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Kidney Patients

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Living Life to the Fullest: How Home Hemodialysis Gave Me the Life I Wanted to Live

This past October, I took part in an important event pointing to the power of community in living with kidney disease.

The NxStageUsers Group, a group independent of NxStage Medical, hosted its first NxStageUsers Meet Up and Conference in the Fall in Las Vegas. The group is composed of and completely organized by patients, all who receive home hemodialysis. The event brought together people I knew in the “kidney community” from Facebook and blogs to actually meet in person and talk about life with kidney disease, home dialysis and to have fun. More than 70 patients and their caregivers came together for the event. Discussions were led on such issues as “Traveling while on Home Hemodialysis,” “A Day in the Life of a Caregiver” and “Being the Mother of a Pediatric to Adulthood Dialyzer.”

Five years ago, many of us wouldn't think of just packing up and traveling to a conference like this. In the past, most of us received dialysis in-center three times a week, making travel (which required scheduling treatment sessions at our destination) difficult. And, this community never before existed. But now, more and more home dialysis patients are coming together, feeling empowered in our own care and wanting to share our stories to advocate and educate others about this option.

I was excited to have been asked to share my story at the conference, and spoke about life as a working mother and a dialysis patient.

When I was a child, a routine blood test at school showed I had lowered renal function, which was most likely caused by an undiagnosed infection. By the time I was 18, I needed renal replacement therapy. It was 1991, I was a senior in high school and I would need to start dialysis to survive. However, my mother was tested and determined to be a match, and I was fortunate to receive a kidney transplant from her that year.

After college, I began working full-time at a financial company in Boston. I was excelling in my career, but I was also starting to feel the impact of my kidney disease. My blood pressure was very high and I felt dizzy and exhausted much of the time.

In 1995 the transplant failed. I began in-center dialysis sessions at a clinic for three-hour-long treatments every Monday, Wednesday and Friday. The dialysis center was not a place I felt comfortable – I was surrounded by many very ill patients and often felt lethargic. Eventually, the schedule and my health forced me to quit my job. Working full time in a fast-paced environment while fitting in dialysis treatments and feeling ill all the time was no longer something I could do. Thankfully, months later I was able to return to work in a new career path with a schedule that fit around my treatments, as a part-time Spanish teacher. During this time, I also met a man named Paul through mutual friends. We started dating, and just a year later, we were engaged. I was on dialysis when we met and I joke that Paul didn't know what he was in for! But my condition has been a part of our lives and he has accepted it from day one.

Two months after our wedding, Paul and I moved to our home in Marblehead, Massachusetts. I continued working part-time as a Spanish teacher. We wanted to start a family, but we knew that kidney disease made pregnancy risky. We began to search for a surrogate and after two different surrogates, many in-vitro fertilization cycles and other procedures, our son, Elan Jacob Shepard was born December 12, 2004, three years after Paul and I married. I took the rest of the year off and returned to school the following September.

Having my son inspired me to try to find another way to do dialysis that would give me more freedom and time to be with my family. Through my own research, I found out about the NxStage System One, which would enable me to do dialysis on my own with a partner at home and on my own schedule. I learned that with home hemodialysis, I would also do dialysis more frequently for shorter periods of time.

Paul and I trained to use the machine at home. Once I began to do more frequent dialysis, I noticed an immediate change in my health. Within the first week, I was able to stop taking all of my blood pressure medication. I had more energy and just felt better.

The next year, we had our second son, again via surrogate. Stefan Magnus Shepard was born August 19, 2006. I truly felt like I had my life back – I was healthier than I had been in years and now could do dialysis when I wanted, spend more time with my family and have more time for myself.

In 2008, we were able to take our first family vacation where I did not need to find a dialysis center at our destination and be assigned a treatment time that would disrupt our plans. We visited Naples, Florida and I was easily able to make arrangements to bring my home hemodialysis machine with me.

With my more flexible schedule, I have been able to not only continue working as a teacher, but also to pursue other goals that before seemed impossible. I've begun a Spanish language-immersion day camp called *My Little Lingos* that grows every year and I've started recruiting work in the medical industry.

I am also interested in raising awareness on becoming a kidney donor. Today, I am on the list of patients awaiting transplant and hope that one day I am fortunate enough to receive one. But as long as I need dialysis, I know that more frequent, home treatments are the best choice for me.

With home dialysis, I feel healthier and freer to dedicate my energy and time to what matters most to me – being a mother to my two boys and a wife to my wonderful partner, while pursuing my career goals. I am inspired to see growing awareness and community among dialysis patients and hope we can continue to share our stories and support so more patients can learn about treatment options and resources.

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