

## Nancy Spaeth's Story: A Little History and a Lot of Hope

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*The preceding historical primer by Savage and Browne documented that access to hemodialysis in the U.S. was not always available. Life-and-death decision making that occurred in Seattle no doubt affected individuals and families dramatically as the following interview illustrates. Lisa Hall, MSSW, LICSW, is the Patient Services Director at Northwest Renal Network (ESRD Network 16). Nancy Spaeth serves on the network's Patient Advisory Committee.*



*Figure 1. Nancy Spaeth – Editor and “mascot” for Kidney School, a program of the Medical Education Institute, Inc.*

Nancy Spaeth is a registered nurse and has been living with kidney disease since 1959. I first met Nancy two years ago, when I moved to the Pacific Northwest. Right away, I realized that she was someone I would admire, even if she had not lived most of her life with chronic kidney disease. When I was asked by *JNSW* to interview Nancy, I considered it an honor, and an opportunity to learn more about this inspiring woman and all she has accomplished. Nancy exemplifies the strength of the human spirit and its ability to triumph over life's

obstacles. She brings thoughtfulness, intelligence, wisdom, and enormous energy to all she does. Nancy is a highly effective advocate on patient, legislative, and administrative fronts for improvement in care and enhancement of personal autonomy, offering the rare dual perspective of both patient and expert caregiver in all her activities. Readers may recognize Nancy's photograph—for over a decade she was the “face” of Kidney School. Her photograph was featured on Life Options posters and brochures, and the Kidney School website modules. The following are excerpts from an interview conducted in June 2012.

**Hall:** Tell me about the early days of your diagnosis with chronic kidney disease.

**Spaeth:** I had just started 7th grade in September 1959 when brushing my thick, wavy blonde hair became difficult. I was a relay runner in school and races became hard to run. My urine became brown. The diagnosis was kidney disease.

In that era, the doctors thought that jostling the kidneys would do further harm, so I was sent to bed until Christmas and only arose to use the bathroom.

In October, my friends gathered around my bed to celebrate my 12th birthday. It was one of those rare times I saw all of my friends, as I was usually alone in the house while my mother was at work. I did my best to keep busy by reading Charles Dickens, Jules Verne, and the Nancy Drew mysteries.

On December 26, I entered the Children's Hospital in Seattle for further diagnostic tests and treatment if needed. A biopsy showed that I had Bright's disease or glomerulonephritis, as it is called now. The doctors felt the cause was multiple stings from a swarm of yellow jackets I had encountered the previous summer while on a camp hike in the Cascade Mountains. I was there [at Children's Hospital] for many weeks and given high doses of prednisone, and then infused with nitrogen mustard to see if it would eradicate the disease. I was semiconscious for several days following this. Eventually, I was awake enough to ask my mother to hold open my swollen eyes so that I could see her. Children's visitors were not allowed in the hospital in those days, and I remember waving at my younger brother, Charlie, through the windows of the hospital.

I entered the 8th grade the following autumn and stayed active throughout my junior and senior years in high school. I loved water skiing in the summers on my custom made slalom ski. At the age of 15, I won a first-place trophy snow skiing in a coed slalom race. As a girl competing with brothers while growing up, I never tired of saying, “I beat the boys.” Back then, I never worried or thought much about my illness, except to be careful of my diet and to follow the doctor's instructions. I always knew I felt better when I watched my salt intake. This was just my life.

In the fall of 1965, I went off to college at the University of Arizona in Tucson, joined the Phi Beta Phi sorority, worked at my studies, went to parties, and dated. By February 1966, I had become too sick to stay in school. Vomiting in the planter boxes outside of my physics class became old after a while. I returned home and continued college at the

University of Washington, and then transferred to Seattle University, which was just three blocks from the Seattle Artificial Kidney Center. I also began my interviews with the Admissions and Policy Committee at the center. We called it “The Life and Death Committee.” All patients being reviewed for dialysis in Seattle, in those days before Medicare paid for treatments, went through this process. It included a visit with a psychiatrist and psychological testing. My mother and older brothers had to meet with the social worker and the financial people. However, I did not know until recently that my family had to have adequate insurance coverage or put up \$30,000. That is a lot of money, even by today’s standards. Luckily, my mom was a social worker for the state of Washington and had excellent insurance.

The committee was looking for people who could recover and go on to work or be “contributing members of society.” The Seattle Artificial Kidney Center was the first out-of-hospital dialysis center in the world and it only had about two dozen dialysis beds. I believe the review process was harder on my family than it was on me, because they worried about the alternative. My sister-in-law reminded me that I might not be chosen, but I was 18 and the implication of death never really occurred to me.

