annual report 2024

PKD
FOUNDATION
OF CANADA

FONDATION
CANADIENNE
DE LA MPR

about

About the PKD Foundation of Canada

Established in 1993, the PKD Foundation of Canada is the only national organization solely dedicated to fighting PKD. Through research, support and education, and awareness and advocacy, we aim to ease the journey for PKD warriors and their caregivers, providing community, connection, and accurate information, as well as funding research to generate hope.

We've been doing this for over 30 years, partnering with health care providers and specialists to offer the most up-to-date information, providing peer support, raising awareness, advocating for improved care, and supporting Canadian researchers as they strive to develop ways to slow PKD's progression and, ultimately, find a cure.

Our Mission
To promote programs of research, advocacy, education, support and awareness in order to discover treatments and a cure for polycystic kidney disease and improve the lives of all it affects.

Our Vision
No one suffers the full effects of polycystic kidney disease.

Financials
Please see our 2024 audited financial statement for more information.

leadership

Message from the Board & Executive Director

2024 was a year of transition at the PKD Foundation of Canada, making it a good time both for reflection and for a recommitment to the PKD community and our mission.

We took the time to listen to patients, their families and caregivers and to refine our programs and services to ensure the Foundation was best meeting their needs.

Because of the generosity of our supporters, we were able to maintain our most valuable offerings, add some new resources and programs to fill emerging gaps, and continue to fund research, the best way to offer hope.

The development of a new strategic plan early in 2024 confirmed our priorities – educational and supportive programs for the entire community, no matter where they may be in their journey; continuing to build awareness of this still not well known disease; advocacy for improved treatment and access to care; and the funding of research into new treatments and better clinical understanding of PKD.

To this end, we engaged healthcare, nutrition and mental health experts to partner with us in the development and delivery of numerous webinars, virtual Summit presentations, blogs, and resources, and we launched PKD Mind Matters, our monthly virtual peer support sessions.

We began planning our online community, considering what platform, format and content would be most valuable to those affected by PKD across the country.

With donor support, new videos were produced to be used in awareness building campaigns and, through volunteer-conducted research, treatment approaches and access to care across the country were investigated.

Our research funding in 2024 aided Dr. Marie Trudel's research exploring the mechanisms behind polycystic liver disease in patients with ADPKD.

With a relatively new staff team, getting to talk to and build relationships with those affected by PKD was a high point internally; these conversations are invaluable as the Foundation, staff and board of directors are all here to serve you, our PKD community, to try to make this road a bit easier to navigate and to ensure that no one travels it alone.

In 2025, we look forward to engaging further with all who have been impacted, launching and growing our online community as a central hub of resources, events, information and connection.

It is with heartfelt gratitude to our donors, volunteers, supporters, event participants and partners that we move forward into 2025; your dedication, belief in what we do, and compassion for the PKD community is the driving force behind all that we envision and achieve, and our appreciation cannot be overstated. Together, we'll continue to move towards a future without PKD.

Stephanie Vardzel, *Co-Chair, and* ***Kathleen Barnard,*** *Executive Director*

our why

1 in 400
to
1 in 1000

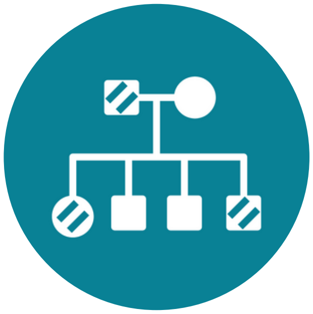
1 in 400
to
1 in 1000
Canadians are affected.

Half of those diagnosed will experience kidney failure by the time they're **54.**

Without effective treatment, the kidneys can enlarge up to **20x** their normal size.

80% of Canadians waiting for an organ donation are waiting for a kidney.

30% of babies born with ARPKD will not survive the first month of life.



Children have a **50%** chance of inheriting the disease from a parent with ADPKD.

On average, patients spend nearly **4 years** on dialysis waiting for a kidney transplant.

our impact

$348,150
Raised for PKD research and patient supports

Record-setting number of Walk to END PKD participants in **5 cities**

To Date

Funded 10 PKD-specific research projects

4 Scholarships to encourage nephrology specialization

27 Educational videos added to YouTube channel
11,000+ views

PKD Summit
7 PKD-related presentations

PKD Summit
208 attendees from
20 countries worldwide

Voices of PKD: Kim’s Journey

Kim Holowatiuk
ADPKD patient

My name is Kim Holowatiuk, and I was diagnosed with PKD when I was 17 years old. At the time, I had two cysts on one kidney, one cyst on the other, and one liver cyst. (Those were the good ol’ days.) 😉

When I first got my diagnosis, I was concerned. I wondered if I would have a normal life, and when PKD would start to affect me.

