VOICE EXPEDITION INTERVIEW TRANSCRIPT
The Oral History of Nephrology
Nancy Spaeth
Interviewed by Dugan W. Maddux, MD
March 8, 2010

DWM: (0:02 - 0:08)
I'm going to start with just a little introduction here because it gives us the date and the place and all that. And just gives a little starting for the interview.

NS: (0:09 - 0:09)
Okay.

DWM: (0:09 - 1:28)
So we'll start with that. So it's Monday, March the 8th, 2010, and I'm in Seattle, Washington with Nancy Stake to talk about her history of living with kidney disease since your diagnosis in September of 1959. So I appreciate your meeting with me today, and let's start at the beginning, Nancy.

Let's start with where you were born and raised, and then we'll get to where you learned about your kidney disease.

NS:
Okay. I was born in Everett, Washington, as was my mother.

And my family came here as pioneers in the 1800s. So a long history. Yes, a long history.

My middle name is Hewitt. The main street of Everett is Hewitt. So that's a little bit of background of why I was born there.

DWM:
What were your parents doing then?

NS:
My mother worked in a radio station called KRKO, and she was a traffic manager. My father was working as a superintendent of a warehouse or mill.

And then that changed after a while, and he did many different jobs. He worked as a machinist for Paine Field, which eventually became Boeing. And Mom continued to work as a traffic manager.

DWM:
And you have brothers, so tell me about your family.

NS: (1:28 - 1:29)
I have three brothers. I have two older brothers who are from my mother's first marriage. My brother is Ted Griffin. He was the man who trained Namu and owned Namu.

And I used to sell tickets later on for people. And my next brother is Jim Griffin. And Ted now lives in Bellevue, and Jim lives in Tacoma.

And my younger brother is Charlie. And he and I grew up together. He was three years younger than I was.

And we were very good friends and played together and always, you know, doing things to irritate the parents.

DWM:
No one else in your family has kidney disease.

NS:
No one else in my family has kidney disease.

However, having done my family research, I have discovered and met a distant cousin over the Internet who came through the German family, and my father was German. And her grandmother died of Breit's disease, which is what they called my disease when I was first diagnosed. So tell me about when you got sick.

DWM:
How old were you and what you felt like and how they figured out that you had kidney disease?

NS:
I was 11 when I was diagnosed. I had been fortunate, which was very unusual in the 50s, that the teacher who ran the track team at our grade school let me be on the relay team with the boys.

And I loved to run. And so I ran relays at the, you know, end of the year when they'd have these little, you know, shows. The kids were running relays.

And the boys never complained. I never heard them complain. So I was always...

But I grew up with boys, so I liked to do boy things. And the next year, when I was in the sixth grade, that was the fifth grade that I started doing that, in the sixth grade, I remember thinking I got more tired when I was running. And I remember my mother saying, when you get older, you get more tired more easily.

So I, at 11, thought I was getting older and getting more tired. And I went to my brother's wedding, my brother Jim's wedding in Scottsdale, Arizona in June, and was very, very tired at that. And I cried through the wedding, which I know now is something easy to do when you're not feeling well.

It's easier to cry. I cried through the whole wedding. My family was about ready to remove me.

And I was crying because I knew I was losing my brother to another woman. But that fall, in September, my mom had become separated from my father. And I remember coming down to her and saying, my urine is brown.

And she said, well, maybe it's something you ate. And the next night, she had a friend over, a friend named Shirley Bartholomew, who's very well known in Snohomish County and Everett. She just died last year.

And I said to them again, my urine is still brown. And Shirley said to my mom, I think you'd better take her to the doctor. So I did go to the doctor, and I do remember going into the hospital and having a cystoscopy or something like that.

I mean, that's the only thing I can figure out they might have done. And then shortly after that, and of course, you know, back then, they didn't talk to me about what was wrong. You know, doctors didn't tell people anything.

But we moved to Seattle, and we were then near Children's Hospital. And I got a nephrologist, a pediatrician who dealt in nephrology named Dr. Frederick Maul.

DWM:
What was the last name?

NS:
M-O-L-L. Frederick Maul. And he was my nephrologist, and he worked with Dr. Hickman. So they were the ones I saw the most when I was young. And I, in December of that year, mother hadn't moved quite yet. She moved at the end of the school year.

But in December, I went into the hospital the day after Christmas. And I was there.

DWM: (5:52 - 9:14)
What year would this have been?

NS:
This would have been 1959. Okay.

And I was there for a long time. I mean, there were no DRGs then. I was there for a very long time.

And they did a biopsy. They had to do it twice because he couldn't get the needles through my back the first time he tried because I was such a strong kid that I was so tense he couldn't get the needles in. And they actually were going to do then a percutaneous biopsy.

They had a needle. They didn't have to do an operation to biopsy your kidney. He was doing it with a needle.

Okay. And I remember, you know, being so tense, and he finally gave up. He couldn't.

My muscles were too strong. He couldn't do it. Of course, I'd been a runner.

And then the next time he tried again, he gave me some anesthesia so that it was easier. And that's when they told my mother that I had Bright's disease, which eventually was known as glomerulonephritis. And it's interesting now because I educate fellows, and they always say to me, which type was it?

I said, I don't think they knew about types back then. We just knew that it was glomerulonephritis. And they gave me huge doses of prednisone.

Now, I cannot tell you what the doses were because they didn't tell us anything then. But I was a tiny little girl, and I was so edematous with that large dose of prednisone that I couldn't get into a child's size 16 dress. I was huge.

I mean, they couldn't even button them. And they didn't have any bigger dresses at the hospital, children's hospital. So I had to wear something over my back.

And then that didn't seem to help. So then they gave me, they came in one day and gave me an IV of nitrogen mustard on top of the prednisone. And I don't remember anything after that for a few days.

I was pretty unconscious. They moved me into a private room. And I remember learning what Mother's footsteps sounded like coming down the hall.

And I knew what Dr. Maul's footsteps sounded like coming down the hall. And if I close my eyes, I can still hear that. I still can hear, I know exactly how he walked.

Because I'd gotten so edematous, and now that I was in bed, my face was so edematous and my head was so edematous that you could push your finger probably down to your first knuckle almost. And I couldn't open my eyes. I remember the volunteers coming in and offering me a doll.

But I was so not myself that I refused the doll. And, of course, when I came out of it, I wanted the doll back, but it was gone. And I do remember coming to enough one day.

I mean, I think I was more aware than they knew I was aware. I could hear what was going on in the room. But I do remember one day saying to my mother, please open my eyes for me.

So she pulled on the lids and opened my eyes so that I could see her.

DWM:
Weeks are going by, you think.

NS: (9:14 – 10:12)
Weeks have gone by, yes.

And I was getting a tutor. A tutor was coming in for me for school. And I don't remember when I went back to school.

But I did go back, maybe in the spring. But, and the edema eventually went away because they stopped the brain stem. And they must have tapered me off of it in the hospital because I don't remember being tapered.

I just took the pills I was given. And I went back to school. And I remember having to write an essay.

I was in the seventh grade now. And my essay was, pills, pills, and more pills. That's what I wrote my essay about.

And so people say, oh, you don't want to take that. That'll be more pills. I said, I've been taking pills all my life.

It doesn't bother me to take a handful of pills. In fact, I should take some right now. It's time.

NS: (10:13 - 10:14)
It's time. I had something to eat.

NS: (10:14 - 10:24)
Now I can take my presents home.

DWM:
You have your handy little carry case there.

NS: (10:24 - 10:24)
Yeah.

NS: (10:25 - 10:39)
It floats. When you live in Seattle with all this water, I suppose you need a pill carrier. Did you see how many I could take with one gulp?

DWM:
Yes, that was how many? Five? Yeah, big ones.

NS: (10:40 - 10:40)
Yeah.

NS: (10:40 - 11:27)
And my friends can't even take one big one. You might as well get it done. Well, I think I learned to do that when people were looking down my throat a lot when I was young.

And nobody needs a tongue blade. I learned how to hold my tongue down. You might as well.

If you're going to have to deal with it, you might as well make it easier. Right, right, right. So you're in the seventh grade.

DWM:
Do you feel sick? I mean, when you came back to the seventh grade...

NS:
I didn't really feel sick.

DWM:
Were you able to just reintegrate back and feel like a healthy kid in the seventh grade?

NS:
I wasn't doing a lot of physically active things, but I don't remember wanting to do a lot of physically active things at that point. And I don't remember feeling really tired.

DWM:
But you were able to get back into school and feel like you were just part of your class.

NS: (11:27 - 11:27)
Mm-hmm.

DWM: (11:27 - 14:16)
Okay. And were you taking medicine still then after you got out of the hospital and started back to school?

NS:
Well, you know what I'm thinking is I'm thinking that that nitrogen mustard happened in the summer.

So maybe you were on prednisone and then came out and then did nitrogen mustard. But I look at pictures of myself and I don't look edematous. So I think that they did the biopsy and the studies when I went in in December and those weeks.

And then after I got out of school, my mother had moved to Seattle and I went back into Children's. And I think that's when they did the prednisone and the nitrogen mustard. It was in the summer when I was there.

DWM:
So you're really, you're feeling bad and everything was just all in the summertime. So you were able to, after your biopsy and everything, just go back to school in the spring and everything.

NS:
What they decided, the way they think that I got it, was the summer between, no, the fourth and the fifth grade, I went to the public, our schools and never had a camp.

And a lot of us went to camp in the summer and slept in these tents with wooden floors that were kind of raised up by the river. And one day we were walking through the woods just on a little hike, a group of girls. And I was at the back talking with another of my tent mates.

And all of a sudden I heard girls screaming and running. And they had walked through a rotten log and there was a yellowjacket nest in the log. And by the time we got there, they were all swarming and we got really stung.

And I probably got stung the most because I was at the end. And it frightened me so much that I just stood there. And I still remember one of the young high school boys who was a counselor yelling at me to run.

And I didn't. I was just stunned because I was covered in bees. And he finally ran in and picked me up and ran down the hill and put me down under a tree where one of the adult counselors was, probably a parent or a teacher.

And all of a sudden I stopped and I said, why are you hitting me? He was slapping me. And he says I'm trying to kill the bees that were in my clothes.

So they decided that I had gotten toxic from the bee stings and that this is what had damaged my kidneys. And I actually, one day, decided to research that on the internet and I found something about it. I actually did find something about bee stings causing pulmonary lymphitis.

So I thought that was interesting.

DWM:
And that's what they thought rather than stress.

NS:
Yes.

DWM:
The strep would certainly have been very common.

NS: (14:16 - 14:43)
Yes.

But I don't remember having strep. I don't remember being on any antibiotics or anything like that. And usually when you've had strep throat, you remember it.

It hurts. So I don't remember that. And I doubt that I would have gotten over it without something.

Anyway, so this little disjointed.

DWM:

So that summer, maybe then your course of Nitrogen Mustard was in the summer after seventh grade.

NS: (14:43 - 14:43)
Yes.

DWM: (14:43 - 15:03)
And what happened then after that? Was there something else?

NS:
Well, I started the eighth grade, excuse me, at a private parole school.

And I just, you know, went to the doctor every so often. And I think they were just watching it. And at that point, they told mother that I shouldn't eat salt.

DWM: (15:04 - 15:04)
Hmm.

NS: (15:05 - 20:40)
So we were watching my sodium intake. And we weren't very good at it because nobody knew about that in the 50s. And you couldn't buy low sodium anything on the shelf.

So we learned to make our own mayonnaise. We even learned recipes to make pickles because I love dill pickles. And I can't eat them.

I don't eat them anymore. My mother made them herself. You know, we grew up with dill pickles.

And my father was German. So we always had sauerkraut and Polish sausage and buttermilk in the refrigerator. Even though he was third generation, we still had all of that.

And I love sauerkraut. But I just close my eyes and remember what it tasted like. I can't eat it anymore.

So I went to school. And we really didn't have a sports team at that girls' school. I did walk to school.

And I don't remember getting that tired walking to school. It was fairly flat. And it was probably at least six, eight blocks.

But I don't remember really being that tired. When I got into high school, so, you know, everything went along as normal. I got into high school.

I moved in with my older brother, Ted, because he lived closer to a high school that they preferred. I did tend. And that Christmas, for Christmas I got snow skis.

I got snow skis and parka and poles and all the gear I needed. My sister-in-law's sister knit me a cap. And I was all ready to go snow skiing.

So I went in the winter. We went to what was a ski school. We went to a place in the university district and caught the bus.

And went, you know, for most of the winter up skiing every Saturday. And at the end of the year, they had a slalom race. And I was in the beginners group.

And so all the beginners were in the same group. And the boys and the girls were in the same race. And I remember watching the boys come down the hill and thinking, those crazy boys are trying to go too fast because the moguls are big.

It's spring skiing. There's ice on one side and slush on the other. And they're going too fast.

So I kind of analyzed what they were doing. And it was my turn to go. I just decided I would go as fast as I could without falling.

And I won the race. I came home and I told my mom and I told my dad, who was in Alaska then. I wrote him a letter.

And I told my brothers, I beat the boys. So I was always very proud of that. I have a trophy that I came in first.

And that's probably... And things just kept going. Obviously I was going skiing, and so I was doing well.

And the next year, I went skiing more. I don't believe I was in that ski school, but I did go skiing with my family. And my senior year, a friend of mine wanted to go skiing and I remember going up to go skiing with her.

And I was 17, because I was kind of young for my class. My birthday was in October, so I was 17. And we went up to go skiing at Hayak, which is on the Snoqualmie Pass.

And I went up and I skied down with her. And I felt terrible that I had disappointed her because I spent the rest of the day in the lodge. I couldn't do it.

I was too tired. It was too hard to get from the lodge to the lift. I just, I couldn't do it.

And then I just felt terrible that I disappointed her. And she had to ski alone. So it was about that time that I really began to feel it.

And during high school, you know, we girls would all get together, a whole bunch of us in a car, no seat belts in. And we would go to a football game, high school football games and the high school basketball games. And then we would go to a restaurant called the Burger Master.

And we had to stay in our cars. You know, it was where they brought the trays and put them on your window. And we were not allowed to get out of the cars because evidently, you know, there had been too many fights and things going on.

And we'd yell at people out the window and we'd all be at the Burger Master ordering our Coke and fries. And my fries always came without salt. So I always ordered my French fries in high school without any salt.

And the girls always thought, oh no, Nancy's with us, we have to wait to get our fries. Because they always had to fry a new batch so I could get mine without salt. So I began watching my sodium really early on.

And I wrote my sister-in-law recently, because I'm writing a chapter for Dr. Ng in his book about low sodium. And I wrote to her and said, do you remember trying to cook me food without salt? Or what do you remember?

So she wrote me and she said, I just remembered that you hated the salt substitute and I didn't know what to do. Yeah, the early salt substitute was I guess...

DWM: (20:40 - 20:40)
potassium.

NS: (20:41 - 31:18)
And it was a little bitter. And I didn't like it. Yeah.

I didn't remember that, but she remembered that when she was trying to cook. She said, I'm trying to cook with two toddlers. So that pretty much was high school.

I didn't turn out for any sports. My doctor who worked with me, went to Dr. Scribner, and also Dr. Emily Fergus, who was working with Dr. Scribner.

DWM:
In high school, while you were in high school?

NS:
While I was in high school, yes. And Dr. Fergus decided that I didn't need to take physical education. She said, Nancy, I don't want those hard-boiled P.E. teachers telling you how much you have to do. You are active. You go snow skiing. You're physically active and I trust that you will stay physically active and you know your own pace.

So I was exempt from P.E. and all my friends were jealous. So I often would go to study hall and just study or go to the library or hang out somewhere with the kids and I didn't have to take P.E.

DWM:
Did you know anyone else with kidney disease during this time? No, I knew nobody else.

But it sounds like it was not a big issue in your life. I mean, other than sort of watching yourself and having to readjust a little bit, you really had a fairly normal life.

NS:

I had a very normal life.

And what I'm really grateful to my family and my brothers for not treating me like an invalid. They never did. In high school, at my brother's house, I had chores to do.

I had to do all the ironing. You know, on spring break, I had to mop floors. Nobody told me I was sick.

And so I just, knowing that I could, you know, that everything was okay, you know. Nobody treated me as if I were sick. Except some of my mom's friends, and I hated that.

So, I don't know. What else do I remember? I do remember getting a little edematous.

I can look at pictures of myself and seeing some edema. And so I probably ate more salt than I knew I was eating because nobody really knew how to do it. But I did my best.

DWM:
And surely your kidney disease was slowly progressing over this time.

NS:
It was. And so I graduated from high school, and I went to the University of Arizona in Tucson.

DWM:
And how did you get from Washington to the University of Arizona?

NS:
Well, my sister-in-law was from Scottsdale. And her sister, and actually that Christmas, my high school year, during Christmas break, my family decided they were sending me down to Scottsdale for Christmas.

And I have a feeling they thought I was going to die. So they were making sure that I got to do all kinds of things. And off I went to Scottsdale for Christmas break.

And I stayed in my sister-in-law's home with her father and his second wife, and with Gail, her sister, who was my age. And Gail and I just hung out. She had a good friend named Harvey Kitchell.

And Harvey would come and pick us up, and we'd go to the movies. And Harvey was going to go to the University of Arizona. And a lot of Gail's friends were going there.

Gail did not go. So I decided I'd like to go there too. So I applied, and I was accepted, and I went to the University of Arizona.

What year would that have been that she started? That was in 1965. And my mother was in a sorority.

She was a Kappa, Kappa Kappa Gamma, as well as my aunt. And, of course, they expected me to go through Rush. So I did, and the Kappas didn't want me.

My grades weren't high enough. But studying was hard in high school. I was tired.

In my last year of high school, I was really tired a lot. So I, in fact, I got out of school early. They let me out of school early because I was tired.

So I joined the Pi Phi's. I became a Pi Beta Phi. And my sister-in-law's brother, Walter, was also going to the University of Arizona and knew all the girls.

So I think he talked them into getting me into that house. I don't know. But, you know, we were the baby-blooming, and they didn't have room in the sororities for us.

So we stayed in the dorm. And I was really having a hard time eating in this place next to the dorm where all the dorm kids ate, in this cafeteria, and avoiding salt. I just couldn't do it in there, and I complained about it.

And so the sorority let me, and I was the only pledge, let me go to the sorority house and eat with the girls there. And the cook would, you know, fry my eggs without salt, and I wouldn't eat bacon. So they were trying to accommodate me.

DWM:
Good for them.

NS:
Yes. So, you know, we tried.

But while I was there, I was really tired. So Walter and his friend Jimmy Kitchell, Harvey's brother, got me a Honda 50 so I wouldn't have to walk to class. So I could just drive my little Honda 50 all around the campus to my classes.

And I had a disabled sticker on my, on one side of the little knee guards in the front and the Pi-Fi sticker on the other side. And the boys would hitch rides and we'd just, you know, to class. And it snowed when I was there in Tucson, and nobody could believe it.

They were all hiding inside looking outside at the snow, and I'm riding my Honda 50 through the snow with somebody on the back of it who was waving his ROTC cap in front like windshield wipers. So, I mean, I had a wonderful time. I mean, it really didn't get in my way.

I dated and I had lots of fun. And I'm still friends with two of my roommates from that time. They're Facebook friends of mine now.

And our other roommate died of cancer, bladder cancer. So, but we're still, I mean, after all these years, we still write back and forth and do that. But at the beginning of the second semester, I was taking physics, and I loved physics.

My dad was good at teaching me that. I began vomiting in the planter boxes outside the physics class in the morning. And I was not feeling well, and it was harder to eat.

