# VOICE EXPEDITION INTERVIEW TRANSCRIPT
## The Oral History of Nephrology
## Nancy Sharp
## Interviewed by Dugan W. Maddux, MD
## June 17, 2015

DWM: (0:00 - 0:18)
Today is June 17, 2015, and I'm here in the Fresenius Medical Office in Washington, D.C., and I have the pleasure to talk to Nancy Sharp. And so, Nancy, thank you so much for being a part of the Nephrology Oral History Project.

NS: (0:18 - 0:18)
You're welcome. Great.

Thank you.

DWM: (0:18 - 1:18)
I'm looking forward to talking to you today about all the work you've done in nephrology. So I want to start with where you were born and raised, where you went to school.

NS:
I was born Nancy Johansson, July 11, 1938, in Gary, Indiana.

My parents were Eric Ragnar Johansson from Kalmar, Småland, Sweden, and Eva Sophia Johansson from Borlänge, Dalarna, Sweden. They had immigrated from Sweden as adults, met at a Swedish dance in Chicago, and were married in Chicago in 1936. I lived in Gary, Indiana until 18 years old, then I moved to Chicago to attend Augustana Hospital School of Nursing.

Then I received my Bachelor's in Nursing BSN from Augustana College in Rock Island, Illinois, in June 1962.

DWM:
Can I ask you about Augustana?

NS: (1:18 - 1:18)
Yes.

DWM: (1:18 - 1:34)
I'd just like to know, so Augustana School of Nursing? Hospital School of Nursing. Nursing.

NS:
There was Augustana Hospital, and Augustana Hospital had a school of nursing, one of those three-year diploma schools.

DWM:
Okay. And so how many students would there have been?

NS: (1:34 - 1:34)
Eighty.

DWM: (1:35 - 1:46)
Eighty students. And so what was it like? So what year was this?

This was... 1956. 1956.

So what was it like to be in nursing school? Was it clinical? Was it classroom?

NS: (1:47 - 1:47)
It was...

DWM: (1:47 - 1:50)
And was it all women?

NS: (1:50 - 1:52)
Oh, yes. It was all women.

DWM:
And did you live in a dorm?

NS: (1:52 - 2:25)
We lived in a dorm in a building next door to the hospital. And we would go to the units and do patient care in the morning, and then we'd get the afternoon off and have classes, you know, study. And then, of course, we'd have homework.

Sometimes we'd have to go back in the evening, do evening care for the patients, you know, back rubs, back in the old days when they did back rubs, and help patients.

DWM:
Yeah. And what were you expected to do as a nurse?

Were you... A back rub?

NS: I mean, that doesn't really happen today as far as I know.

DWM:
It doesn't happen.

NS: (2:26 - 4:39)
Well, we... In the morning, when you did patient care, you did... The patients...

Gave them a bath. First of all, you got their diagnosis from the head nurse, and then you got your assignments, which was like three or four patients, because you were a student. And you would give the patient a bath, you would change their bed.

We learned how to roll patients, you know, and make the bed under them when they were, you know, immobile. Gave their medications, so we had to learn the medications. We had to look those up the night before, so we knew what they were, and then give the medications, and give injections, and we helped with things like a range of motion to keep the patient's arms and legs.

That was... It wasn't before PT. They had PT, but PT asked, you know, had us on the floor.

The nurses on the floor also do range of motion exercises to keep the patient going. And got the patients up, ambulate them if they could, walk with their IV pulse, just like we do now, you know, and just get them up and walking, and trying to pass gas. Surgery.

Surgery, you know, trying to get them going. And then we'd go for classes in the afternoon, and then we'd come back and help with their meal. If they needed help eating, we would help, you know, cut the food, and, you know, serve the food.

Feed them, actually, if they needed that kind of help, and some of them did. Some of them really needed that help, and then get them up to the bathroom, and then walk them again, and give them evening medications, and then if they... If they liked to have a back rub, you know, we asked about back rub, and did their oral mouth care.

So, a lot of physical stuff, a lot of physical taking care of the patient, probably more like what nurse's aides do now. They do all that kind of care, real patient, you know, hands-on, clinical patient care. But we had to know all the stuff.

We had to know the medication. We had to know the diagnosis. We had to know what their plan was, you know, if they were to ambulate or not, and turn them on their side every two hours, you know, all that kind of stuff.

I'm guessing a lot less paperwork than nurses used to do.

DWM: (4:39 - 4:40)
Oh, yeah.

NS: (4:40 - 9:41)
Yeah. A lot less paperwork. I mean, we wrote down, but it was not like they have to do now, you know, just at all.

DWM:
So, how did you get interested? I mean, that was your college experience, nursing school, so how did you get... Why did you pick nursing?

NS:
Well, that's a good story. Actually, I wanted to be an architect. In high school, in eighth grade, in Gary, Indiana, all the boys and girls, we all took drafting, you know, drafting, mechanical drawing, drafting.

And I liked it. I thought, oh, this is good. And my father was a carpenter.

He came from Sweden as a carpenter, and he worked as a carpenter. So then for sophomore year, ninth grade, wait, nine, 10, 11, 12, eighth grade, we all took it. Yeah.

