

# Fight to End PKD Transcript

**Brittany:** Welcome to Living Transplant.

[00:00:02] **Courtney:** The podcast that takes you behind the scenes of the transplant program at Toronto General Hospital,

[00:00:07] **Brittany:** and brings you open and honest conversations about the transplant experience.

[00:00:11] **Courtney:** My name is Courtney and I'm the communication specialist for the Centre for Living Organ Donation.

[00:00:16] **Brittany:** And my name is Brittany. I'm a bedside nurse in the Ajmera Transplant Centre.

[00:00:20] **Courtney:** Full disclosure: we are not physicians.

[00:00:22] **Brittany:** No. And we are not here to give you medical advice.

[00:00:26] **Courtney:** Think of us like your guides through the world of transplant, as we know it,

[00:00:29] **Brittany:** Whether transplant is your past present or future your passion, or your curiosity ,

[00:00:34] **Courtney:** Living Transplant will show you the world of transplant like you've never seen it before.

[00:00:40] **Brittany:** Welcome back to living transplant. Our guest today is the founder of the PKD foundation of Canada. His name is Jeff Robertson.

[00:00:49] Thank you so much for joining us today, Jeff.

[00:00:51] **Jeff:** Well, it's good to be here. Good morning.

[00:00:53] **Courtney:** So typically we start off by asking our guests about their connection to transplant, but I feel like knowing a little bit about your story and how the PKD foundation of Canada was started, I feel like those things are a little connected. So maybe do you want to tell us the origins of the PKD foundation.

[00:01:11] **Jeff:** Sure, sure.

[00:01:12] So polycystic kidney disease shortened to PKD is the largest hereditary disorder affecting the kidneys in the world. It affects approximately one in a thousand people on a global level. What it does is - the effected organ over time is taken by golf ball size cysts, and they grow and manifest on the effected organ eventually causing in the majority of patients, renal failure.

[00:01:40] The PKD foundation of Canada was founded in 1994 by my parents and another couple. And this was after they were all diagnosed and had been living with - PKD two of the four members with PKD for a number of years and there being no support out there. My mum was actually diagnosed in 1979. So from 79 to 94 she was being seen by Dr.

[00:02:04] Janet Roscoe. And then later she was being seen by Dr. Levy for two and a half years while she waited for her transplant, but they founded the PKD foundation of Canada, which was under a different name at the time. It was a provincial charity to connect patients affected by polycystic kidney disease and to help bridge that gap from newly diagnosed to getting connected into the PKD community.

[00:02:29] And in 1998, April of 98 after two and a half years on the wait list, my mom had her first liver transplant. So polycystic, even though it's polycystic kidney disease and she has the liver disease as well, it was her liver that was predominantly affected.

[00:02:46] She looked nine months pregnant for the first 17 years of my life. So 98, she had her first liver transplant, and then close to 10 years to the day we were actually in the planning stages of her having her ten-year anniversary. She suffered a bile duct infection, and the bile duct caused her donor, organ to fail.

[00:03:08] So she had to go back on the list and then had her second gift of life on March 30th, 2008. So we're coming up to 13 years with her second transplant.

[00:03:21] **Courtney:** Wow. That's incredible. Yeah. I remember talking to - Brittany, I've also met Jeff's sister,

[00:03:25] Megan - who spoke at an event we hosted two years ago, I guess. But she said in the interview with her that she, you know, Toronto General, she thinks of his just as her second home. Like she feels like she grew up there basically. Do you have that feeling as well?

[00:03:38] **Jeff:** More so the second time around.

[00:03:40] So I was a bit young when my mom had her first transplant. I remember when, when she first got the call on her, on her pager that obviously dates the first transplant. I was at my like grade 10 semi-formal and we were at like The Tannery, this, this venue in town here. And all my friends are like your parents are here and I'm thinking like, Oh my God, what did I do?

[00:04:03] What's wrong. What's happening? And it was literally my mom getting the pager beep and that they were going to get the call. Now. It didn't happen that night. It happened a little while later, but we were in school while a lot of this was going on. Come full circle to the second transplant. I was there maybe 18 to 20 hours a day. I'd go home for three to four hours and sleep and then go back. And I would do like the night shift with my mom through the night because she was so sick.

[00:04:29] None of us wanted to leave her alone. The hospital was so gracious to, to give me one of those, you know, out chairs. I had a little portable DVD player would stay up through

the night just to, to keep her company. And then Megan would come and visit. Dad would come when he wasn't working, but of course he's the only one working.

[00:04:46] So that had to stay in place, you know, to make sure that they were okay financially. TGH [Toronto General Hospital] was definitely a major part of our lives. I mean, I was getting ultrasounds every three years or so to be tested, to see if, if any cysts had developed on me,

[00:05:02] and then eventually working with, with Dr. Pei and a study that he was doing, it was found conclusively that Megan and I don't carry the PKD genes. So that was at 25. So those first 25 years, I was probably in a hospital more, more times than the average family. My mum and dad, certainly lived there.