And I had a nephrologist down there who had been recommended to me from here, and his name was McGregor. They gave me two names, and I picked McGregor just because of, he's the one that had the carrot patch, isn't he, in the children's rabbit book, Mr. McGregor's patch. Anyway, I really liked Dr. McGregor, and he was really a great guy and really helped me a lot. And so I went to see Dr. McGregor, and they put me in the hospital and decided that I needed to go home. So, everything was starting to get arranged. The sorority house had me come in, and they initiated me all alone into the sorority.

The rest of my class followed later before I had to leave. And I remember flying home, and Mom picked me up and took me straight to the university hospital. And I was there with Dr. Scribner, and I remember waking up in the morning and hearing seagulls outside the window and knowing I wasn't in Tucson anymore. I was not in Tucson.

DWM:
And did they actually admit you to the hospital?

NS:
They admitted me to the hospital, yes.

Yes, they did. And I'm sure my blood pressure was pretty high at that point. And I remember being given Aldomet, which just dropped my blood pressure so low that I had to crawl on the floor.

And so they had so much trouble regulating my blood pressure with that Aldomet. And then at that point, Dr. Scribner transferred me to maybe it was, I don't know, somewhere in this period of time. It was all very foggy to me because I was pretty sick.

I came home in February, and I got pretty stabilized because I worked for my brother that summer selling tickets to the Seattle Marine Aquarium and for people to see Namu. And so my brother hired me, and I sold tickets.

DWM:
And this would have been the summer of...

NS:
The summer of 66. Okay. The summer of 66.

And I think it was during this period of time that I must have started going through the committee.

DWM:
Yeah. And I want you to, in any details, anything you remember about going through the committee. And you mentioned on your website that it was called the Admissions and Policy Committee.

NS:
And we called it the Life and Death Committee. Which is what a lot of people call it.

DWM:
I'm not sure I've ever really heard the formal name of it.

NS:
It was the Admissions and Policy Committee. And we called it the Life and Death Committee.

And today when people say death panels, I say, no, no, no. Everyone's going to die. It's a life panel.

A few get picked to live. So I'm trying to reframe that for people.

DWM:
Yeah. So you think in the summer of 66 you would have started that process.

NS:
I think so.
DWM:
Scribner would have had you start that process.

And at what point do you remember, I'm sure they were looking through your records and things that you weren't even aware of that they were doing. But what part of it was your part of dealing with the committee?

NS:
Well, when I came home I was so bored.

Mom was at work. At that point she had gone to work for the state of Washington as a social worker. Because she did have a degree in political science.

Mama did. From 1930.

DWM: (31:18 - 31:19)
That's amazing.

NS: (31:19 - 34:20)
Yeah. So she got a job as a social worker at, because I don't think there were social worker degrees back then, at the state. And I think she knew this was coming.

And she had double covered herself with insurance. She moved to Seattle so I'd be near children. She got a job at the state level.

She was totally planning. And I can look back now and say, oh, Mama, you really did a good job, right? But nobody's telling me anything.

They just drive me to this appointment, drive me to that appointment. And I'm too sick to really know. And what I remember, the details of what I remember, is I remember having to go see a psychiatrist.

And maybe before that I took two days worth of psychological testing. I remember this very nice woman, some psychometrist probably, took two days. I did two days worth.

And I'm sure it didn't take all day, but maybe a couple hours one day and a couple the next. And I remember, you know, it may have been like the MMRI. And because I remember, the one question I remember the most was asked over and over again in different ways are, do you love your mother?

Do you love your father? And that was in there so many ways and written in so many ways. And it wasn't the exact same question, but it intimated that.

So that was, I kept thinking, that's odd, why do they keep asking me if I love my mother and love my father? And of course I did, so that was okay. And I remember Rorschach tests, ink blots, and you know, they'd ask you, what is this?

And I'd say a butterfly. You know, anything that's symmetrical that prints out that way. So I remember the butterfly.

And one of the other questions I remember, these are actually still in my mind, these specific things, were being shown these pictures of people doing things and being asked, what are they doing? And I do remember one because I was in college, I was getting a teaching degree. There was a woman standing with a pointer, and I said, well, that's just a teacher at the blackboard, you know.

So pretty simple, I didn't say crazy stuff, so I guess I was all right. And I did get really bored after I came home, so I did go spring quarter to the University of Washington. And I applied a little bit late, but I just couldn't sit at home alone anymore.

I was just going nuts. And so I applied a little bit late, and I talked to somebody in the admissions office, and they said, well, you're a little... So I went to the university, and I sat in the dean of admissions office and waited, just talked to him.

And finally he came in, and he said, well, you applied late. And I said, I know, but I've been sick. And you have to let me go to school because I just have to go to school.

And he let me in.

DWM: (34:21 - 34:21)
Good for you.

NS: (34:22 - 43:36)

So I got into the University of Washington for spring quarter and went to the sorority house there. So I got to be with some of my friends. Actually, there were a couple of my friends in that from high school, and I got to be socially involved again and go on dates and was back to my normal routine.

So that helped a lot.

DWM:
What happened? And then the summer came, right?

NS:
So, and then I worked with my brother. And in the fall, my brother, who lived in Tacoma, was good friends with Booth Gardner, who was a former governor of our state and who was on the board at University of Puget Sound. Now, Booth Gardner, and I don't know this for sure.

I guess I could call my brother and verify it. But I got into, and I put pieces together since then. They said, come to Tacoma and go to the University of Puget Sound.

I didn't know why. I just did what I was told to do. So I left the University of Washington and all my friends, and I went to UPS in Tacoma.

And I never could figure out why I was going there. I didn't really think about it very much. It was a really hard time for me.

It's a time where I did a lot of philosophizing and a lot of thinking. But I still kept my grades at a decent level. And I still went out on dates, and they had a pie-pie house there, too.

It wasn't a house. It's more of a room. And got to know a gal named Gina, whose dad was a judge.

And we became good friends. But while I was going there, I remember it dawned on me that I had a terrible problem, but other people had terrible problems, too. And everyone's own worst problem was the worst problem in the world.

And that stuck with me all my life. It just dawned on me that, you know, I'd see these girls who didn't have any problems as bad as mine, but they were hysterical and more upset than I was. And I realized that that problem for them was the worst thing that could happen.

So then it made it easier for me because I knew that that was... But I was getting sicker and sicker during this period. And Christmas break came, and I was at my brother's house.

And all of a sudden, I got up one morning. My sister-in-law would take my nephews to school. And I think Scott was...

DWM:
How old was Scott?

NS:
Scott was maybe in kindergarten or first grade. And he's 50 now.

He... She would take them to school. And I remember getting up in the morning and having this terrible, terrible, terrible abdominal pain.

And they had a housekeeper who lived in and helped with the kids because... Anyway. And I can't remember.

No, Asher was born in 69, so... Okay, so there were two boys in them and a third boy. And I was just in terrible pain.

And Wendy came home and called the doctor in Seattle. And at this point, my doctor was Dr. Pendrous. And earlier that...

A few weeks before that, my sister-in-law said something. You know, I'm jumping ahead. I didn't tell you about going to see the psychiatrist.

DWM:
Let's go back to it.

NS:
Really?

DWM:
Let's go back.

NS:
So after I did all the Rorschach tests... You know, I get tangential here. Something reminds me of something.

After I did that, I remember... I do remember Mother driving... Oh, my gosh.

Did that fall out of my pocket? Driving me to the psychiatrist. And I remember her trying to figure out how to get there.

It was in Bellevue, which is on the east side of Lake Washington. So it was a neighborhood we weren't familiar with. But driving me around and trying to find this particular office.

And I remember going in. I remember she sat in the waiting room. And then I went in.

I remember that he was not a very tall man, had dark hair. I sat down in a chair in front of his desk. And he basically said, Tell me about yourself.

That's it. Just tell me about yourself. So I'm 18.

No, I was 19. I just had my 19th birthday. I said, you know, I don't remember what I told him.

I probably just said, Well, my parents are divorced. My dad lives in Alaska. I have three brothers.

I'm going to UPS. You know, whatever I told him. And I must have sounded normal.

So that was the other thing I know. I also know that my mother had to go and talk to the financial people. And to the social workers.

And probably about 15 to 18 years ago, I went to the university and read through my records and came across my mother's conversation with the social workers. And lo and behold, I discovered my brothers were there too. My two older brothers.

So what I discovered was that whatever mother's insurance wouldn't cover, they would pick up. So, I mean, they were the ones that got me going skiing. And they're the ones that helped in so many, so many ways.

The other thing that they did for me was they got me water skiing. So one of the Christmases, I got a Wally Burr custom-made water ski. And I went to Wally Burr's basement and he made me double boot bindings.

So that I learned to water ski, I could jump off a dock with both my feet in the boots. And, you know, they kept me active. They never said, you can't do this.

And that's something my father never said to me. I do remember saying something to my father when I was young. Oh, Daddy, I can't do this.

And he said, Nancy, there's no such word as can't. You can do anything if you want it badly enough. And that really has helped me.

So, where were we? We were going back to where I had this abdominal pain. Right, at Christmas.

And Sis Wendy threw me in the car. She's panicked. She's driving way too fast down the freeway to Seattle.

But there wasn't as much traffic as there is now. So we're driving down that freeway to Seattle. And I went in the hospital.

And I think that's about the time that Dr. Pendras became my doctor. And he... So I was in the hospital.

And I had appendicitis. So they removed my appendix. And I think they were thinking of, while I was out, that they would put my cannulas in.

Because at some point, I got accepted. And I don't even remember. I remember sometime in the fall, my sister-in-law saying to me, you know you may not be chosen.

And I basically turned to her and said, I think I will. That's the only time I remember anybody saying anything to me about it. I think she was just so nervous about it that she couldn't help herself.

And they were in their late 20s, you know, around 30. They were young. So anyway, I woke up from the appendectomy.

And then they told me, we're going to have to go back and do another surgery. We couldn't put your cannulas in because it was too infected. So I had my cannulas put in.

I went home for Christmas. And I remember opening a present and getting up and going and vomiting. Coming back and opening another present and feeling just awful.

And I had, you know, I had a big scar on my tummy and a big owie on my arm. And, you know, it was Christmas. And the interesting thing to me was, they took me to dialysis at Eklund Hall the day after Christmas.

And that was the first time I went to Children's was the day after Christmas. So everything always happened the day after Christmas. Yeah, the 26th of December.

DWM:
I want to talk about the cannula before we get too far from that. Tell me what you remember about the cannula, that first cannula. You, I'm sure, became very familiar with cannulas and all after you got started.

But when you first went home with that cannula, what did it look like? What did you think about it?

NS:
The cannula was in the lower part near my wrist of my left hand.

DWM:
Yes, and we're looking at your scar now.

NS: (43:36 - 43:36)
Yeah.

DWM: (43:37 - 43:46)
You can see the scar. Yeah. And this was the venous entry and this was the arterial.

Yeah. And at the time, I mean, when you were 19?

NS: (43:47 - 43:47)
Yes.

DWM: (43:48 - 48:05)
Yes. What did you think about that cannula in your arm?

NS:
I didn't really think a lot about it.

It hurt until it stopped hurting, you know, the surgery. I had to wear a brace around here. Around your hand.

Yes, and it went down the back and then you wrapped curlips or gauze around it to protect the cannula. Right. And to keep your arm from moving because it was all Teflon.

DWM:
And you understood enough about dialysis before you started to understand that this cannula was going to allow your blood to circulate through the machine?

NS:
I knew that. That's about all I knew.

DWM:
Okay. Had they showed you a machine?

NS:
No, they hadn't shown me anything.

I knew nothing. Yeah. I just showed up.

Yeah. So, and the first one had, you know, a straight venous tube, Teflon tube, and then the arterial one. And then there was a little curved tube that hooked the two together.

And it was, I don't know, it was a little U-shaped that hooked them together. And we usually wrapped our gauze so you could see the tip of the U-shape and always keep an eye on it to make sure that it wasn't clotted.

DWM:
And this cannula we're talking about was a Scribner shunt.

NS:
Yes.

DWM:
And did you understand that Scribner, who you knew, who had taken care of you, had been responsible for developing this special shunt?

NS:
I can't remember.

I probably knew afterwards, but I was so sick right then. That I really don't remember. I just remember that's what you had to do.

DWM:
And the cannula, the Scribner shunt that you had put in, did it have the metal pieces where the connector was?

NS:
Yes, it had a metal piece that was taped down to keep it from moving because it was so stiff that it would damage the tissues in the arm. And as you can see by looking at it here, that wrist is different than the other one.

Yes. It got infected eventually. It got pretty infected.

And this blue mark has been there ever since from the infection.

DWM:
How long did you have this first cannula?

NS:
I don't remember how long I had it.

But it became infected and then they would move it to your right arm. And then when that one didn't work anymore or something happened to that one, you'd go back to the left arm. But I didn't have the straight Teflon with the metal plate holding it in place for very long.

Because not long after that, they hooked the Silastic to the Teflon and it was much more flexible.

DWM:
And they could get rid of the metal plate.

NS:
They could get rid of the metal plate.

And at that point, we had a straight connector that was a male connector that would go into the two arterial venous cannulas and hook them together. And then we had taped little tabs to each side and taped it together to keep it.

DWM:
Is that called a tape bridge?

NS:
Well, we didn't call it a tape bridge, but it certainly is a tape bridge. We didn't have names for it. And you know what I forgot to bring today that I wanted to bring and show you is I still have a cannula clamp.

DWM:

Ah, that would be fascinating.

NS:
I have a little cannula clamp. And I was just rushing so much this morning.

If I don't do things the night before, they'll get left out in the morning. But I still have one of those little cannula clamps where we would clamp it to separate it and hook to the machine. And I would, after that, well, I'll talk about that later.

But anyway, so I had that, and I started dialysis the day after Christmas. So where did you actually go to start dialysis? I went straight outpatient.

And was that at Swedish Hospital? That was at Swedish Hospital in a building called Eklund Hall. Eklund, E-C-K-L-U-N-D.

It was on the corner of Columbia and Boren Street, and it's still there. That building is still there. I pass it now and then.

DWM:
So you show up for dialysis, was it in the morning, in the afternoon? Do you remember?

NS: (48:05 - 48:06)
I don't remember.

DWM: (48:06 - 49:10)
And were there other people dialyzing? There were lots of men there. There were lots of men dialyzing.

DWM:
Do you think there were 10, 15? How many people were there on that particular day?

NS:
Ten or fewer, maybe.

DWM:
So you think maybe you were the only woman there?

NS:
At that point, I don't remember seeing any other women there. Later, there were some women.

So I was so sick because, you know, it was just a couple days after the cannula was put in and just a few days, a couple days after I had my appendix removed. And I was so uremic.

DWM:
I'm sure you were very uremic, yeah.

NS:
That I just don't remember very much. I remember I could tell you, I could go there now and tell you which bed I was in because of my view of the nursing station.

DWM:
And you were lying in a bed.

NS:
We were in a bed.

DWM:
Old hospital beds that you cranked up.

NS: (49:10 - 49:11)
Cranked up, yeah.

DWM: (49:12 - 54:39)
And do you remember anything about the machine they were using?

NS:
I don't, but I can tell you because I was on that machine for a little over five years that eventually when I, you know, got better. The only thing I remember about that day was watching everyone in the room.

I felt like I was in a dream, you know, it felt like a fog. And I know this is a spiritual statement, but the only thing that kept flowing through my head in that fog that I was in watching the nurses and the other patients was all is one. We are all one.

And that completely dominated my mind. That's what I remember about that day more than anything else. And I remember telling that to Dr. Pendress. And he goes, oh, a lot of people hallucinate when they're on the machine. And I patronized him. Just let it go.

That's maturity at that point. To not argue with him about it. But it has been an issue.

DWM:
I think, you know, I'm a nephrologist, and it is an issue. And one of the reasons I think it's very important to talk to you today is that it's very difficult for those of us who've taken care of a lot of patients. We've seen a lot of people in dialysis.

We know a lot about dialysis. But having not ever been there, it's definitely a different experience.

NS:
It's very different, yes.

I think every renal fellow should have to go and sit in a chair and stay there for four hours. We did it overnight, of course. In fact, when they first dialyzed me, this is what I remember.

I only weighed 88 pounds because I hadn't been eating very much. And I was on a pediatric Kiil. So it was half the size of the normal Kiil.

And they dialyzed me 12 hours.

DWM:
That first day?

NS:
I think so.

And because I couldn't take that volume reduction that quickly. I just was too small. And so I was dialyzed in long periods of time.

DWM:
How many days a week would you go?

NS:
I was going three days a week. And eventually I didn't miss any school.

I went back to school in Tacoma at UPS, but the dialysis center was the only one in the world that was outpatient. So I had to drive three times a week back to Seattle, get my dialysis overnight, get up in the morning, and drive back to UPS for my 7.30 class. This is where my friend Gina came in.

She heard me saying that I was falling asleep on the freeway. Now, still today, people are driving themselves home from dialysis. I don't know how.

It's like being on drugs. You really don't feel very well. And I was being in one lane of the freeway and wake up in another lane.

Luckily, it was 6 o'clock in the morning, and it was Seattle in 1966, and there wasn't very much traffic. And when Gina heard that, she started driving, coming and picking me up. And I had forgotten that.

And later I'll tell you how I found out that she remembered. So these are the things that I remember about then, and I did finish at UPS. And I thought, I can't do this anymore.

I cannot. I just cannot be driving back and forth like this. I can't do it.

I just feel too horrible. Eventually, I did get to a larger keel. And they did a study.

I remember them doing a study and taking me from the pediatric keel to a full keel. And Susie Mong was the nurse. And I hadn't been on a full adult keel.

And they were running down, and they were measuring the dialysate that was going in and measuring what was coming out of me and testing. I don't know what research they were doing on this, but testing to see how much uremia was in there. I don't know.

Anyway, they were doing this, and my blood pressure was dropping and dropping and dropping and dropping. And Susie kept telling them, she's not doing very well. But they were doing research.

They were not looking at the patient. They were only looking at the fluids, you know. And Susie took me off the machine, which she, as a nurse, had to do.

She was responsible to do that. I was her primary thing. And they got pretty upset, and she stood her ground and she said, I'm not going to watch this patient die because you're looking at her.

So, in fact, the patient next to me was Tim Myers, and he was telling also Susie she needs to come off. And he was, you know, a patient next to me. And he was a businessman and family man and father, and so he was always very protective of me.

DWM:
Well, let's talk about the other patients. In that first couple of months of your dialysis, I gather, I'm sure you were in a fog in the first couple of treatments.

NS: (54:39 - 54:39)
Yes.

DWM: (54:40 - 55:01)
Gradually, did you feel a little bit better?

NS:
I did, yes, because I did. I felt well enough to go back to school.

DWM:
School, yes. And, you know, your mind becomes more clear.

NS:
Yes.

DWM:
And, you know, you can think better and problem-solve better and not so short of breath. Were you dialyzing with the same people? Did you see the same people when you came into the unit?

NS: (55:01 - 55:04)
Eventually, yes.

DWM:

Did you all get to know each other pretty well?

NS:
Yes, we did.

NS: (55:05 - 58:09)
I dialyzed on Tuesdays, Thursdays, and Sunday nights. And I went in the evening. Usually, these men were already on the machine because they were bigger and they had to run longer than I did.

And there are some pictures out there of Jim Myers. I've seen them, you know, in some of the historical pictures with Susie. And he usually was in the bed next to me.

And he really was very watchful and, you know, kind of watched out for me. And then there was Harvey Gentry. And there was Jim Miller.

And there was Chow Chin-Yang, who was a well-known photographer in Seattle. And later, I remember three women. One of them's name was Joyce Abbott, and she came on after I did.

But mostly they were men. I would say men around 40 to 45.

DWM:
And were they pretty stable?

I mean, at least you all were on dialysis, which was a big, difficult treatment. But did you feel like, everybody feel like, well, you came and you did your dialysis, and then you were well enough to go about your life?