I inherited the PKD gene from my dad, and around the time of my diagnosis I was just starting to see what he was dealing with, health-wise. But he was very stoic and never complained, so it shielded me from the struggles that he may have been going through.

Besides my dad, his half-siblings and his father (my grandfather) also had PKD. They’ve all passed away from the disease.

At the time I was diagnosed, I had a good “textbook” overview of what PKD was all about, but not a first-hand, “living with it,” point of view. Looking back, I wish that I had known that, as a female, I had a higher chance of also having polycystic liver disease (PLD). I also wish I had known about the risk of brain aneurysms.

Aneurysm

I ended up having a brain aneurysm in 2010. It was an unruptured middle cerebral artery (MCA), and I went through the scary process of having brain surgery (craniotomy), as they needed to clip the aneurysm rather than coil it, due to my younger age. I will be the first to tell you that my surgeon, Dr. Garnette Sutherland, was brilliant – although his hairstyling skills around my scalp incision were a hard zero out of 10. 😆

At age 50 I was diagnosed with PLD, and over the past four years my eGFR has gone from a high of 32 to a low of 17. My last blood work showed an eGFR of 19, and I am hoping to hold on as long as I can before going down the route of transplant or dialysis. I have been on Jinarc (tolvaptan) for the past eight or nine years, which has prolonged my kidney function.

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Tolvaptan
A little bit about my experience with tolvaptan, for PKD patients who are curious: tolvaptan has been very manageable and helpful for me, for the longevity of my kidneys.

The main issue that is aways talked about with tolvaptan is not knowing what to expect in terms of the frequency and urgency of going to the bathroom. I live in a rural area outside a city, and the long highway drive was a concern at first.

There is an app called “Where to Wee” (funny right?!🤣) that I used in the beginning if we were going out. This app actually locates washrooms, and rates each bathroom on cleanliness, etc. I was surprised at how manageable it was, being on tolvaptan.

Once your body adjusts to the medication it’s really not that bad. You just get in a routine, for example, using the washroom before you leave your house or work, and having water on hand all the time as you do get thirsty and drink a lot.

I drink between 5-7 liters a day, and prefer it super icy cold. I am up only once at night, and it really hasn’t been that bad. I take my medication early, at 7:00am and 3:00pm, which really helps alleviate the need for nighttime bathroom breaks.

You need to have your liver function checked regularly when you're on tolvaptan, as liver damage is a rare side effect. Between my kidney care team and the Jinarc or Orijin Program, they are very good about keeping my lab results completed and recorded in the required time frames.

At first I was tested monthly, then every three months, and then every six months. I have had no side effects while on this medication, other than the noted and expected increased urination.

I was concerned about liver side effects from tolvaptan after being diagnosed with PLD, but to this day my liver function continues to be normal.

I wish I had known that all the "unmanageable bathroom issues" associated with tolvaptan were not really a concern for me after all, and that the liver side effects, although possible, are mitigated very well with close monitoring.

If you have PKD and are offered the option to go on tolvaptan, go for it! If your nephrologist feels it is appropriate for you, I think you should try it. It's very difficult to take in the amount of water suggested for kidney health without being on this drug, and if it helps prolong your kidneys for two, three, or more years, that is totally worth it.

My only advice is to make sure you have a drug plan that covers it. It is an expensive drug, and I was lucky to have coverage for many years. Once I no longer had extended health care benefits through my job, I was accepted into the compassionate relief program, for which I am very grateful.

PLD
One of the things that has surprised me the most about PKD has been experiencing the co-occurrence of PLD. I had no clue that females had a higher rate of PLD, since it is estrogen-driven. It was complications from my massive liver (which MRI has shown is the size of 2½ footballs) that first alerted me to the PLD issues. I was

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having trouble bending over to tie my shoes, gardening, etc., and had a very distended abdomen that was hard, and very sore. I could even feel what turned out to be my largest cyst, near my stomach.

It turns out I had three large cysts (the largest was the size of a baseball) on my liver, compressing my stomach and making it uncomfortable to eat, bend over, and even breathe. Laying prone – or putting any pressure at all on my abdomen, for that matter – was impossible.

I ended up having a fenestration surgery of the three largest cysts (which involved cutting open the cysts to drain them). This helped alleviate some of the pressure, but sadly other cysts just started to grow in their place.

The pressure in my abdomen from both my liver and my massive kidneys (each the size of a football) has left me with an umbilical hernia that is not treatable without a nephrectomy (to alleviate the massive pressure). The hernia is an additional hindrance to my quality of life.