**Hall:** What was dialysis like in 1966?

**Spaeth:** I started dialysis the day after Christmas 1966, while continuing to be a full-time university student. I was active, went to parties with my friends, dated, and was a pretty normal student, except that I went on dialysis at bedtime three nights a week for eight hours and avoided salt at all costs. I took up snow skiing again, although I carried a tourniquet and cannula clamps with me on the hill. I had a Scribner shunt, an external Teflon and Silastic tube connecting an artery and a vein, located on my inner forearm where it was vulnerable to infection, clotting, and being pulled out. I covered it with gauze to keep it warm and protected. We allowed the end junction to show, in order to keep an eye on the blood color and check for clotting. I often volunteered for research studies, thinking that anything the doctors learned would benefit me as well as others. I was planning for the future—my future. In 1968, after over two years of in-center dialysis, and while still in college, I went to home dialysis training at The Coach House, where the University of Washington conducted research. I was taught to be a nurse and technician. Dr. Belding Scribner, accompanied by Dr. Joseph Eschbach and Dr. Christopher Blagg, was there to oversee my health and training. It took three months for me to learn how to dialyze, [how to] repair the Drake-Willock machine, and how to rebuild the Kiil dialyzer, which I would be using in my home. (Information on this historical technology is available at <http://homedialysis.org/index.php/types/museum/P5>.) [At home] we prepared a room in our basement with an old hospital bed for sleeping during overnight dialysis. On Sundays, my priority was to clean and rebuild the kidney. Dialyzers today come ready to use, a big advance for patients. Mom and I eventually gave free

room and board to a university student in exchange for help with the machine. My hematocrit hovered around 20 to 23 in those days, and I had frequent blood transfusions. I still went on dates, but had to be home at night in time for dialysis.

In June 1970, I graduated from Seattle University with a Bachelor of Education degree with minors in Art and English.

**Hall:** How does your early dialysis experience compare with treatment for kidney disease today?

**Spaeth:** Frankly, my dialysis was better [back then] because I dialyzed overnight, and did not have to give up my days. In the 1980s, when I lost my kidney transplant and went back in center for dialysis, I had to dialyze three days a week for four hours each visit. Nobody could prescribe anything else at that time. I felt much worse on that schedule. I was anemic, my hematocrit ran from 11 to 15, and EPO was not available yet. They weren’t performing blood transfusions as frequently, due to concerns about building up antigens that might preclude another transplant, and getting infectious diseases (Hepatitis C and HIV).

If I were to go on dialysis again, I would definitely choose to do daily home nocturnal dialysis, or possibly CAPD.

**Hall:** Can you provide a summary of the various treatment modalities you've had over the years?

**Spaeth:** In March 1972, during my youngest brother Charlie’s spring break from college, he gave me his kidney after I had dialyzed from 1966 to 1972. He returned to school at Stanford a week later. That summer, I married. My first child, Joshua was born in February 1974. My daughter Sarah was born in August 1976. They were beautiful, healthy babies, though born four and three weeks early. They are still beautiful and healthy today. After Sarah was born, I was a substitute teacher and taught kindergarten through 12th grade, all subjects.

In 1979, I lost my transplant due to food poisoning, and was divorced. Public schools were closing, and many teachers were out of work. I was unable to get a teaching job, so I returned to school for a nursing degree, and dialyzed at what was now called the Northwest Kidney Center. The center was using a new, more efficient type of dialyzer that physicians thought would permit a shorter treatment schedule. I remember telling Dr. Scribner that I did not feel as well using this new machine on a four hour dialysis schedule. I also disliked taking time out of my day for treatments. I had preferred sleeping away my time during overnight dialysis, so that I would have my days free for school, work, and my children.

Fortunately, I soon received training for home hemodialysis. I liked managing my own life and not letting dialysis manage me. This time, the machine was small enough to keep in the kitchen where I could interact with my children and supervise dinner. My hematocrit hung at around 15. I was getting fewer transfusions now, as a protection against HIV infection and accumulating antigens, in the hope that

a low hematocrit would stimulate production of red blood cells. For that purpose, I also received the male hormone, decadurobolin. Nothing seemed to work.

