

## Musings from the Chair

2018 is almost over and this month we celebrate the 4th anniversary of PKD Australia (PKDA). With the growing recognition of the impact of Polycystic Kidney Disease there is the likelihood of more clinical trials, including in Australia, being announced in the near future.

Just some of the most exciting things that happened at PKDA recently include:

- Together with Genome.One, PKDA held an information evening at the Garvan Institute in Sydney where we were given a tour of the genetic testing laboratories and we learned about the amazing developments in Whole Genome Sequencing that enables confirmation of the specific genetic mutation in a PKD family and offers the potential to eradicate PKD from a family.
- Together with representatives from 3 families with PKD we had a meeting with the Federal Health Minister at which the Minister expressed his confidence that Jinarc (Tolvaptan) will be listed on the PBS very shortly. Another very significant outcome of the meeting was the inclusion of ARPKD on the gene panel for the trial of Mackenzie's Mission Screening Project.
- September was a busy month with the KidGen Conference followed immediately after by the Australia & New Zealand Society of Nephrology Annual Scientific Meeting at the ICC in Sydney. PKDA held a very well attended Patient Seminar to coincide with the KidGen meeting and both of the conferences had official sessions focussed on PKD research.
- The following month PKDA conducted a Patient Seminar in the NSW regional city of Orange. Amongst the speakers were a committed nephrologist/renal transplant surgeon from Westmead Hospital, an inspired PKD researcher from Macquarie University and a very informative local dietician.
- In response to the often-expressed statement at Patient Seminars that "until now I had never met anyone else with PKD outside my family" we are gradually helping to set up Local Support Groups centred on a Local Hero. The first of these is in Wollongong, NSW and following a meeting of interested local PKD families another one is in the process of being established in Canberra.
- Following the discussions with our UK counterpart earlier in the year we recently held discussions with US PKD Foundation to assist the aim of forging closer bonds between

the PKD groups such as ourselves, to support the estimated 12,000,000 people living with Polycystic Kidney Disease worldwide, a little less than half of the population of Australia.

- Applications are now open for the next round of PKDA research grants consisting of 2 grants for 12 months valued at \$30,000 each.

Prof. Carol Pollock, Chair of KHA commemorating 50 years since the establishment of Kidney Health Australia, referring to kidney disease, in general, stated “more people die from kidney related disease in Australia each year than those who die from breast cancer, prostate cancer and road accidents combined”.

PKD is different from other forms of Chronic Kidney Disease insofar as there is no longer an inevitability of outcome with PKD. New drug therapies and wellness strategies will slow the decline of kidney function; genetic breakthroughs will provide new options in areas such as family planning.

PKD may not have to affect generation after generation after generation.

This is a very exciting time for PKD research. To find a cure for ADPKD & ARPDK, **together** we must fund the most brilliant Australian scientists and doctors in the field of PKD research

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

## Please Donate Now

See [www.pkdaustralia.org](http://www.pkdaustralia.org) or email [info@pkdaustralia.org](mailto:info@pkdaustralia.org)

I want to acknowledge the yearlong selfless effort from my fellow directors, Judi, Mel and Manager Charmaine who handle communication, media and many other functions and thank the Scientific Advisory Board, the PKDA Ambassadors, the PKDA Local Heroes and the speakers at the seminars for their ongoing support.

Wishing the PKD Community a happy and safe holiday season and a healthy 2019

Robert Gardos - Chair