The physical changes involved in PKD and PLD have been challenging. I am always uncomfortable. I have flank pain. I am short of breath due to all my organs being squished. I am limited in what I can do physically, due to the size of my abdomen and my hernia.

BUT, I think the most difficult thing for me is the effect of PKD and PLD on my mental health. This is hard for me to talk about, and will probably sound very vain, but having the equivalent of 4½ footballs inside your abdomen changes your shape, and my abdomen sticks out quite a bit now.

I am SO very self-conscious, and feel very embarrassed about how I look. I worry that I will be judged by others, and do not socialize as much as I used to, since I am just not comfortable. Unfortunately, in my 20s my boyfriend at the time was extremely superficial and obsessed with my looks/weight. That was very detrimental to my self-esteem in those formative years, and has always stuck with me. Thankfully, I now have an amazing husband, family, and friends who support me, but I still struggle with this aspect of my life. It is a work in progress.

Mandalas

One of the activities that has really helped my mental health is mandala painting. I first started because it looked pretty, but the slow, methodical pace and precision needed to create these paintings has brought me so much peace.

When I am painting, I become totally enveloped in the progress, and watching the designs build. I find that my mind can truly relax and let go of all of the worries and stress that I have around my day-to-day struggles: thinking about tests, picking a treatment modality, contemplating transplant, or finding a living donor (!! this is a VERY stressful topic). Painting has allowed me to almost "channel" some of my journey into my art, and I really find so much joy in it.

Another thing that has given me a lot of hope or comfort on my PKD and PLD journey is the fact that organ donation is now being talked about more than it was in the past. I think the "Logan Boulet Effect" has really had a positive impact, decreasing the discomfort and stigma of talking about organ donation.

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Awareness
I think that to understand more about PKD, people need to appreciate how amazing your kidneys are, what they do for you, and how their function is impacted by PKD. I think people would be surprised at how much work your kidneys do for your body. Even more amazing is the fact that you can live with only one kidney!

I hope that I get a few more years out of my current kidneys. When the time comes, I hope that I am able to find a living donor and get a pre-emptive kidney transplant, so that I don't have to experience dialysis.

Maybe eventually I will also get a single or double nephrectomy, to help alleviate my abdominal discomfort and pressure, giving the rest of my organs some actual room in my abdomen and, of course, providing me with some increased quality of life to do more – like tie my shoes!!! 😜

People can help those with PKD by something as simple as being a support for someone they know with PKD. You can share posts about the disease on social media to help raise awareness. Donate to research.

Sign your donor card and tell your loved ones about your wishes, or even consider becoming a living kidney donor, to give someone the gift of life.

Marie Trudel, PhD
Université de Montréal

2024 Funded Research Project

Research Focus: Polycystin1/PKD1 Targeted Polycystic Liver Disease: Anatomic Remodeling, Molecular Mechanisms and Targets

This study aims to investigate the mechanisms behind polycystic liver disease (PLD) in patients with autosomal dominant polycystic kidney disease (ADPKD), specifically targeting the Polycystin-1 (PC1) protein.

PLD often significantly impacts patient quality of life, even more than kidney cysts. Current non-pharmacologic treatments are only partially effective and temporary. Preliminary studies using mouse models have shown that mutations in the PKD1 gene and altered PC1 trafficking lead to severe liver issues.

By understanding the molecular pathways involved in hepatic cyst formation, this research seeks to identify potential therapeutic targets, which could lead to the development of effective liver treatments for ADPKD patients, significantly improving their quality of life.

At the PKD Foundation of Canada, we are dedicated to funding innovative research that paves the way for better treatments and, ultimately, a cure for polycystic kidney disease. Our mission is made possible by the generous support of our donors, and the tireless efforts of our grant recipients – researchers and scientists who are leading the charge in PKD research.

We are proud to showcase the remarkable work of our grant recipients. Their groundbreaking research is making a significant impact in the fight against PKD, and bringing hope to thousands of Canadians affected by this disease.

people

2024 Board of Directors

Dianne Hillier, Co-Chair
Stephanie Vardzel, Co-Chair
Trinda Blackmore, Treasurer
Sara Hillier, Director

Our 2024 Staff

Kathleen Barnard, Executive Director
Sandy Kenney, Development & Fundraising Manager
Michelle Lynne Goodfellow, Communications & Engagement Manager

Volunteers

The organization thanks its incredible volunteers for their dedication and passion. Their leadership in local awareness and events like the Walk to END PKD has united the community and raised vital research funds. By sharing personal stories through Voices of PKD and other initiatives, they inspire hope and raise awareness – especially on PKD Awareness Day. Their ongoing commitment drives progress toward a future without PKD.

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

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