



Australia

Vol. 7 December 2019

Musings from the Chair

As we approach the end of another busy year we highlight that our updated name, **PKD Australia**, and logo have flown at Everest base camp thanks to the amazing efforts of our supporters Vimla and Geoff who did the climb to honour their friend, PKD Australia Ambassador Mike Cornell, happily celebrating the first anniversary of transplant of his new kidney donated by his Mum, Judi.

Well done also to Team HoBro who drove “Polly”, decorated in PKD Australia colours in the KHA Kidney Kar Rally, placing 5th outright and winning Rookie Team for 2019 and highest virgin fund raiser.

A special thank you to Senator Malarndirri McCarthy for taking the courageous step to announce in the Parliament that she has PKD as do many members of her family. She has since publicly referred to PKD Australia’s advocacy and support of the PKD community throughout our country.

Sen. McCarthy and another of our supporters from Darwin, David Croker addressed an ADPKD Symposium held in Sydney in October and attended by nephrologists from Australia, New Zealand and elsewhere overseas.

My thanks go to all community members who have raised funds in so many different ways throughout the year. Without your efforts we would not be able to support the amazing research happening in many centres.

We had another of our PKD patient seminars, this time in Wagga Wagga where despite the cold night we had a very good attendance by patients, family members, GPs, nurses and specialists.

Further evidence confirming the cutting edge research being done here in Australia came with Professor Ian Smyth from Monash Biomedicine Discovery Institute being awarded a highly competitive 2 year research grant by US PKD Foundation.

As always, the PKD Australia Scientific Advisory Board has been at the forefront of advocacy and research including making application for Medicare funding of genetic testing for inherited kidney diseases including PKD and trying to get government funding for a high quality ANZPKD Registry. Unfortunately, that particular application was not successful but PKDA feels that it has such merit that we are urging the proponents to revisit the application and submit it again at the earliest opportunity. Our thanks go to each and every member of the SAB including the most recent to join, Dr Aron Chakera from Perth, and to all those other health professionals who respect what Hippocrates said over 2,000 years ago *“it is more important to know what sort of person has disease than to know what sort of disease a person has”*.

New clinical trials commencing soon increase the likelihood of new treatment options in the not too distant future.

Together with PKD support organisations in other parts of the world PKD Australia is looking to establish a global network to give one voice to the estimated 12 million people worldwide with PKD. Each group can learn from others' experiences.

Thank you also to the leadership team, to our Ambassadors, to our Local Heroes and to the PKD Australia community wherever you are. Congratulations to Dr Charmaine Green on the birth of her little daughter.

As has been clearly shown Australia has world-class researchers so the more money we can raise, the more interesting, hopefully life-changing research projects we can support.

Please help us to help the PKD community by **donating now**.

See www.pkdaustralia.org or email info@pkdaustralia.org

As always, I wish everyone a safe and happy holiday season and look forward to a new year with many new developments that will make living with PKD easier.

Robert Gardos - Chair