Written Testimony of Ashli Littleton

Before the United States House Ways and Means Health Subcommittee

Hearing on Improving Kidney Health Through Better Prevention and Innovative Treatment

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Chairman Buchanan, Ranking Member Doggett, and distinguished members of the Subcommittee, thank you for the opportunity to testify today.

Dialysis is the reason I am alive.

My name is Ashli Littleton, and I live in Clarksville, Tennessee. I am living with end-stage renal disease (ESRD). My kidneys no longer function, and for the past nine years, dialysis has done the job my body can no longer do. I am a ten-year kidney patient and a nine-year dialysis warrior—not by choice, but by necessity.

My kidney journey began the way it does for far too many people: with years of uncontrolled high blood pressure and diabetes. In late 2015, I went to my family doctor because I was experiencing symptoms related to both conditions. After several tests, I was diagnosed with chronic kidney disease (CKD). I was told that dialysis was ten years away.

But because of a lack of clear education, communication, and understanding of how severe my kidney damage already was, my disease progressed rapidly. In November of 2017, while I was at work as a preschool teacher, I received a call from my doctor telling me I needed to start dialysis immediately.

On November 18, 2017, at just 27 years old, I reported to a dialysis center for my first treatment. I was devastated. My life changed overnight.

I began in-center dialysis every other day before work. I woke up at 4:00 a.m., arrived at the clinic by 5:00 a.m., completed treatment around 9:00 a.m., and went straight to work by 10:30 a.m. I worked with children ranging from six weeks to six years old.

Imagine running a marathon before caring for infants and toddlers all day - that was my reality. I was exhausted, but those children were the best part of my day. Their smiles and hugs kept me showing up, even when my body felt completely drained.

It was through my work that I met a parent who recognized what I was going through and asked a simple question that changed my life: *"Have you ever been told about home dialysis?"*

I had not.

I did not know there were options beyond in-center dialysis. No one had explained them to me. That parent connected me with a new primary care physician and nephrologist who took over my care and truly partnered with me. Together with my family, we began making informed decisions about my treatment for the first time.

I transitioned to peritoneal dialysis, which allowed me to dialyze at home every day after work. A catheter in my abdomen allowed fluid to cycle in and out, cleaning my blood. While this option gave me more flexibility, it was not sustainable for me. I experienced repeated infections and severe drain pain. This pain was so intense it felt like my insides were being pulled through a straw.

I spoke up and asked about another option: home hemodialysis.

With proper training, which took about two weeks due to the demand of working as a preschool teacher and the support of my mother as my care partner, I began home hemodialysis. This choice gave me something I had not had in years—control. I was able to make my dialysis schedule with the help of my doctor and medical team. I was able to make changes, if needed, with the help of my dialysis team. When I was on in-center dialysis, every decision about my treatment was made for me. It was difficult to switch days or even hours. I had to make sure I was on time because my chair was not just my chair. There were other patients waiting their turn. Being at home, I was able to work full-time. I could now travel to visit family. I managed my treatments, monitored my blood pressure, responded to alarms, and communicated directly with my care team.

I want to be clear: I am not glorifying dialysis. I still hate that I need it to survive. But home dialysis allowed me to live my life with dignity, independence, and flexibility. It allowed me to be a participant in my care, not just a patient.

In September of 2022, I received what kidney patients call "the call" for a kidney transplant. It was one of the happiest days of my life and also one of the scariest. I received that call September 8, 2022, the day Queen Elizabeth died. After waiting many hours, I rolled into operating room 13. I thought that was an odd number to be in and I was right. When I woke up, I was told that I had a sleepy kidney. However, my doctors still had hope that it would wake up and start working. I was sent home with tubes, multiple medications, and hope. I would go back and forth to the doctor several times a week for 2 weeks. During that second week I was told that my kidney had clotted and it would need to be removed. The devastation broke my heart. I remember the nurse praying for me.

I had no definitive answers, but my weight, particularly abdominal weight, was repeatedly cited as a concern. My nephrologist advocated for me to remain on the transplant list. With support of my medical team, I remained listed as inactive until I could meet the required weight-loss goal.

That process took time. Stress, depression, and the demands of daily life slowed my progress. But with medication, determination, and the support of an accountability partner who is also a kidney transplant patient, I reached my goal. Today, I am once again actively waiting for that call and actively seeking a living donor.

Dialysis is a treatment. Transplant is a treatment. There is no cure for kidney failure.

Despite everything, I am grateful. Dialysis allows me to wake up each morning and see the sunshine. It allows me to live. I work out daily. I feel better now than I did in my twenties before my kidneys failed. I prioritize my physical and mental health, and I have learned to advocate for myself.

But I know that my experience is not the norm.

Every day, I see patients in online support groups asking the same questions I once had, questions they should have had answered by their healthcare providers. Too many patients are making life-altering decisions without fully understanding their options. Education is inconsistent, rushed, and often delivered only once and at the exact moment patients are most overwhelmed.

Patients cannot make informed decisions if they are not informed.

Kidney patients deserve clear, repeated, and patient-centered education about all available treatment options. They deserve time to ask questions, involve their families, and align care decisions with their personal goals and lives. That requires a healthcare system that values collaboration, communication, and patient empowerment - not just survival.

Today, I chose not to be silent.

I am an advocate, an ambassador and health coach for kidney disease. I am also working with another kidney warrior to develop a support group that advocates, educates, and empowers people about CKD and ESRD. I believe in doing this because no patient should have to rely on social media to learn how to survive kidney failure. Together with other patients and advocates, I am committed to improving education, awareness, and outcomes for kidney patients and their families.

I am living proof that when patients are informed, supported, and trusted, they can take control of their health and their lives.

Thank you for the opportunity to share my story and for your commitment to improving kidney care in this country.