



Finding a cure for PKD

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Musings from the Chair

This month we celebrate 3 years since inception of **PKD Australia (PKDA)**.

Every time I write to you there is so much news.

PKDA said thanks & farewell to Sarah who helped set up **PKDA** and now we say welcome to Dr Charmaine Green who will add her particular skills as an embryologist, a young mother and a **PKD** patient herself.

Just some of the highlights since the last musings are

- Applications are now open for the **PKD Australia/US PKD** jointly funded 2 year \$US160,000 research grant. We are thrilled that the **PKD Australia's** 50% is being supported by an Australian private philanthropic foundation.
- Applications are soon to open for the 2018 round of **PKD Australia** seed grants.
- **PKDA** is very grateful to have received a bequest dedicated to kidney research, in memory of the late Audrey Florence Wright.
- A video of the life of a family with **PKD** has been produced with educational support funding from Otsuka Pharmaceutical Australia. Do look for it at www.pkdaustralia.org
- **PKDA** has presented well-attended public patient seminars in Perth and Darwin. The next one is being planned for the Illawarra in the first quarter of 2018
- **PKDA** has been represented at
 - ANZ Society of Nephrology Annual Scientific Meeting at which there was an entire session devoted to **PKD**
 - CKD-CRE symposium in Brisbane
 - BEAT-CKD Research Forum in Adelaide
 - BEAT-CKD meeting in Sydney
 - KidGen – Meet the Scientist in Melbourne
- **PKDA** has established MOUs with Kidney Health Australia, Transplant Australia, Genetics Alliance and GenomeOne



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- **PKDA** will be at the KidGen Renal Genetics Symposium in Melbourne 7-8 December
- Tolvaptan, the first pharmaceutical product approved in Australia for ADPKD is expected to be available in early 2018. We understand that it may not be suitable for all patients but it is hoped that other medicinal drugs will follow as will other therapies.
- **PKDA** director Helen Coolican and I were privileged to attend the Indigenous Patient Voices Symposium as a part of the ANZSN meeting in Darwin. As the outcome it is hoped that our nation's leaders will take immediate steps to remedy the disadvantage affecting so many chronic kidney disease patients in regional and rural Australia. For more information please see https://www.menzies.edu.au/page/Research/Projects/Kidney/Indigenous_Patient_Voices/

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

BREAKING NEWS

Dr Deborah Lewis, Consultant Physician in Paediatric Nephrology at The Children's Hospital has agreed to join the **PKDA** Scientific Advisory Board.

PKD is a disease that affects generation after generation after generation. Only by offering to fund research will the most brilliant Australian scientists and doctors focus their minds to the task of finding a cure.

Now is a good time to make a tax-deductible donation.

Please Donate Now

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

Robert Gardos - Chair