[00:05:20] That was a second home to them for sure. But we were, we were lucky that with the first one, I think that, that there was a bit of a distance because it's, it's hard for young kids to see their parents like that. Especially back then, there was very little support very little education and information for, for kids of our age, like teenagers adolescents And that was again, that goes back to why my parents founded, what I turned into the PKD foundation of Canada was because there was no literature out there.

[00:05:50] There were no handouts. This was pre-internet. You know, the only reason my, my parents and this other family from Oakville got connected was because they had both called the PKD foundation in the U.S. and said, look, you guys have an organization, you have a charity, we have nothing here. What do we do?

[00:06:07] How do we get started? And this, I guess, predated confidentiality agreements. So the U.S. PKD foundation just said, well, we've got you two people, we've looked at a map. You're about 40 kilometers away. We're going to share your contact information with each other and get you guys connected. You know, that, that would lead to terminations nowadays.

[00:06:26] But it, it was the, the grounding that started the foundation and PKD advocacy here in Canada.

[00:06:34] **Brittany:** When I first started in transplant, I literally knew nothing about transplant. And then I was somehow introduced to this big world of all these world first and just completely blown away. So on the other side for you growing up, you knew what transplant was like, you had witnessed it yourself.

[00:06:52] So what was it like to grow up in a household where medical conditions and transplant were discussed so frequently?

[00:06:58] **Jeff:** Very different. When I talked to my friends about, you know, their upbringing and their lives from early childhood on, we went on two very different trajectories. You know, I was fortunate as a kid, my parents got us operation at a very young age, so we had the game and that's where I learned the basics of transplantation was getting zapped.

[00:07:22] **Brittany:** I think that's where we all started with our anatomy.

[00:07:24] **Jeff:** [laughter] But jokes aside. No. So we, when we were young, a lot of the information that was shared earliest was about the disease was about PKD. So very early on my family, we learned about what the kidneys do, what the, what the body function of, you know, the involvement of the kidneys and the liver.

[00:07:50] That tied into then transplantation. I used to do our, our science projects when we used to have to do science fair projects would always be on PKD, polycystic, kidney disease or transplantation. Because again, these were things that, that affected our family. And it was, it was usually around the science fair days when I would look at the boards and go, I'd look at what the other kids are doing.

[00:08:15] Right. And it's like volcano and, and cloud formation and, you know, areas, rocks and mortar type of things. And then minds on like these gross looking cyst, riddled kidneys, and like it's actual medical pictures. And, you know, you do have kind of that, that model that looks like the guy from operation up on the board and yeah,

[00:08:38] **Courtney:** Having seen your mom in the hospital and what PKD had kind of done to her body and how your family life had essentially come to revolve around her health status? Were you at all afraid that you were going to inherit PKD?

[00:08:52] **Jeff:** I went through ebbs and flows as, as anyone with, with hereditary disease in the family or a chronic disease in the family does very young.

[00:09:01] I only focused on the academic side of it.

[00:09:03] I knew processes, policies and why they were there. Then as I got older and you learn more and, you know, as I mentioned, I was, I was 15. When my mom had her first transplant. So you're old enough now to really see what's happening. And you know that when your mom and dad go away for the night or whenever they get the call that your mom is going to have surgery and you know how invasive that surgery can be.

[00:09:29] And, you know, the, the positive statistics are obviously all there and present, but not necessarily at that time at 15, I think that was the year I got my first email address, and had 30 minutes of internet usage and computer class. And that was it. So I wasn't using it to go, okay, what's the lifespan of a transplanted liver.

[00:09:50] What's the, you know, I wasn't doing it for that. It was trying to download one song off LimeWire or something like that, you know? Then in my teens, I rebelled against the idea of, of getting a hereditary disease. I was a smoker foolishly I was a drinker foolishly in my teens and twenties.

[00:10:09] Neither of which I, I indulge in now, but it was, that was my self-medicating, if you use that term of, of dealing with the stress of the possibility of having this disease, even though I'm doing the two things that are the worst possible thing for that disease drinking and smoking that was where I, that was how I coped.

[00:10:34] That was how I got through that first transplant. When I was 25, 10 years later much more reasonable man and was able to throw myself in. And I got into the caregiving side of my mom's transplant. At that point I was, I was hands on talking with every doctor. I knew every lab result. I knew every day, my mom's activities.

[00:10:55] Yeah,

[00:10:56] **Courtney:** In a way, it sounds like PKD and your - well PKD just made you grow up really quickly.

[00:11:02] I, I mean, you, you referred to your 25 year old self as, as like a man. And I would hesitate to refer to my 25 year old self as a fully formed adult. So -

[00:11:12] **Jeff:** When you're forced to survive, you'll thrive.

[00:11:15] Right?

