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Musings from the Chair

It's hard to believe that it is coming up to three years since we first learned the term COVID-19, and the word pandemic entered our everyday lexicon, yet it is still around and continues to disrupt our lives and if that hasn't been enough there are folks amongst us who have endured severe flooding. I know that sometimes I dread to look at the news because there is yet another setback to resuming our "normal" lives. Let's hope that 2023 brings with it a more positive environment. There is so much new work taking place in science and medicine that we have good cause to be optimistic about a better future.

While it is a by-product of the pandemic, webinars serve a purpose in being available to a wide audience as evidenced by the very good webinar on Preparing for a Pregnancy with PKD in September. The following month the Annual Scientific Meeting of ANZSN 2022, held in Sydney, had attendees from interstate and overseas and was available virtually. There were consumer days, one presented by the KidGen Collaborative with its focus on genetic kidney disease, the other a consumer and carer day, put on by Kidney Health Australia (KHA) and a session to understand the patient/carer journey through a public health lens. In all cases the emphasis was on patients and carers talking about their experiences. This increasing focus on these patient/consumer perspectives is important as we move towards precision medicine.

A novel presentation in the main part of the conference *"To identify the role of photobiomodulation (PBM) in managing chronic kidney disease (CKD)"* was about a non-invasive technology that has been used and well understood in other medical applications for many decades for its effectiveness against inflammation.

A feature of such meetings is the chance to learn about new concepts. Although I had heard of epigenetics previously, I didn't know much about it but *"Epigenetics is the study of how your behaviors and environment can cause changes that affect the way your genes work. Unlike genetic changes, epigenetic changes are reversible and do not change your DNA sequence, but they can change how your body reads a DNA sequence."* The example that I was given was that a pregnant woman smoker is likely to give birth to a child that will be affected by the mother

having been a smoker **and** the offspring's future child will also likely be affected by the grandmother having smoked. The fact that such an epigenetic system affects three generations is startling. And smoking is only one of many causes of epigenetic changes. Will epigenetics help or hinder understanding about inherited conditions such as PKD?

KHA spoke of the broadening of their focus to encompass "HEALTHY KIDNEYS", an acknowledgment that prevention is better than a cure. Obviously, this strategy can only apply to some acquired CKDs but not **to** inherited diseases.

It is always inspiring to learn about the work of the discovery scientists, translational researchers, clinical scientists, geneticists, patient-centred public health researchers all focused on kidney disease and it's satisfying to see how many projects have had funding from PKD Australia.

This year we gave two grants to Early Career Researchers; the funds for one of which came from a special community fund raising effort, and one full grant. They encompass discovery, translational and public health projects. Applications are now open for the PKD Australia Research Grants 2023.

In July we said good-bye to our manager Carolyn Cass. We are appreciative of the good work that Carolyn did while she was with us and wish her all the best in her new chosen direction. Now we say a very warm welcome to Amy Luchterhand who has joined us this month. Amy brings with her experience from a range of different sectors that we are sure will help us to build on our existing programs. She is also well acquainted with ADPKD.

As always, thanks go to our pro-bono service providers, the always supportive PKDA Scientific Advisory Board led by Prof Gopi Rangan, the amazing leadership team, our ambassadors, our local heroes, the loyal donors and the PKDA supporters all over Australia.

It's always a good time to make a donation to PKD Australia to support further important research and if you would like to become more involved with PKDA please contact us via our website pkdaustralia.org.

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

On behalf of PKD Australia I wish you all a joyful festive season and a safe and healthy new year.

Robert Gardos - Chair