NS:
Yeah, they got up and got dressed, put on their suits, and went to work.

Pretty healthy looking. And eventually, I got up and got dressed and went to school. So, I eventually changed to Seattle University because only a couple blocks away from the dialysis center, my sister-in-law was very angry at me.

And she kept saying, you're selfish, you're not thinking of anyone else. And I said, I said, Wendy, if I don't take care of myself, you're going to have to take care of me. And I cannot drive, just drive anymore.

She was very, very angry.

DWM:
Why was she angry?

NS:
Well, this is what it took me years to figure out.

And my younger brother was clearing the table because he was living with them permanently and going to a boys' school down there.

DWM:
He was living with your older brother?

NS:
Yes, yes.

So, we were both living there at that time. And this was not Ted, this was Jim. And he came in and he was so upset that he said, you need to stop.

You need to stop. Because he didn't like us arguing. I used to remember exactly what he said.

I don't remember anymore. But he was very upset. Because Wendy kept saying, you're selfish, and I kept saying, I'm not.

And eventually I did change and I applied to Seattle University and I changed over. What I figured out was it cost them more money for me to go to Seattle University than it did to UPS because Booth was on the board and I think they got a discount. I think that he arranged for a lower tuition for me there.

And this was upsetting because now it was going to cost them more money for me to go to a different college. It all makes sense. I mean, I figured it out.

DWM:
But you didn't really know or understand?

NS: (58:09 - 58:10)
I didn't know then.

NS: (58:10 - 1:00:34)
I couldn't figure out why they were so angry at me at wanting to go to a school that was only a couple blocks away where I wouldn't have to drive on the freeway and fall asleep. And my friend Gina was very supportive of me because she came and helped me move back home. She came and she lived in Tacoma and she helped me move back home.

And so then once I got into Seattle University Stop me if there's something else you want me to say. Once I got into Seattle University and I was living back on Capitol Hill where my mother lived you know, less than a mile, maybe a mile away everything was close. Mom was close.

The college was close. The kidney center was close. Swedish was right there.

Dr. Pendris decided I really needed to gain some weight. And I hadn't been gaining very much. So...

DWM:
Take your time. This is no problem.

NS:
He arranged for me to eat all my meals in the cafeteria at Swedish Hospital with one of the residents.

And I don't remember her name. It was a female resident. And she would come rush...

This was... He was an order from... She would come rushing in and find me in the cafeteria and sit and eat with me.

And he made me... He made her sit and eat with me. And I think it was more that I would eat with some company.

And she could talk to him and say she ate whatever. And so... But I think it was a pretty wise decision on his part, Dr. Pendris. And he was sort of the medical director of the kidney center then and my physician. Dr. Scribner had passed me off to him. So I ate with her all three meals.

Breakfast, lunch, and dinner. And I could walk across the street to Seattle University because it was literally almost just across the street. And then...

And eventually as I began to gain weight, he said, OK, you don't have to go for breakfast anymore. Just lunch and dinner. Nutrition has always been a big issue for him.

And eventually I didn't have to go for dinner anymore. Just lunch.

DWM:
So feeding you and having someone eat with you was a very good solution.

NS: (1:00:35 - 1:00:35)
Yes.

NS: (1:00:36 - 1:01:30)
And it worked. And I did begin to gain some weight. But I've always been small all my life.

I've always had trouble. I can always remember my dad making me finish my dinner when I didn't want to finish my dinner. I remember going to the officer's club at Payne Field because Dad was working there.

And even though he'd never been in the military, we got to go to the officer's club and eat. And it was cheap so that's probably why we went. And I remember Mother being gone on a trip and he took us there for dinner and ordered us...

You know, we were kids. I was in the fifth grade or something. He ordered us these meals that were adult meals.

And I remember not being able to eat anymore. And he kept saying, eat, eat. And I would...

You know, you grew up on German farms in Wisconsin. They just keep pushing the food at you. And I just couldn't eat anymore.

And finally he said, well, drink your milk. So I picked up my glass and I took a swallow of milk and it came right back up on my plate. And he goes, never mind.

I think you're finished.

NS: (1:01:31 - 1:01:32)
We're finished. We're finished, yeah.

NS: (1:01:34 - 1:02:34)
So I never was a big eater. I was more of a grazer kind of kid. And my son is exactly the same way.

And we're all thin. And my dad was thin. That's who we are.

So it really was. It's always been hard for me to gain weight all my whole life. And I'm working on it right now because I was so sick.

In November I had pneumonia. In December I had to get antibiotics. And then December I had bronchitis really bad.

I had the worst cough. People still remember my cough that talked to me during that. And then I got a stomach flu two days before Christmas Eve.

So all that Christmas food for a week or so I wasn't eating very much. And I really did lose, oh, probably 8 to 10 pounds. So I'm still trying to gain that back right now.

Anyway, back to...

DWM:
Yeah, so as you start dialysis in Christmas and the winter of 66, you were feeling better.

NS: (1:02:34 - 1:02:35)
I was.

DWM: (1:02:35 - 1:04:03)
Did you look back and say, gosh, it's been a year since I've felt this well. Could you then in retrospect say, I've really been sick for a long time. I really feel better now than I did.

NS:
I wasn't that analytical. Because I was 19. Right.

And I think 19-year-olds look at the now, and they don't look at the future, and they don't look that much at the past. It may have served you well, I mean, at that point, not being real worried about... Because you're invincible.

DWM:
Yeah. And I can imagine at 19 if you'd really been able to think about it, you'd say, oh, my lifetime is going to be dialysis, but it's good that you didn't have that concern, I think.

NS:
No, not at that point, I didn't.

Within a year or two, I did. But because I was starting to watch the people around me and watch some of them not come back.

DWM:
Right.

NS:
So I wasn't that analytical. There were other times in my life I felt that. But at this point, I just knew that I was able to get up and get going.

It was like having the flu and finally being over it and getting up and get going again. We talked about the patients there in the unit when you started. Tell me about the staff there.

The nurses, it sounds like, were functioning fairly independently to some extent. Quite independently because we were there at night. They were wearing white dresses and hats.

DWM:
They were all women.

NS: (1:04:03 - 1:04:04)
They were all women, yes.

NS: (1:04:04 - 1:05:10)
They were all women. Oh, I'm beginning to think of some other things. I'm going to write this down so I don't forget.

Fundraising. We were a non-profit. Right.

So there was fundraising and, oh. We were all getting the same dialysate. There was a central system that mixed the dialysate in this big room and it came through the wall to each bed and we all got the same.

Okay, here I am, you know, the 90-pound 19-year-old with these men who were 150 to 250 pounds and I'm getting the same dialysate. So in some of those early days, I'd get off of dialysis and be eating chicken broth and salting crackers to get my blood pressure back up.

And I remember the nurses sitting there chatting with me at 3 o'clock in the morning while I'm eating my salty broth and eating my crackers so that I could get up and go to school.

DWM:
Were the nurses setting up dialyzers? I mean, when you came in, was your dialyzer in your machine? Ready to go.

NS: (1:05:11 - 1:06:19)
Ready to go. I think they had technicians. And sometimes in the night, this occurred fairly frequently, the central system would go off and the blood wasn't warmed.

So the dialysate was coming through cold, the blood was cold, and the nurses were scurrying around getting these old metal bedpans, filling them with hot water and curling our tubing into the hot water in the bedpans and then throwing blankets over all of us. And then the technician that always came in the middle of the night was Louie Lopez. And we'd cheer when Louie came through the door.

Louie knew we all loved him. And he would go in and fix it and then the dialysate would get warm again and we could go back to sleep.

DWM:
Aside from the central machine going out, were there any other sort of issues that would come up fairly often?

I mean, were there leaks?

NS:
I know there were membrane leaks. I don't remember any leaks because, you know, they were tested for leaks.

Yeah, yeah. I don't remember any leaks. So things would go pretty smoothly.

DWM:
You don't remember any?

NS: (1:06:19 - 1:06:19)
Usually did.

NS: (1:06:20 - 1:09:23)
And, you know, Tim Miller's wife would often buy pizza and bring it in for everybody. I mean, we were on a long time. And our dinners sometimes would come down from Swedish Hospital.

And I would usually do my homework in the evening on the machine. And eventually Mom bought me a little tiny television that I could sit on the bedside table and watch. And I can remember one night one of the patients yelling to me, Nancy, Nancy, turn to Channel 7 because he's yelling about your brother in Nam.

And so, because it was a big deal back then. And this particular commentator didn't like my brother and he thought it was bad for him to have him. And he was just greedy and trying to make money.

Well, if you knew my brother, that was the last thing he was. He just was an animal himself. I think he used to be a fish in a different life.

And that's just what he did. I mean, he still does it today and he's in his 70s. He still has big aquariums.

So, you know, they'd all yell at me. Turn it on, you know, your brother's on TV. Or they're yelling about him and, you know, talking about him.

So, I don't know. We were all kind of a big family at that point and eating our meals together every night. I mean, three nights a week.

DWM:
Yeah, yeah. So, you get back to school. And what happened as you graduated from college?

NS:
Well, then I went to Seattle University. And during this period of time, I'd been on dialysis about a year and a half. They decided that it was time for me to take my dialysis home.

So, I remember going into the closet in my mother's bedroom and my bedroom and trying to figure out how we were going to get all this stuff in there. What we ended up doing was moving. And we moved to another house in a place.

We were on Capitol Hill, in the north end of Capitol Hill. And we moved to a place called Broadmoor, which was a gated community, and a bigger house. And there was a huge basement that was nice.

And Mother had somebody come in and remodel and make this one area into two rooms. And so, one of the rooms had a big metal slanted sort of counter and a big sink. And then behind it was a place where we would have these containers, which I did later.

But anyway, and then the other room was... So, what I ended up doing was I went to the Coach House at the University of Washington.

DWM:
Tell me about the Coach House.

Why was it called the Coach House?

NS:
Because it was an old hotel. It had been an old motel, kind of.

It was one floor.

DWM:
And the university had purchased it?

NS: (1:09:23 - 1:09:24)
I believe so, yes.

Years before.

DWM:
And what was the purpose of the Coach House?

NS:
Well, they did research there.

And, I mean, they may have done other things there, but I only went to learn how to run my machine.

DWM:
So, you did home hemodialysis training there.

NS:
I did my home hemodialysis training with my teal at the Coach House in, let's see, that would have been, that would have been the summer probably of 68.

DWM:
Okay. And... So, when they were training you in the summer of 68, what equipment were you training on?

Were you training on a Drake Willock?

NS:
I was training on a Drake Willock and a Kiil dialyzer. Okay.

Kiil kidney. And then we had this little old hard Samsonite box type overnight case that sat by the side of our bed, and all the controls were in there, the on and off switch and all of that was in there. A little dial, you know.

And we would... So, I would have to learn how to replace parts on the Drake Willock. I had my little toolbox.

And, you know, I had to learn about the deionizer and the proportioning pump and all of these different things. And actually, on that machine, the pump kind of made a little bit of a thud when it was moving.

DWM:
And what else?

NS:
And the keel, we learned how to take apart, and we would scrub it and clean it with soap and water. And then we would put the first plate down, and there were grooves in the plates. And we would take this cellophane, two pieces of it.

DWM:
And just as a sheet, the cellophane was just a sheet?

NS:
A sheet. It was a rectangular sheet that fit on the rectangular...

DWM: (1:11:26 - 1:11:27)
Frame of the keel.

NS: (1:11:27 - 1:13:57)
Yes, on the plate. And so we moistened it, and then we'd lay it down and roll it out with these big rollers that were kind of foam. Roll it out, and then we would very carefully pull the wrinkles out so there wouldn't be any wrinkles to obstruct the flow.

And we'd very carefully... And then we would take the next plate and very carefully come straight down exactly on top of the other one because you couldn't move it back and forth. You'd make wrinkles.

DWM:
So it came down, and you felt exactly where the sides were, and you put it down exactly right. And then in between, at the end, you'd put in the...

NS:
Oh, I have to think of it.

Anyway, it was a blood port. Called it the blood port. So you'd separate those two pieces of cellophane, put in the little blood port in there, and it fit.

There was a little place where it fit. And then you would do the next layer exactly the same way. And once you got them down and got all the wrinkles out and got everything established, you'd bring up these metal arms with these big bolts, and we had a torque wrench, and we would torque them down to 15 pounds of pressure.

And then we would rinse it with bleach, clean it out. And I can't remember. I think the bleach would dwell for a period of time.

And then we would rinse the bleach out and store it with formaldehyde.

DWM:
And how often did you have to rebuild, clean, and rebuild your Kiil board?

NS:
Once I took it home, we did it on Sundays.

DWM:
Once a week?

NS:
Once a week.

DWM:
And how long would it take you to do that?

NS:
So anyway, I was at the coach house for a couple of months. They did come in and do a study on me again. And they were giving us CO2 or something and measuring.

I don't remember. And they wanted me to just relax and not be nervous about it, and that was easy for me because I'd already been on dialysis for a year and a half. And I was reading Atlas Shrugged, so I was so into my book that I just pretty much ignored them.

And I do remember there was a couple from the Philippines there learning home dialysis. Mother had them over for dinner a few times.

DWM:
And they would train, and then they were going back to the Philippines.

NS: (1:13:57 - 1:13:58)
The Philippines, yes.

DWM: (1:13:59 - 1:14:47)
The keelboard was pretty heavy, too, I gather. Was it physically difficult?

NS:
No, each one individually wasn't too heavy.

The whole thing together was heavy because it had this huge metal frame. Right. But each plate was not that heavy.

DWM:
And your Drake Willock, was it pretty simple to deal with?

NS:
It was pretty simple, yeah. And if I couldn't figure it out, I'd just call them up, and one of the techs would come over.

We weren't that far from the university. We lived pretty close.

DWM:
So several months training in the coach house, and just go home.

NS:
About two to three.

DWM:
So where in your house did you set all this up? In the basement.

NS:
It was in the basement.

DWM:
And so what was your dialysis routine once you were home?

NS:
My dialysis routine was I'd go on at 10 at night, get off at 6 in the morning.

DWM:
In the basement, and were you just by yourself? Did your mother help you?

NS: (1:14:47 - 1:14:48)
No.

NS: (1:14:48 - 1:17:26)
In the beginning, they made this little thing that we could put our cannulas in so that we could hook ourselves up. It didn't work very well. It was really hard to do.

And they trained mother also how to get me on and off the machine. My mother was terrorized by this. She just, she was so nervous that she made me nervous.

And I would just sit there watching her thinking, oh mom, poor mom. And I finally said to her one day, Mom, we live so close to the University of Washington. Why don't we offer free room and board to a student, and I'll train them how to do this?

And that's what we did for three and a half years. I had Chris Klein items from Germany. I had another.

So I had four. And Pam, I'm still friends with today, and she was dating Guri Rojati from Indonesia. And they're still married, and her parents pretty much disowned her for marrying this person who was not white.

But Guri has a PhD in oceanography, and he's a great guy. And they have three beautiful kids. Anyway, a little diversion there.

DWM:

You didn't have any difficulty with these students from the University of Washington training them? They were not as intimidated by the training?

NS:
They wouldn't have applied for the job if they had been intimidated, really.

So that was very helpful. So I taught them how to order my supplies. I taught them, because this was still hard for me to do.

My hematocrit was around 20, 23. I was getting blood transfusions. And the other thing people have forgotten is we had a centrifuge at our house.

We did our own hematocrits. We'd spin our own blood and do our own hematocrit. And then I'd call in and say, Oh, my hematocrit's this.

And then they'd order blood.

DWM:
So let's talk about your hematocrit. You think it ranged between...

Around 20 to 23. And so how low would it get when you would say everybody would decide you needed a...

NS:
I don't remember.

I really don't remember.

DWM:
Could you tell the difference in how you felt when it got low enough? Can you tell me what you felt like before the transfusion and then after the transfusion?

NS:
Well, it was hard to climb stairs. You just had no strength and short of breath. I don't remember cognitively that much about it.

DWM:
But you definitely felt better after you had a transfusion?

NS: (1:17:26 - 1:17:27)
Yes.

NS: (1:17:27 - 1:17:48)
Oh, absolutely.

DWM:

There's a lot of discussion today about EPO and whether it's really necessary to have, you know, maintain hematocrits that are more normal or whether... I mean, I don't think we have a lot of quality of life...

NS: I have to say that it's extremely important. And I can talk about that later. So I'm going to get some juice here.

NS: (1:17:48 - 1:17:50)
My throat needs it.

DWM: (1:17:51 - 1:27:34)
So we were talking about the Sundays, cleaning your dialyzers, resetting up for Kiil with these folks from the University of Washington who were living for room and board, were helping you out, placing your supply orders. It sounds like that was a big support for you.

NS:
It was a huge support, yes.

And Mom, you know, they just lived in the house. They could fix food or do whatever they wanted to do. And we were really close to the university so they could, you know, walk.

It was a long walk, but they could do it. Most of them did. I'm trying to remember if any of them...

I don't think any of them had a car. So that was good. And then, you know, it was sort of company for me.

And they slept in... There was another old hospital bed. And we'd gotten these hospital beds that were the old crank-up hospital beds from Swedish Hospital because they were getting rid of the old beds and getting some new beds.

So we bought these for pretty much next to nothing.

DWM:
What else? And then you were still going to school yourself.

NS:
I was still going to school at Seattle University, yes. And not because I was on dialysis, but because I was... I tried to change schools so many times that I had to...

Each school had new things they required. So it took me five years to get through instead of four. But anyway, that's another story.

DWM:
Getting through five years is really a great thing.

NS:

Okay, this school requires this. Now I have to take all these extra courses again.

So during this period of time, and I was going to school, I did fundraising for the Northwest Kidney... Well, it was still the Artificial Kidney Center, Seattle Artificial Kidney Center. And Nordstrom's, which started here in Seattle...

DWM:
I didn't really know that.

NS:
Nordstrom's would have these fashion shows that were put on by emeritus stewardesses, airline stewardesses. And they had this stewardess emeritus group who did fundraising, and they would arrange...

And I did this two separate years. They would have these fashion shows, and another gal and I, who were young and thin because we were on dialysis, would model. And that would raise money for the Northwest Kidney Center or the Seattle Artificial Kidney Center.

And we did that for two different years. Another thing that we did for fundraising was there would be... And I don't know how they arranged this.

You know, I wasn't involved. I was just asked to show up. I showed up at the race track, the horse racing track.

It's called Emerald Downs now, but it was called something else then. And it was kind of where... We have a big mall now.

Anyway, I would show up there, and so we would get the money from the winning horse, something like that. And so I got to be up in this special place and watch the races. And then I would be the representative, you know, kidney patient icon kind of thing who would go down and accept the flowers for the horse.

So I would get to go down and be by the horse and get my picture taken. That was about it.

DWM:
You also mentioned on your website that Scribner would periodically have people in at his house.

NS:
Oh, yes, I need to tell you about that. So he did that when we still lived on Capitol Hill before we moved to Broadmoor. And then later, afterwards, he would call me on the phone.

And he would say, Nancy, I'd like to invite you for dinner. Are you busy Saturday night? And I would say no.

And he would say, well, I'd like you to put on that black cocktail dress and come down for dinner and, you know, be here at six or something. And I had this black sheath cocktail dress, sleeveless. And he liked that because my arm with the gauze around it would show.

And so, and I was 20. So I would go down the hill because we really, he lived at the bottom of the hill and I lived halfway up the hill. I would just drive down the hill to his house for dinner and Ethel, his wife, would usually fix a standing rib roast with no salt.

She didn't cook with salt. And we would have dinner and often he would invite one of his sons. Rob usually was the one that came and Rob eventually became a doctor as well.

And Rob would be there because, you know, in those days they liked to have a balance of men and women. And then there would be these people from X?X?X Corporation. And I remember one of them being Japanese men.