[00:11:16] **Courtney:** Yeah. And I think it can go either way though. Like when you spoke about self-medicating to kind of cope with the anxiety of potentially being diagnosed with PKD, like, I, I think it can go either way. Like It takes a lot of strength to really step up to accept whatever cards you're going to be dealt or, and, or to just step up as a caregiver.

[00:11:36] And I feel like we don't really, we should do a mental health episode talking a bit more about mental health and transplant.

[00:11:43] **Jeff:** It's, it's, it's huge. And in the transplant community, it's huge and the chronic kidney disease. Sector or chronic disease of any nature.

[00:11:52] I mean, mental health is a huge component and that's why, you know, one of the webinars that we did with the foundation at right at the beginning of COVID was on the importance of mental health, because especially during a lockdown, I mean, it's, it's scary times for people, you know, and, and the resources as limited as they are virtually are, are hard to come by.

[00:12:13] So -

[00:12:15] **Courtney:** Absolutely. Could you speak a little bit about some of the mental health needs or issues that you see in the PKD community?

[00:12:22] **Jeff:** Yeah. So a good deal of, of the issue issues, stem from the hereditary component and dealing with the thoughts and feelings associated with, with possibly passing on a genetic disease to family.

[00:12:38] That's a, that's a hard burden to, to live with. I know that firsthand, my mum before it was found out that we didn't have, it would talk often about the guilt that she felt from having, having possibly based on the genes to which she didn't even know at the time that it was a hereditary disease.

[00:12:56] You can't be blamed for something you didn't know and, when I talk to people that, that have children and that have that concern of, of possibly handing it down, I mean, it's important to look at the statistic.

[00:13:08] Yes, it's, it's a 50% chance, but that 50% chance could work in the favor that it has in, in my family. You know, the disease has stopped with my mother. It doesn't pass a generation, it doesn't skip a generation. So my daughter isn't at risk of inheriting the disease.

[00:13:25] You know, when, when you're newly diagnosed, it can feel very, very lonely, especially if you don't know what this disease even means.

[00:13:35] And if you're the first one in your family to have it, which is called a spontaneous mutation, if you neither, one of your parents carry the gene and you end up carrying it you're a spontaneous mutation and that's, that's about 10% of PKD. Patients are a spontaneous mutation, meaning they're the first in their family.

[00:13:54] So that can come with, some. Mental burdens

[00:13:57] I think the depression that can come with a diagnosis may not get the care that it needs initially, because we're often, as Western society is, has trained us -

[00:14:08] - the body is generally the primary focus and then the mind afterwards, when a lot of people are, are newly diagnosed. Okay. So their, their plan of attack is get their GP to give them a referral, to get to a nephrologist, to get into the clinic, get your labs, have an ultrasound, have your blood work, possibly get a nutritionist.

[00:14:28] Okay. And we haven't even touched on the social worker or talking about your feelings or booking a psychiatrist. You know and I'm a strong, strong advocate for mental health. I think, I think everybody should have a, an appointment a week with a therapist.

[00:14:44] I think it would do us all. A lot of good. Absolutely.

[00:14:54]

[00:14:54] [musical interlude]

[00:14:54] **Brittany:** I don't think it's a weird thing to say that it's a bad, or it's a good time to get polycystic kidney disease because of all the resources and education that's out there. It's pretty substantial now then I guess it would have been in 1979. I think when you said your mom had -

[00:15:09] **Jeff:** - even much more recent than that.

[00:15:12] I mean the, the first treatment Tolvaptan or Jenarc was approved in 2015. So prior to 2015, there was no treatment option available. There's still no cure, but there wasn't even a treatment option available for anyone with PKD before 2015. So it was a lot of what I remember a lot from my childhood was -

[00:15:37] It was kind of just the hurry up and wait. It was okay, we'll see you when a year. There's literally nothing we can do for your disease. It's progressive. We know this it's

progressing. We know yet. Diet, you're doing everything right. You don't drink, you don't smoke. You exercise, see you in a year. And that was defeating for the community for so many years just saying, okay, well there's no, there's nothing we can do to slow it down.

[00:16:00] Drink your water, cut your caffeine back. We'll moderate your, your meat intake. Take the salt off the table, things like that. But you can only hear those, those tips and tricks so many times before you go, okay, let's get to some, some action. Let's get to some treatment options. Let's get to some clinical trials coming down the pipeline.

[00:16:24] And that over the last 10, 15 years is where we've really seen the differences, the drugs that are coming down, the pipeline, the. Invested research into this disease. People are now going, okay. This is a, a hot button disease that affects a large number of people and is a burden to the healthcare sector.

[00:16:47] When you look at the cost of, of transplantations and the medication tied to them or the dialysis a year living with kidney disease is a very costly process. So if, if drugs on the market can slow the progression of someone going to the dialysis chair or someone needing a transplant now you're seeing hope now you're seeing there's options.

