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YOUR VOICE, YOUR HEALTH: A KIDNEY COMMUNITY NEWSLETTER

BROUGHT TO YOU BY THE KIDNEY PATIENT ADVISORY COUNCIL OF THE FORUM OF ESRD NETWORKS

MY RARE KIDNEY DISEASE JOURNEY

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I am Janice Starling, one of six siblings born to the late Mr. Jimmy Lee Sr. and Mrs. Viola Starling of St. Petersburg, Florida. My family has owned and operated Starling School and Day Care Center, Inc., since 1974, proudly serving children and families through education and childcare.

At the age of 18, I was diagnosed with hypertension. Both of my parents also had hypertension, yet I often wondered why I was the only sibling to develop kidney disease.

In 1999, my primary care physician informed me that I had protein in my urine. Unfortunately, I was never referred to a nephrologist or told that proteinuria could be an early warning sign of kidney disease. My journey took a challenging turn in 2000, when I was diagnosed with end stage renal disease (ESRD).

In 2003, during my kidney transplant evaluation, a spot was discovered on my left breast. I underwent a left mastectomy so I could remain eligible for the

transplant waiting list. During surgery, a complication caused severe internal bleeding, and I required 30 blood transfusions to survive. While the good news was that I did not have breast cancer, the transfusions resulted in an extremely high antibody level, making it much more difficult to find a compatible kidney donor.

Over the next 14 years, I tried multiple dialysis modalities, including peritoneal dialysis, in-center hemodialysis, home hemodialysis, and nocturnal home hemodialysis. During this time, I learned that education and knowledge are essential to maintaining a good quality life while living with kidney disease. Determined to learn all I could, I became actively involved with World Kidney Day, national and local kidney organizations, and kidney support groups. I encouraged others to attend educational programs with me because I believe that informed patients are empowered patients.

After two years of IVIG treatments to reduce my antibody levels, I received a kidney transplant on December 13, 2013. I was blessed to enjoy 10½ years with my transplanted kidney. During that time, I learned that my native kidneys had failed due to Focal Segmental Glomerulosclerosis (FSGS), a rare kidney disease that causes scarring in the kidneys. Seeking a deeper understanding of my condition, I pursued genetic testing and discovered that I carry the APOL1 and APOL2 genetic variants.

My rare kidney disease (FSGS), and APOL1&2 journey has taught me the importance of self-advocacy, education, and empowerment. These tools have been essential in helping me navigate every stage of kidney disease while maintaining hope and purpose. Today, I am passionate about helping others overcome healthcare disparities by providing knowledge, support, and resources that improve quality of life. This journey has not been mine alone. It has been a path walked alongside family, friends, healthcare professionals, and a caring community whose support, strength, encouragement, and love have sustained me every step of the way.