

# Choosing a Partner with Kidney Disease

By **Deron Johnson**

Let's not sugarcoat it. Kidney disease is not fun.

There are approximately 739,000 Americans currently dealing with end stage renal disease, according to the U.S. Renal Data System. Factor in countless family members and other loved ones who are affected by the disease, and you soon realize you are not alone in the fight.

For every victim of this horrible disease, there are almost always at least one or two primary caregivers. I am not talking about the wonderful doctors, nurses, and other health professionals. Their expertise and caring ways are unmatched. I am referring to the lay person caregiver; usually a spouse, a parent, or other family member. I know a little bit about this because I am one of them. If you are reading this as a caregiver of a loved one with kidney disease and hoping to

get all the answers to every question you might have, you are going to be disappointed.

But, I will tell you this. As daunting as this is, it can be very rewarding. My wife, Kim, was born with focal segmental glomerulosclerosis – FSGS. That is a mouthful, I know. So, we are going to keep the technical terms to a minimum. Just know this – through no fault of her own, she was dealt bad cards and born with kidney disease. Sometimes kidney disease is known as the “hidden disease” and, for Kim, kidney failure was not diagnosed until age nine.

She struggled gaining weight and was sick often during her childhood, but she still managed to live a normal life, that is, until her kidneys began to completely shut down. By age 16, it was time for dialysis. Her brother, Kurt, stepped up and, while not a perfect match, was a good enough match to donate one of his kidneys. After a few years, however, Kim's body began

rejecting the kidney. After getting back on the transplant list, Kim's second transplant happened in 1998. That kidney lasted a remarkable 13 years.

That is where I come in. I met Kim in 2010. We were introduced at a social event by a mutual friend. We hit it off immediately. The night I met her, Kim told me about her disease. She never hesitated. She told me almost matter-of-factly, as if she felt I needed to know and just got it out in the open right away. I knew what kidney disease was, of course, but did I ever have a lot to learn.

Within a couple of days of us meeting, casual lunch plans were discussed. It was difficult to arrange, however, because Kim was doing in-clinic hemodialysis at the local DaVita Center. She said I could come visit her there, if I wanted to. I thought about it and decided to bring lunch to her. This was my first eye-opening experience. I had no clue. I knew she was getting dialysis but I had no idea what that enormous machine was doing.

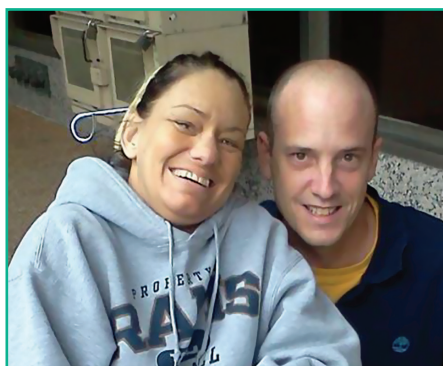
It was then I decided I was going to have to buckle down and learn as much as I could, if this new relationship was going to go anywhere. Kim needed a third transplant. But there was a checklist of items we had to do to get her there. Within a few months, we had made it on the transplant list at Barnes Hospital in St. Louis. By April of 2012, Kim was very sick and doing home peritoneal dialysis. That is when we got the call. A kidney was available! Immediately you go from elation, to sadness for the person who had passed away but made a critical life choice to be a donor, and on to nervousness.

The surgery was successful. By 2015, Kim was working full-time and leading a relatively normal life. We had married in 2013 and were raising kids. Sure, there were the follow-up doctor visits, the numerous blood draws and hospitalizations. But, we were leading a relatively normal life. Hospitalizations are frequent. Remember, the immune system is shot, especially in Kim's situation, having had three transplants.

Things had been fine. Her labs were normal – or at least normal for someone in Kim's situation. That all changed in the summer of 2016. Kim had been feeling abnormally ill, extra fatigued, and nauseous. We were making the two-hour drive from our hometown in Quincy, IL to St. Louis to see the doctors there. On the trip, Kim was very quiet. I asked

her what was wrong, and she said she knew her kidney was failing. Ever the optimist, I tried to pep talk her. "You'll be fine," I said. "Everything will check out." Kim, the realist who has been fighting this her whole life, disagreed. Once in St. Louis, doctors did a biopsy. Waiting for the results was excruciating. Sadly, Kim was right. The doctors came in. You could see by the look on their faces that the news was not good. The lead doctor came right out with it. There is no easy way to say it. "The kidney is in bad shape," he said. "It's failing." They left the room and Kim and I sat quietly for a minute. I hugged her. I sat back down, and I did something I rarely do. I started bawling. The emotions flowed out of me.

As a caregiver, I sometimes feel like I do not make a good husband. Conversely, as a husband, I sometimes feel like I do not make a good caregiver. It is a constant struggle. But I am learning every single day. Kim is back on dialysis. She does not like it, but the alternative is ... well, there is no alternative. So, we wait. We are back on the transplant list in St. Louis. We have



now made two trips to Chicago to try and get listed there. We figure the more options, the better the odds. If nothing else, we are getting great advice and talking to some of the smartest people in the world about Kim's condition.

I do what I can to help Kim. I prepare her machine for dialysis every day. That is about a 20-minute process. I inventory her supplies and stay on top of what is needed. Every out of town doctor appointment she has, I drive her. These are relatively small things, but they are important to Kim. One thing I have learned: work as much fun into this as possible. Kidney disease is not fun. But there is still a life to lead. When we went to Chicago recently, we went to a Cubs game the night before the appointment (even though I am a diehard Cardinals fan). Chicago is a 5-hour drive, so that is a long haul just to go and do doctor appointments. So, it is important to work in fun things to do when possible.

Getting a fourth transplant is going to be hard. The antibodies in Kim's system are very high. But we have two choices. Fight. Or not. We are choosing to fight.

Kim received her fourth transplant on November 17, 2017 at Barnes-Jewish Hospital in St. Louis. Subsequent doctor visits have all been positive. Her kidney is performing great! Her creatinine has been in the low 1's which is remarkable ●