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## Musings from the Chair

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### PKD Australia Team Updates

While outwardly the last six months have been business as usual at PKD Australia we have started a renewal process both at the board level and at the Scientific Advisory Board.

PKD Australia manager, Amy Luchterhand, who only joined us last December has stamped her distinctive style on the role and together with collaborators Filter Your Future and DATA Victoria mounted a really interesting webinar, titled *Preparing for the unexpected, supporting the vulnerable* to celebrate World Kidney Day. The case studies were so representative of Australia.

Long-time PKDA Ambassador Vanessa Cullen has joined the board as an associate director. Vanessa is an extreme athlete, runs her own very effective social enterprise business, has ADPKD, and is a consumer representative on several PKD-related committees. Vanessa's vitality and broad experience will enhance the board's current capabilities.

Dr Amali Mallawaarachchi has accepted an invitation to join the PKDA Scientific Advisory Board (SAB). Amali is Australia's first dual-trained Clinical Geneticist-Nephrologist; a recipient of a PKDA Research Grant in 2021 and in 2018, working alongside Prof. John Shine AC received a prestigious 2-year research grant jointly

funded by US PKD Foundation and PKD Australia. She works at RPA Hospital Sydney and The Garvan Institute.

An original member of the PKDA SAB, Professor Carmel Hawley, has stepped down from the role due to other commitments. We sincerely thank her for sharing her experience and knowledge so readily.

### Grants & Research Projects

A few years ago, PKDA was a recipient of a generous bequest, in recognition of which we welcome Emily Major as the inaugural grantee of the Pamela Maud Ratcliff PKD Australia PhD Scholarship, co-funded by Australian Rotary Health. What is even more pleasing about Emily being the winning candidate is that she will be supervised at La Trobe University by Dr Brooke Huuskes, who is, herself, a PKDA grant winner and who attained her PhD at Monash Biomedicine Discovery Institute under Prof. Sharon Ricardo, also a PKDA grant winner and SAB member. A wonderful PKD research dynasty in the making.

Since 2015 PKD Australia has funded 33 Research Projects with a total value, to date, more than \$800,000. This does not include funds contributed by co-funding partners such as US PKD Foundation or Australian Rotary Health nor does it include the 2023 PKDA grant round just decided.

Reflecting on 2019, that year dawned with great excitement; Tolvaptan became available in Australia as the first therapeutic drug for ADPKD. While it wasn't suitable for everyone and even for those for whom it was prescribed it was burdensome, but it gave hope. There is talk of other drugs and some clinical trials are underway with more planned. The Covid-19 response suggested the possibility of more streamlined ethics approvals and perhaps novel ways to develop new therapeutic treatments and we often we hear that precision medicine is coming and it probably is, but not yet for PKD.

### Personal Acknowledgement

Despite the interesting findings that we are regularly seeing from researchers globally a cure for PKD is still elusive. I was reminded of this when I attended the funeral not long ago of my friend (and plumber) Peter, known to his close friends as Greenie. Peter's Dad who had ADPKD struggled with kidney issues before he died. Peter was a very good sportsman when he was young, a lifelong keen fisherman, a really hard worker, and a wonderful loving father to two children, to one of whom he passed on ADPKD and who has in turn passed it on to at least one baby. He was also very proud of his four grandkids. Peter had his first aneurysm at 46 years of age, managed to get over it and return to work, only to have another one a few years later. Again, he recovered and was able to resume work. He knew that he needed to stay hydrated, but it was a nuisance for him. Finally, his kidneys gave up and he had to go onto dialysis. It didn't

work well for Peter; he got an infection and was in and out of hospital for many months before dying at age 63. As is typical of PKD families there was no mention of the condition although some mourners did take the opportunity to use the envelopes available to donate to PKD Australia in Greenie's memory.

Many of you will fondly remember Peter's daughter, Charmaine who, not only worked at PKD Australia for several years but she was a strong PKD patient advocate and still is. After the funeral, she said to me that only now has the full reality of having PKD really hit her. Peter felt guilty that he had passed on ADPKD to his older daughter, Charmaine, who feels similarly because her son inherited it from her. She also knows what likely lies ahead for her. People with PKD would give anything to have healthy kidneys yet, here in Australia, at least, Polycystic Kidney Disease is suffered stoically and in silence. People don't talk about it with friends; they don't mention it at work and often they try not to think about it until it eventually affects their day-to-day.

### PKD & Lifestyle

The best advice for all members of our society including those with PKD remains to deal with the symptoms and thereby try to avoid the complications, viz.

Maintain good blood pressure control.

1. Follow a low-salt diet.
2. Eat fresh food, avoiding processed foods and drinks high in sugar.
3. Exercise
4. Maintain a healthy weight.

The specific recommendation for anyone who thinks that they may have PKD is to get a referral to a renal specialist as early as practical. This way there is a high chance that good kidney function can be preserved.

Maybe if my friend Peter had not ignored his PKD for so long he would still be listening to Australian rock music, fishing, and enjoying his beautiful family.

The dilemma facing PKD Australia is how can we tell the world that chronic kidney disease (CKD) is not nice; if those of us, who have inherited it could avoid it, we would and we would urge anyone in our community who can possibly avoid CKD, through wiser lifestyle choices, they should. Healthy kidneys are so important that while we can still only dream of a cure for PKD we are very keen to also see research being undertaken into how to live more easily with PKD.

We hear of the diets and supplements that may slow kidney cyst growth but as always PKD Australia wants clinical science-based evidence before taking a stance in such discussions.

## Thanking Our Community

As always, I offer my thanks to our pro-bono service providers, to the always supportive PKDA Scientific Advisory Board led by Prof Gopi Rangan, to the amazing leadership team, to our ambassadors, our local heroes, the loyal donors and the PKDA supporters all over Australia. We would not be what we are without this collective effort. We don't want Greenie's family and the many families like Greenie's to feel the ongoing inevitability of PKD for any longer than necessary so please:

**Make a donation to PKD Australia NOW to boost this critically needed research.**

If you would like to become more involved with PKDA please contact us.

Thank you for taking the time to read these musings and please keep in touch with our news via social media and our newsletter.

Robert Gardos – Chair

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