

...continued from front

having surgery also terrified them because they had never experienced a procedure like that. I felt rejected, but realized that I needed to overcome the fear and move on. My social worker kept asking me about different people and suggested the idea of doing a video. I decided to approach my pastor and he was open to the idea. I also approached some friends, but found out that a lot of them had medical issues. This made me realize that if I did receive a kidney, I would try to do everything I had to do to take care of it.

I was feeling down about not finding anyone to get tested. The four people that did get tested were not accepted. At this point, I went to God in prayer. I considered the video as a last resort. I ended up feeling so thankful for the participants and the questions they asked. I knew that I would not survive years on dialysis. Thankfully, a donor saw the video and came through anonymously. I got to meet her after the surgery and I pray that she will always have good health.

Asking someone to donate an organ is not easy because you always think of rejection. But, you must keep asking. It's been five months since my transplant surgery. So far, my numbers are good, and I feel well. I encourage everyone reading this to consider organ donation.

Learn More

For more information about treatment options, please contact Quality Insights Renal Network 4.



Quality
Insights
Renal Network 4

1586 Sumneytown Pike #1470

Kulpsville, PA 19443

(610) 265-2418

(610) 783-0374 (Fax)

(800) 548-9205 (Patient Toll-Free Line)

www.qirn4.org

To file a grievance, please contact Quality Insights Renal Network 4 at: Patient Toll Free Line: 1-800-548-9205, www.qirn4.org, 1586 Sumneytown Pike #1470, Kulpsville, PA 19443.

This material was prepared by Quality Insights Renal Network 4, an End Stage Renal Disease (ESRD) Network under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services (HHS). Views expressed in this material do not necessarily reflect the official views or policy of CMS or HHS, and any reference to a specific product or entity herein does not constitute endorsement of that product or entity by CMS or HHS. Publication No. ESRD4-122221



PATIENTS HELPING PATIENTS

*My Journey with
Kidney Disease:
Lula's Story*



Quality
Insights
Renal Network 4

My Kidney Disease and Transplant Journey

By Lula Brown

In 1998, I started having high blood pressure readings. Doctors tried all types of medications, but could not get it under control. Tests showed that scar tissue from a surgery I had the previous year had wrapped around the opening of my left kidney. Doctors believed this was causing the high blood pressure. I ended up having my kidney removed, which relieved the blood pressure for a short period of time. However, it never became controllable. My other kidney served me well for the next 20 years, but then slowly started to fail.

In 2019, I had gotten to a point that I could barely walk one block and I had issues with walking up stairs. My test at the kidney doctor showed that my creatinine number was increasing and that protein was leaking in my body. In October, I met with the Kidney Smart team. The next step was to determine the most suitable type of dialysis for me during my next appointment with my doctor in November. But, that never happened because on November 2, 2019, my life changed.

It was a beautiful day outside. Although I was not feeling quite myself, I made my way to a meeting at my church. My pastor was

presenting to the church and I remember sitting in the back because I felt like resting. My body began to hurt and my chest felt bad. At lunchtime, I went downstairs and started feeling worse. I told everyone that I had to go home because I was feeling ill. I walked to my car in the parking lot. By the time I reached the car, I could barely breathe. I was going to drive to the hospital, but instead, I hit the telephone button and called my son. Thank you, Lord, for the iPhone! I looked back at the church and it appeared to be swaying. I was driven to the emergency room barely breathing. I was told to dial 911 next time because it was so serious. They put me on a BiPAP machine. I was admitted to the ICU. During the week, tests revealed that fluid had filled up in my lungs and the cause was kidney failure. I had to go on dialysis. A graft was put in my arm so that dialysis could be performed immediately in the hospital. In my mind, this was a death sentence.

It took time to adjust to the lifestyle changes brought on by my disease. I had dialysis on Mondays, Wednesdays and Fridays for four hours each day. When I finished, my body was so tired that I didn't feel like doing anything. I also continued to work at least three days a week. I had to watch some of the foods that I ate. For example, I couldn't have potatoes, tomatoes or cheese, which are foods that I loved to eat. My fluid intake was also limited to 32oz. per day, including the fluid in my food. I tried to cut things out slowly and I

checked for kidney-friendly recipes from the American Kidney Society and DaVita Dialysis. I lost weight, and I could breathe so much better and climb stairs.

I got a lot of support at the dialysis center. They provided patient and nurse coordinators, doctors, a dietician, counselor and financial coordinators. I thank God for these people who helped me tremendously in this process. However, the idea of having needles put in my arm three days a week still didn't sit well with me. My prayer was to get a kidney transplant. I began the process of getting on the list for a kidney transplant. This process started in January 2020 but stopped in March due to COVID-19. In June 2020, I was able to continue having tests. I met with the doctor and the transplant coordinators whose job was to determine if I was of the age and ability to get through the process. My medical records, age and mental status, along with tests, were reviewed by a team of doctors at the Jefferson Transplant Center to determine if I could be listed for a kidney transplant.

In September 2020, I received word that my tests were good and I was going to be placed on the kidney transplant list. While a new kidney would allow me to return to a normal life free of dialysis, the thought of randomly asking people to donate a kidney terrified me. I wanted my two sons to be an instant match, but didn't realize that the thought of

...continued on back