



Finding a cure for PKD

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Musings from the Chair

What an amazing first half of 2018. Just some of the highlights

- You will recall how moved we were by the speakers at the Indigenous Patient Voices Symposium in Darwin last year. We can report that there will now be a Medicare Item Number specifically for remote area dialysis.
- Jinarc (Tolvaptan), the first drug therapy to treat the symptoms of ADPKD has been approved by TGA but now we are eagerly awaiting a decision on funding the drug to make it accessible for those likely to benefit from it.
- In March we met with local PKD patients and their families at our first Patient Seminar to be held in Wollongong. Speakers included a local clinician, a renal dietician, a researcher/clinician and a local patient. As always an important part of the proceedings is the opportunity for members of the audience to ask questions.
- We are grateful to ABC Illawarra who helped to publicise the seminar
- **PKDA** is very proud that in 3 years the focus on research into PKD has grown to the extent that 18 exciting projects to be undertaken in research institutes around Australia applied for funding from PKD Australia (PKDA). The results are: -
 - Six Australian researchers were up against worldwide competition for the 2-year grant for US\$ 160,000 co-funded with our colleagues at US PKD Foundation. Dr John Shine Ph.D. with his team from the Garvan Institute of Medical Research in Sydney was the successful applicant
 - Against four other equally impressive projects Professor Gopi Rangan and his team from Westmead Institute for Medical Research, Sydney were judged the winners of the 1-year grant for \$30,000
 - Professor Sharon Ricardo and her colleague from Monash Biomedical Discovery Institute, Melbourne are the winners, over 6 other strong applicants, of the 2-year grant for \$50,000
- As a part of an effort to expand the PKDA community we started our Illawarra Support Group around our Local Hero. This is the first group and over time we hope to have similar groups throughout the length and

The PKD logo consists of the letters 'PKD' in a white, bold, sans-serif font, centered within a red rectangular background. The background of the entire page is a photograph of four smiling people (two women and two men) wearing sunglasses, with a decorative cluster of white and red dots in the upper right corner.

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breadth of the country, wherever PKD families want to meet with people going on a similar journey.

- It has been pleasing that in the scientific literature there has been growing recognition of the fact that PKD is more than just a disease of the kidneys. As a genetic condition patients with ADPKD are most often able to predict their future health challenges long before the symptoms become a problem. ARPKD, being the form of PKD that often affects babies even before birth carries its own unique stresses. It is hoped that this acknowledgment of the emotional burden will lead to more and varied counselling services including renal dietetics and genetics.
- On the subject of genetics this year's budget made specific mention of genetic testing for rare diseases. Whole Genome Sequencing is an area that will become more relevant as patients and their clinicians gain a better understanding of its potential.
- In recent discussions with UK PKD Charity we agreed to work towards an alliance of PKD support groups worldwide to highlight this disease that affects generations of families regardless of race, gender or age.

Upcoming Public Patient Seminars are planned for **Sydney** Sunday 9 September, to coincide with the annual Nephrology Conference and **Orange** Wednesday 10 October. For details please see **PKDA** website closer to the date.

Here's how you can help

- ✓ Raise money to fund the research that will assist in the discovery of a cure.
- ✓ If you have experience or skill that you feel could help the Board or in the administration or in any other practical way please contact us.
- ✓ Offer to be a **PKD** Local Hero to promote the **PKD** story in your area

PKD is a disease that affects generation after generation after generation. Only by the PKD community being able to fund research will the most brilliant Australian scientists and doctors continue to focus their efforts on finding a cure for ADPKD & ARPKD.

Please Donate Now

See www.pkdaustralia.org or email info@pkdaustralia.org

Robert Gardos - Chair