In 1981, I received a cadaveric transplant from a young woman who fell from a ladder on a fishing barge in Alaska. The following year I graduated from nursing school with a 3.9 GPA and went to work full time. When my transplant failed in 1986, I once again went on dialysis, for the standard four-hour day. My hematocrit again dropped to 15, and I felt quite tired from the anemia—more so than in the past. I soon opted for home hemodialysis, again in the kitchen. This time, however, the kitchen was in the [new] house that I had built (acting as my own contractor). Still, the four-hour schedule was not enough to help me feel as well as I did on overnight dialysis during the 1960s and early 1970s. Unfortunately, nephrologists no longer prescribed that type of overnight schedule. *[Editor's note: In recent years, access to longer and overnight dialysis has begun to become available again as the medical community has recognized the benefits.]*

Not long after, I was accepted into the erythropoietin study conducted by Dr. Joseph Eschbach at the Northwest Kidney Center, and my hematocrit climbed to 40! I could walk up stairs again, rather than having to crawl. My daughter Sarah, no longer needed to keep coming into my room while I was napping to make sure Mommy was okay. It is a frightening thing to have a sick Mommy. The Food and Drug Administration eventually approved Epogen (EPO) in 1989. Patients today have little knowledge of just how lucky they are to have this drug. It was unbelievable how much better I felt. With EPO, I was able to spend more active time with my children, but because of that terrible four-hour dialysis schedule, I still never felt well enough to work full time.

In 1989, I received my third transplant, again a cadaveric kidney, this time [from a person who was in] a motorcycle accident. I continued to substitute teach and do per diem nursing. For fun, I even tried a spin around Lake Washington on water skis. I made sure that my children learned to snow ski; I know that my son Josh has been grateful. I returned to full-time nursing in 1993. It was great to bring in a good paycheck again and have better medical coverage for doctor visits and medications.

In 1995, I lost my transplant due to chronic rejection and returned, again, to dialysis. As terrible as it is to lose a transplant, I feel that trading off the side effects of dialysis for the side effects of the transplant drugs and vice versa, has contributed to my longevity. I continued to work in the clinic during this period and only took time off for the placement of a Tenckhoff peritoneal catheter so I could start continuous ambulatory peritoneal dialysis (CAPD). The only accommodation I needed was an IV pole at home and in my office so that I could do an exchange while at work,

and a microwave oven to warm the dialysate fluid to body temperature. I did four exchanges of fluid a day and was amazed at how much better I liked PD than hemodialysis. I had much more freedom, more consistency in the way I felt, and no more post-dialysis fatigue. It was easy to travel, and my diet was much more normal. I did not lose weight and actually gained some! After one year, I increased to five exchanges a day. The Quantum machine did the fifth exchange at night while I slept. A timer on the machine automatically opened and closed the dialysis tubing.

In June 2000, I received that awaited call—another kidney had been found, a four-antigen match. Sarah stayed by my side until I recovered. She took me to my appointments, arranged for extra help, and cried when Dr. Cooper told us that part of the new kidney had necrosed, explaining to her that it meant that a portion had died. Today, my kidney is working well and I feel healthy. During a hike in the Wasatch Mountains of Utah, I only had to stop once to catch my breath and reminded my hiking companion that I live at sea level.

**Hall:** Did you ever struggle with depression?

**Spaeth:** Never. Though I was living with a chronic disease, I realized that everyone has a burden of their own. It is easy to mistake fatigue, listlessness, and a lack of interest for depression but these are symptoms of how one feels with anemia and poor dialysis.

**Hall:** What is your experience with managing pain?

**Spaeth:** Having restless leg syndrome was hard, but it eventually cleared up. When I received my bilateral nephrectomy, I was given nothing for the pain. Sure it hurt,

but I have always been able to accept the pain as part of it. Getting up and [being] active helps pain, slowly of course, building up over time.

**Hall:** Where did you seek support for coping with kidney disease?

**Spaeth:** My family was always there for me, but they never babied me. I guess you could say we were interdependent. Even as a youth, when I lived with my oldest brother and his wife, I was given chores and baby sat my nephews. My mother provided a stoic example of sticking with something until it was finished. My father always said to me, “Nancy, you can do anything if you want it badly enough.”

**Hall:** Is there a particular social worker who helped you with your adjustment to illness?

**Spaeth:** In the 1960s and 70s, Eloise Jensen was my social worker. Our families were connected and she was a great support and friend to me. Mary Mason, who is now a living donor and a social worker at Virginia Mason Medical Center, was my dialysis social worker and later my transplant social worker. She inspired me, encouraged me, and treated me like a person—not a patient.

## “I liked managing my own life and not letting dialysis manage me.”

**Hall:** What advice would you give to patients for having a good quality of life with kidney disease?

**Spaeth:** The way to keep doing the things you love is to keep doing them. Life is a classroom, an adventure. You need to find something to work toward, to hope for. I am hoping for a PhD in “Wisdom.” I learn a little bit more every day.

Throughout my adulthood, I have continued to work, support my children, travel, and enjoy life and my family. I garden, walk the dog, climb stairs instead of using the elevator, and still enjoy skiing. I have learned over time how important it is to stay physically active, to maintain a good diet, take phosphate binders, and to maintain a positive attitude. During the day, I still do stretches and exercises [that were] taught to me by my physical therapist while I was on dialysis. They have served me well and kept me strong. Above my desk and on my refrigerator, I have a picture of a pelican eating a frog that is squeezing the bird’s neck. The caption says: “Don’t ever give up.”