[00:17:10] And that's made a big difference in, in people's mindsets when, when talking about this disease. And that's what I mean when I say now is the best time to be diagnosed, you know, this time and this, this situation that we're faced with right now, with all of the specialty clinics, with all of the nephrologists, with all of the pharmaceutical companies, doing the research people diagnosed now won't have the same journey that their parents faced or that my mom faced or that my grandmother faced.

[00:17:40] And that's promising. And that's why, you know, when it comes to family planning, I let people know that that having a child now versus having a child 20 years ago, are two very different situations, but that's a hard stigma to, to remove yourself from right. All of those years thinking, you know, if your child did have it and there's nothing that they could do.

[00:18:02] Whereas now if your child inherits it, there was a drug that they could potentially benefit from. And by the time they were old enough to take said drug, there could be three.

[00:18:11] **Courtney:** Yeah. Like, you never know what's going to happen. Like, things have progressed so rapidly. If you think about when the first living donor kidney transplant was, which I think is in the fifties between two twin brothers.

[00:18:23] If you think about how far treatment for end-stage kidney disease has come since then, it's crazy. So with Jenarc and what was the other one you said?

[00:18:35] **Jeff:** Tolvaptan and Jenarc are the same drug. So one is the -

[00:18:37] **Courtney:** - generic. Yeah. Okay. Gotcha. So, so what does that do that just kind of slows the progression or prevents -

[00:18:43] **Jeff:** - it slows the progression of the cysts.

[00:18:46] **Brittany:** How does it do, how does it do that?

[00:18:47] **Jeff:** Well, that's a whole other podcast. The science of essentially is buying the individual time, before they would need a transplant or dialysis by slowing those cysts down. It's giving them a better quality of life.

[00:19:06] But the important thing to remember is that the current drug that is available on the market Tolvaptan is the only one, but it is only It is only beneficial for certain PKD patients that's not even talking about the recessive form, autosomal recessive PKD (ARPKD).

[00:19:24] Because this isn't for that. So that's a whole other demographic and they're the ones that's more the pediatric PKD. So over, across the street from you guys at SickKids Hospital is where they would treat the ARPKD. But we can't stop as a, as an advocacy foundation with one drug.

[00:19:43] We're not, we're not waving one drugs flag. We need there to be countless options out there to prolong the quality of life. Then you have to fight for equal access to those drugs, right. So that everyone can afford them. That's the biggest challenge now is if you don't have coverage, You're not, you're not paying out of pocket for drugs.

[00:20:02] **Brittany:** Definitely not. You've obviously been studying this since you were a kid in your science fairs. Why did you create this foundation?

[00:20:17] **Jeff:** I remember when I was young. And as I've mentioned before, there was no information out there for kids. There was no there's hardly any information out there for adults. There was no support for us as a family. You know, we all went to for different types of family therapy to talk about our feelings, but there wasn't anything that we could talk to specific to organ donation, you know, and transplantation.

[00:20:40] And that's where like the social worker would come into play nowadays. So I wanted to, to create a national organization that catered to providing information to those that historically hadn't been able to access it. I wanted to make it more, more accessible for, for kids to learn about this disease and not be freaked out.

[00:21:00] You know, Dr. Google can make you think you're going to cut your hand off with a paper cut. So, you know, I shudder to think what someone could find if they Googled PKD, you know what I mean? And didn't land on a reputable site. You go down some of these, these public forums and chat rooms on Facebook, and it can sound like a death sentence and it's not.

[00:21:21] **Courtney:** Yeah, and that's kind of like a gap that exists - is talking to kids and teenagers about transplant, about chronic disease. Yeah. How do you guys kind of tackle that?

[00:21:37] **Jeff:** So I take after my mom and I do the high school circuit my mom used to come into our high school much like, you know, mad would come in and talk about drunk driving or, you know, the, the ex drug addict would come and talk about addiction.

[00:21:50] My mum would come in and talk about transplantation in polycystic kidney disease. And so, so we, we go out in that respect in a very organic route, but we also have there's, there's resources on our website. There's, there's vignettes that are catered to kids to, to have kind of a shorter snapshot of what living with this disease is like.

[00:22:13] And I think, you know, infographics and things of that nature that make it more palatable. You know, there's, there's one image. That's heavily circulated in the PKD community and it's, it's a diseased kidney next to NFL football. And this picture is older than I am probably. Right. Like, it's just, no one can source it's original where it originally came from, but it's, it's the original, like, this is what this disease can look like.

[00:22:36] And that's not necessarily the first image I will want to see as a kid or, or even as an adult necessarily. Right. So we have to put information out there in different, different ways, we have to keep the information as fresh as possible so that it's palatable because. For one reason or another kidney disease doesn't have that sexy factor, you know, that other, that other disease organizations can play off of. You know what I mean? I, I, I often romanticized having the, the brand power of Movember you know what I mean?

