What will the 2018 Health Budget mean for us?

As the 2018 Budget was announced we welcomed the new investment into health. A few words stood out to us from the Health Budget: **Rare, genetic and chronic.**

To us **Rare genetic and chronic = PKD.** So, we put together a wish list of what we hope the 2018 health Budget could mean for PKD.

"The Government will deliver $6 billion in record funding for Australia's health and medical research sector, including $3.5 billion for the National Health and Medical Research Council, $2 billion in disbursements from the Medical Research Future Fund and $500 million from the Biomedical Translation Fund."

Dr Gopala Rangan (the chair of our SAB) is the lead investigator of the PREVENT-ADPKD clinical trial which is funded by NHMRC. Research funding is critical to provide meaningful outcomes for PKD patients and their families. Last year Dr Amali Mallawaarachchi, a genomics researcher at the Garvan Institute of Medical Research, was awarded one of PKD Australia's four enabling grants which helped establish the new genetic test to diagnose ADPKD in Australia.

We are excited by the possibilities that genomic research brings to PKD and welcome the announcement of the Budget's new $500 million Australian Genomics Health Futures Mission – the centrepiece of a $1.3 billion health and medical research growth plan. "The first genomics project will be *Mackenzie's Mission*, with $20 million being provided for a pre-conception screening trial for rare and debilitating birth disorders including Spinal Muscular Atrophy, Fragile X and Cystic Fibrosis."

We believe ARPKD should be part of the preconception screening trial. ARPKD is a rare form of PKD diagnosed in infants, either before or after birth or later in young children. The

most severely affected babies may not survive the first few months. For those that survive the newborn period, approximately half will need dialysis or a kidney transplant by the age of 10. In the general public, 1 in 70 people are carriers of an abnormal ARPKD gene. When both parents are carriers, the chance of each child inheriting the abnormal gene is 1 in 4.

“The Turnbull Government will invest $2.4 billion on new medicines; this includes a new $1 billion provision to maintain their commitment to listing all new medicine recommendations by the independent Pharmaceutical Benefits Advisory Committee.”

As many of you know Tolvaptan is up for review by the PBAC in July. PKDA are hoping for the approval of Tolvaptan as the first treatment **of many** available in Australia for PKD. In order for our hope that a treatment and one day cure for PKD will come to fruition, we are going to need some investment into ground-breaking research that we thrive to support at PKDA.