021
- Le Page, Kennedy, Durkan, Chaturvedi, Walker, Sypek. Incidence and predictors of vascular events following endstage kidney disease in childhood. Nephrology (Carlton) . 2021

Any Suggestions Regarding Data Collection/Annual Report?

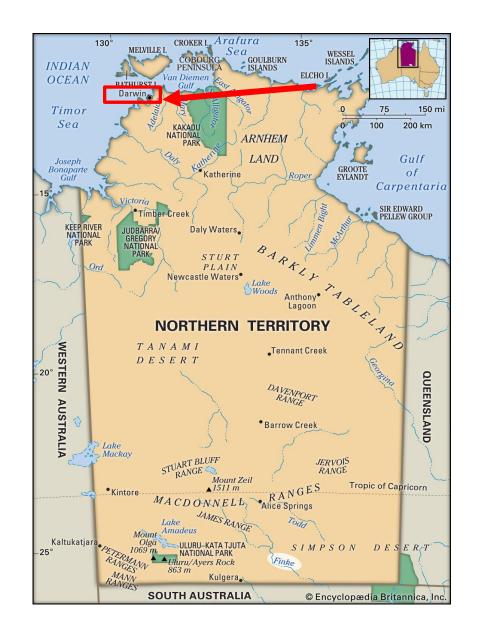
ANZPNA meeting 9th Sept 2021: Improving First Nation's Care

Dr Swasti Chaturvedi, Paediatric Nephrologist, NT

"I would like to begin by acknowledging the Traditional Custodians of the land on which we meet today. I would also like to pay my respects to Elders past and present."

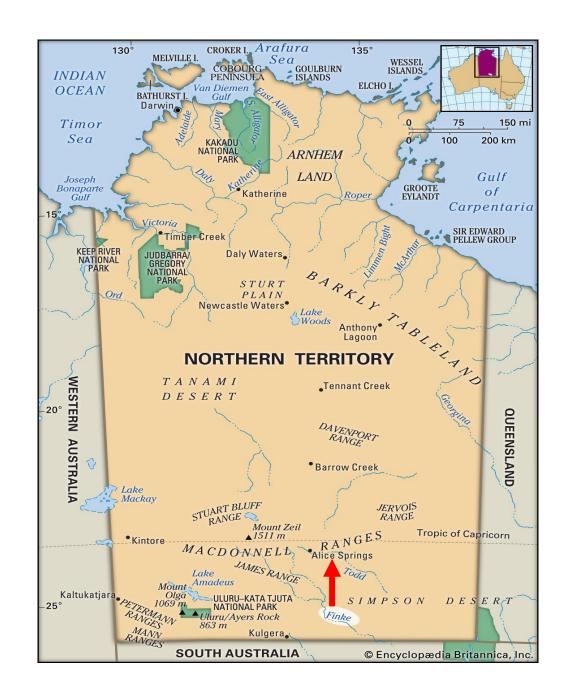
Child 1

- 13 Years old Aboriginal male
- From East Arnhem Land, lives in Darwin now
- Ex 29/40 pre-term, twin-twin transfusion
- ESKD since July 2018
- PD: 2nd catheter, 1X peritonitis
- Listed for transplant: May 2020
- Blood group O pos



Child 2

- 11 years old Aboriginal male
- Central Australia, lives in Alice Springs now
- Treatment resistant Nephrotic Syndrome: 2015
- ESKD: Jan 2020
- PD: Second catheter, 2 x peritonitis
- Listed for transplant: Feb 2021
- A pos



Common struggles

- High burden of CKD
- Remoteness
- Dislocation
- Housing
- Poor Health literacy
- Social isolation and fragile family structure
- Financial stress
- Child Protection service involvement
- Co-morbidities



Others waiting......

- 14 yrs old Aboriginal female
- Neurogenic bladder
- Reflux nephropathy
- Poor adherence to CIC/Recurrent UTI
- Moved from remote community to be in Darwin
- Stage 4 CKD

- 9 year old Aboriginal male
- Cystic kidney disease
- Severe hypertension
- CKD 3b
- Will need to move to Alice Springs

And more:

- 1 year Aboriginal boy
- Single hypodysplastic kidney
- CKD 4

Rising Incidence of End Stage Kidney Disease and Poorer Access to Kidney Transplant Among Australian Aboriginal and Torres Strait Islander Children and Young Adults



