NEPHROLOGY NEWS & ISSUES

30 YEARS PATIENT PERSPECTIVE

RIDING A WAVE OF RENAL RESEARCH
30 YEARS INTO THE FUTURE

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I was diagnosed with chronic kidney disease in 1959 at age 11 after walking into a bee hive the previous summer at camp and getting stung by a swarm of bees. It was when dialysis for chronic kidney failure was not yet possible. The long-term therapy got its start in Seattle during the years that my kidney function declined.

By 1966, my survival depended on dialysis. But there was no guarantee I could get it. The supply was very limited, and demand was high. The Seattle Artificial Kidney Center (first in the world, now called Northwest Kidney Centers) used an admissions committee of community members to assess candidates and dole out the available dialysis resources.

I was among the fortunate. The Admissions and Policies Committee chose me and I started dialysis 50 years ago. That may make me the longest-surviving kidney failure patient in the United States.

Medicare did not yet cover dialysis. I dialyzed eight hours overnight three times a week in-center. We didn't call it nocturnal, we just called it dialysis. We all dialyzed this way. Eighteen months later, I performed dialysis myself at home after spending the summer in training at the University of Washington Coach House, attended by Dr. Belding Scribner, Dr. Christopher Blagg and Dr. Joseph Eschbach. We home patients had our own centrifuges to spin blood samples and identify our hematocrits. I could call the center to report my hematocrit, and a taxi would deliver my unit of blood, which I would hang during my dialysis. My hematocrit usually hung around 18 to 24.

During this time, I finished college. After I graduated, my mother advised me that her insurance would no longer cover me, and that I needed to get a job with good insurance. So I did. I continued to run overnight, and each morning I went to my full time job with Washington Natural Gas Company.

Spaeth dialyzing at home in the 1960s. Photo courtesy of author.

In 1972, now aged 24, I received a kidney transplant from my brother Charlie. I got married shortly thereafter and had two children, Josh and Sarah. Life was good. Then, in 1979, I got divorced and lost my transplant due to E. coli picked up at a restaurant.

I went back on dialysis at home but for only four hours, three times a week. I was very upset and found this shorter dialysis inadequate. I felt terrible, had frequent cramping and very poor energy. I called Dr. Scribner and told him that I wanted my old Kiil kidney back so that I could run overnight again. He replied, "Nancy, we sent them to India." I was terribly disappointed.

Ms. Spaeth, who lives in Seattle, was treated by famed nephrologist Belding Scribner. This month, she notes 50 years of living with renal disease. Learn more about her in a 4-minute video at www.youtube.com/watch?v=4DPv2Mdfl2E

I attended nursing school the next two years while I dialyzed at home but faced severe anemia. The blood transfusions that used to be a common part of dialysis treatment were now restricted because of the newly discovered Human Immunodeficiency Virus (HIV), which could not yet be identified in the blood. Because of this, my hematocrit was around 15.

In 1981, I received a kidney from a young woman who had died in Alaska. I graduated from nursing school in 1982 and took a job at a local hospital's nephrology/urology floor, working nights. My children stayed with their father that year. I started working at an internal medicine clinic during the day the following year so my children could come back home.

This second transplant failed in 1986 and I went back to the four hours three times a week dialysis at home. It was just too hard to work with only 12 hours of dialysis a week and the low hematocrit. I am grateful that my nephrologist, Dr. Millie Tung,

called Dr. Eschbach and asked if I could be considered for the erythropoietin trial.

It wasn't my first experience with kidney research. In the 1970s I had volunteered at the University of Washington after my kidneys were removed and before I received the kidney from my brother. Doctors took samples of my bone marrow. In a separate test, they drew blood, labeled the red cells, and gave it back to me. Later, they would draw my blood and the labeling would be analyzed. These tests were the early research studies that would lead to better understanding of erythropoietin,

After I entered the erythropoietin study, my hematocrit went from 15 to 40 in only a few weeks. Before the trials, my children came home one day to find me sitting in the middle of the front stairs, wanting to know if I was okay. "I'm just resting," I said, hoping not to frighten them. I had been crawling up the stairs, but after the erythropoietin trials, I could run up the stairs.

Looking back, I also now realize that I helped with research in a different way. Dr. Scribner would call me saying, "Nancy, if you're not busy Saturday night, would you put on your black cocktail dress and come down to the house? I've got ____ corporation coming to dinner." On the appointed evening, in my sleeveless dress with my Scribner shunt wrapped in kerlix gauze, I would drive to Dr. Scribner's house above Portage Bay. I did this three or four times and one day he called me and said, "Nancy, we got the grant!"

In 1989, I received my third donated kidney, this one from a local young man who died in a motorcycle accident. I began substitute teaching and do per diem nursing. In 1993, I returned to work full time in an outpatient physical medicine and rehabilitation clinic at a Seattle medical center. I lost my third transplant in 1995 and began continuous ambulatory peritoneal dialysis (CAPD), doing exchanges at work, in cars, airplanes, and at friends' homes. In June 2000, I received my fourth transplant and kept working after my recovery. Today I am mostly retired but still do substitute teaching and nursing, as well as international speaking. My kidney continues to work for me.

Over the past 50 years I have been riding a wave of kidney disease treatment innovation. As I look to the blue skies of the future, I see great promise for those who have or are at risk of developing renal disease in the next 30 years. Current studies and practices have the potential to enhance all of our lives and decrease or eliminate kidney disease.

- The ***wearable artificial kidney,*** invented by Dr. Victor Gura, is being studied at the Kidney Research Institute in Seattle. It allows someone constant dialysis, freeing patients from the restrictive renal diet. We hope it can read our chemistries automatically and activate dialysis as needed, much like insulin pumps of today. I hope that it can become small enough to fit into a fanny pack or eventually become implantable.
- The ***kidney on a chip,*** also being developed at the Kidney Research Institute, is a small micro-fabricated device containing human kidney cells to test new drugs and discover those that won't injure human kidneys. Research can be modified for different people with different types of tissue and DNA. It hopefully will eliminate animal testing and save our organs. How wonderful to get rid of toxic drugs that harm us.
- ***Organogenesis*** is also being studied. It is a method to rebuild damaged organs and to make new organs.

Another goal is to decrease or eradicate type 2 diabetes, which often leads to renal failure. Already a current drug, Empagliflozin decreases the body's absorption of sugar and increases the amount of sugar that leaves the body in the urine. Liraglutide is a long-acting injectable medication that reduces hunger, increases insulin secretion, and decreases glucagon secretion. Patients have shown reduced body mass index and reduced incidence of diabetes. With these improvements to diabetics, renal failure is less likely.

I am looking forward to immune tolerance for kidney transplants—a time when immunosuppressant drugs are no longer needed. I also hope for ways of continuously purifying water for both an implantable artificial kidney, as well as for peritoneal dialysis. Gene modification for those at risk for hereditary diseases such as Alport's Syndrome and polycystic kidney disease is a goal as well. I would love to see them go to physical therapy for strengthening and endurance to become better fit and get their lives back.

There is great promise for decreasing, and perhaps eliminating, the burden of kidney disease. I am ready to ride the wave of wiser research and innovation. ***NN&I***

Resources

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