You know, and they bowed when I came in and we had dinner with them. And I don't really remember a lot about the conversations that went on. I was at the other end of the table.

He always had his two glasses of wine because he was quite the wine aficionado. And he would have the cheap wine and the expensive wine in two glasses next to each other. It was usually red.

I think he liked red wine. And we all were to taste the wine and he loved to see who could tell which was the good one. A game he played.

And the first time that this happened, and I have a feeling it was a Japanese man. It may not have been. But I remember that he left the room.

After dinner we went into the living room. Ethel went into the kitchen to clean up. And he got up and left the room.

And I thought he'd gone to the bathroom, but he never came back. And so there I am sitting there with these Japanese men, alone with these Japanese men in my black cocktail dress. And I finally began to feel uncomfortable.

And they began to feel uncomfortable. And I got up and went into the kitchen and I said, Ethel, where is he? And she goes, oh, he's gone to bed.

And she just went back to doing the dishes. She never really joined in with the social part of this. She just, you know, did the dishes.

So I didn't know what to do. I walked back out there. You know, I'm not very old.

And I basically just sort of winged it. And I said, you know, Dr. Scribner was quite tired. You know, he gets up really, really early in the morning.

He does best work early in the morning. I didn't know he did, but he did. And he wanted me to wish you good evening and thank you for coming.

And I would see them to the door and off they would go. And I remember telling this story to Dr. Blagg, who laughed and laughed and laughed because he said the same similar kind of thing had happened to him where Dr. Scribner had disappeared. He didn't know where he'd gone.

So I did that on a number of occasions, you know. And he would just call and say, put on that black cocktail dress. You know, I've got so-and-so coming for dinner.

And then sometimes he would call me a couple weeks later and say, Nancy, we got the grant. I had no idea that he was doing this to get grant money. He didn't tell me all that.

He didn't tell me the details. Just show up in the dress.

DWM:
Did it bother you having the access there?

NS:
No, it bothered my brothers. My two older brothers, it bothered them a lot. And they used to insist that if I were at their home, I'd wear long sleeves.

And finally one day I said to my brother Ted, Ted, it's summertime, it's hot, and I am not going to wear long sleeves. And if I can't look at this and accept it, how can I ever expect you to do it? How can I ever expect you to accept this?

And he thought about it and he said, you're right. So Ted from that day on was fine. Jim was always a little bit, cover it up.

But, you know, I just didn't. It was hot, I didn't cover it up. I mean, I just did normally what we do normally.

So it didn't bother me. After a while, you have to accept these things, you know. How can you move forward if you're always timid and holding back?

DWM:
Excuse me. So you start dialyzing at home. And how long did that last, this home dialysis?

Did you finish college?

NS:
I finished college. I would go on dates.

And I always had to be home at 10 o'clock on these specific nights.

DWM:
To dialyze?

NS:

To dialyze.

I had to be home by 10. And I still remember going out with one young man who actually had just graduated from Harvard Law and was working in a firm in Seattle. And he just could not understand, I was a senior in college at this point, understand why I had to be home at 10.

DWM:
Did you talk to him about moving on dialysis?

NS: (1:27:34 - 1:27:35)
Eventually I did.

NS: (1:27:35 - 1:32:14)
Not always, it depended. You know, if I wasn't going to see the boy anymore, there was no point in telling him, right. But I did date Mike for a long time.

You know, maybe 9 months, 12 months, anyway. Long enough that I had to tell him. Right.

And, you know, eventually he saw what was in my arm. And he, you know, I just remember standing on the porch, my porch at my house, explaining to him why it was. And he took it pretty well.

He was, you know, a fairly educated young man, right, from Harvard. And he got it. And he didn't drop me.

We kept dating. So that went quite well, depending on the boy.

DWM:
Did you feel like having this illness made a difference in whether people were interested in you or willing to have relationships with you?

NS:
A little bit, yes, I did. You know, I mean, some of them, it was so strange to them because it just was. I can't remember any specific people who really were grossed out and turned away, you know.

DWM:
But I probably would have, you know, not picked that person anyway. And today, of course, dialysis is not an uncommon thing. But I would, were there people, did they really know about chronic kidney disease?

NS:
Not so much. Well, we did in Seattle. They knew in Seattle because I was, we were out there doing fundraising, right?

We got a lot of press. In 65, NBC did that.

DWM:
Have you seen that documentary?

NS:
Who Shall Live? Yes, so NBC did that big documentary. And Dr. Scribner actually gave me the tape recording of it, which I made into CDs. And he gave it to me. He had written on it, you know. I can't find the original tape.

I can't figure out what happened to it. So I may have loaned it to Dr. Blagg. I'm going to have to ask him if he has it.

So people in Seattle pretty much knew.

And my friends in high school knew that I was sick because I was ordering my french fries without any salt. And I went to Young Life in the summer, one summer, and having to watch what I ate.

People that knew me knew me and grown up with me knew it. And that was just who I was.

DWM:
So you're dating and doing chronic dialysis, and you graduate from college.

And what came after that then?

NS:
I got a job. I got a degree in education with a minor in art and English.

Some days wished I hadn't gotten that degree in English because the grammar today is driving me crazy. In the last 10 years, it has gone way downhill. And I run into other people who totally notice it too.

But anyway, that's a totally different story. But I did, and I was so tired of school that I didn't really want to go into another school. So I got a job at Washington Natural Gas Company in customer service and joined the Teamsters Union, which probably was a really good thing because I had fabulous insurance with the Teamsters.

And now I was responsible for my own bills. And I do remember Mother, right after I graduated in June, saying to me, My insurance won't cover you anymore. You need to get a job, and you need to get one really soon.

Here's Mom planning ahead again, right? And I got the message. She says, You have to get a job or you're going to have good insurance that will cover you.

And not a lot of jobs gave insurance back then. You know, it was a whole different system.

DWM:
What year was this?

NS:
This was 1970. So I got a job at Washington Natural Gas. I knew someone who had worked there, and the Teamsters did a great job insuring me.

I sent the kidney center $100 every month. Pretty big contribution back then. Because I don't think I earned much more than that.

I earned between $400 and $500 a month. That was probably all I got.

DWM:
And you continued to live with your mom.

NS: (1:32:14 - 1:32:15)
I still live with my mom.

DWM: (1:32:15 - 1:32:17)
And dialysis in your basement three nights a week.

NS: (1:32:17 - 1:32:17)
Yes.

NS: (1:32:17 - 1:39:05)
Actually, for a period of maybe a quarter, one summer, from spring till summer, if we back up a little bit, I moved into an apartment with some classmates at Seattle University. So four of us moved into an apartment and shared the rent. I think it was $200 and I paid $50.

And during that period of time, my brother Jim had been giving me an allowance. And I got tired of getting the allowance from Jim because he always thought that he could tell me how to live my life. And I'm now 21, and I don't want my brother telling me how to live my life, so I decided to quit taking money from him.

And I wanted to show him that I could get a job. So I got a job at Harborview Emergency Room. And Harborview is part of the University of Washington.

And it used to be called the Public Health Hospital here. King County Public Health Hospital. I got a job as the admissions person, evening shift, at the Harborview Emergency Room.

Now there, and I worked all summer doing that job. And I had my own money. And I pretty much quit listening to my brother.

I did what I wanted to do. And one of the things that had sealed that for me was that my boyfriend Mike, the one who had been from Harvard, and I were going to go skiing. We went up and went skiing because my brother and some friends of his and my brother Ted built this ski area called Alpental.

And they had a condo up there. So Mike and I went up one weekend and stayed in the condo and went skiing. And then one of the people in Mike's firm, I think his name was Lou Pepper, he had a condo at Crystal Mountain ski area.

And he offered Mike the condo for the weekend. And Mike said, let's go over there for the weekend. And I called him on the phone and I said, how do I get my skis?

Because my skis were at Alpental in a special place. And I said, how do I get my skis? And he goes, you're going to drive all the way up to Snoqualmie and get the skis and then go to Crystal.

And I said, yes. Well, you know, we were young, right? And he got really upset that I was going to spend the weekend with my brother or my boyfriend, spend the weekend with my boyfriend at Crystal Mountain at the condo of an attorney that my brother knew.

You could see all this stuff coming in. And we didn't go. I couldn't get my skis.

So my relationship with Mike pretty much went away after that because he realized that my brothers had way too much control. And that's when I got my own job. I went out and got a job and quit taking the money from my brother so I didn't have to listen to him anymore.

And I could get my own skis and bring them home and go anywhere I wanted to go. So I got my job at Harborview in the emergency room. And boy, I grew up.

That was the summer of 69. I grew up a lot that summer at Harborview ER. I saw young people coming in on drugs, on LSD.

I saw one young man come in. We called his parents. She came in in her fur coat, was quite uppity, and moved him over to Swedish Hospital.

And I tried to speak with her and say, he'll get better care here than he will at Swedish Emergency. They're better at it here. Because it was the main trauma ER in the whole state. But she, you know, didn't believe it. She wanted him to go to Swedish and she took him away.

I remember one night, this very tall man coming back to the parking lot, because it used to be in the back of the hospital. It's moved to the side now. And I heard this chanting, like Indian powwow chanting.

And we all looked out the back window and there was this very tall, naked man coming in with a policeman on either side of him laughing. The policemen were in hysterics. They've got this man who's chanting and dancing and naked and brought him into the ER.

And we just all started to laugh. We don't know what drug he was on, but it could have been LSD, I don't know. That was an amusing day.

We had another man who would come in and need something. He had some mental illness. So we'd give him an aspirin and he would leave.

Then I remember a young woman coming in who was hemorrhaging because she'd tried to give herself an abortion with a coat hanger. This is before abortions were legal. And there are so many people today who never lived through that and don't understand why we need to have legal abortions because these women died.

And they may have two children at home and now these children were motherless. So I do remember that day very vividly when this gal brings her friend in. She's in a wheelchair and her friend is hemorrhaging.

And they're freaking out. And I said, let me go back and talk to the doctor so I'll get you in. So I did that.

And I was on dialysis during this period of time and had my arm wrapped in gauze. And all the residents were fascinated by the fact that this dialysis patient was working in the ER. And one of them became a nephrologist, Dr. Fleet, a nephrologist at the University of Washington. And he worked at Harborview. And I went to a fundraiser years later where he was getting an award. And I spoke to him and he goes, I remember you.

I didn't remember him. He remembered me. I remember you.

Because I had the gauze on my arm, right? And I was working with my hematocrit 23 or whatever, right? I wasn't doing anything that physical.

DWM:
Once you get to the ski lift and get up, you can ski down, right?

NS:
Yeah.

DWM:
But with that hematocrit 23, skiing was probably quite a...

NS:
You do adjust to it after a while. To a certain extent. Not completely, but to a certain extent.

You do adjust to it. And I was still young. So, you know, I had the energy of youth.

DWM: (1:39:05 - 1:39:05)
Yes.

NS: (1:39:05 - 1:40:22)
And I did take... I took a tourniquet and cannula clamps with me.

DWM:
Very wise idea.

NS:

I hadn't thought about that, but yes. So in case I fell or...

DWM:
Right.

NS:
I could wrap it in a tourniquet, clamp him off, and get down the hill. Yeah. I mean, you have an external blood flow.

Well, the first time I told Dr. Pendras, I went skiing. He goes, you did what? And he was a skier.

He says, it's a good thing you didn't ask me because I would have said don't go. But he understood because he was a skier. So I went skiing, you know.

And, you know, my brother made sure I was okay. He owned a ski area, right? Everybody knew I was on the hill skiing, right?

So I didn't know that then, but I, you know, I didn't go to the most black diamond places.

DWM:
Other than your anemia, did you know of any other... I mean, now we obviously know a lot more about chronic kidney disease and calcium phosphorus metabolism.

Did you... Do you remember having any other issues besides the anemia, like your phosphorus being out of control?

NS:
I don't remember them talking to me about my labs.

We talked about BUN in those days.

DWM: (1:40:22 - 1:40:23)
Right. That's it.

NS: (1:40:27 - 1:41:53)
And I do remember starting to take Allucaps. And nobody told me what they were or why I was taking them. I just was told I had to take my Allucaps with my meals.

And eventually, you know, they didn't want that aluminum in our blood, so they quit the Allucaps. And I do also remember at one point before that where I was having a lot of shoulder pain, and I think Dr. Pendris decided it was calcium in my arm and my shoulder. And then later I was on the Allucaps.

DWM:
So... Because I do know with the early patients, Clyde and Roland Hemming and Harvey Gentry, that they began to see those things that they had not really thought about or seen

before when people were on dialysis. Neuropathy, calcium phosphorus deposits in the joint and soft tissues, and the anemia issues as well.

NS:
Well, one of the patients, and I can't remember his name anymore, he must have had a worse problem than all the rest of us because he would have a towel and be scratching all through dialysis. Itching. Itching, itching, itching.

And I remember a few times itching, not too many. So I must have... You know, I followed the rules.

I did what they asked me to do.

DWM:
And other than salt restriction, have they given you any dietary things that they wanted you to be particularly careful about?

NS: (1:41:53 - 1:41:53)
Potassium.

NS: (1:41:54 - 1:42:17)
Potassium. We did have to be careful of our potassium. I don't remember the numbers, but I remember being told what was high in potassium and not to eat it.

No bananas, you know. I didn't drink a lot of juice. I wasn't thirsty that much.

I didn't eat a lot of salt. So I was... We didn't know about...

I didn't know about soda pop having phosphorus in it until much later.

NS: (1:42:17 - 1:42:18)
Yeah. I didn't know that.

DWM: (1:42:18 - 1:48:27)
They may not have really understood that either. I know that you then in 1972 had your first transplant. When did they first start talking to you about kidney transplant?

NS:
Dr. Pendris talked to me about it. And he... I remember him saying, I think you should have a transplant.

I think that would be a really good thing. So of course I go home and I mention it to my family. Well, my two older brothers, Ted and Jim, totally freak out.

But they just to this day can't deal with anything medical. They're getting better because they're in their 70s and they're having to deal with it in their own lives, right? But they just completely...

And I got the impression that I wasn't going to get one of their kidneys. And I don't remember a lot of talk about it. I was going to CLU.

I remember Charlie was going to Stanford. And I remember Charlie writing me a letter and saying, I've done a lot of research at the Stanford University. And I've talked to a lot of physicians there.

And I've decided I'm going to give you a kidney. So, you know, I went over. I told, you know, I don't know who I told her.

I showed them the letter. I remember showing the letter to my art teachers in the student union building when we were in there having coffee together. And they were so excited about it.

So, I... And I don't remember when he wrote the letter. But we planned to do the transplant in March of 72 because he would come home from his spring break, give me the kidney, and go back to school.

And that's what he did.

DWM:
And where was it done?

NS:
At the University of Washington.

Dr. Marcuro.

DWM:
Spell that.

NS:
It's like March.

M-A-R-C-H-I-O-R-O. And his wife's name was Karen. And he was...

I can't think of it. I'll think of it in a minute. Tom.

Thomas Marcuro. Yes. He's a blonde, blue-eyed Italian.

And he had grown up in Montana. So, he was pretty... He was a...

He'd grown up in a blue-collar family in Montana. Anyway. So, I went in.

I was working at Washington Natural Gas. I went in to the hospital in, I don't know, January or February. And I had a nephrectomy.

They thought, at that time, that if they left the original kidneys in, that my blood pressure would stay elevated. The next year after that, they quit doing that. So, they removed my original kidneys, which was really sad, because I still had residual kidney function after all those years.

And life got really tough after. Because they didn't know that I was still making erythropoietin. Yeah.

And I... All of a sudden, my kidneys are removed. I couldn't go to work.

I couldn't walk. I was just exhausted. And I was getting by with the hematocrit of 2023.

And I don't know how low it went, but it must have gotten down really low. And so, Dr. Quadracci, who was working there then, and he's in Wisconsin now, I understand, he was doing research for Dr. Scribner. Because Dr. Scribner had all these different fellows doing different research. You know, Dr. Eschbach was supposed to do the anemia, and Dr. Sherard was doing the bones. And I think that Dr. Quadracci was working with Dr. Sherard. And so, they told me that they'd pay for all my parking and everything if I would come in and let them do some studies.

So, I went in, and they would draw my blood, take blood out, and then they would mark the cells and give me the blood back. And then I would go in a week later and they would check to see, you know, how many cells died, probably, if any got replaced. And they were studying all this.

Of course, they didn't tell me, and I didn't ask. But I'm assuming some of this. And they also did some bone studies.

And I thought that they were taking my bone marrow. But Dr. Sherard or somebody the other day said, no, they weren't. They were taking your bone.

So, I was going in, and they were taking samples of bone from me. Now, this hurt. And they didn't anesthetize.

But then I had a nephrectomy without any pain medicine because Dr. Mercuro didn't believe in it. I got no pain medication after my nephrectomy. I remember waking up.

I remember all my family standing at the foot of my bed. And I said something to the nurse about I needed something for pain. And she said, Have you forgotten?

You can't have any. I don't remember what I said to her, but my brothers do. They were surprised that I said that.

So, getting back, where was I?

DWM:
We were talking about getting ready for your transplant.

NS: (1:48:28 - 1:48:28)
Yes.

NS: (1:48:30 - 1:50:44)
So, I didn't get anything for pain while they were taking this out either. And I said, okay, I'll do it. But just give me a nurse's hand to squeeze.

And that's what I did. I squeezed this nurse's hand. And I did that at least twice.

And here all these years, I thought it was bone marrow. It was bone. And they were studying all of this.

And this is how they learned a lot. And I was glad I could help. And I always volunteered because I thought whatever I did would help me in the future.

And it has. So, I did that. And then I think that something happened to my cannula.

I don't know. That was later. I get all these different things mixed up.

So, anyway, I did go in. I had my transplant in March, middle of the March or somewhere. In 1972.

1972. And Charlie came home and gave me his kidney. And I was in a private room with a private nurse.

And I got nothing for pain with my transplant. But I got a lot of prednisone. So, when you get a lot of prednisone, you don't notice the pain as much, right?

So, that was okay. But Charlie didn't get anything either. And you know how they did transplants.

I mean, they ripped his whole side open.

DWM:
He had a big flank incision up there.

NS:
Yes, he did.

And he didn't get anything either. But Marcurell believed that it would mask symptoms. So, he didn't give it.

And I remember the floor was full at the university where I was on, one floor. And Charlie was on the floor above. And I remember he walked into my room in his hospital gown with his IV pole on his hand.

And the nurse freaked out, made him sit down, you know. But he had come down to see how I was doing, you know. He wanted to make sure that I was okay.

So, that was good. And I wanted to make sure he was okay. So, I remember Charlie coming down to check on me.

DWM:
What medications other than prednisone were they using in 1972?

NS: (1:50:45 - 1:50:45)
Imuran.

DWM: (1:50:45 - 1:50:46)
Imuran. That's it.

NS: (1:50:46 - 1:51:41)
Imuran and prednisone. Imuran and prednisone. And I do remember that my prednisone, I don't remember all my creatinine and BOM levels, but I do remember the dose because I had to take the pills and count them out.

I was up to 300 milligrams of prednisone a day. So, if you think back to all that prednisone I had as a kid, and now I'm getting all this prednisone. And eventually, it got tapered down.

But, boy, talk about psychotic when you're on that much prednisone. I luckily tolerated it pretty well. I just remember standing in the entryway of our house and crying and wondering where Mother was and she was right next to me.

I mean, you know, crazy stuff like that. But eventually, it got tapered off and I went back to work.

DWM:
How was your transplant function?

Did you start peeing right away?

NS: (1:51:41 - 1:51:41)
I did. Yeah.

NS: (1:51:42 - 2:00:52)
I did. I started peeing right away and I remember Dr. Hickman coming into my room and doing a little dance and a jig around my bed and he was singing. And, you know, I was in a foley.

