



What is PKD?

If you or a loved one have recently been diagnosed with polycystic kidney disease (PKD), you likely have many questions about the disease and next steps. Know that it is possible to live a happy, fulfilling life with PKD!

There are two different types of PKD – ADPKD and ARPKD. The difference between the two is genetic – this means it is passed down through the family, rather than contracted or developed.

Autosomal dominant polycystic kidney disease (ADPKD) is one of the most common life-threatening genetic diseases, affecting approximately **1 in 400** to **1 in 1,000**. There is usually a family history of the disease, and parents with ADPKD have a **50 percent** chance of passing the disease on to each of their children. It does not skip a generation. Certain patients with ADPKD will require a transplant over the course of their life, but treatment is available for some. Many patients living with ADPKD can live with the disease symptom-free for a number of years before requiring additional medical care.

Autosomal recessive polycystic kidney disease (ARPKD) is a rarer genetic disorder, occurring in approximately **1 in 25,000** individuals. It affects boys and girls equally, and can lead to mortality in the first month of life. Most children living with ARPKD will require a transplant early on, between the ages of 4 and 10 years old. In some cases, symptoms of ARPKD do not appear until later on in childhood or even into adolescent years.

In both forms, some of the most common symptoms include:

-  **HIGH BLOOD PRESSURE**
-  **BACK OR SIDE PAIN**
-  **HEADACHE**
-  **INCREASE IN THE SIZE OF YOUR ABDOMEN**
-  **BLOOD IN YOUR URINE**
-  **FREQUENT URINATION**
-  **KIDNEY STONES**
-  **KIDNEY FAILURE**
-  **URINARY TRACT OR KIDNEY INFECTIONS**

There may be some adjustments you need to make following a PKD diagnosis, either for yourself or your loved one. Prolonging optimal kidney health is a priority for all those living with PKD, as is maintaining a high quality of life throughout diagnosis and treatment. You should first strive to maintain good overall health through diet, exercise, and controlling risk factors for cardiovascular disease, including hypertension, which is very common for those living with PKD. To learn more about some of the frequently asked questions related to both forms of PKD, visit our website at endPKD.ca/learn!

The PKD Foundation of Canada is here to support you on your PKD journey!

From the first research grant awarded in **1999**, the **PKD Foundation of Canada** has set up chapters and support groups across the country, built an expansive and passionate volunteer network, and connected with PKD groups around the world to best serve the PKD community on a global level.

Today, the **PKD Foundation of Canada** is the only national organization solely dedicated to fighting PKD through research, education, advocacy, support and awareness.

RESEARCH

The **PKD Foundation of Canada** is the nation's leader in clinical research and fellowship funding in the field of PKD. Since **1999**, we have funded over **\$1M** to Canadian research projects and fellowships. We remain committed to improving the quality of research investigated in Canada, while also strengthening the future of PKD specialists through fellowship funding.

ADVOCACY

Voices of PKD is a collection of testimonials and photos that tell the story of PKD through the eyes of the PKD community. With the help of our volunteers, our stories help shine a light on a widely unknown disease.

EDUCATION

The PKD Foundation of Canada's goal is to help those affected by PKD live happy, healthy lives. To ensure that PKD patients and their loved ones have all of the resources necessary to attain this goal, we have educational resources available through our website.

The PKDFOC hosts **educational webinars online!** Webinar topics cover a variety of PKD related content such as diet, managing mental health with chronic illness, how COVID-19 affects the PKD population and more!

Patient Forums are a great opportunity to hear about PKD topics from top local PKD specialists!

AWARENESS

Since **2015**, Health Canada recognizes **September 4th** as **PKD Awareness Day**. This is a day when people from all over the world shine a light on PKD, spread the word, share stories, and encourage others to learn more about this disease. Municipalities all across the country show their support with local proclamations, flag raisings and monument lightings.

SUPPORT

The **PKDFOC** provides emotional support for PKD patients and their families throughout their PKD journeys, by way of our chapter support meetings, online meet & greets, and connecting individuals with local PKD Foundation of Canada volunteers.



For online resources,
scan the QR code!

PKD Foundation of Canada
3-1750 The Queensway, Suite 158
Etobicoke ON M9C 5H5

Toll-free patient hotline: 1-877-410-1741
Email: endPKD@endPKD.ca

The PKD Foundation of Canada is a registered charitable organization with the Canadian Revenue Agency,
Charitable # 852683853RR0001