



Vol. 9 Dec 2020

Musings from the Chair

2020 has been a challenging year, like none before it, for us all and for everyone it has thrown up individual hurdles. The smoke and the bushfires at the beginning of the year followed for some by floods and then the impact of Covid-19 have caused us all to become more resilient; to adapt to isolation; to working from home or not working at all; to having elective surgery deferred and to using teleconsultations rather than face-to-face doctor's visits. With vaccines soon to be made available, in part through our island status and in part through good scientific advice being acted on by our nation's leaders Australia appears to have avoided the worst of the pandemic. Additionally, the selfless efforts of so many of our normally unrecognized compatriots including healthcare workers, teachers, emergency personnel, transport providers, supermarket staff and so many others contributed to our general safety. Our thanks go to them.

Like so many other organisations PKD Australia has adapted. We added webinars as a way to connect with the PKD community and while a webinar cannot provide the direct contact of a live seminar it enables a much wider audience to listen to experts speaking from diverse parts of the country or from other parts of the world. Just recently we attended the first virtual Australian and New Zealand Society of Nephrology Annual Scientific Meeting at which the first keynote speaker, Professor Lisa Guay-Woodford, a world renowned paediatric renal specialist, from Washington DC, in a wonderfully informative lecture informed us that currently there are 124 clinical trials underway for PKD around the world.

In 2019 PKD Australia gave a grant of \$25,000 to join with the Australasian Kidney Trials Network, a pillar of the BEAT-CKD Program, to support Assoc. Professor Andrew Mallett and his University of Queensland team in their IMPEDE-PKD clinical trial investigating Metformin to slow the progression of renal dysfunction in ADPKD. Subsequently we were thrilled this year when the Medical Research Futures Fund granted them \$2.57 million to complete the trial. We are excited that once again our enabling seed grant has led to much bigger things.

The response to our 2020 call for applications for funding of PKD research projects was of such high quality that for the first time PKD Australia gave four \$30,000 grants plus we have again joined with US PKD Foundation to together fund a 2-year USD160,000 research project should an Australian researcher be selected by the US review panel. Three Australian projects applied in the preliminary round, one of which was then asked to submit a full application.

Now looking ahead to 2021 there are some dark clouds over scientific research funding. A Sydney Morning Herald article <https://www.smh.com.au/national/not-a-way-to-live-scientists-brace-for-bleak-christmas-as-covid-cash-crunch-hits-research-20201203-p56kda.html> states that due to the diversion of Government funding to deal with the pandemic *"Results of the federal government's final medical research funding round of the year were quietly released to researchers earlier this week. The sector estimates about 90 per cent of applications were unsuccessful, the lowest success rate on record."*

It is imperative that the momentum of PKD research in Australia is at least maintained, if not increased. We cannot allow that these committed PKD researchers be forced to look at other areas of work because of lack of funding so to our wonderful current donors and to those who are yet to help us to fund this work this is a **call to arms**. By supporting this vital research, we will have a much better chance of unlocking more of the mysteries of PKD and ultimately finding a cure for the disease. Please help PKD Australia to fund vital PKD research and consider a regular donation, workplace giving, a fundraising event or a bequest. Details about **how you can help** can be found at www.pkdaustralia.org

Finally, as always, my thanks go to the small and incredibly committed PKD Australia leadership team, to our manager Dr Charmaine Green, to our Scientific Advisory Board, to the experts who have shared their knowledge at PKD seminars and webinars, to our pro bono service providers, to our ambassadors, our local heroes, to the wonderful researchers who recognise that finding a cure for PKD will benefit so many families and most of all to our staunch Australian PKD community. On behalf of PKD Australia I wish you all a safe festive season and a more normal 2021.

Robert Gardos - Chair