Cohort and Methods

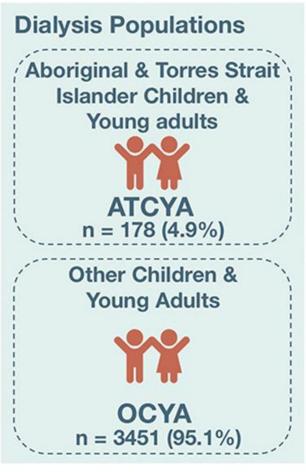


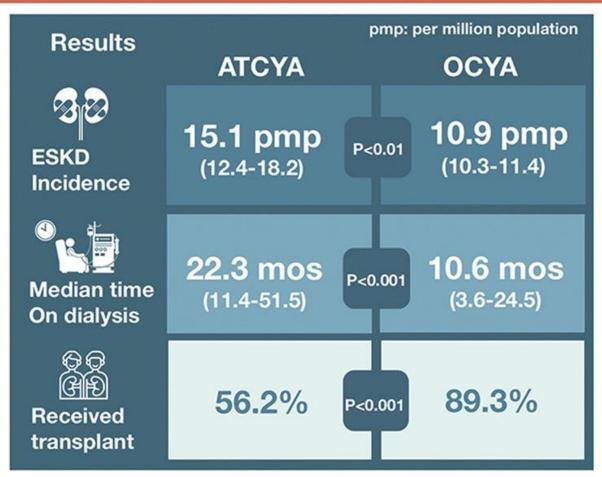
Australian and New Zealand
Dialysis and Transplant Registry

1963-2017



n = 3629







Chaturvedi S et al, 2021

Visual abstract by:
Pablo Galindo, MD

@galindozip

Conclusion Our study shows rising incident rates and poorer access to kidney transplantation among ATCYA with ESKD in Australia. The reasons for this health care disparity and barriers to transplantation need to be explored further and require addressing.

Conclusions

- ATCYA have higher incidence rates of ESKD
- The commonest cause of ESKD was GN followed by CAKUT in both groups.
- Diabetes mellitus and hypertension leading to ESKD were more common in the ATCYA cohort
- ATCYA spent over twice the duration on dialysis compared to OCYA
- ATCYA have lower access to pre-emptive kidney transplantation, with higher need uptake of deceased donor kidney transplantation and poorer access to transplant overall
- The reasons for this health care disparity and barriers to transplantation need to be explored further and require addressing

Solutions?



Suggestions?

- Is Kidney Transplant successful in ATCYA as other Australians? Plan to analyse this next
- Early/ Intensive family support process
 - Many patients have contraindications to transplantation
 - What should this look like?
- Do not have equal access to live donor kidneys. Review current strategies for assessing and supporting parents for live donation.
- HLA frequencies vs. donor pool
 - Little access to preferential offers for well matched kidneys in young recipients
 - Extra Points for Aboriginal children in the allocation algorithm?
 - Consider listing high risk HLAs as high cPRA rather than just avoiding??

Suggestions?

- Strategies utilised in other states/countries?
- Currently NT children go to WCH, Adelaide
 - Is this the optimal referral centre?
 - Would a centre who can transplant patients at a smaller size potentially assist in reducing wait times?





30 August, 2021

Dear ANZPNA Executive,

It is my pleasure to introduce you to BPOzKids, a recently-launched multidisciplinary national network devoted to addressing problems related to blood pressure in children and adolescents. The network is governed by the High Blood Pressure Research Council of Australia and is supported by the National Heart Foundation of Australia and Murdoch Children's Research Institute. Further information can be found at our website www.bpozkids.com, and we have also launched Twitter (@bpozkids) and LinkedIn profiles.

We are keen to create linkages and interactions with other professional bodies. Given the relevance of paediatric hypertension to ANZPNA members, we are reaching out to see if you would like to work together. In the first instance we would be delighted if you could spread the word about the network, direct members to our website, provide a link on your website and put out a call for members who might be interested in joining the network. If you are agreeable, we would also list ANZPNA as a supporting body on our website.

Finally, we are holding a Paediatric Blood Pressure Symposium on the 6^{th} of December in hybrid format, featuring a number of internationally renowned keynote speakers (see our website for details). We would be most appreciative if you could spread the word about this also.

I look forward to working together as the BPOzKids network develops.

Yours sincerely

A/Prof Jonathan Mynard

Josethan Mynard

BPOzKids Convenor

Heart Research, Murdoch Children's Research Institute Department of Paediatrics, University of Melbourne

Department of Biomedical Engineering, University of Melbourne