VOICES OF PKD

Polycystic kidney disease (PKD) is one of the most common, life-threatening genetic diseases affecting thousands in America and millions worldwide. There is no treatment or cure for PKD. Read on to learn more about those affected by PKD and their experiences.


I heard the words polycystic kidney disease for the first time in 2011 at 2:30 a.m. in the emergency room after a cyst rupture. After the initial shock of finding out, it caused a lot of concern in my family as people stressed about whether or not to get tested. There was a feeling of “do we all have this disease?” But, I am part of the PKD population that developed the disease as a spontaneous (new) mutation, so I am the first in my family to have this.

My two children now have uncertainty about PKD, as they each have a 50 percent chance of having it.

Understanding PKD is an important part of living with it. The PKD Foundation is a key element in educating myself, family and friends about the basics of PKD.

Heather Gillis – Phoenix

When a child passes away, there are no words that can take away the pain of a parent’s loss. It is unimaginable to think of a child dying, but in many people’s lives this is their reality, especially in those affected with autosomal recessive polycystic kidney disease (ARPKD), which affects 1 in 20,000 children.

This became a reality in the lives of our family three years ago, when our son Bowen lost the fight to this disease after 13 days. We had no idea that Bowen was going to be born with ARPKD. After he passed away, we were devastated, heartbroken and left with a lot of questions unanswered. Even though we were only able to hold Bowen in our arms for a short while, he will hold a place in our hearts forever. Bowen may not physically be here with us, but the love we have for him still exists.

Mariann Waltz – Pittsburgh

PKD runs rampant on my dad’s side of the family, with PKD claiming him and three of his siblings. My brother, sister and I all have PKD. And now, my 14-year-old daughter has PKD. I grew up knowing my fate and never let it hinder me or any decisions I ever made.

Though I thought I was prepared for dialysis, it was still a shock. Being on dialysis has hindered my lifestyle significantly. I had to quit my office job, but thankfully, I work from home. I treat dialysis like a job. When I come home from dialysis I’m beat. I don’t schedule anything those evenings and I don’t even cook for my family those nights. I try to compensate the other days of the week, but there never seems to be enough time because so much is spent on dialysis or recovering from dialysis. My family suffers and they have to fend for themselves often. But, I am thankful that we have dialysis to keep us alive.

Update: Mariann received a transplant in October 2014 and is recovering well.

Lena Keys – Philadelphia

I am 16 and in 11th grade. I had high blood pressure when I was nine, and that is how I found out I had PKD. I still haven’t told most of my friends at school because I am worried they will treat me differently.

It is hard to be a teenager with PKD. The biggest challenge for me is not being able to eat junk food. Most teenagers can eat macaroni and cheese, ramen noodles and chips, but I eat mostly fruits and vegetables to keep my kidneys healthy. And I drink water by the gallons hoping to prevent the growth of cysts.

I attended the 2014 PKD National Convention and loved being a part of the teens track. This was the first time I met other teens with PKD and I loved making new friends and hearing about their experiences. My best advice to them is that it isn’t as scary as it seems.

My mom has PKD, and it is hard to watch her go through it. But, it has brought my family closer as we work to fight PKD together. She and I have both participated in clinical studies to support research in finding treatments. This has helped us feel like we’re making a difference.
Katie Burge  
– Cedar Rapids, Iowa

My husband, John, has PKD and so does my oldest child. My husband’s journey is ongoing, as he is nearing the fifth anniversary of his transplant. Through this journey, I have become a caregiver, an advocate for the person I wake up to, and a good listener.

I became a caregiver early in our relationship, taking John to the hospital for his first kidney stone episode soon after we were married, feeling helpless while my husband was in extreme pain with a ruptured cyst and taking him to all of his appointments. A week after John’s transplant, I had to drive in an ice storm to pick up his immunosuppressive medicine. I cook healthier meals every day, and I know how important it is for John to have exercise in his daily life.

I worry about my son and how PKD will impact him. I am challenged with helping him learn more about PKD and what he can do to manage it. I am also reminded that I have to take care of myself, because if I don’t, I can’t be there for my family when they need me. I would tell other caregivers to learn as much as you can about the disease, focus on your health and get involved with the PKD Foundation.

Melissa McCutcheon  
– Peterborough, N.H.

PKD has affected my life as long as I can remember. My aunt died when she was seven of a brain aneurysm related to PKD, which greatly impacted our family. Growing up, my grandpa lived next door and was on home dialysis for 15 years due to PKD, so a lot of my childhood was spent watching my grandpa hooked up in the corner. My mom has PKD and had a transplant thanks to my father donating his kidney, but I watched her nearly lose her life before it.

I found out I too had PKD right before my wedding. I was counseled not to have children, but I went ahead, and I now have a 14-year-old daughter and 17-year-old son. They are amazing and why I keep going. But of course, I worry they will have PKD.

In order to be a part of research and help my kids, I have participated in two clinical studies and made trips to Capitol Hill. Anything I can do to help my kids and future generations not be affected by PKD as previous generations, I will do!

Josie DaCosta  
– New York City

My story begins in 2008, the year I was going to marry the man of my dreams. We were happy and looking forward to what was ahead for us, such as a new home and starting a family. Six months later that all changed when I was diagnosed with PKD. I was devastated. It was not only unfair this was happening to me, but unfair to my new husband, who did not sign up for this so soon. It was for better or worse right out of the gates.

My kidney function decreased, and in order to avoid dialysis, I needed to find a living kidney donor. My husband created a “Josie needs a Transplant” Facebook page and the response was unbelievable. But, the best option for a living donor transplant would be someone in my family. The blessing was that no one else in my family has PKD, so I had potential kidney donors. It turned out my sister, Frances, was a perfect match and gave me a kidney in 2009.

I will forever have a bond with Frances, and be grateful for her selflessness in donating a part of her to me so that I can look forward to living life. I was very fortunate to receive a kidney, but there are many PKD patients who are still waiting for a transplant. This is why I continually fight for treatments and a cure.

Visit Voices of PKD for stories about people affected by PKD: pkdcure.org/voicesofpkd.