You know, I had a foley bag, but he could see this urine coming out. So, he was excited about it. I mean, here he'd known me since I was 11.

So, and now I'm, you know, how old was I? 24. So, that transplant worked really, really well.

And that is when I noticed the difference between dialysis and a transplant. I had to be in the hospital for a month. I was there about four weeks, something like that.

And I remember having all this edema from the prednisone. You know, I had these penny loafers that were just already stretched out from when I was in Arizona. But I remember going up to Dr. Mark Farrell and saying, I want to go outside. Can I please go outside? And so he said, sure, you can go outside. It was a month staying inside.

You know, you look out and you want to smell it. And I remember walking outside and they had just mowed the lawn for the first time in the spring. And I could smell that grass.

And I could smell the canal, the water in the canal. And I could hear the tugboats honking. And it was like coming out of some dark cave into the light.

There was a huge change in what I could sense. My sensations all worked so much better. Food tasted better.

And I could see better and hear better and smell better. I mean, everything was better. And I do remember that really, really vividly.

Thinking, oh my gosh, where have I been in some cave somewhere? But you know, that's so insidious that you don't notice it. But it's not insidious going from dialysis to a transplant at all.

I mean, it's like night and day overnight. And so the kidney did start working right away. I don't remember my original Imuran dose.

But eventually, I got down to 15 milligrams of prednisone a day and 12.5 of Imuran every third day. That's tiny. Tiny dose.

And later, Dr. Scribner told me that it was a perfect match. So during that summer, I got married. And my husband got accepted into a PA program in Michigan, at Duke, and the University of Oklahoma.

And he chose Oklahoma. Why, I don't know. I would have rather been in Michigan or at Duke.

But we were in the godforsaken middle of the United States with red dust and wind in Oklahoma City. And that's where my son was born. Josh was born there.

And I remember working at the gas company. And I eventually was working down in the lobby because, you know, people would come in and complain about their bills. And I guess I was pretty good at handling those people.

So usually, we'd just go down there for shifts of a couple weeks at a time. And eventually, I noticed that nobody was coming down to relieve me. And I said, you know, why am I staying?

Well, because fewer people come up to the management and complain when you're down there. So I got to stay down there, which was nice. I kind of liked that.

And I remember missing my period and going in and talking to the nurse. Now, I think her name was Mrs. Florence. Mrs. Florence. I don't remember. She was an older woman, white hair. And she was the nurse in the clinic.

And I remember calling her and saying, I missed my period. And she goes, Nancy, I think you better come in and pee in a cup and we'll see if the rabbit dies. So I went in and gave them some urine and went back to work.

DWM:
Did it make anybody nervous that you had this transplant and you were pregnant?

NS:
Well, it was over a year later because I had the transplant in March. So it was, what, 12, 15 months later, about, I think.

And I got a call from the resident. I don't remember this resident, except I remember him saying on the phone that he did not think I would be able to carry this baby and that I might have to abort the baby. So, that's all I remember.

But you know what used to drive me crazy is having been a kid that grew up in a hospital. I hated residents going out on their own and telling patients things without running it through the attending. Drove me crazy because you'd hear one thing from this doctor and something else from the attending.

Drove me crazy. All my life, it drove me crazy. So, I remember going into the clinic and sitting down with Dr. Marcuro. And I still remember being in the exam room and it was just the two of us. And I said to him, so what am I going to do? Where do I go to get the abortion?

And he looked at me. He's Catholic. He said, abortion?

You want to talk about that? You can go over there and talk to them because I refuse to talk to you about that. I have five children.

You never know what you're going to get. One of our children was born with a heart problem. You just don't know.

You just take what you get. And I looked at him and I said, are you telling me I can have this baby? He said, of course.

You're over a year out from your transplant. Your numbers are all good. And of course, you can have this baby.

So, Josh was born in Oklahoma. He wishes he didn't have to tell people that he was born in Oklahoma. But the doctors at the hospital there were great.

It was a Dr. Merrill who was the physician I followed there and I really liked him.

DWM:
It sounds like your babies were born just a little bit early, but otherwise you had a pretty uneventful pregnancy.

NS:
Yes, and I really watched my sodium intake then because, boy, talk about edema when you're pregnant.

So, I was very, very careful. And I wore support stockings. I looked ridiculous because I'd have on white Bermuda shorts and black support stockings because you could only get them in black.

And a smock. Because we didn't show our bellies then like the girls do today. And we drove to Oklahoma.

We drove down to Oklahoma. Josh was born there. And then Sarah was born two years later when we came back.

DWM:
So, you were back in Seattle. So, Josh was born down there.

NS:
He weighed, I don't know, four, just under five pounds.

Four. And he wasn't breathing when he was born. He had a pneumothorax.

So, he aspirated some. But I remember asking why my baby wasn't crying. Because, you know, everything I'd watch, babies cry right away, right?

So, I was asked, where's my baby? Why isn't he crying? And the room is, you could have heard a pin drop.

Nobody is talking to me. My husband is in there. He's not saying a word.

And all of a sudden, I heard somebody say, Oh, look. He's pink now. What color was he?

You know? So, that was a problem. And then, but, you know, they solved it.

And then I remember they laid him over on me and he peed all over me. So, I thought, well, he's got good kidneys, you know. And that was that.

And I took him home and holding him in an arm like you hold a baby was hard because he kept, he would fall through the hole here between your elbow and your body. It was so tiny. But he did well.

And at nine weeks, he had hernias, inguinal hernias that had to be repaired. Two of them. I need scars now.

And he cried for those first nine weeks a lot. And I would sleep with him. I would sleep on my back with him on my tummy and that's the only way he would sleep.

And, or sometimes I'd get up in the middle of the night and sleep in a chair with him because my husband was going to school and couldn't have a crying baby all night.

DWM:
So. Now with you, while you were, once you had your transplant, what did they do about your shunt?

NS:
Oh gosh, they removed it probably before. No, I don't remember. You know, I don't remember.

I don't, they must have removed it afterwards because they had to wait and see if I needed some dialysis. I just don't remember. But at some point they probably took it out.

DWM: (2:00:52 - 2:00:52)
Yes.

NS: (2:00:52 - 2:01:24)
They did. And I never needed any dialysis done. So, so Josh was born.

We stayed there. We were there for two years. We came back to Washington.

And I wish people from Washington D.C. would say D.C. because I live in Washington. They live in D.C. Anyway, we came back to Washington. My husband got a job as a P.A. in Forks. Now have you heard about the Twilight series?

DWM: (2:01:24 - 2:01:25)
I have.

NS: (2:01:25 - 2:10:23)
Yes, who hasn't? Forks. We lived in Forks.

So Forks really exists. Yes, we lived in Forks. And it's a rainiest place.

And No vampires or werewolves, I guess. No, no. And the funny thing is my husband worked in the clinic like the werewolf's father did, right?

And I substitute taught in the high school. And so, and then Josh, you know, when he was first on Facebook would write to his friends and say, yes, I lived in Forks and no, I'm not a werewolf. And yes, my father worked in the clinic.

But you know, so it was kind of funny. We lived there and Sarah was born while we were living in Forks. And I remember we came back in October and moved in and my husband had grown up in Port Angeles.

So we were an hour from Port Angeles and his family. So we weren't far away from family. His mom still lives there and his two sisters, three of his sisters.

And so, I would go into the university and get checked. I mean, I would get checked at the clinic in Forks but occasionally I would go in. But before I had Sarah, we came back in October and it was December and I went into the clinic and met with Dr. Marcuro. And he used to have this room where you would meet in the clinic. And he would have this table and he would have this great big book on the table with all of our numbers in the book. So we would sit on one side of the table and he would sit on the other side of the table.

And there would be all these renal fellows or residents, I don't know who they were, standing around, maybe a couple women, a couple, I don't know. They'd be standing around. I never knew who they were.

They were always there. And we would, he would basically talk to them. I'm sitting there.

He's basically talking to them, not me. And eventually after all this was finished, I said to him, I'd like to have another baby. And he said, what are you asking me for?

Well, of course, all the young men in the room thought that was hilarious and they laughed. And I said, okay, so I can have another baby. Of course, you know, so I had my IUD removed and I was pregnant with Sarah by the end of the month.

So I was quite fertile, quite healthy. And she was born in August. And she was, Josh was four weeks early.

She was three weeks early. But she was small and a bit chubbier. Josh was much more lean.

She was a little chubbier. And she weighed, I don't know, five, ten. So she was a little bigger than he was.

And, you know, she came out chewing on both fists and, you know, with this dark hair sticking out. And Josh had peach fuzz hair. Sort of, you know, my husband used to say, you know, how come he has red hair?

And it was kind of this strawberry blonde color. Anyway, you know, she was obviously very healthy. Kicked all her blankets off immediately.

She's still like that. And, you know, so I had these two very healthy babies even though they were early.

DWM:
And did you stay at home with them?

I mean, you had been working before you married.

NS:

Well, when I was in Oklahoma, I was managing the apartment complex where we lived. I was assistant manager, which was great because he's in school.

He's getting 450 a month from the GI Bill. And I've got our rent for free. So I had rent free and plus I got, I think I got 350 a month plus the free rent.

So we were doing very well at that point in time. You know, cost was lower and we had more money then than afterwards when he started working.

DWM:
And your insurance then also. I mean, you know, you need to get this health care and buy your medications. Were you insured?

NS:
I think I was insured with him under the GI Bill, I think.

Yeah. You know, I've forgotten all of that.

DWM:
So Sarah's born and are you working in, when you all are in Forks then?

NS:
I was substitute teaching. And so I could, you know, obviously I didn't work right away when she was born, when she was a little bit. After she got a little older, I was substitute teaching and the woman across the street had two little boys and so she would take the kids.

DWM:
At some point, you began to have trouble with your transplant, I gather.

NS:
What happened in 79, early 79, is I decided that my marriage was not working well. I talked to my brother about it and I made a plan and I said, I'm going to get through Christmas.

And when Christmas is over, then I'm going to make some changes. So I moved back to Tacoma with my mother and for a while to determine what I was going to do. And while I was there, Josh had his fifth birthday and I remember my brother Jim and his wife buying him a big wheel.

He was so excited. And so he had his birthday there and my college roommate with whom I'd lived when I was working in the Harborview ER who became a nurse, invited me to have lunch with her in Edmonds, which is, she lived in Mukilteo which is on the water. There's a ferry from Mukilteo that goes to Whidbey Island.

So we met in Edmonds at a Mexican restaurant. Now I wasn't having any problem with my sodium or edema at this time because this kidney was perfect. I ate an enchilada.

She had the same enchilada. Josh luckily had a taco and I got food poisoning. Probably E.

coli. I'm guessing it was probably. She went to the opera that night and was sick as a dog.

And I went home to my mom's and I was sick. And by the time I could get up and get in the car and drive back to the university to get tested, it had been a few days because I was vomiting and had diarrhea. I was really, really sick.

And by the time I could get there, my mother, who just is not medical at all, should have thrown me in the car and taken me there, but she didn't. And so I finally drove myself in. It was a Friday.

I went to the university. I had Josh and Sarah with me. And I was going to spend the weekend with another old friend from Seattle University who lived in Bellevue.

And so I stopped by the university. I told Florence that I didn't feel well, that I'd been really, really sick. So I had my labs drawn.

I got in the car and I headed across the bridge to go to Bellevue to my friend's house. It was pouring rain. I had to stop and figure out where I was and get directions to get to her house, which I did.

I walk in the door and she answers the door and you could see her kitchen from the front door over to the left. And I saw a telephone sitting on the counter. And I said, I'm sorry, Marlene, I've interrupted your phone call.

And she goes, No, that phone call's for you. That's Dr. Marcuro. He had called as soon as I left and was already on the phone by the time I got there.

And she said, I told him you weren't here yet. And he said, I'll wait. So the minute I picked up the phone and heard his voice, I started to cry because I knew, I knew that things were really bad.

And I knew how bad I felt and I knew how swollen my feet were. And he said, Nancy, you've got two hours to get to the hospital. And if you can't find somewhere to take the children, I'll take them to my house.

So Marcuro was a gruff doctor who made the residents and the nurses cry. But boy, did he take care of his patients. He really took care of us.

So Marlene, of course, is my friend. And she, of course, takes care of my children for me for the weekend. And I call my brother, Jim, who picked the children up on his way to Alpenthal to go skiing for the weekend.

And the kids went with him. And I drove over to the university. And I was there for a while.

And I know that my, at this point, I'm learning about my creatinine. And I know that before I got sick, my creatinine was .7. But not anymore. And so I end up in there and they, you know, give me tons of prednisone and all kinds of stuff, seeing if they can stop this.

DWM:
And do you think with the illness that it was the dehydration or had you missed several days of keeping your prednisone and in and out?

NS: (2:10:23 - 2:10:24)
No, I didn't.

NS: (2:10:24 - 2:10:33)
Was it possible that I did? No, I don't know. You know, I hadn't thought about that.

I was really good at taking my pills.

DWM:
Yeah, but if you were throwing up, I mean, were you actually sick?

NS: (2:10:33 - 2:10:35)
And I was sick. Yeah. It's possible.

DWM:
Yeah.

NS: (2:10:36 - 2:15:36)
Maybe some combination of the two. It could have been. Right.

But, you know, I was wise enough then to try to take my pills when I didn't, when I thought I could keep them down. And I was pretty good with a clear liquid diet. Yeah.

I was really good with a clear liquid diet at that point because I learned it because I used to go to the medical classes with my husband when he was in school. I'd go up for an appointment and wherever he was having a class, I'd sit in and listen. And his friends would look around and say, what's she doing here?

You know, I'd sit in on the OB lectures when I was pregnant and, you know, nobody cared. And the PA school then was with the medical school. So the PAs were in the medical students' classes with them.

And I'm sitting in there learning all this too. And so when people would call after Jim was a PA, would call with nausea and vomiting and he was busy, he said, you talk to him. So I'd give him the clear liquid diet.

I was really good at that. So I really did know how to take care of, you know, GI problems pretty well by then. But I was in the hospital and my husband had to come and get the children from my brother's house.

And I have a picture of them that's, they're sitting on the porch of my brother's house. Josh has his arm around Sarah. She's looking just kind of blurry-eyed.

He's kind of looking to the side. And my nephew, the one that's 50 now, who was five, took the picture. And you can just see those two children sitting there with Josh's, he's got his arm around, he's five, and he has his arm around his two-and-a-half-year-old sister.

And it just looks like they're saying, Mommy's sick and we're waiting for her to come home. And they went to their fathers. That was in February.

I got better. Got stabilized. Knew I was going to have to go back on dialysis.

Spent, had my cannulas placed. Again, cannulas. My cannulas placed.

And was, remember sitting on a lawn chair on the 4th of July in the neighbors of my brother's house watching the fireworks over the lake. And then I decided I had been going around during this period of time through the spring trying to figure out what I was going to do because I knew I was going to find a teaching job because the schools were closing because the baby boom was over and teachers were out of work. And I knew I wouldn't find a job.

So I thought, well, I could get a master's in social work. I could do this. And finally, Pat Smith, who was now the nurse in the clinic, said to me, why don't you go to nursing school?

You already know all this stuff. So I went up and talked to the nursing class, nursing instructors or whoever the powers were then at the University of Washington. And they pretty much blew me off, laughed me away and said, there's no way you could do this.

You're much too sick. So I went down and told Pat. She goes, oh, don't listen to those old ladies.

She said, go to Bellevue Community College. They've got a fabulous nursing school there. So I did.

And they accepted me and were happy to have me in. And so I had been staying with my friend Marlene who lived in Bellevue near the Bellevue Community College. And so I found a house to rent.

Mom came down with me and we found a house that I rented not far from the school. And I decided that I would take a chemistry course because I checked out going to school and I needed chemistry. I had to repeat my chemistry course because it had been 10 years.

And I hated chemistry. And I thought, if I can get through this chemistry course as crummy as I feel pre-dialysis, I'll make it through nursing school. So I took the chemistry course and got an A.

And I walked out of that chemistry course after the final and went to my first dialysis, return dialysis, back at Eklund Hall. And Dr. Henry Tenckoff was there at that point. He wasn't at the university anymore.

He was at Eklund Hall. And I remember saying to him, I walk in, it's not the same kidney center anymore. There are different people there.

They have technicians who call me, I can't remember what they call me, ma'am. They were calling me ma'am and I'm going, I grew up in this place. Everybody knows my name.

Why are you calling me ma'am? And that bothered me. And I said to Dr. Tenckoff, you've got to get me out of here. You have to get me home to get me to home dialysis. And they did. So I went to home dialysis training and went back home into my rental house.

DWM:
And what was the dialysis machine that you were using when she went back?

Do you know?

NS: (2:15:37 - 2:16:01)
This is 1979. I don't know. Now I heard somebody talk about an old machine the other day and I went, I recognize that name.

And I mean, and Braun, I recognize that name. And then there was another name that you don't see anymore I recognize. And I can't remember, I could draw you a picture of it.

It had fake looking wood in the front. You know, it was one of those, you know. It was a square.

DWM: (2:16:02 - 2:16:02)
Yeah, yeah.

NS: (2:16:03 - 2:16:11)
Boxy thing. Yeah, yes. I don't remember.

DWM:
And what kind of dialyzer were you hanging then? By then a hollow fiber dialyzer?

NS: (2:16:11 - 2:16:11)
Yes, it was.

NS: (2:16:11 - 2:18:02)
And I was just shocked. That only seven years earlier I'd been using this Kiil. And now I had to dialyze four times a day.

And I had cramps and I didn't like it.

DWM:
And... What was your dialysis schedule?

NS:

I was doing it three times a week, four hours a day. And I remember there was some kind of a little celebration at the university about some anniversary for dialysis. And I went over and I saw Dr. Scribner. And he said, Nancy, you weren't supposed to lose that kidney and that was a perfect match. And he invited me for dinner. So I went back over.

And now he'd moved from the house to the houseboat. And I went over and had dinner and his family, his boys were there and Rob was there. And we had dinner.

And I told him, I hate this dialysis. I hate this four-hour dialysis. What's wrong?

Who decided to do this? This is terrible. I don't like it.

But nobody could or would prescribe anything different at that time. They couldn't do it differently. That's what they had.

But I didn't like it. And I really, really, really had to watch my sodium then. Way more than I'd had to do when I was on a Kiil dialyzing overnight.

I just didn't like it. And I told him. And he said, here we were trying to do it this way and make it shorter.

And I said, right. But you've interrupted my day. I want to sleep away my time on dialysis and have my days free.

I don't want this interrupting my day. I don't want to have to do it at night so I have to get off and go to bed because I feel so crummy. I didn't feel this crummy before I got up and went to school.

So I really always hated it.

DWM:
And what do you think was the biggest difference? Was it that it was a lot of dialysis in a short period of time?

NS: (2:18:02 - 2:18:02)
Yes.

NS: (2:18:02 - 2:21:31)
It was too fast. Too fast. It was too fast.

It pulled off too much too fast. And you couldn't adjust your equilibrium. Couldn't adjust that fast.

It was just... And they wouldn't give you the leeway at home to just say, well, I'm not going to dialyze in four hours. I'm going to dialyze in eight hours.

I did what they told me to do. Yeah. And if they were to do that to me today, I surely would.

But I didn't, you know, I was in my early 30s and I still didn't, you know, I was just trying to be a good patient and do what I was supposed to do.

DWM:
Well, and that's, you were then at that time taking care of your home dialysis as a single parent to your children and attending nursing school.

NS:
That's right.

That's what I was doing. And, oh, I forgot to mention that without my kidneys in me anymore, my hematocrit dropped to 15. So I went through nursing school basically with a hematocrit of 15 getting a blood transfusion rarely.