[00:23:12] Or the heart and stroke foundation,

[00:23:14] **Courtney:** I was going to ask what the, like the sexy disease campaigns are but that makes sense -

[00:23:20] **Jeff:** Like that, Movember created a generation of, of my age group growing stashes. And it's brilliant. It's but you're left going, like, how did we not.

[00:23:29] **Courtney:** I think those, I think, I think you're right in saying that, you know, everyone knows what that means, but whether or not anyone actually takes any meaningful action to like help, like yeah.

[00:23:39] **Jeff:** It's the same thing. A mustache doesn't translate to knowledge about testicular cancer.

[00:23:44] **Courtney:** Exactly.

[00:23:45] **Jeff:** And that's, that's more to what we, we emphasize is that whether you're watching a two-and-a-half minute video or a two-hour webinar we want to paint you a realistic picture of what living with this disease is like, and hope is a huge part of that puzzle that we want to make sure that people recognize is out there

[00:24:05] **Brittany:** Mm. How do you get into high schools to talk about these things? I've always wondered.

[00:24:12] **Jeff:** There's, there's different ways. Generally someone at the school or even a teacher is affected by PKD.

[00:24:18] So they, when are, when they're looking for speakers kind of connect the dots and I've had actually, in some schools, the, the kids are required to find the speakers and then do a presentation on it. So I've been called into classrooms to teach about PKD because

they were doing kidney disease, or I did one and I tied PKD to organ donation because it's such a seamless story.

[00:24:41] Right. Where 60% approximately of PKD patients, 50 to 60% will either require dialysis or transplantation. So the messaging is often linear there. But it's, it's through word of mouth, a lot of it. And that's, that's. Grassroots advocacy at its finest, right? Is, is just getting the word out there and, and offering to speak to whether it's, you know, groups like a hundred men who care the a hundred men who give a damn and the a hundred women who care and or speaking before legislature and getting things, you know, speaking with your MPS and your MPPs.

[00:25:17] We work with our volunteers so that they're comfortable sharing their journey with, with whoever will listen, because that's the best way that people are going to learn about this disease. That's

[00:25:29] **Courtney:** very true. Anyone we have that we've met. I guess through our, I don't know that we find out later that has ties to, to your organization.

[00:25:38] Like they are very open and comfortable and confident when telling their stories like there, they really are open, open books when it comes to their experience with the PKD foundation.

[00:25:48] **Jeff:** That goes for the PKD community on a global level. I mean, these people we work closely with organizations and foundations across the world and.

[00:26:02] You see those, those synergies everywhere. It's the same determination and, and like almost war to your ask confidence that these patients have in telling their tail. And, and that, that makes my job, one of the best gigs in the world is I get to work with these people, share their incredible stories see their stories, touch other people who then get involved and then they have a story of their own that touches someone else.

[00:26:28] It's amazing what you can see with that domino effect.

[00:26:31] **Courtney:** yeah, it's, I feel like the first time we met Jeff, we talked a lot about or I was talking about the power of storytelling and you were just like aggressively nodding. And I feel like we're both on the same, same page with that.

[00:26:43] Cause I, I, it's amazing how everyone in organ donation and transplant everyone knows each other and everyone has met through people being really open about their, their stories. And this morning I was just. Doing a little news scan and green shirt day is coming up on April 7th. So they, the Boulets just kind of released everything that's coming up in preparation for this year's green shirt day.

[00:27:04] And there is just so many reminders of how many people, Logan Boulet has inspired, including living kidney donors, people that, you know, have donated parts of their body while alive, in honor of Logan, which is so cool.

[00:27:18] **Jeff:** Yeah. No, it's I mean there's no other story like that, right? The, the Humboldt Broncos. Yeah. It's it's, I can't even say it's inspiring because that cheapens the

impact he has had , on the world. You know what I mean? You can't even say nationally, like he is an international hero in, in the organ and transplantation community

[00:27:39] I mean, it's, it's been a huge, huge driver of raising awareness across the board. So they've the positive impacts from their campaign as a family. Is just outstanding.

[00:27:52] **Courtney:** Oh, a hundred percent. I think beyond raising awareness, it actually has created real action, which is, which is hard I think with the Boulets, they really.

[00:28:01] We're able to turn awareness into action, which was amazing. And just going back to what you were saying about inspiring cheapening the movement, I think it's so funny that in transplants, there are so many words that I would have never used that , there are no other words for it. Like the words magical and miraculous and inspiring, and all these things come up in this podcast all the time,

[00:28:23] there are no other words for it.

[00:28:24] **Jeff:** No, no. And I mean the gift of life, and

[00:28:28] **Brittany:** I love that you said, I love that. You said earlier that your mom, when she received her second gift of life, as opposed to referring to it as a transplant, I was like, it's

[00:28:37] **Jeff:** all we know it as you know, I mean, we're, my mom calls it a miracle.

