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Musings from the Chair

It is hard to believe but it has only been 6 months since the official launch of PKD Foundation of Australia. So many things have happened in that time. We have had wonderful communications with the clinical and scientific communities; distributed information flyers to renal clinics and nephrologists throughout Australia and New Zealand; had discussions with other not-for-profit organisations in which they have generously shared with us the successful and the unsuccessful methods by which they have tried to fulfill their charter and also had a lengthy meeting with the CEO of Kidney Health Australia, Anne Wilson who left recently. I strongly believe that there will be numerous opportunities for our two organisations to collaborate on projects focused on Polycystic Kidney Disease but with broader benefits for all sufferers of kidney disease.

Just two weeks ago we were fortunate enough to have a telephone conference with the management team of the US PKD Foundation, which was founded in 1982. As they listed the important steps along the road to becoming a significant funder of research, provider of education and advocate for the PKD community, I mentally ticked them off, one-by-one, secretly hoping that there was one critical one that we have overlooked, but, bitter-sweetly, no, we can be satisfied that we are addressing all of the key points. However, they did remind us that we have only been in existence less than 18 months and have already given out four enabling grants in our first year. Just last week we received an update from Prof. Jacqueline Phillips on the interesting work that her team are doing, funded by one of these grants.

We are very excited to be holding our first patient seminar at Macquarie University on 28 June with a panel made up of a renal professional, a clinician, a lifestyle adviser and a PKD sufferer. Depending on the feedback from the evening we will determine whether to do more in the future.

In response to the often requested registry of PKD patients and their families, we have commenced an investigation into the best way to create

such a database in a timely and cost-effective way bearing in mind that it must be very robust and fully sustainable into the future. We have had initial discussions with a clinician with experience with such a register overseas and we have more meetings scheduled to discuss this further.

We are very grateful to the chairman of our Scientific Advisory Board who together with some colleagues is finalising up-to-date guidelines, for Australian PKD sufferers, that will soon be available on our website www.pkdaustralia.org

I would like to acknowledge the efforts of our ambassador Vanessa Cullen who is tirelessly raising funds for and awareness of the foundation, to the Scientific Advisory Board, to Sarah our General Manager and to my fellow board members, Helen Coolican & Ian Cornell all of whom are doing so much to achieve the Foundation's goals.

It is said that PKD is the second most common genetic disease after Cystic Fibrosis and there are 6000 families affected by PKD in Australia. Our aim is to contribute to the well being of not only those people who are living with the symptoms of PKD but also those who are yet to experience the symptoms, while at the same time focusing on supporting research into finding a cure. Therefore it is imperative that we connect with everyone with an interest in PKD. Together we will make the journey easier and together we will help to find a cure for PKD.

Please consult our website www.pkdaustralia.org and Facebook page regularly for up-to-date information about our activities and connect with us via the website or by emailing sarah@pkdaustralia.org

We really want to offer additional research grants this year so if you are able to help us with a donation or a bequest please donate now www.pkdaustralia.org or email sarah@pkdaustralia.org. With 30 June almost here I remind you that all donations over \$2.00 are tax deductible.

To a cure!

Robert Gardos
Chairman