They didn't want to give us blood transfusions. AIDS had come on the scene, right? And they didn't, they kept thinking, well, if we withhold the blood, she'll start making her own, but I never did.

So I didn't have any way to make it. I had no residual kidneys. My old kidneys were gone and the other one was, you know, turning to the size of an almond.

I mean, I wasn't, I didn't have anything. I couldn't do it. We were still spinning our own hematocrits, though, with our own centrifuge and calling and getting blood at the blood bank.

So, and I'm all negative. They hated giving me their blood. The blood bank hated, they even would say to me, you know, we don't have very much of this blood, and I'm going, I'm sorry, but I need it and I can't get any of your other choices.

So they didn't like that. They didn't like giving away their own negative. They wanted to save that for emergencies.

So, you know, I was still getting hemat, you know. I remember calling my neighbors one day and it was an older couple and saying, could you drive me to the blood bank? I don't think I can drive.

My hematocrit dropped to 11. There was no way I couldn't drive myself to the blood bank, which was in Seattle. And I was living in Bellevue.

And this couple took me over to the blood bank and got me some blood.

DWM:
And you would hang your own blood at home?

NS:
Yes.

We hung our own blood, you know. You would, they would deliver it to our door. I'd like to go negative, okay.

So we hung our own blood.

DWM:
So you finished your nursing school?

NS:
I finished nursing school.

DWM:
While dialyzing?

NS:
Well, actually, after two years of nursing school, in 81, in July, I got a kidney.

DWM:
So you had gone on the waiting list?

NS:
I had gone on the waiting list and I got a call in July and I got a kidney and I went to the University Hospital. And that kidney came from a young woman in Alaska who had fallen off of a ladder, I believe, on a fishing barge. And she was young and I got this kidney.

I have no idea what the antigen match was. They never told us.

DWM:
What drugs were they treating you with for immunosuppression then?

NS: (2:21:32 - 2:21:34)
Same thing. Imuran and prednisone.

NS: (2:21:37 - 2:26:50)
And I think my Imuran may have been a little higher than maybe 25, something like that. It could have even been higher than that. At first, yeah.

Eventually. Eventually, yeah. And then I was on 15 milligrams of prednisone again.

And if you look at my graduation picture, which we showed in a talk I did the other day, my face was pretty puffy. So I finished nursing school on these drugs and I graduated with a 3.9. So I wanted to go back and show that to those nurses at the university. And I got my first B after my transplant in OBGYN.

I got a B. And one of the gals who also had a four-point along with me said, what was it like getting a B? I said, oh well, I'm not going to die.

I got a B. So I did graduate with a 3.9 and I got a job at Virginia Mason Medical Center working on the urology and nephrology floor. The difficult thing was nurses tend to eat their young.

And I walk in there with a transplant and they have just started doing transplants at Virginia Mason. And I pretty much knew more than they did about the drugs and the side effects. And I was really trying to keep my mouth shut and report, which was always hard for me because when I knew something I wanted to speak up and say I know about that.

But I watched every morning for days this young woman at the end of the hall was having shivering and chills. And they were going in every morning and doing blood cultures on her. Now having had blood cultures, I know how painful that is to dig down with that needle and find the artery in the middle of your arm.

And I felt so sorry for her but I kept my mouth shut. I was just a new nurse. But I knew why.

I knew why she was shivering and cold. She was having night sweats from Imuran. Imuran caused night sweats.

You'd get all wet and cold and you'd start to shiver because you sweat and got wet. And so one day she got assigned to me. I was so excited.

I went straight to the linen closet. I got a stack of gowns and a stack of bath blankets, those bed blankets, those flannel things. And I walked down to her room and she was a very shy, quiet girl.

And I said to her, Are you waking up at night sweating and then you get cold because you're wet? And she said yes. I said, When that happens I want you to take off your wet things.

I want you to put one of these bath blankets on your bed and another one over you and get dry and see if you can go back to sleep. That's all it took. Once she was dry, the chills went away.

And in the morning when the resident came through, I explained to her what I'd done and she rewrote the orders. And the nurses looked daggers at me. But you know, I couldn't have told them.

I just had to do it. And that was hard, you know. And they didn't like it that I knew more about that.

And we had people doing peritoneal dialysis on the floor. Now, the dialysis nurses would come in and do that but we had to empty these giant huge bags that were hard to lift and they were huge bags. And, you know, empty those in the morning and check on the people and stuff.

And then there was a separate hemo unit where they did the hemo dial. And, you know, I had, it was urology too so we had men's having terps and penile prosthesis and all kinds of interesting things to learn about which I didn't learn that much about in nursing school. And

I still remember the resident coming in one day when this man who had a terp and he had to be irrigated frequently because he kept getting blockages and finally the resident came in and he said, show me how to do this.

And so I had him do it. And then when he left he goes, what do you call that again? He ran out the door and I go, I am a nursing, just barely out of nursing school teaching these residents.

Oh, I think that happens all the time. He was already out of nursing school teaching them how to do this irrigation and telling them what it was called. We can only imagine how much residents have learned from that.

So you know, I started thinking, oh my gosh, he'll listen to me but the other nurses won't. You know, I learned a lot you know, in that situation.

DWM:
So your cadaveric transplant then worked for a while.

I have down here that you did very well with that second transplant until 1986.

NS:
Yes, five years. I had that five years.

Yeah. I left Virginia Mason and went to work for three internists. I made you know, less money per hour but the children had spent that year with their father while I was finishing when I was working nights at the hospital.

DWM: (2:26:51 - 2:26:51)
Yeah.

NS: (2:26:51 - 2:28:37)
Because that first year I worked nights and he had wanted the kids and so I said, okay, this will be a good time to take them while I'm working nights. So, and I had a boyfriend who was working nights at the jail. He worked for the sheriff's department.

And so, you know, we were both working nights and he's, you know, moved in with me and would have breakfast ready in the morning when I'd come home because I worked ten hours and he only worked eight. And that worked out really well and then the kids essentially came back home at the end of the year and I thought and I planned ahead so I quit the night's job and I knew even if I went to days I'd have to work some weekends and that wasn't going to work for me being a single mom. So, I got this job with these three internists in Kirkland and they were so accepting of me and they taught me how to draw blood.

They taught me how to draw blood out of hand veins. They taught me how to look under the microscope at urine and they taught me how to do EKGs, how to do ear flushes, how to

do sigmoidoscopies. I learned so much from those doctors in those three years I worked for them.

And, you know, in the last year I worked for them I started losing my kidney and I remember vomiting at work one day. And so the kidney was failing. It was basically chronic rejection because I was never one to not take my pills.

And, you know, it was really hard for me but I thought, okay, this again. I've done this once. I guess I have to do it again.

And, I went back on dialysis again. Same four hours three times a week that I hated.

DWM: (2:28:37 - 2:28:38)
At home.

NS:
Yeah.

NS: (2:28:38 - 2:29:48)
I was in the center for a while until they could get me into the home program. And I did it at home again.

DWM:
And what kind of access were they using then?

NS:
Because this was 1986. I have a Gore-Tex graft. A Gore-Tex graft.

DWM:
Did they try to do it

NS:
I think that I got this first Gore-Tex graft after I had the cannulas in 79. They eventually put this Gore-Tex graft in.

DWM:
Okay.

All right.

NS:
And so when I went back on I said, well, can we just put another Gore-Tex graft in that arm? So they just put on top.

DWM:

Yeah, this is actually pretty impressive here because you would have had your cannula right at your very distal part of your wrist. And then your first Gore-Tex graft is sort of mid-forearm. And then they've overlaid another Gore-Tex graft also in your forearm.

NS:
Yeah. And Dr. Moorhead did this one. And Dr. Mack did this one at Swedish Hospital. And I said, can't we just do it here so I can put in my own needles because I always put in my own needles. And that's what we did. Yeah.

Now if you feel, I mean, actually, I mean, my hands are cold because it's so cold in this room. Yeah, but you have good perfusion. I have good in both hands.

DWM:
Yeah. Did they try to do a fistula at all?

NS: (2:29:48 - 2:29:48)
They never tried.

NS: (2:29:49 - 2:30:42)
They pretty much said, we don't think we could do one with as much as your... All right. Because actually, not only did I have the cannulas and shunt here, but it had moved.

You can see a little hole there. Mm-hmm. I had them at different points of this arm going up.

Moving the cannula up. Just like I do on the left arm. Right.

Moving all the way up. When the movement of your cannulas and the reason you had so many cannulas, did you have clotting issues or infection issues? Sometimes there were some clotting and they used to de-clot them.

And they pretty much shoved the clots into us. Yeah, I gather. With some heparin.

Yeah. Luckily, I didn't feel, it didn't make you feel bad. I don't think there was a lot of concern about emboli from that.

Well, you probably, if my hands were warmer, my veins would be bigger. I mean, I am blessed with big veins. Yeah.

DWM:
And you're thin.

NS: (2:30:42 - 2:30:43)
You're very thin.

NS: (2:30:44 - 2:31:04)
I can remember both of my parents having huge veins on their hands. So big that I would sit there and play with them. Mm-hmm.

And push them down and watch them pop up. So, I was lucky that I had really good veins. I mean, you can see.

And these, your grafts, we have a lot of discussion today about the fact that a fistula is even better than a graft.

DWM: (2:31:04 - 2:31:04)
Yeah.

DWM: (2:31:05 - 2:31:09)
Did these work well for you? Did you have clotting issues with those? You had good flows through your growth.

NS: (2:31:09 - 2:31:10)
I had good flows.

NS: (2:31:10 - 2:32:08)
Never had a problem. Yeah. You know, speaking of flows, back when we had these cannulas in our arms at Eklund Hall, they would put an air bubble in and time it.

And the nurses would say, Nancy, your flows, I could hardly do it because my flows were so fast.

DWM:
Yeah. They call that the bubble racetrack, I think.

NS:
Yeah. And it was just literally a stopwatch. There was this little place on a sleeve and a stopwatch and she'd pop the bubble in, pop the bubble, and then the bubble would get caught in the drip chamber.

But she would time it. Yeah. She had excellent flows.

I had huge, excellent flows. I had these big blood vessels and I was, you know, I had been water skiing in the summers and I had been snow skiing in the winters and I was active and, you know, I probably had a higher creatinine than some other people my size because I was pretty physically active. Right.

DWM:
So when you go back onto dialysis in 1986, you're using a Gore-Tex graft.

NS: (2:32:08 - 2:32:08)
Yeah.

DWM: (2:32:08 - 2:32:14)
This one on top of this one. And self-cannulation.

NS:
Yes.

DWM:
Were you using a buttonhole technique?

NS: (2:32:15 - 2:32:15)
No.

NS: (2:32:15 - 2:32:19)
We'd never heard of that.

DWM:
So you were rotating sides.

NS:
Well, you can see.

Rotating sides.

DWM: (2:32:19 - 2:32:20)
Yeah. Yeah.

NS: (2:32:20 - 2:32:29)
It looks like I have tracks. Yeah. Yeah.

You can see where they, where I did them from here to here.

DWM:
And when they sent you home.

NS: (2:32:29 - 2:32:30)
This is venous.

DWM: (2:32:30 - 2:32:39)
This is arterial. Right. Okay.

When they sent you home, what machine do you have, did you have then? Do you remember?

NS:
I don't remember.

DWM:
A Cobe?

NS:

Might have been a Cobe.

DWM: (2:32:39 - 2:32:41)
A Gambro? Could have been a Gambro.

NS: (2:32:41 - 2:32:43)
Yeah. Could have been a Cobe. Could have been a Braun.

Yeah.

NS: (2:32:44 - 2:32:44)
One of them.

DWM: (2:32:44 - 2:32:46)
And hanging a hollow fiber dialyzer.

NS: (2:32:46 - 2:32:47)
Yes.

NS: (2:32:47 - 2:34:10)
Still four hours, three days a week. Still cramping. Not feeling good.

Going to bed after I got off. And my hematocrit was 15. So, in this last year working for the doctors, I had decided I wanted a house and I bought some property on Mercer Island.

And I had started building a house. I got my contractor's license and I had subcontractors coming in. I had a good friend who was an architect and really good at kneeling down and putting up and putting up and doing the framing and I had started building this house.

And then my kidney fails in the fall and I quit working, I think, on November 1st. But I have house payments now. I've borrowed money to build this house, right?

I mean, I paid for the land but I owe the bank and I have to pay my rent and this. And I have to start back on dialysis. So, I started back on dialysis at home and my helper was named Jose.

He was great. He helped me in so many other ways. And...

DWM:
When you say helper, he was assigned to you?
NS:
Well, you know they call them caregivers now?

DWM: (2:34:10 - 2:34:11)
Yeah.

NS: (2:34:11 - 2:35:13)

We call them helpers. So, it was like a home help or an extension of the dialysis clinic? The kidney center trained them.

Okay. And they were our helper.

DWM:
And what did they, what was his job?

NS:
He came in, set the machine up for me, put me on the machine.

DWM:
3 days a week?

NS:
Yes.

Put me on the machine. I put in my own needles. He did the rest.

DWM:
And would he stay during your treatment?

NS:
He stayed during my treatment because I shouldn't be alone with cramps and blood pressure problems and two little kids in the house. And he did that.

DWM:
But when you had been back in, when you first started dialysis in the 60s, late 60s, and you were doing home dialysis 12 hours, was somebody sitting there with you?

NS:
Yes. Those helpers that I got from the university who we gave free room and board to were sleeping in the bed.

They would be sleeping there in the bed. And the kidney center, though, didn't feel like they had to assign somebody to you. They weren't assigning somebody.

Well, they hadn't even thought of that yet because mostly, my mother was supposed to do it, right?

DWM: (2:35:13 - 2:35:13)
Yeah.

NS: (2:35:13 - 2:35:14)
They trained mom.

DWM: (2:35:14 - 2:35:14)

Yeah.

NS: (2:35:14 - 2:37:40)
But mom couldn't do it. It was too frightening to her. So, I trained my own helpers.

DWM:
Yeah. But you would have been responsible for having a helper then. And it sounds like you wouldn't have, when you were doing that slow dialysis overnight, you weren't having the problems that you were having during the short period.

NS:
No, I didn't have the cramping as much. Yeah. And I always ran on zero negative pressure.

Right. So, now they're really ultra-filtering and you're having a rapid dialysis. And I'm still running on zero negative pressure.

And I was running on a zero K bath. So, you know, it was, I don't know, it was difficult and I hated it. But I couldn't do anything else.

DWM:
So, Jose would set up your machine and he would be there through your whole treatment.

NS:
And then he would clean it and set it up and store it and come back two days later.

DWM:
Okay.

NS:
And so, eventually, I think, When did we move? We moved in May. So, I went back on dialysis in November.

And in May, when I figured the house was barely livable, I moved. The carpets were not down yet. There was running water in the spigot outside the front door and in the bathtub upstairs.

And that was it. But we had running water. We had heat.

And we moved in. And I moved the kidney, you know, the dialysis into the kitchen. And that's where I dialyzed before it was in the kitchen.

So, we moved it in the kitchen. And eventually, you know, then I hired somebody to come and paint. And I got the carpets in.

I got the tile down because we were walking around on the subfloor. And my brother hired some contractors to come in. And they came.

They were like little puppy dogs. What do you want us to do first? I said, I want you to get the water to the laundry room first.

I need to do laundry. So, they got the washer and dryer first. Because I could go upstairs to the bathtub and get water to bring down to the kitchen.

But I really needed... I had two kids. I needed to do laundry.

And by this time, Sarah was in the fifth grade and Josh was in the seventh grade. So, we moved in there.

DWM:
And you were not working.

I mean, you were just trying to take care of your children.

DWM: (2:37:40 - 2:37:40)
At this point...

NS: (2:37:40 - 2:41:33)
And dialyze three days a week. I couldn't work. You know, I was 40 now.

My hematocrit was 15 again. And it was one thing to go to school with a hematocrit of 15 and sit still in a classroom and go home and sit at the dining room table and study. But to drive somewhere and walk and work all day, I couldn't do that.

Not with a hematocrit of 15. So, I finally, for the first time, went on Social Security Disability. I had my 40th birthday in that house.

And we got, I don't know, for the three of us, somewhere around 800 on Social Security. I was still getting some money. My father had passed away when we were in Oklahoma.

And he had some land that had been sold. And I was still getting some, like, $300 a month from the sale of that land. So, that helped.

That supplemented it. And between that... And then I got some child support.

So, between Daddy's money and the child support and the Social Security, we were okay. We made it. But the Youth and Family Services on Mercer Island called and got us special tickets for free to go to the ice capades.

And would I mind taking another single mom? And I took a single mom whose name was Nasreen. She was from Iran.

And she was a doctor. And so, her two boys would come over for dinner and I'd have her over all the time and helped her, you know, talk to her about finding a job. And that was really fun, you know.

And I also had a Japanese student living with me when we moved. An exchange student. I couldn't travel.

So, I wanted the children to grow up without prejudice and learn that we're all the same. So, I had her... Naoko was her name.

And she lived with us. And then she finally moved out because I needed some help and she wasn't helping me. And she was starting to smoke in the house.

And she wouldn't eat with us and sit down at the table and eat with us. And she'd go into the kitchen at night and cook. I mean, it was just not working very well.

And I could tell that she wasn't. So, she finally moved in with another family who went to the same Buddhist church that she went to. And we ran into her a few times and waved and said hello.

And then later, we got another Japanese student, Masayo. And I found her because she was in the paper. And they were looking for homes for these people.

And she would pay $350 a month to live with you. And she was a great helper. She would sweep and, you know, clean up after the kids a little bit and help me in the kitchen and help me cook when I was on dialysis.

And she was fabulous. So, that was a big help. Yeah, she was a big help.

And, you know, when I helped her and I let her use my car, you know. And so, that went really well. And earlier, I forgot about this.

Before we had Masayo, we had Masao. Masao lived with me when I was on dialysis in, what was it, 81. Back in 81, or 79, when I went on dialysis.

I was so sick because they were only dialyzing me two days a week. And I, at Thanksgiving, the kids had been with their father. And so, I said, would you keep Sarah?

I'll take Josh back because he has to go to kindergarten. But if you keep Sarah, because I'm not feeling very well. I'd gone to the dentist and I could barely get out of the chair.

I was in a soul-forgiving way. My potassium was too high. Twice a week.

DWM: (2:41:33 - 2:41:33)
Yes.

NS: (2:41:34 - 2:45:50)
And so, I eventually got switched to three times a week. But I remember that night thinking, what am I going to do? Sarah was with her dad and Josh was upset because, number one, he was very sensitive.

He knew exactly. He read me like a book. And he was kicking the newspaper.

And I said, okay, it's time for you to go to bed. And I pulled myself up and got into bed and came back and was folding up the newspaper. And I saw this ad that says, Japanese student wishes to trade household duties for room and board.

I called him right up. My son moved in. And he was a great help.

Really, really great help. And he still works in Seattle at Benihana.

DWM:
Ah, good.

NS:
He's a chef at Benihana. So, I had myself first. Then I had myself.

Then I had an uncle. And that always helped to have somebody, you know. Just to help out.

DWM:
Help out in the house, yeah. You mentioned on your website that finally in 1989, EPO came around.

NS:
No, it was before.

Well, that's when it got approved.

DWM:
Yes. Okay, so when did you find EPO?

NS:
In, I call it EPO. So, in 1987, I was started back on dialysis. And I have moved into this new house I'm building.

And it has three floors. And I am crawling up the floor. I'm crawling up the stairs on my hands and knees.

I remember the kids came home from school one day. And they looked at me sitting in the middle of the stairway in the entryway. Mom, why are you sitting on the stairs?

