

Patient Testimonial: Why I Chose Transplant



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It has been over 40 years since I was diagnosed with End Stage Renal Disease (ESRD). The probable cause was strep. Unexpectedly starting hemodialysis at age fifteen was not only scary, but it made a huge impact on my life as a young teen in high school. As I look over the early years, my parents had no one to talk to about what was happening or why. I spent three days in a coma after my trial on dialysis. My parents were going to let me go. I was blessed with a doctor that said, "Let's give her another chance. Let's put her back on dialysis." Dialysis did save my life. Those were rough years. I was a compliant patient, following doctor's orders for diet and medication.

In October of that year, I had a living donor transplant. My father donated his kidney to me. Things started out good. I was home for three days but then returned to the hospital. Six weeks later, the transplanted kidney had to be removed. I was devastated. The kidney had developed blood clots. Not a normal occurrence. Not a rejection. The anti-rejection drugs used in those days were hard on my body. My emotions were all over the place, and my physical appearance had changed dramatically. At that point in my life, I told them I don't ever want another transplant. I returned to dialysis and for the next three years. I went to school, got off the bus, got in the car and my father would drive me into dialysis three evenings a week. I was determined to not let my high school years be interrupted. I did get a few calls from transplant over those three years, telling me they had a kidney. I shared with them why I did not want another kidney at that time. I think my parents had something to do with keeping me on the list.

Then it happened. March 23, 1981. Three months prior to my high school graduation. My family and I just came home from visiting my Grandmother. The phone was ringing. I answered it. It was the transplant center telling me they had a kidney for me. My response - "I am graduating in three months. There are a lot of things going on I don't want to miss." We hung up. I suddenly had this overwhelming feeling that I should have said yes. Then the phone rang again. The person on the other end said, "Can we talk to your parents?" They continued to tell me a little bit about the deceased donor and that it was a 'perfect' match. It was then I said to my family that I better go in.

What a huge difference it made on my life. The kidney lasted 18 years. No dialysis for 18 years. I would

say I felt so normal. I was very careful. Followed all instructions and went for my labs. I graduated from high school three months later, went on to college, got married and even had a child. He is now 29 years old and has recently gotten married.

I never knew what normal was until that second transplant. I felt so good. I wasn't dealing with medical issues like I had while on dialysis. I felt so free and happy. I guess the better word to describe it was "exhilarating." I started the new experimental drug Cyclosporine. Cyclosporine and prednisone were my anti-rejections medications.

Eventually, I did return to dialysis. Eighteen years is considered good with a deceased donor transplant. I don't regret going for that transplant. Upon returning to dialysis, I decided to opt for in-center nocturnal hemodialysis for the next twelve years. I felt comfortable in the beginning with this treatment option, so decided against transplant. I've already had two. Would I be selfish?

Over the past decade I have learned so much about kidney disease, treatment options, what high phosphorus levels can do, as well as a wealth of other information that I never knew of. I had finally decided it was in my best interest to try for another transplant. On June 22, 2011, I was called for my transplant. Fortunately, it was another success. Keep in mind that everyone is different. We can experience different outcomes. Dialysis started to take a toll on me. For me, transplant became an educated choice.

Transplant today is not something to fear. Yes, it's just another option, not a cure. It may or may not last a lifetime. The benefits for long term health are good.

You do have the option. You can call your local transplant center and talk to them. They can discuss transplantation with you. Let them help you to determine whether transplant is for you. Be informed.



To file a grievance, please contact Quality Insights Renal Network 4 at Patient Toll Free Line: 1-800-548-9205, www.qirn4.org or 630 Freedom Business Center, Suite 116, King of Prussia, PA 19406.

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