[00:28:42] I'm a firm believer of, of both miracles and science. So we're not ever going to discredit the good work of the, of the surgeons at TGH that, that took care of my mum. But yeah. There is without a doubt, something higher that has, that has watched over her. And that's, that's a Testament that was as true with her first transplant and the timing around it to her second transplant.

[00:29:04] She was so sick. The second time around, she was literally, she was days away from no longer being here and for a second liver to come through in that perfect moment. You know, and because she was so sick, her kidneys started to decline. And I remember there was talks of, of doing a double transplant and the transplant surgeon was dead set against, it was like, there's no way she'll survive a double transplant as, as unwell as she is right now.

[00:29:31] If we transplant the liver, the kidney will stabilize and it did exactly what he said it would do. It stabilized her kidneys. She's had 13 years where they've only gone down a handful of points, you know, she's at 20% function now, but her in order for her to have been given those gifts at the time that she needed the most, I mean, that's, that's beyond surgical schedules I come from a much different world where, where you don't talk much about miracles and gifts of life. And, and that's why I love the work that I do because it, shows the good in the world. I, and I mean, I need this more now during a pandemic and a lockdown for my own mental health than I've ever needed it before working with this community and hearing their positivities and, and their, their positive outlooks on things.

[00:30:22] And still hearing people getting transplants and having kids and living their lives is what's keeping me going. If it's, if you just watch the news and listen to CP24 it's doom and gloom.

[00:30:35] **Brittany:** Yeah, I was, I told Courtney earlier in the year, especially in January when things were just dark I told her I'm like, honestly, the only thing that really keeps me excited is this podcast because we get to hear these amazing stories from people all over

[00:30:51] and then you turn on the news and it's one right after the other of just negativity and how the world's going to end. In five minutes if we don't do this. So hearing

[00:31:03] **Jeff:** people's so many golden buzzer, America's got talent, right? That's like an, I need other things.

[00:31:13] **Brittany:** It's like an instant serotonin boost.

[00:31:15] **Jeff:** I will, my wife will come home from fundraising,

[00:31:17] And if I've gone down a rabbit hole, I'll be sitting on the couch balling and she'll be like, what's wrong? And I'm like, she just got the golden buzzer. Ha, yeah, it's a big boost.

[00:31:30] **Brittany:** The golden buzzer is almost like getting a transplant.

[00:31:34] **Jeff:** think it's the reality TV show equivalent, I guess.

[00:31:37] Yeah.

[00:31:38] **Courtney:** I'd say, I'd say when the, when the pandemic first started at the center, we were really worried about, you know, our transplant recipients or transplant candidates, feeling isolated. But really, it's kind of funny. There that's been a community that I've really I mean, I've like kind of just been a part of through work, but that I've just really like leaned into, because people with chronic disease, , transplant, recipients, transplant, candidates are all so resilient

[00:32:03] If you think about, you know, it's all doom and gloom, when you read the news, what is it like getting diagnosed with PKD like that you have that initial kind of it's all doom and gloom, and then you, you gathered the tools and the resources and the coping mechanisms, the healthy coping mechanisms to move forward with your life and still enjoy yourself.

[00:32:21] I find the, the transplant community and by extension the PKD community, a real source of, of, of joy during the pandemic, because they know how to live life and enjoy themselves, despite some of the more negative things that are going on.

[00:32:36] **Jeff:** For sure. And I mean, you know, not presenting this as a joke in any way, they're also used to waiting, you know, so for, for the average person in lockdown right now, what's one of the hardest things you've had to adapt to is not getting things your way on time when you wanted it right away being priority.

[00:32:57] Number one, and, you know, heaven forbid you're on the wait list for a long period of time. You're used to watching good days go by the window. and waiting your turn. And I think that, that, , that natural mentality of your time will come when it's the right time, I think is a blessing for some of them to, to endure this pandemic. But like you said, the positive resilience of them is, is huge. And what we've really seen this spike in since the lockdown is the desire for connection virtually.

[00:33:34] So we're seeing that now people are at home. They're not necessarily getting their fix. They're not seeing their doctors as often short of it being a major appointment, they miss that PKD connection and, and by giving them opportunities to get involved virtually, it's built a stronger community. , which is an absolute gift from a pandemic that you can actually come out with a stronger educational resource, then, then you went into it.

[00:34:01] You know, it's, it's a pivot that, that panned out well.

[00:34:05] **Courtney:** Are the focus of the webinars PKD myths or is it mental health focused or does it run the gamut?

[00:34:10] **Jeff:** It runs the gamut. So, you know, a couple that we did because of the time sensitivity was, so it was obviously like polycystic kidney disease and COVID. And, and what risks are immunocompromised kidney patients at with this disease? Then we did one on the importance of mental health with a chronic disease diagnosis.

[00:34:30] So that one focused on the positive aspects in one's life, we've done PKD research. Our most recent ones were in English and French on the vaccines. So a lot this year was sensitive to pandemic and PKD. But that's because they had to be, we had to get ahead of the misinformation.

