From Recurrence to Recovery: A Transplant Patient’s Perspective

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As I reach the end of my time as an undergraduate student, I often reflect on my journey as a patient, how it has shaped me, and how it will hopefully shape my career. When I was 3 years old, I was diagnosed with idiopathic nephrotic syndrome and, although it took almost a decade, it progressed to FSGS and eventually ESKD. As these conditions worsened, I went through the whole gamut of treatments in hopes of some kind of recovery: steroid treatment, immunosuppressive therapy, both hemodialysis and peritoneal dialysis, and—finally—kidney transplant. Thankfully, my mother was compatible as a living donor and I am now blessed to live a healthy, mostly normal life. Now, as I move forward into the next stage of my life, I also know that I will never stop being a patient, because maintaining my health is just as involved as is becoming healthy.

In my perspective, there are many difficulties and obstacles that need to be overcome in nephrology, ranging from the lack of definitive therapeutic options for many CKDs all the way to the inefficiency of dialysis—the most prevalent treatment for patients with renal disease of any origin. Furthermore, many diseases that cause kidney failure are still idiopathic, making the identification of new therapeutic options even more difficult. Despite these difficulties, I am hopeful for a better future. This year, I had the opportunity to attend the American Society of Nephrology (ASN) Kidney Week 2019 as a STARS (students and residents) awardee with my laboratory at the University of Miami’s Katz Family Division of Nephrology (Figure 1). After this incredible experience, it is clear to me that patients are not the only ones who see these challenges. Indeed, nephrologists across the world are very keenly aware of the obstacles ahead of them and are passionately and creatively conducting research to generate the new knowledge we need to overcome them. This is crucial to improve the health and the sense of hope of our kidney patients and, although I can only speak to my experience, were it not for the ongoing research in nephrology I may not be here today to share my story.

I cannot say that I remember much about how my journey began because I was only 3 years old when I was diagnosed. As I grew older, however, I started to question the small things, asking my parents things like, “Why am I always getting my blood tested? Why do I have to take this medicine? Why can’t I eat these things?” The older I got, the more curious I became, moving on to harder questions like, “Why am I always in the hospital?” and “What is nephrotic syndrome?” That last question is one that did, and still does, plague me. I found that the more I asked it, the less I seemed to understand. What are the causes of this disease? What makes it worse? What makes it better? As I grew up, it became more and more frustrating to realize that these questions did not yet have solid scientific answers. As far as I am aware, none of my doctors figured out the original cause in my case. Worse than that, no one seemed to know how to fix it, just how to slow it down and buy me more time until dialysis. It was not until I started doing research myself that I understood the scope of these kinds of questions, and just how difficult they were to answer. When I went to ASN Kidney Week for the first time in 2019, I felt seen. I saw that these questions were not just being ignored, but they are being tackled by incredible research scientists, who are generating new knowledge about nephrotic syndrome and plenty of renal diseases I never even knew existed. I was particularly impressed by the amount of new knowledge and potential treatments about FSGS, the disease I was eventually diagnosed with, which most patients can barely even pronounce. As a hopeful future nephrologist, I felt my passion growing by the second, while as a patient I felt comforted by the amazing work being done in the field. As I continue in my career, I am incredibly excited to see all of the advancements in research and hope to be a part of the ongoing fight on behalf of patients with kidney disease.

This experience, however, was far from my first experience with research medicine. After all, something incredibly important happened before I knew what ASN Kidney Week even was. By the time I was 14, I knew what it was like to be on the rollercoaster of dialysis treatment. It soon became clear that my best hope at a normal adult life would be through a kidney transplant. I still remember parts of the process very clearly: the myriad appointments at a new, confusing hospital; the countless tubes of blood drawn for compatibility testing; and, most importantly, the kindness and patience of my new doctors. I look back now and realize how truly blessed I am. Whereas many of my friends in dialysis had been waiting years for such a

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chance, I had only waited about a year before my mother was found to be a match and decided to donate a kidney to me. However, almost immediately after the transplant, the FSGS began to come back and I went into anuria. When it seemed as though there were no options left for me, my doctors gave us one more option. They were running an investigator-initiated experimental therapeutic research trial that seemed to target my case specifically, using an immunosuppressant, abatacept, to treat post-transplant recurrent FSGS. I was treated with two doses of the drug and, as if by a miracle, it worked. If either part had been missing, either the doctors or the research, I may not be here to tell my story today.

In my eyes, I am living, breathing proof of the great things that can be done for patients when you start at the bedside, take the problem to the bench, and bring a solution back again. That is why I have so much hope for the future of medicine, especially nephrology. The amount of empathy, thoughtful care, and passion for the profession in nephrologists is some of the greatest I have seen in my life. These experiences as a patient and as a student researcher are what drive me to become a nephrologist myself, and I hope to use my story to bring hope to my future patients. On top of that, I also wish to serve as inspiration for the current and future professionals in the field and to remind them of the difference they make in patients’ lives. There is still a lot of work to be done before we can start curing our patients, but I am confident that if we continue this upward trend in passion and opportunity, we will get there sooner than you think. Who knows, maybe patients like me and my peers will be the ones to lead the way forward.

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