



Vol. 6 June 2019

## Musings from the Chair

If you have been keeping up with the news via our newsletters and social media you will have seen that the pace of activity has remained high. The long hoped-for Government funding of Tolvaptan, through the PBS system, has triggered a completely new understanding of living with ADPKD. Previously there was an inevitability in the progression of the disease besides good blood pressure control and living healthily. Tolvaptan offers hope to at least some patients to somewhat delay End Stage Renal Failure and the need for dialysis or kidney transplant. There has also been a surge in clinical trials for other drugs and therapies including the PREVENT-ADPKD trial, which is well past its mid-point with the results eagerly awaited.

As part of Kidney Health Australia's task from the Government to develop a strategic plan for the treatment of kidney disease into the future, PKD Australia was invited to contribute to the discussion. This identified that ADPKD, ARPKD and most other inherited kidney disease are a distinct subset within Chronic Kidney Diseases (CKD) insofar as they are dynamic meaning that those likely to have it will usually be aware of it in their family long before experiencing any symptoms themselves. While this now provides opportunities to manage the progression, it can, at the same time introduce new burdens such as increased emotional stress and discrimination. We are engaging with like-minded organisations to advocate for assistance with these issues.

To take advantage of the excellent International Society of Nephrology World Congress we were thrilled that Prof. Albert Ong, an internationally recognised ADPKD clinician/researcher, agreed to be one of the speakers at a very well received Patient Seminar held at Monash University. The feedback was very positive.

The 2019 grant round attracted applications of such high quality that, rather than the proposed 2 grants, based on the Scientific Advisory Board's review the PKDA Board has decided to award 3 grants of \$30,000 while trying to find ways to assist at least some of the other high quality but unsuccessful applicants.

I would like to acknowledge the hard work of the PKD Local Heroes who are building the PKD communities in Canberra, Melbourne & Wollongong, our Ambassadors, Dr Charmaine Green, manager of PKD Australia, who in addition to her normal role in writing the newsletters, organising seminars and running grant rounds, etc. did such a commendable job in writing the PKD Australia Strategic Plan that was delivered to the health minister prior to the election and that is now available on the website for all to read. My thanks also to my fellow pro-bono board members and associates who tirelessly continue to do whatever is required to further our cause and finally a big thank-you to all our supporters without whose assistance by donation and in kind enables us to continue to support the work that is being done by the fantastic researchers who are passionately trying to understand and eventually cure Polycystic Kidney Disease.

**If you are able to, here are just some ways that you can help us to make a difference**

- ✓ 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

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