

Media Release

Date: For immediate release

Polycystic Kidney Disease Awareness Day: More than 25,000 Australians have PKD, the most common life-limiting genetic disorder and fourth leading cause of kidney failure.

PKD is the most common life-limiting genetic disorder and fourth leading cause of kidney failure, accounting for 6% of new patients requiring renal replacement therapies, representing a significant burden to the community.

Polycystic Kidney Disease (PKD) is relentlessly progressive. As the disease develops, cysts appear on both kidneys and the kidneys themselves enlarge, often up to five times their normal size, leading to kidney failure.

For the PKD victims that develop kidney failure, dialysis and transplantation are the only available treatments.

“Knowing that you are likely to end up with kidney failure...is like having a ticking time bomb.” PKD patient

PKD, let alone Chronic Kidney Disease, is not given the attention needed at a policy level and awareness surrounding the disease is low. PKD Australia believe that it is more important now than ever before to raise awareness for PKD.

PKD Awareness Day takes place each year on September 4th and is our day to raise awareness for Polycystic Kidney Disease. Though PKD affects more than 25,000 Australians and millions worldwide, most people have never heard of this disease. Together, we can change that! The more people that know about PKD, the closer we can get to additional treatments and a cure!

Mark your calendars for PKD Awareness Day on September 4 and join us in our fight against this devastating disease.

Remember PKD Awareness Day is not just about awareness - Early detection and treatment can reduce or prevent some complications of PKD.

PKD Australia have the vision that PKD patients receive effective and personalised care for their disease that lets them live a healthy, productive and long life with the assurance that PKD patients receive adequate, appropriate, affordable and sustained access to health care. Better care will lead to better outcomes with their disease. Key measures to ensure this can be found in An Action Plan for Critical Change in Polycystic Kidney Disease Outcomes in Australia. Version 1- April 2019. Read it here: <https://pkdaustralia.org/wp-content/uploads/2019/05/An-Action-Plan-for-Critical-Change-in-PKD-V1.pdf>

About PKD

PKD is a lifelong, genetic disease of which there are two types.

The most common form of PKD, **Autosomal Dominant PKD (ADPKD)** affects around 1:1000 people. If you have ADPKD there is a one in two chance of passing the faulty gene onto each child. About half of people with ADPKD will have kidney failure by 60 years of age. Hypertension and pain are common. Patients usually become symptomatic after the age of thirty to forty when the latent disease begins to show itself. Symptoms include urinary tract infections, aneurysms and heart disease, many will experience regular pain, incapacity and anxiety throughout life.

"Looking back at my father's suffering I fear what is ahead for me, looking forward at my children and grandchildren, I have guilt at what I have passed on to them"

- ADPKD patient

Autosomal Recessive PKD (ARPKD) affects around 1:20,000 births. Both parents must have the faulty gene, and then they have a one in four chance of passing both faulty genes onto each of their children. Around 1:70 people are a carrier for the gene and most are unaware they are carriers. ARPKD often presents before a baby is born and may be diagnosed before or after birth or later in young children. About 1 in 3 babies with ARPKD die from breathing problems within the first four weeks of life. Of the children that survive the newborn period approximately half will need dialysis or a kidney transplant by the age of 10. It is difficult to predict the outcome for those diagnosed with ARPKD.

About PKD Australia

PKD Australia was established in 2014 to fund research to find a cure for PKD. We connect, support, educate and advocate for Australians and their families affected by PKD.

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