[00:34:51] Myth-busting chaos that is social media and get in front with a message from, you know, Dr. York pay at TGH and Dr. Boucher in Montreal too, to let people know that this is a safe opportunity and that you absolutely should go and get the vaccine. That was, that was the first time the PKD community on mass had heard that.

[00:35:13] So that was that's incredible information, but other topics, we, we can make some that are disease specific and focus on PKD, but then we try and also make them so that they're like CKD related. So anyone with chronic kidney disease can relate. The mental health aspect, doesn't differ for a PKD or a diabetic.

[00:35:32] living with kidney disease, you have the same concerns.

[00:35:35] **Brittany:** What are some of the myths about common myths about PKD?

[00:35:39] **Jeff:** That it's a death sentence is a big one, you know, many years ago, people would say, that autosomal recessive PKD. So ARPKD that the, the likelihood of a child surviving that, and the first few years was grim. That's thankfully been proven otherwise. Now kids are reaching 10, 11, 12 years old before they're having their first transplant.

[00:36:00] That's part and parcel now because technology and there's been so many advancements with prenatal care that some patients are being diagnosed prenatally.

[00:36:08] That you can't live a normal life is another misconception, you know You can, I can name off a handful of people that are avid dialysis cruisers, you know, so they take their dialysis and go on cruises. They've been to places I'll never go. So they're, they're strapped to a machine and they're traveling the world. So it's hard for, for anyone to tell me otherwise that you can't live a normal life. And I'm seeing you know, people post-transplant jumping out of planes. We have a woman in Barrie, Ontario that just celebrate a milestone, jumped out with a sister of hers.

[00:36:43] Post-transplant, she's run the half marathon, you know, and those are two things I'll never do as a, as a, as a healthy male, you know, it's, it's wild, but what you can do I

[00:36:54] **Brittany:** think that definitely getting a transplant makes you realize that you need to live life to its complete full list.

[00:37:01] Absolutely. We talked to Dr. Cole in a recent interview about how not having a transplant is not the worst because being on dialysis, there's so many advancements in the last, however many years with just having hemodialysis and peritoneal dialysis So getting a transplant is not always the best answer for everyone or the best treatment option, but being on dialysis is not always, again, like you said, a death sentence

[00:37:29] **Jeff:** the both transplant and dialysis, it was looked upon as a blessing that they're even options that are out there.

[00:37:35] You know, when, when that time comes a lot of patients will obviously aim for that preemptive transplant to avoid dialysis. But those that, that do begin to dialyze realize very quickly that that it's manageable and it's a lot to take on much like a diagnosis when you're told that you're about to dialyze.

[00:37:55] And if you do it at home, you're in charge of the machines and the reservations are there, but very quickly people, and this goes back to the, the resilience of patients. Just pick it up. That's now in their life, they go about their life.

[00:38:10] They make the adjustments as needed and they treasure

[00:38:12] **Brittany:** the ability to adapt in healthcare. Whereas a patient is pretty

[00:38:16] **Courtney:** insane. Yeah, absolutely. So someone wants to get involved in the PKD foundation of Canada or volunteer or go to your, some of, some of your events. Where would you direct? So

[00:38:28] **Jeff:** our website is [endpkd.ca](http://endpkd.ca)

[00:38:32] From there the best place that they can start to get connected with us is by joining our email list. You can do that right from the home page. At the top of the search bar there's chapters, people can find their, a local chapter if there is one in their area, or if there isn't. And they're interested in getting involved, our email and contact information is on the website throughout the year.

[00:38:53] We have, we have our various campaigns, so I mean this year, we're again doing the virtual walk to end PKD. That happens over the month of September. September is a big PKD month, even though March is national kidney month and world kidney day is coming up. September we have. September 4th, which is actually national PKD awareness day recognized by health Canada.

[00:39:15] And because it's also the start of our walk campaign, which is our signature fundraising event, we wanted to shine a spotlight, unique to polycystic kidney disease. So September is a big month for people to get involved because we rely on them to work with their local constituents to get advocacy or pardon me proclamations for PKD awareness day flag raising.

[00:39:37] We're always looking for more teams and families to join us for the walk to end PKD. Like this is an event for those that, that have attended the, the physical events. It's a party. These are opportunities for people to get together from the PKD community that have grown to become close friends. Over the years at our events, we get about 650 people at our Toronto walk.

[00:40:01] And It's a celebration more than anything we're walking to celebrate that we're all together in this fight to end PKD that, you know, to, to everyone who was, who was there with us to those that are no longer with us, we walked for them.

[00:40:14] So if, if they go to NPK d.ca, there's a ton of opportunities to get involved. And my contact info's there very easy to get in touch with. Awesome.

[00:40:24] **Courtney:** So you had

[00:40:26] **Brittany:** kind of mentioned this a little bit, but about having used the golden buzzer when you're having your tough days, but other than that, what do you do to keep going through tough days and maybe what are some things that you want everyone to know about PKD?