And I said, Oh, I'll just be here a minute. And I crawl up the other half of the stairs. And so, Dr. Millie Tong was my nephrologist in Bellevue at that time. And she called Joe Eschbach. And said, Would you put Nancy on the EPO trials, please? I don't even know if they had a name for it yet.

And so, he took me into the trials. And I go into Seattle. And I can't remember how I was getting my EPO then.

But I go in there frequently. And my hematocrit went from 15 to 40 in a matter of weeks.

DWM:
And you think they were giving you a subcutaneous injection?

NS:
Later I did that. I really don't remember.

DWM:
And you were getting intermittent EPO on just the research, whatever research.

NS:
Yes, whatever they were doing, yes.

DWM:
And you thought it was dramatic?

NS:
It was dramatic.

I cannot tell you the difference. It was like going from dialysis to a transplant almost. EPO changed my life.

It really changed my life. If you can imagine having a hematocrit of 15 crawling up the stairs on your hands and knees. I remember one morning, I had just gotten the kids off to school.

And I'd gone up and laid down on my bed. I was exhausted. And my sister-in-law called.

And said, what are you doing? And I said, Becky, what can I do? My body has me in prison.

I can't do anything. And not long after that, I got the EPO. And Dr. Eschbach said, Nancy, don't you think you could work again now?

And so I did start working part-time again after that, when I got the EPO. I didn't work enough that I'd lost my Social Security. But I did work part-time and I did feel better.

And I could run around and play with the kids and run up the stairs and have a life back. It really gave me my life back. And in that time, nothing changed about your dialysis.

DWM:
You attribute that all to your change in hematocrit.

NS:
It was all hematocrit. And bless...

I mean, we got to have a hematocrit of 40 back then. I loved it. And I have big veins.

So I think they should assess your vein size before they decide your dose. If you have tiny veins, then, well, you might have to have a lesser dose because you might clot. But if you have big veins, you're less likely to.

But we're all treated with the same ruler. And I love EPO. I mean, I love that today.

If there's any drug that I worship, it's EPO. It changed my life.

DWM:
It's quite an endorsement.

Yeah, for sure. I mean, it sounds very dramatic.

NS: (2:45:51 - 2:45:51)
It was dramatic.

DWM: (2:45:51 - 2:47:01)
Certainly, you had this long history to really be able to see that change.

NS:
Well, I have an aunt. I had an aunt.

Grace could be 103 now. But she would come to visit us. She was my father's sister.

And she was a retired nurse. And she would come to see me when I was on dialysis crawling up the stairs. And then a few months later, she came to visit.

And I was running up the stairs. And she looked at me and said, What happened? You're running up the stairs.

And I said, Oh, Aunt Grace, I'm testing a new drug. And she goes, What's the name of the drug company? And I said, Amgen.

She ran right out and bought 10 shares of stock. And a couple years later, she gave me the stock. And then it just started splitting and splitting and splitting and splitting.

What a wonderful thing. And then she went out and bought some more for herself. What a smart woman.

And when she died, she still had Amgen stock that my brother and I split. And we got more. And we never bought any.

I never bought any. Well, Grace was a smart woman. She was.

To recognize the dramatic change.

NS: (2:47:01 - 2:47:02)
Oh, my gosh. She ran right out.

DWM: (2:47:03 - 2:54:03)

What a good story. Now, I have in my notes here that you were on home hemodialysis after your loss of your cadaveric transplant in 86, but did eventually move over to peritoneal dialysis. I did.

So, I was on the EPO. And so, I dialysed for two and a half years. Four hours at home.

Four hours, three times a week, which I continue to hate. We'll never do that again. And in 89, I got another transplant.

And we had just... This was a cadaveric transplant. This was a cadaveric transplant.

In the meantime, I had sold the house that I built, walked out with some money in my hand, and was able to make a really good down payment on a one-story house. Because I figured that I was, at some point, going to make sure that I had a one-story house. And I still live there today, 21 years later.

So, we moved into the new house. I was still dialysing. Jose was still coming.

And I got a call. I had just moved into that house. Anyway, I got this transplant.

And it came from Bellevue. It was somebody riding a motorcycle without a helmet. So, I got that transplant at Swedish Hospital.

And my drugs at this point now are prednisone and cyclosporine. I didn't like cyclosporine. It took me a long time to figure out why I was having terrible migraine headaches.

But I had them a lot. And that really killed my quality of life. My hematocrit was 40 with my new kidney.

But my quality of life was terrible from these headaches that would come and go. And I think I had that kidney for six years. And in the meantime, I went back and took a nursing refresher class.

And got another job at Virginia Mason Medical Center in physical medicine and rehab. And the reason I decided to take that job, I went in there as a temporary. And I thought, this is a perfect job for me.

Nobody comes in here with any infections. It's physical medicine. They come in with a limp.

They come in with a back problem. They come in with a neck problem. A shoulder problem.

So, it was perfect. So, I said, I'd like to apply for the full-time. And so, I worked there for almost 17 years.

And it was perfect for me. And I learned all about workman's compensation and injured workers. And it's a whole different ballgame.

But, I liked working there. And I liked the doctors. So, I worked there for two years.

And then my kidney began to fail. And I do believe that it failed because we didn't know how to adjust the dose of cyclosporine. And it probably just became toxic.

We certainly saw in the early days cyclosporine nephrotoxicity. So, in 95, my nephrologist was Kate Thompson at Virginia Mason. I could just run upstairs to my appointments.

It was very convenient. And she pretty much insisted that I do PD. Pretty much insisted.

So, finally I said, okay. I'll do it. And I did CAPD.

And the first year I did four exchanges. And the second year, I, as my residual kidney function was gone, I did an exchange at night on a quantum. I did an exchange on a quantum machine at night.

And, one reason it was really good for me is I actually could gain some weight. Which I've struggled with all my life. Right.

And I gained some weight. And my daughter said, oh my gosh, you know, my mom has a tummy. You know, when I was dry, she was like, you have a tummy, mom.

Because I never did before. I had skin and muscle on my tummy. And that was it.

She said, you had the flattest tummy of anyone I know. And now you have a real lady's tummy. So, I did gain some weight.

And that was a really good thing. Yeah. And my manager, bless him, I loved him, brought me an IV pole.

Put it in my office so I could do an exchange at my desk. Perfect. We had a microwave.

And so, around, you know, 11-15, I would take my bag in and, warm it in the microwave. And I would do squats against the wall to get my legs strong. And that's one of my favorite things to do is squats now.

Because I could never do those before. While my bag was warming, I was doing squats, trying to get my legs strong. And, then I would go back to my office, and I would drain and fill.

And that's when I saved my phone calls and I'd call my patients back while I was doing my drain and fill. And did you have any information I had two in five years. I had two peritonitis in five years.

But that was all. Okay. Pretty good.

DWM:
And did you have a Tenckhoff catheter?

NS:

I had a Tenckhoff catheter. Thank you, Henry.

I had a Tenckhoff catheter. I didn't really like where they put it because he put it right on my waistline. Yeah.

And my waistline would rub on it. Yeah. That bothered me a little bit.

You know, if I had to do that again, I'd say, can we pick a little bit better place? I think they were trying to do that. They may have just not judged it right.

I mean, they're trying to stay away from your waistline. But yeah, I don't know. Anyway, that was 1995.

1995. And so, I really only missed a tiny bit of work to have the catheter placed. And that was it.

DWM:

So, did you do PD up until you had this last catheter?

NS:
I did. Five years.

Yeah. I did five years. I joined Life Options Rehab Advisory Council during that time.

I traveled with my PD. I did it on airplanes with somebody behind me holding the bag. That was on traveling to a meeting and the person behind me was a nurse who was on our council.

So, she would hold the bag. And I did it in airports. You know, I'd run into some little fast food restaurant and say, can you warm this bag for me?

I said, only do it. So, I would only let them do it a short period of time and then I'd test it. And then I'd put it back in a one that was, I didn't want to, I didn't know how hot and hot it was.

I didn't know how fast their microwave was. then I'd say, okay, perfect. And I'd grab it and run off somewhere and do my exchange in the airport.

And I did them in the backs of meetings against the wall where the meetings were going on. I'd stand in the back doing my exchange in the meeting. I did them in hotels.

I mean, I did it everywhere. I did it in friends' houses hanging it from the cabinet in the kitchen while I was having a glass of wine. I mean, it was great.

Well, that certainly was the purpose of perineum dialysis to really try to give patients a treatment that's very portable.

DWM:
Yes. And it really did give you much more freedom and much more life.

NS: (2:54:03 - 2:54:03)
Yes.

NS: (2:54:04 - 3:01:43)
And I gained weight and my diet was a little more liberal and it worked really, really well for me.

DWM:
Yeah. And then you were transplanted again.

NS:
Yes. In 2000, I was in the cafeteria at work having lunch and my physician's assistant walked by and went, Dr. Cooper's trying to get a hold of you. And my doctor was on vacation so I knew the only reason that Mindy Cooper was trying to get a hold of me was because there was a kidney.

And she goes, she's trying to beep you. Well, I guess my beeper's battery had gone and I hadn't gotten the beep. So, you know, I said, okay, I'll run up to the ER.

So I ran up to the ER and they draw those huge quantities of blood trying to make you anemic again, huge quantities of blood. And I did have EPO while I was on PD and I did give myself my own EPO, Sub-Q. And I was able to keep my hematocrit at 40 then.

But later it got changed down to 36. So, I ran up to the ER and they drew all the blood and I went home. I went back to work then I went home.

And they called me, they thought I was going to have to come back in the middle of the night but they eventually waited until morning because now this is the kidney from Bellevue, I think. The one before that was the one from Alaska. This one was the Bellevue, with the, about the helmet.

And so that came across the bridge. And this time I had it at Virginia Mason. I had it at Virginia Mason where I worked.

So, it was pretty convenient. So, I had it the next morning for the transplant. And it did really well.

None of my transplants did I ever have to do any dialysis afterwards. None of them. Good function right away.

I remember sitting in the exam room with Dr. Cooper. She is talking to the blood center on the phone. Now, this blood center knows me well.

They have done the matches for all my transplants. They have a huge file on me there. And Mindy says to me, she thinks this is a really good match.

There had been one that had come a while earlier that was a perfect match from Massachusetts. And I had gone into the hospital and had the IV started, was on the gurney, headed out the door when the phone rang. I pick up the phone on my way out and it's Dr. Chris, my nephrologist, saying, we're not going to do it. There is something wrong with the kidney. And he told me nobody got it. There was something wrong.

Too bad. It was a perfect match. Came from Massachusetts.

But, you know, even though it was a perfect match, having to be flown that far, it probably wouldn't have been perfect. So, this one coming across the bridge was probably better. And I've had it for ten years.

Oh, no, you know what? I'm getting really mixed up. I've had too many transplants here.

The 81 was from Alaska. The 89 was the helmet and the motorcycle. The 2000, what we're talking about now, was a young man who was in a car accident in Spokane.

So, this one came from Spokane. And I understood from what I heard that he was with his mom and his wife. They'd been to something together.

And so, I got it from Spokane. And now, I've had that transplant for ten years. And my creatinine is 1.2. Perfect. Yeah.

DWM:
And what medications do you take for this transplant?

NS:
I'm taking um, tacrolimus and mycophenolate.

And at one point, and I've just done really well with this. I mean, I worked and I, you know, took the summer off. I got the transplant in June.

I took the summer off, went back to work in September because I was out of sick leave. I didn't feel that well, but I just kind of faked it. Because the drug levels were pretty high still and it wasn't until um, November.

I remember on Election Day in November, I think I feel better because they'd been tapered down enough that I felt a little bit better. It was really a year before I felt kind of stabilized on the dose. And at some point a few years ago, I was watching my numbers so carefully that I watched my tacrolimus level and my creatinine going up side by side.

And I pointed it out and I said, I don't like this. And so, we dropped the tacrolimus from three milligrams a day to two milligrams a day and both the levels came back down. Perfect.

And so, I've been fine since then. Yeah. And, my kids got married.

Josh got married. I have a grandson. I told Josh, he's my exponential miracle, honey.

And he goes, you've never said that before. I said, I know, but you were my first one and that's why your name is Joshua because it means gift from God. And Sarah means princess.

So, and she is. She's pretty much a princess. You have put together this extraordinary life, dealing all the time with this chronic disease After my transplant, Josh invited me to go skiing at Mount Baker.

And, he would ski down and he was, I'm going, honey, that's a black diamond hill. I haven't skied in ten years. He goes, oh, mom, you can do it.

And he had the skis and the boots and everything ready for me because he worked in a ski shop. And so, he would ski down the hill and wait for me and then I would ski down to him and then he would ski down and wait for me again and I would ski down to him. And, I, I, I said, honey, you have to wait for me.

And he goes, oh, no, mom, I don't mind. And at the end of the day, when I was getting ready to thank him, he thanked me for skiing with him. So, you know, I've just been so lucky to have these kids and really have a normal life.

And since that transplant, I've traveled to England, I've gone to Wisconsin, I have been back to Rhode Island where my mother's family lives. My father's family came from in the 1600s and my dad was born in Wisconsin and I've gone back there and met some of those people. I went to England and met my fourth cousin, my Hewitt relatives because my middle name is Hewitt and I've met them in England and I've been to Scotland a year and a half ago and got to meet my Hume clan and it's just, it's been a huge, wonderful life and I, I, I have had to take some EPO during this transplant.

It didn't make blood as well as my other transplants. It didn't make enough EPO. But since my hematocrit has dropped to 1.2, I haven't, The creatinine. I'm sorry, the creatinine. The creatinine dropped to 1.2. I haven't had to give myself any EPO since December. I went in a week ago and my hematocrit was 36 and my hemoglobin was 12.5 so it's still sitting in the refrigerator.

DWM:
Perfect. I want to talk, just to see who you know and what you remember about some particular people.

NS: (3:01:44 - 3:01:44)
Okay.

DWM: (3:01:45 - 3:06:47)
And let's start with Scribner. I know we talked a little bit about Scribner but you want to tell me what you think of him, what you remember about him, what you remember about his role in really starting chronic dialysis.

NS:

I just love Dr. Scribner. He was almost a father to me because my father was far away in Alaska. And I remember before that. And he was so much of a collaborator.

He did not have the ego that some doctors who like to invent have. He shared. He called you on the phone.

Nancy, what do you think about this? He was always asking people what do you think about this? He never patented what he did.

He just loved doing it. He loved doing it. He loved helping people and saving people and figuring things out and solving problems.

And he was not into money. He lived a very simple life. And on that houseboat, you know, they lived a very simple life.

I just had a huge amount of respect for him. And later on, 10, 12 years ago, he was really, really upset about the inadequate dialysis. He was upset about KT over V, which he said was a stupid, useless number.

He said what mattered was how many hours you ran on the machine, not your KT over V, how you're functioning in life. That's what mattered, not your KT over V. And so he was very upset about this.

And he didn't like where dialysis and nephrologists were going. And he was very angry that people were eating too much sodium on dialysis. Neither of us could ever figure out who came up with the medicine 2,000 milligrams a day.

Because we both thought that was ridiculous and too much. Because he always had us keep our sodium under 1,000 milligrams. And I'm still doing that today.

I had to take a Lasix this morning because the food here at this convention is too salty. So he was a teacher. He gave me tools to get through life.

And one of the best ones was watching my sodium. And the other one was, you know, go out and live your life and do what you want to do and that kind of thing. That's what I remember about Dr. Scribner. A lot of people say, too, that the things that he accomplished, he would observe things and then get people to try things or do things differently. But some of the things that in today's world with regulations and approval and that some of the innovation that he was able to accomplish would not have been done. That's absolutely correct.

Because he could just do it. He'd say, I want to do this. And he'd do it.

He didn't have to apply for any application or anything like that. And that he really was observing patients and problems and then trying to find solutions to those problems. He loved to figure out.

He loved problem solving. And that's why he had, you know, Dr. Eschbach working on anemia. He had Dr. Sherrard working on the bones. You know, he had assigned these duties that he had noticed were a problem to his fellows, his renal fellows and residents. You know, they were all working on these things that he thought. And look where we are today.

I mean, he identified them all then. Yeah. He really did.

He identified most of them. Not all of them, but most of them. A lot of people say that he truly was visionary too.

He imagined things that other people... I mean, I think at a time when people could not have imagined chronic dialysis, he was willing to consider if he could solve the access problem or not. Yes.

I mean, he told me that he, you know, took this... I mean, Jim Albers was a physicist who married Joanne, the nurse. And he helped figure out the dialysate with him.

So, he did not go to other doctors. You know, Jim says... He would say, Jim, what do you think about this?

And Jim would help him figure it out. So, they would go to some kind of a seminar or convention and try to show this to people and they just pretty much laughed at it. Until people started to live.

Until some of us started to, you know, live and have a normal life. And then they began to listen. Were you aware of this sort of history that, you know, here you were at age 19 starting dialysis, this opportunity to sort of live a normal life.

DWM:
Were you aware at all? At what time did you become aware that there had been people, you know, within a decade before that, within five years before that, who were not, you know, who couldn't live. I mean, chronic dialysis was a fatal disease.

I mean, chronic kidney disease was a fatal disease.

NS: (3:06:47 - 3:06:48)
I don't know.

NS: (3:06:48 - 3:07:19)
It's kind of, you know, back there in my memory. I can't identify exactly when I figured that out. Yeah.

I think I began to figure it out when they started doing little celebrations. And we'd hear about this or hear about this history or hear about that history. And we'd hear about these celebrations.

When you're in the middle of it, I mean, you play this very important role in the history of dialysis. And yet, you've been busy living your life and probably have not...

DWM: (3:07:19 - 3:07:20)
What's the point?

NS: (3:07:20 - 3:11:17)
What is the point? If you're going to live, you may as well live. I mean, what is the point of just laying there and doing dialysis where you feel like horrible.

You feel really, really horrible. And then having to go to bed and get up the next day and, you know, the next day be back at it again. I mean, what's the point?

If you can't live a life, that's the whole point. And the thing is, all of us, in the beginning, all were working or going to school full time. We all were.

Every one of us. So we knew it could be done. And I had this wonderful family who expected me to keep going.

I never really thought about it. I think after I started dialysis and I started to feel a little bit better and I got my job at Washington Natural Gas and I bought myself a little MG. I had a Mustang before that that my brothers bought me so I could get back and forth to dialysis.

And I got myself a little MG and I used to drive around Lake Washington trying to kind of figure things out. And I became very spiritual kind of during that period of time and decided that this was a gift that had been given to me so that I could really learn. Because it's important to learn in life.

And I have learned a lot. And Dr. Springer really helped with that. He really did.

He gave me so many tools and the fortitude to keep going.

DWM:
Also, did you know Jack Cole?

NS:
I did know Jack Cole.

DWM:
What do you remember about him?

NS:
Well, I don't remember Jack Cole a lot other than Jack Cole is still involved with Northwest Kidney Centers and his daughter is on the foundation board with me. But when I got to know Jack the best was about ten years ago.

Nine, ten years ago. When Dr. Springer was calling me all the time because he was trying to write a book and he needed some help and he said, Nancy, I really need your help. And he was trying to find some help because he wasn't feeling that great.

And so eventually, Jack and Henry Tenckhoff and I and another gal named Sandra Marvany from the University of Washington met every Saturday for months and months writing and editing for Dr. Springer's book. And he'd written a good part of it. I wrote the chapter that you obviously have read.

That was supposed to be a pioneer chapter. And I helped edit the nutrition chapter because it was written in too cerebral a language for a common patient to understand. And we were working really, really hard on that.

And it was, he had paid a publisher. And too bad it wasn't later where he could self-publish because he certainly could have done that more easily. And then he died and the book never got published.

But the reason he was motivated to write that and that he asked Jack to help him because Jack was there with him all through the early designing days. And Henry was there. And I was there.

