



# Australia

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## Musings from the Chair

PKD Australia (PKDA) is in its seventh year of a long journey that we know will have its share of disappointments along the way. Since we started we have compiled a PKD “playlist” that speaks of our journey and so far it includes some memorable tracks including, in order *Que sera, sera, whatever will be, will be*<sup>1</sup>; *The impossible dream*<sup>2</sup>; *Long and winding road*<sup>3</sup>; *Magical mystery tour*<sup>4</sup>; *Some days are diamonds, some days are stones*<sup>5</sup>.

The good news is that despite some temporary road closures we continue to enjoy some incredible hits that make this journey such an important and critical one for the future. As we’ve come out of hibernation and are progressively getting vaccinated against Covid-19 we see that the curiosity of the PKD researchers is even more pronounced than before. We have just announced three 2021 grants; two to researchers who have been previous recipients of US PKD Foundation grants, one of which was co-funded by PKDA and one grant to an Early Career Researcher starting her own PKD laboratory. The grant applications were of such a high standard that we are indebted to the Scientific Advisory Board (SAB) for reviewing and ranking them for us again.

We are again very pleased to be co-funding with US PKD Foundation a two-year research grant; this time to Prof. Melissa Little at Murdoch Children’s Research Institute who proposes to use patients’ own cells to create kidney organoids with which to better understand the mechanisms in ARPKD. Professor Little has also just been awarded the prestigious Homer W. Smith Award from the American Society of Nephrology for her outstanding contributions that fundamentally affect the science of kidney health. Again this confirms that we have world-class researchers doing extraordinary work right here in Australia. This project exemplifies the increased attention on ARPKD research, a pleasing development because until recently, due to its relative rarity, it has remained under the radar.

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<sup>1</sup> Justice Crew

<sup>2</sup> Josh Grogan

<sup>3</sup> Beatles

<sup>4</sup> Beatles

<sup>5</sup> John Denver

Last week there was a piece on television about PKD and genome sequencing with reference to ground-breaking developments at the Garvan Institute, proudly funded, in part, by PKD Australia <https://www.facebook.com/garvaninstitute/videos/1067394403784937>.

Recently we learned from the PKDA webinar on clinical trials that there is a lot happening both here and overseas and as Prof. Carmel Hawley explained there are more efficient trial models available that compare different drugs. We will be advocating for their utilisation to achieve more meaningful clinical trial results sooner.

One thing that we have been pushing for, for a number of years, is a 21<sup>st</sup> century PKD registry that will store not only a patient's medical data but also Patient Reported Outcomes and to be collecting data from early adulthood before kidney function is impacted by ADPKD. Key renal specialist including members of PKDA SAB are supportive of the concept and although applications for Government funding have been unsuccessful so far, we will not give up. This may require consumer advocacy so if anyone has any suggestions on how to do this most effectively please reach out.

Worryingly, an esteemed researcher in a different field said to me recently, that 70% of his time is spent writing grant applications, most of which are unsuccessful.

**This is a travesty! PKD researchers need to be devoting the vast majority of their time, their brainpower and their energy to finding a cure.**

The best way to achieve this is to fund more research and the only way to do this is to raise more money. There is already a small core of PKD Australia supporters who regularly donate to PKD Australia because they want more options for their children and grandchildren. They can't be the only people who care, can they?

Kidneys are not sexy but they're certainly important. The entire PKD community wants a cure for PKD so we must all share the load – GIVE NOW to fund PKD research.

Together we can move from *the long and winding road* onto a *highway of love*<sup>6</sup> to the *Land of Hope & Glory*<sup>7</sup>.

Please stay in touch with PKD Australia [www.pkdaustralia.org](http://www.pkdaustralia.org)

Robert Gardos - Chair

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<sup>6</sup> Aretha Franklin

<sup>7</sup> Edward Elgar – music; AC Benson - lyrics