

Me & PKD



Amy Winder and daughters

“I feel blessed to be here for my children and not be on dialysis.”

“When I was a child I would sometimes visit my grandparents at their second home in Jefferson City. It was a small place they’d purchased for convenience, as their farm was more than an hour away in Crocker. They had to be in Jefferson City several times each week so my grandma could get her blood cleaned through dialysis. She had Polycystic Kidney Disease (PKD), as had one of her parents and an aunt who’d passed away from what was believed to be a brain aneurism related to the disease. These visits were just part of life, just something grandma had to do. My mother was very casual about it when it was occasionally brought up that she also had PKD. She is one of six children. She and her brother were the two who got the not-so-lucky genetic mutation. My uncle’s transplant marked the first time that I knew a person who had to have a major surgery. The thought of another person’s organ in his body seemed really strange. It wasn’t something people talked about much. It was something you saw in movies or on the news. Other than needing to take medication for blood pressure, my mom continued to remain healthy.

As for me, there were some signs that could’ve been considered red flags, now that I know how prevalent PKD is genetically. I remember getting a physical to play basketball and the doctor hearing a heart murmur. Turned out later to be a mitral valve prolapse, a common occurrence among PKD patients. In my early 20s, I had a few UTIs, also common. But it wasn’t until I was 28, getting ready to have my first baby that the biggest red flag of all happened. I was diagnosed with preeclampsia, a condition in which the blood pressure shoots up and stays. After a couple days of bedrest my OBGYN decided to induce my labor. It took 42 hours, but my beautiful daughter was born healthy and happy. The issue was that my blood pressure didn’t go back down, which is usually not the case with preeclampsia. Knowing about my mother’s PKD, the first order of business was an ultrasound of the kidneys.



Sure enough, cysts galore. From there I was referred to a nephrologist. I went to the same doctor that my grandmother and mother had gone to. He'd become our family's nephrologist for generations. When I first saw him, he told me there was nothing to worry about; that I likely wouldn't have any major issues until I was around the age when my relatives started having troubles. That would likely be in my 50s.

Over the next five years I went on to have two more beautiful, healthy daughters. I got preeclampsia again with my second, but did okay with my third. Though my pregnancies were considered high risk and I saw a specialist throughout, complications were minimal and I went on living normally. I tried to drink a lot of water and minimized the amount of caffeine I allowed myself to have. I was scheduled to see my nephrologist once a year, just to check in. Then in the summer of 2011, at 35, I started having an issue with one of my feet and a big toe. I went to my family doctor because I was having a hard time walking on my foot and my toe was killing me. My doctor diagnosed me with gout, told me to get some cherry juice, took some blood and sent me on my way. The next day he called me back in. He let me know that my creatinine level was high, which signals a decrease in kidney function. He wanted me to see my nephrologist right away.

At the appointment, the first thing my nephrologist said was, 'Do you have any potential kidney donors set up?' I was floored. He'd led me to believe I was good to go for at least a couple more decades. 'Uh, no!' was my response. He let me know that my kidneys were working at about 20% and that, that number would continue to decline.

Over the next few months, I worked with the staff at Barnes Jewish Hospital in St. Louis to get listed on the UNOS transplant list. My very supportive family and

friends worked hard to help me look for potential donors. I had several loved ones go through the matching process, but because I am type O and the antibodies in my blood were fairly high, I wasn't the easiest match. I'd been told that the average time for someone with my characteristics to be on the waiting list was 3-5 years. I started getting more and more sick. As my kidney function fell, I felt tired all the time, because of severe anemia that kicked in and started having intense cramps in my legs and feet. I'm fortunate that I was born with a positive disposition, but it was still a pretty big bummer to have to deal with. I wanted to play with my kids, not lay around.

While I waited on UNOS, I was also preparing for dialysis. I got connected with a vascular surgeon to place an AV fistula in my arm that could handle dialysis. Unfortunately, my veins were less than cooperative. Two fistulas died not long after they were placed. A third fistula clotted and had to be reopened. Just a few days after my fourth fistula surgery, 18-months after going on the list, I was sitting at my desk at work and got a call from Barnes. There was a deceased donor whose kidney was a perfect match. I was told to get to the hospital right away.

The next morning, I was given the gift of life by someone whom I had never met. The match was so close that I'm on far less anti-rejection medication than I would be otherwise. It's been four years and all is going great. I named my donor kidney Peewee and it is a champ! I will be forever grateful to the family of the person who died but wanted to help someone else live through the gift of organ donation.

I feel blessed to be here for my children and to not be limited by dialysis, which didn't appear to be a great option for me. I encourage everyone to opt-in to donation through their driver's license and to make sure their friends and family know they want to be a donor."

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