And there were different perspectives from each of us because Jack isn't a doctor but he's a certainly, you know, wonderful technical person. And so what happened was he died and it didn't get published. You all do carry a lot of the history.

DWM:
I mean, Jack Cole and Henry Tenckhoff and you all three share a lot of the history among you.

NS: (3:11:17 - 3:11:17)
Yes.

NS: (3:11:17 - 3:13:00)
You put together a lot of the history. Well, after he died, Ethel had been at the grocery store and she came home and found all these people on the dock fishing him out of the water. And I heard from Mary Mason who's a social worker at Virginia Mason and that's not a coincidence.

That was her father and grandfather. And she called me on the phone and she said one of the Scribner's sons, Tom, I think, had called her and told her. So I knew before the media knew because Mary called me.

He called Mary because Mary used to live down there and Mary's father was a urologist. And she called me at work in the afternoon. And so within hours, I knew.

I mean, that was really hard. Really, really, really hard for me to do that. Yeah, he was such an icon.

DWM:
How about Henry Tenckhoff? Did you know him personally?

NS:
I knew Henry.

And, you know, he worked a lot on peritoneal dialysis. I didn't know Henry really well but my first really, really good memory of Henry was in August when Sarah was born. And Sarah was born in 1976.

And Dr. Mercuro always took August off. So he was gone. And Henry would come up and pick Sarah up and walk around the room with her in his arms.

And that's when I really got closer with Henry because he was so excited about this pretty little baby girl, you know, and he would carry her around and come and see me and be there for me.

DWM:
I've talked to Henry and Laura Tenckhoff and they certainly were very family oriented. They had their children.

NS: (3:13:00 - 3:13:01)
I knew their daughter.

NS: (3:13:04 - 3:14:20)
She worked at Virginia Mason with me. We had lunch together many times. And, oh, that's where I was going.

When Ethel was alone, I would go pick Ethel up and then I would go pick Henry up and we would go down to Magnuson Park where Sandpoint Mule Air Station used to be and walk. We would go for walks because Henry has diabetes and he needed to walk every day. So we did that many times Ethel and Henry and I would go for walks and I really enjoyed that.

And sometimes I'd pick up Ethel and the three of us would go out for dinner. I really love spending time with older people. Well, and you all share this very special history too, which is, I'm sure.

And my aunt married a retired urologist and when she died, I used to go visit her after mom died, and then when Aunt Mimi died I would go visit Harold and he and I would go out for lunch and dinner and coffee and stuff. So, you know, I miss them. They keep leaving, you know.

DWM:
Did you know Robin Eadie?

NS:
I did know Robin. I didn't know him well.

I didn't know when he was here dialysing. I remember Scrib telling me that he'd picked him up off the plane and carried him to his car. Sounded like he was very ill.

DWM: (3:14:20 - 3:14:21)
Very, very ill.

NS: (3:14:21 - 3:19:44)
Very, very thin. Very, very ill. And his family had read about Dr. Scribner and sent him here from England. Yes. And Scribb told me that he dialysed Robin, but he couldn't keep dialysing him here because there was no money to pay for it. And so Robin went to Canada.

Yeah. And eventually then, I think, was with Eli Friedman in Brooklyn and went to medical school. Yes.

Yeah. Yes. But I met him at the Lasker Awards because Effa got really sick and was in the hospital and while she was in the hospital, Scribb was alone and he wasn't very good at eating properly and taking good care of himself.

And he ended up, and I don't know all the details, but she came home and then he ended up in the hospital. And I was up visiting him in the hospital and this must have been around 2002. We were watching a Mariners game, watching football, or baseball, and watching this Mariners game and during the commercial, he turned to me, he's in bed, and he said, Nancy, would you like to go to New York?

I said, New York? Why are you inviting me to New York? Well, I can't go, so I'd like you to go.

And I said, why? And he said, oh, I'm winning an award and I'd like you to go because I really want patients who have been well-dialyzed and well-cared for to show up there and show them what needs to be shown. Because he was so upset the way people were being dialyzed today and not watched on their sodium and stuff.

So he sent Robin Eady, he sent Linda Johnston, who's a physician in California, and myself, to New York. And when I got there, his whole family was there, Ethel's sons, who are letterers, the letterer boys, three of them, and then Scrib's kids were all there, and Robin and Linda and myself. And when Sarah, my daughter, heard that I was going to New York, she goes, New York?

Can I go? So I said, sure, you can go. So I went on Hotwire and I found us a room at the Crowne Plaza for like $67 a night and I got a JetBlue flight into New York and Sarah went with me.

And we went on Tuesday and the awards were on Friday so that we could tour New York beforehand. And it was wonderful. I mean, I got to meet Robin and sit and talk with him and visit with him so that's the only time I really met him and talked with him.

But Linda I remembered because she was around the University of Washington and got her transplant room at the time I was running around there. So she only dialyzed nine months and then she's had two transplants. So I did meet Robin, yeah, and his wife, they were there.

DWM:
Did you know Joe Eschbach very well?

DWM:
Yes, but I want to say one thing before we finish with Robin. When I got back home, Dr. Scribner said, where's the bill?

I want to pay for your trip. So I showed him how much I'd spent on the hotel and my flight. He goes, Sarah went with you.

I said, yes. He goes, I'm paying for Sarah too. And so I said, okay, this is what we spent.

And he goes, yours is less than everyone else's. I said, well, I didn't want you to have to pay very much for us so I got JetBlue and Hotwire. And he goes, well, I won $25,000.

I mean, he was giving it away to all of us. You know, that's the kind of man he was. He was not a greedy person.

And so he wrote me a check and I took a picture of that check before I cashed it. I have it somewhere around the house.

DWM:
So you used his award to get everybody there.

NS:
Yeah. And Joe, I did know Joe Eschbach because he was there when I was learning home dialysis at the coach house. And I first knew of him then.

I didn't know him well. But I got to know him quite well when we were doing the EPO trials. And I got to know him much better during that period of time.

And, you know, over the years at different things, I've just gotten to know him. And then more recently, I was going to these theosophy meetings once a week. And there was a gal, oh, once a month.

And there was a gal there who said, don't you know Joe Eschbach? And I said, yes. And she says, well, he's giving a talk at church.

She went to a Presbyterian church, very liberal Presbyterian church. And he's giving some talks at church that I think you might be interested in. So one day I showed up at the church and walked in and Joe goes, Nancy.

So I got to know them better during that period of time. And, you know, we saw each other around and at different kinds of things. And I got more involved with the kidney center and then, you know, he'd be at all these different things.

And we got to be quite close during that period of time. And then he died, of course, just a couple of years ago. Yes.

He died of lung cancer and he never smoked. And he was very much like Scrib in the fact that he just liked to figure things out. And when he retired, he had a party for his patients.

He didn't expect a party for himself. He had a party for his patients.

NS: (3:19:45 - 3:19:46)
Good idea.

DWM: (3:19:46 - 3:39:57)
Yeah. How about Chris Blagg?

DWM:
And Chris I know very well because he was walking around with Joe Eschbach and Dr. Scribner while I was in training. And I did something that Dr. Scribner was trying to research and that was the artificial gut. Ah. And he was trying to figure out how to get nutrition into people who couldn't eat it.

So he decided that the cannulas were a perfect way into the bloodstream. So he asked me if I would do this experiment and I said yes. And this was in 69 when I was working at Harborview.

And he said, Okay, this is what you have to do and this is what you can't do. You can't eat. We're going to give you this IV and it was in an old glass bottle.

So they brought over the IV pole and Dr. Black brought it. And he remembers that because it tore the upholstery of the door of his Mustang. That IV pole.

He always reminds me of this. So he brought over the IV pole and I don't remember who brought all the things but eventually, you know, they would hook up and I would get one or two bottles of this a day. Amino acids.

And occasionally, they'd put in some alcohol so I'd get more calories. So I'm getting IV alcohol and amino acids. And I'm working evenings at a Harborview emergency room.

And he told me, You can't have anything to eat but sugar. That's it. Sugar doesn't make waste products.

You're not going to be able to go on dialysis. I don't want you on dialysis. I just want you doing these IVs.

So for three days, I ate hard candy and rum and Cokes. When I get home, Mom would fix me a rum and Coke from work. And I could have Coca-Cola and alcohol and hard candy.

That was it. Pure sugar. So I did that for three days and eventually, I started vomiting.

And I said, I can't do this anymore. I have to go to work and this is getting too hard to do. So he said, Well, don't quit yet because I've got to send somebody over to take your picture.

So they came over and took my picture with the glass bottle and I'm kind of popped up in bed, not feeling very well. And I still have that picture. I've sent it to Dr. Blagg so he can use it in some of his talks. Chris Blagg, that sounds like he was sort of Scribd's right hand man. And then, you know, very involved in the outpatient and the chronic dialysis. Then, yes, he became the medical director at the Northwest Kidney Center and it all kind of changed and it moved from Eklund Hall over to Haviland across from on the other side of Swedish Hospital.

And when he took over, right around just before I went back on dialysis the first time, I remember having a meeting with him in his office which is all in this beautiful emerald dark green, forest green. And I remember sitting there and saying to him, number one, you cannot paint the walls yellow in a dialysis center. Our skin is already too yellow.

And it just makes us look worse. And you need to have pictures that aren't flat. You need to have landscapes where we can disappear into those pictures while we're on dialysis.

Rivers, forests, planes, something that's a landscape where we can disappear into the picture. So we talked about all these kind of different things and I said, people need to know our names and not call us ma'am and sir. I said, I just can't tolerate being called ma'am.

I grew up here, everybody knew my name. So those are the things. And Chris took them to heart.

And he did all of those things. He did.

DWM:
I don't know if you knew Clyde Shields.

NS:
I did not know.

DWM:
You had won the Clyde Shields Distinguished Service Award. Clyde was gone by then.

NS:
And when did I win that? In 2002 or something. It was a while ago.

DWM:
Tell me about the award and why it was given to you.

NS:
I don't really know. Other people nominated me.

I didn't nominate myself. I think it was just because I was trying to go out into the community and educate people. And I was always an advocate and I always was outspoken about it.

And I was just trying to help other people. And I don't even remember what I was doing back then. I know that for years I have gone to senior centers and volunteered and gone in and taught them how to protect their kidneys.

And I went to the cafeteria where I worked and said, you're serving too much salt and this is a hospital. Those kind of things. And somebody else, you'd have to ask the people who nominated me.

DWM:
Yes, but you've had a lifetime of service in educating caregivers and patients about kidney disease. And I'm sure that's been very important to them.

NS:
And I was working as a nurse.

Yeah. Trying to help people get rehabilitated.

DWM:
Yeah, absolutely.

A very important part. Because that brings us to talk about the Northwest Kidney Center and what they do today to support kidney patients.

NS:
They're a huge outreach into the community center.

They're a non-profit. They have Hispanics here every year. They have an African American Fest where they go in and they cook and show people how to cook.

And Katie Wilkins, our dietician, is fabulous. And they show them how to cook. And I go down and volunteer.

Take their blood pressures. Teach them about exercise and how important that is. All that kind of thing.

And they do that. They built a center near SeaTac. So for surge capacity, if there's ever a disaster, people can fly in and use that.

And we've got generators there and that kind of thing. We do a lot of foundation work. We give scholarships to people going to school.

Boy, you're wracking my brain. I wish you'd told me before you were going to ask me this question. I'm going to have to reach back.

And we supplement people who don't have as much money. I'm on the foundation board and I can't remember all the things that we do. We do a huge amount of outreach into the community.

We print lots and lots of educational materials and give them. I just had house guests last weekend, Donna Smith and her husband Larry, and they were in the movie Sicko. And Larry's had some cardiac problems and quite a few open-heart surgeries.

And she sleeps with a CPAP machine, so I brought out my handout on sodium. I think that you might feel better if you did this, especially you with your heart problems and you with your CPAP. Let's reduce your sodium.

And so they were very vigilant. I was cooking no sodium food for them. I mean, I can't not do that because I'm trying to save lives.

And if I kept my mouth shut and let those people... I mean, how can you help people if you don't educate them? So I have to be careful that I don't intrude too much, but I'm very much an advocate of trying to keep people healthy.

And I'm doing it because I love people. I'm not doing it to be obnoxious. I'm doing it because I love them and I want them to feel better and live longer.

That's a great thing. You were also involved in the network and gathering. That was a long time ago.

That was in the early 80s, and it was pretty new then. And I was on it because Dr. Pendrous, my physician at that time, was on it and recommended me. So basically we did a lot of...

You know, we didn't do a ton back then. We did a lot of complaints from patients, that kind of thing, and help patients with those kinds of problems. And there weren't a lot of for-profit centers yet back then, and they were just starting to come in.

And, you know, we had complaints from our own patients. So that's what I remember the most was going to those meetings and resolving that kind of thing. And Dr. Pendrous died of a brain tumor. And Dr. Mahl died of a heart attack when I was working at Harborview. So it's been really hard over the years to lose these people who were like fathers to me. And all of them were.

Yeah. And all of them educated me. And, you know, it's your mentors that keep going away.

DWM:
What do you think, and we've talked a lot about these milestones that you've seen in all these decades of dialysis, you know, improvements in vascular access, improvements in dialysis machines, and EPO, changes in transplant medications. What do you think in the next 10 years?

[Speaker21]
I think the doctors need to look more at the patient.

They need to look at the numbers, but they need to look at the patient because if the patient isn't doing well, I don't care what the numbers are. So there needs to be a shift to that because that's what Scribner did. And I'm noticing that it's coming back that way.

I mean, they're talking more about sodium and volume now, which he wished 12 years ago they'd been talking about. They're talking about overnight dialysis now. Which he wishes 12 years ago they'd been talking about.

Look how long it's taken us to get back. I remember at Life Auction saying, oh, they're going to talk about nocturnal dialysis. And I'm going, you know, in the 60s, we dialyzed overnight, but we just called it dialysis.

It wasn't nocturnal. It wasn't all these different names they've given it. It was just dialysis.

So I've seen all of that come a long way, and I know they're talking about wearable kidneys. But you know what I want to live to see? I want a cloned kidney that's perfect for me.

This is what I want. And this is what I'm hoping. That's a good, I'm glad you brought that up.

I'm going to talk to some of these guys about that. Because I know they've been working on it with pigs. And that's what I want.

I want them to go to my brother and take a little piece of his remaining kidney and grow me a new perfect kidney that I will have forever. Because I plan to live to 100. Perfect.

DWM:
Yes. In the interim, you think that it would certainly be an improvement to go to longer, slower dialysis?

NS:
I know it would be an improvement because that's what we know works.

And I know some people now who are dialyzing every night overnight, and they would never go back. They tell me they will never go back because they feel like normal people. They're getting, you know, they're not uremic.

They're not having these huge highs and lows in between dialysis. They just never would go back. I mean, when Bill Peckman went to short daily, he said he would never go back to three hours.

And now he's doing, he extended his short daily to long daily, and he's doing it overnight. And I do believe that if and when I have to go back on dialysis, I will either do it overnight, you know, or maybe an improved PD with an improved solution. I know they're improving the solutions because now it's been 10 years since I've been on my solution, and I know that that's improving.

It is remarkable that you have, through all these changes, going from dialysis to transplant, back to dialysis to PD, that you have not been discouraged. I mean, you have just said, okay,

what's the next step? And it's worked very well for you, piecing together these various, these quilts of treatments over time.

Mm-hmm, mm-hmm. How have you done that? Well, first of all, you know, I was always good at following the rules, but I'm also very good if the rule isn't working for me, speaking up and saying, you know, my tacrolimus, I think, is too high.

And patients need to learn how to do that, but they have to be educated in order to do that. Luckily, I went to nursing school. But Scribner taught me all this stuff.

And actually, to prepare my own classmates for the board exams, my instructors came to me and said, Nancy, we want you to teach the fluid and electrolyte review for the boards. And if I can do that, I could teach patients how to do that. And they're surely better than they used to be, because they're being told more about their numbers and more about self-care than we ever were in the early days.

Except Scribner did quite a bit more. In fact, they would let us carry our charts around the hospital because they'd say, well, it's you, you know, why would you not carry yourself around the hospital? So they were very good here in Seattle about educating us and helping us do that.

But I wanted to say also that your ability to understand in some manner that there wasn't just going to be one solution to your kidney disease, that the solution to your kidney disease was being flexible over a long period of time to do transplant. And when that transplant ran out, to go back to dialysis.

DWM:
So the willingness to not expect that one thing would be the solution for you.

NS:
You know, I pretty much did what I had to do. And, you know, what's the Robert Frost, the road not taken? So I always try to take a new road and see what's down the path.

And I luckily had a mother who, and I'm telling you, those first days of dialysis when I'm getting the dialysis that all the men were getting, the dialysate that all the men were getting, I did not feel well during that period of time until I went home and had my own special dialysate. And I can remember being collapsed on, and then we were getting headaches and they're giving us Phenergan, you know, codeine and Phenergan and Demerol. And I remember there was something that was making me very hyper and I couldn't stop walking, just constant.

And then my mom's friends would come over to play bridge and pat my head, oh, you poor thing, and I hated that. I really hated that. And on the really tough days, my mom would say to me, the sun is around the corner.

There's always sun around the corner. So I think that became part of me, the no such word as can't and the sun is around the corner. Because you just keep going like you're going to live forever, and maybe you will.

I mean, one of the things I said in the talk I gave yesterday is, when one says to you there are no guarantees in life, you immediately think, there are no guarantees that I'm going to live very long. But I'm saying, there are no guarantees you're going to die either. So if I could talk to every kidney patient, there's no guarantee you're going to die.

Look, you can live forever. I mean, there are no guarantees. So you can reframe that to the other direction and say, you know.

It's a positive thing. But you know, my brothers never spoke to me about it, but they acted it out. My brothers helped for me to pay to go away to college a year before I was starting dialysis when I could have died.

But they still sent me off to college. I still went. And they could have said, why send her to college and spend all that money?

She's going to die next year. They didn't. And now that I can look back and analyze all this, I am just...

I remember when Jim took me to the airport to get on the plane. I used to write a lot of poems. And I wrote a poem, and I can't remember all of it now, but there's a scrabbling mind within me.

I grew up in a family that played Scrabble all the time. Lining up old words to make new thoughts. And I ended it with thoughts that say, I love you.

And I gave that to my brother when he put me on the plane. And they were always there for me. They were there for me with physical support.

I lived with both of them. They made sure that I got... my college tuition got paid for.

They made... their wives made sure I got to the doctor. I mean, they were there for me all the time.

That kind of support is huge. Nobody ever said, you can't do that, or you're a poor thing, except my mother's friends, and I hated it. And then my younger brother comes along and gives me a kidney, and Dr. Marcuro says, of course you can have this baby. So I got all of this support and positive input from everyone all around me. But I was really lucky to live in Seattle. Yes.

At the exact right time. Oh my God, my nose is itching. But you want to make sure that we talk today and I've been struggling a little bit, and you can decide whether...

And there was a little trouble with Sarah's 33. She missed a huge bonding period in my life, between two and a half and three years old. And that...

So she came to me one day and she said, I didn't know my mother when I was... but I did. And when my sister-in-law said, you may not be chosen, I said, I will.

So part of that's being young and invincible. But if you don't think... and look for the silver lining.

You know, there are heart... I think they're just coming up with a liver machine, I heard. But all these years, there hasn't been a liver machine.

But there was a kidney machine. So... And transplants?

Because I've had four transplants, you can see that I prefer that. So every time I was on dialysis three more times, I went on the list immediately. And I kept myself healthy, so I'd be ready for that kidney.

I mean, that's my responsibility. If I want a good life, I'm responsible for that.

DWM:
I thank you so much, Nancy, for spending that time with me today.

NS:
Oh, you're welcome. We've spent a lot of time, haven't we? This has been great.

Oh my gosh, four hours.