



Finding a cure for PKD

Vol. 2 May 2017

Musings from the Chair

It has been a whirlwind first five months of the year for PKD Australia (PKDA). Since February, patient seminars have been held in Newcastle, Sydney, Brisbane, Melbourne and Perth with one also planned in Darwin to coincide with the 2017 Annual Scientific Meeting of the Australian & New Zealand Society of Nephrology in September. Thanks to the support of local renal professionals, more patients and their families are attending the seminars where speakers have included renal specialists, geneticists, researchers, social workers and patients. A very pleasing part of each session is the interaction between the speakers and audience, which is helping break down feelings of isolation some PKD patients experience. A special thank you to our guest speaker from the U.K., Professor Fiona Karet, who shared her vast experience with us at the Sydney, Brisbane and Melbourne meetings. Our gratitude also goes to Deborah Oswald for again moderating the Sydney seminar in her beguiling way.

As we did in 2016, PKDA has provided four enabling grants for a diverse range of research projects, this time at Garvan Institute of Medical Research, Macquarie University, Monash University and Westmead Institute of Medical Research. You can read more about these and outcomes from last year's grants at www.pkdaustralia.org

We are very excited by several recent developments we believe will benefit the PKD community including:

- ✓ PKDA signed a Memorandum of Understanding with Kidney Health Australia. Together our two organisations will seek opportunities to educate and advocate for PKD patients and kidney patients generally.
- ✓ The Government's recent recommitment to the eHealth Record is a positive step and will be very useful to many patients with PKD who often have to repeat their story to health professionals.
- ✓ In April, JINARC® (tolvaptan) was added to the Australian Register of Therapeutic Goods. Whilst only the first step, it is hoped it will soon be available for consideration as a treatment for certain ADPKD patients.



I would also like to thank the following,

- PKDA Scientific Advisory Board for evaluating the grant applications and for their ongoing technical advice
- Ambassadors Vanessa Cullen, Melanie Cornell & Michael Cornell for spreading the word about PKDA
- The volunteer Board of Directors
- Our wonderful pro bono webmaster Pete Gilmour from Drip Creative
- General Manager Sarah Metcalf
- All PKDA supporters and advisers

Kidneys may not be sexy but they are vital to every one of us.

Many kidney disease sufferers are only diagnosed when their kidney disease is at end-stage and often when Renal Replacement Therapy (RRT) is the only option but **PKD is different**. Because PKD is a genetic disease, many sufferers will be aware of its existence in their family. Now, under good renal care there is every likelihood kidney function can be maintained for much longer thereby deferring the need for RRT. This care may include medication, therapies and lifestyle recommendations, etc.

A particularly interesting characteristic of ADPKD is many of the symptoms are shared with other kidney disease patients and patients with other conditions but, as ADPKD patients can often be identified before their symptoms become evident, they can often be candidates for clinical trials for new medications and therapies.

ARPKD, on the other hand presents unexpected challenges to families of affected children from birth. Their experience is often not known or understood beyond family and friends. PKDA is working to develop information and bring more focus to this area, which is often overlooked because of its younger age group and smaller numbers.



Since its formation less than three years ago we have known the future success of PKDA lies in the PKD community.

- Last year you helped raise \$20,000 supporting our City-2-Surf team.
- This year, we will have teams in the City-2-Surf and Melbourne Marathon.
- While many people with PKD prefer not to talk about it, we will only succeed in raising funds for more and bigger research projects to find a cure if we do talk about PKD. I urge every one of us to promote the value of research to your network of family, friends, acquaintances and work colleagues and the broader community.

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

The end of the financial year (EOFY) is a time when many people think of making a tax-deductible donation. **EOFY is nearly here – Please Donate Now.** See www.pkdaustralia.org or email info@pkdaustralia.org