Maintaining good nutrition has been a lifelong habit of mine. My mother prepared food without salt when I was a youth. I rarely needed antihypertensive medications, except during pre-dialysis, because I am faithful to the low-sodium diet, staying lower than 1000 mg per day.

As I mentioned earlier, from the start of dialysis in the U.S. in 1960, a “Life and Death Committee” met to determine who would receive this costly medical treatment. By 1962, the committee decided to employ a vocational guidance counselor, to be certain to select dialysis patients who could be rehabilitated to be “productive members of society.” In 1972, a national ESRD Program was created to extend Medicare benefits to cover the high cost of medical care for most individuals with ESRD. Returning patients to their prior level of functioning is the reason Medicare began to pay for dialysis. Dr. Belding Scribner testified to Congress at the time that, unless a patient was rehabilitated, the treatment was inadequate. He emphasized that most patients who received funding would be on home dialysis or transplanted, and would be taxpayers. We actually had a vocational counselor at the kidney center where I received dialysis, and I received assistance with my education and career, first as a schoolteacher, and later as a nurse.

Coverage under my mother’s health insurance ended when I turned 22 and graduated from college, so I had to get a job with insurance to pay for dialysis. Remember, I was on dialysis way before Medicare covered ESRD. I retired from my nursing career in 2011, but still substitute teach all grades (including kindergartners!) and nurse per diem in pediatrics.

**“I am hoping for a PhD in 'Wisdom.' I learn a little bit more every day.”**

**Hall:** What advice do you have for social workers on ways to facilitate treatment adherence?

**Spaeth:** You have to start where the patient is, and instill confidence in them. Let them know you believe in their ability to make changes, and support their efforts. Start with small goals that are important to the patient, and challenge them to try new things.

**Hall:** Tell me about your contributions to renal-related education and advocacy.

**Spaeth:** I worked as a member of the Life Options Rehabilitation Advisory Council (LORAC), a group that supports education and rehabilitation for dialysis patients. In addition to LORAC, I have served on numerous boards over the years, including: the Northwest Renal Network (Network 16) Board of Directors and Patient Advisory Committee; the American Kidney Fund Education Committee; and the

Northwest Kidney Center’s Foundation Board, Quality Committee, and Regional Councils. I also serve on the board for Western Washington Physicians for a National Health Program, and am an elected Precinct Committee Officer. In 2003, I received the Clyde Shields Distinguished Service Award from the Northwest Kidney Centers.

I speak at regional and national renal community meetings about having a good life with kidney disease. I enjoy educating patients and renal professionals about the history of dialysis and rehabilitation for dialysis patients. I’m most passionate about the importance of patients improving their quality of life, whether through home treatment options, transplantation, vocational rehabilitation, and/or physical therapy. I meet with all of the renal fellows who come through the University of Washington and Northwest Kidney Center’s programs, and have done so since 2000. I was honored to talk recently with the renal fellows at Seattle Children’s Hospital as well.

Additionally, I have advocated in Congress to get kidney disease laws changed, and testified regarding anemia and ESAs. A paper of mine was published in the *Oxford Journal* in 2007 entitled, “Nurse, Mother of Two and Four Transplants — Nancy Spaeth Tells Her Story.” I was invited to write a chapter on sodium for the soon-to-be-published book, *Dialysis, History, Development and Promise*.

**Hall:** What do you see as important new developments in ESRD technology?

**Spaeth:** I want to see patients get better, longer dialysis, which will increase their quality of life, allow them to be more active physically [and] socially, and in the work force. We can do so much more to rehabilitate people with CKD, as Dr. Belding Scribner promoted. I am also excited that there are new programs available to help donor/recipient pairs with blood types that are otherwise incompatible

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find suitable donor [pairs]. I think we can do a better job of reaching out to the community regarding living donation to reduce the wait time for kidney transplants. I am hopeful that we will find a way for kidney transplants to last without medications. In the meantime, we have to continue to advocate for Congress to eliminate the 36-month Medicare limit on Part B immunosuppressant coverage.

**Hall:** Is there anything else you would like to share with *JNSW* readers?

**Spaeth:** I never really liked the term “Life and Death Committee.” I always considered it a “Life Committee.” They chose [for] me to live—and with that privilege there was a responsibility to realize my full potential. I also prefer chronic kidney disease (CKD) over ESRD and wish that could be changed. I am thrilled that I had the means to help my children with college, and I am quite amazed and feel blessed to have lived to hold my grandchildren. All I ever wanted was a normal, decent life with children and the opportunity to give back to society at least as much as I have been given. I continue to strive toward that end.