[00:40:45] **Jeff:** So I'll, I'll tackle the first part first. So for me, what keeps me going. I do a lot of meditating. A lot of yoga mindfulness reading has become a massive distraction, a positive distraction for me over, over to the pandemic. I think I'm turning off the television and just. Embracing the silence at nighttime with a book, has been very they're great for me it brings peace of mind when I need it most.

[00:41:14] So I think, you know, getting out is obviously a huge part. We've got a dog now, a six month old pug that we have. So that's getting out and going for walks three, four times a day is, is huge. I think that's important, you know, and I'm one of those guys that when there's a lockdown, I don't even want to go out for a walk.

[00:41:31] You know what I mean? Like I want to be the good, the goodest of lockdown boys and just stay in and not lock down Boise that fresh air, right. We need to get out. We need to change the scenery. The house and our apartments can feel like the walls are closing in. So I think everybody just needs, like, you need to know that there's a.

[00:41:51] There's an end. There will be an end to this when I'm not sure, but I have faith that, that those that are working towards it will get us there.

[00:41:59] What I would want people to know about the PKD community.

[00:42:03] Or if, if one is newly diagnosed, what, what they can do to become part of the PKD community is, is to just reach out find out that you're not alone. You know, a lot of people, their first contact will be an email to me. And it's just, I was diagnosed with this. I don't even want to go online. I don't want to look at anything.

[00:42:20] I just want to talk to somebody and I, and I'll talk to them two days after diagnosis or two days after their child's been diagnosed. It's important that anyone with a chronic disease or, or someone that struggles with something to which there is a community out there for that you get involved. I don't care if that's mental health, if that's you know kidney related, if it's.

[00:42:43] Anything, if there's a support group out there that's catered to making your life easier, connect with them because all they want to do. And this goes for our organization. All we want to do is help you on your PKD journey. We want you to know that you're not alone, that you don't have to go through this alone.

[00:43:00] So that's, that's kind of the takeaway message I would leave.

[00:43:03] **Courtney:** I love that. I also love the idea of lockdown boys as a great pandemic band name.

[00:43:09] **Jeff:** That's going to be my lockdown band.

[00:43:14] **Courtney:** All right. All right. You, you keep it. Jeff - Brittany and I started doing something silly, but fun where we like to guess our guests, - guess our guests? Yeah. Okay. Guests our guests' Zodiac signs at that end of the episode. Brit, what are your thoughts?

[00:43:30] **Jeff:** Okay, so give you both the shot. Yeah.

[00:43:33] **Brittany:** Yeah.

[00:43:34] So I have two guesses. It's either - my guess is one and Aries or the second guest is an Aquarius.

[00:43:45] **Courtney:** Interesting. I was going to say Leo or Sagittarius. I think I'm going to go with Sagittarius.

[00:43:55] **Jeff:** Ready? Yeah. Scorpio.

[00:43:59] **Courtney:** Oh, that was going to be another, damn.

[00:44:01] **Jeff:** I thought I was, I thought it was like by the book Scorpio, I thought this was going to be a breeze for you guys to just do one of these.

[00:44:09] **Brittany:** I can tell score. I can tell Scorpio's vibe like almost instantly, you do not give the vibe of Scorpio.

[00:44:13] **Courtney:** A very unusual Scorpio.

[00:44:17] **Brittany:** And I actually just quickly looked up Aquarius because I was like cause Aquarius are reading.

[00:44:23] **Courtney:** Yeah.

[00:44:23] **Brittany:** I had to look, Aquarius is, are very progressive, original, independent, and humanitarians. So it would have been very fitting.

[00:44:33] **Jeff:** I'll be sub sub Aquarius, Aquarius.

[00:44:39] **Courtney:** Maybe you have like Aquarius is your rising sign or something. But I do think it's funny, we have another water sign on here just saying but anyway, thank you so much for joining us. Jeff. This has been great.

[00:44:49] **Jeff:** My absolute pleasure. Thanks for your time guys.

[00:44:53] **Courtney:** Yeah.

[00:44:53] **Brittany:** Thank you. Thank you for sharing this awareness about PKD, because it's definitely like, I know what PKD is, but they didn't know that there was this type of community out there for it.

[00:45:04] **Jeff:** We can always do part two.

[00:45:05] **Courtney:** Thanks for listening to this episode of Living Transplant. If you have questions or suggestions for future episodes, email us at [livingorgandonation@uhn.ca](mailto:livingorgandonation@uhn.ca)

[00:45:16] **Brit:** Don't forget to subscribe, rate, and review living transplant on iTunes, Spotify, or wherever you listen to podcasts

[00:45:22] **Courtney:** and follow us @givelifeUHN on Facebook, Twitter, and Instagram.

[00:45:26] **Brit:** See you next time.