Ninth grade, I chose it as an elective, and 10th, and 11th, and 12th, by 12th grade, senior, I was the only girl, and I was the only one who got an A, and I loved it. I wanted to be an architect. And I still have the drawings and the maps, the things that I did in those classes.

I still have them. And we moved twice. We're in a retirement home, retirement setting in Silver Spring.

And in the bottom drawer, I have those. So anyway, so then I wanted to go to college. Well, I learned that 1951, that architecture school was five years, and we had no money.

But in high school, I also took the sciences. I took math and science as a backup. Well, I would need that for architecture too, but for backup.

So the pharmacist, there was a pharmacist in a little drugstore, Gary, Indiana. He offered a $500 scholarship to go to nursing school. I'll take it.

So I applied, and I took it, and I went. That paid for the whole tuition, the whole $500 tuition for the three-year school of nursing. So that was paid for.

But I wanted, in 1956, I knew I wanted a bachelor's degree. I knew I wanted a college degree. I didn't just want the three-year diploma.

So I said, OK, I'm going to get it. So I went off, let's see, how did I do this first? Oh, I know what I did first.

Wait, 56. 56, yeah. 56, I went first one-year college, Augustana College, Rock Island, Illinois.

And that, Augustana is Lutheran. It's all Lutheran. It's a church, Augustana Lutheran Church, so we're part of that.

OK, I went to the college first, one year. But I saved that $500 for the nursing school. So I had one year of college, and I went to Augustana College because it was part of the Lutheran thing, and they didn't have drafting.

But then I ran out of money. We paid for the first year. So then I came back home to Gary, Indiana, worked at the library, the city library, and saved every penny I could.

Then went back to Augustana College for my second year of college. Then I went to the School of Nursing in Chicago. So I lived two years in Rock Island, Illinois with that one year in between at home because I wanted a bachelor's degree, not just the three-year diploma.

So I was just adamant, and I can't. It amazes me now that some people are still going for the three-year hospital degree. Don't they know you've got to have a bachelor's and then a master's and PhD?

But anyway, so then I went to Augustana Hospital School of Nursing back in Chicago, where I got all my clinical work. And then in June of 1962, I graduated with both the three-year hospital diploma and the bachelor's of science from Augustana College in Rock Island, Illinois. So it was a six-year process for me because I had to stop that one year to work at the library.

So I was thinking about this pharmacist back in Gary. Why do you think he was offering a scholarship? I don't know.

Just a good thing to do. He wasn't expecting you to come back and work at Gary? No, not to come back to work at Gary.

No, just a straight-out $500 scholarship. And that was the amount that it cost for a three-year tuition for a three-year hospital. And that was so cheap.

And we were workers in the hospital. I mean, we did patient care in the morning at classes, came back for evening care. And as soon as we graduated in those three years, we were in charge of units.

DWM:
And did most of the nurses stay there at Augustana?

NS: (9:41 - 9:41)
A lot of them did.

NS: (9:42 - 12:59)
But we had a big contingent. Because there's a lot of Lutherans and Swedish people in Michigan and Wisconsin, a lot of the girls came from Michigan and Wisconsin to Chicago School of Nursing, even though they had some schools up there, but they wanted to come to the big city. So those mostly went home to Wisconsin and Michigan, to little hospitals up there.

And I don't know what the percentage would have been. A quarter, maybe, would stay in the hospital? I don't know.

That's a good question. But I'm sure a lot did, because then the hospital offered openings for new nurses. And they knew they were good, because they just trained them.

Yeah. So it worked out fine. So in 1962, you finish up, graduate.

DWM:
What are you thinking?

NS:
Well, I'm thinking, OK, now I have to get a good job. So my first job, in June, let's see.

Oh, actually, I got out of the hospital school of nursing. I got out in March, I think. For some reason, I had my credits all together.

And so they offered me a job in the ICU at Augustana. In 1962, ICUs were new. There wasn't much.

So I remember two of our patients, one was a cholecystectomy, and one was a heart attack. I mean, they're new ICUs. They didn't put big stuff like that now.

So I was the nurse, one nurse, 1962. And one aid. We only had two patients, right at that beginning.

I mean, eventually, it filled six beds. And then the evening supervisor, who had been a nurse there, a gray-haired nurse who had been there 1,000 years. So if you needed something, had a question, needed help, you called her.

And that was just how you did it. But she was the supervisor for the whole hospital. The hospital was kind of small, maybe 300 beds, two, three hundred beds.

On the near north side in Chicago, Augustana Hospital. It's torn down. It's gone.

And they built fancy condos. But anyway, the School of Nursing, there are people there still in Chicago that bring together alumni dinners, alumni reunions, and things like that. So I've been to the big ones, like the 25, 35, 45.

I didn't go to 50. I forget. Oh, I was moving it here.

It was all big stress. So one of the things that amazed me about those reunions was the number of times the nurses, who were all my age, would take a break and go out and smoke outside. They're still smoking?

Haven't they heard that smoking is good? They would get up and mask and go outside and smoke. So anyway, I never smoked.

And I can't imagine all those people still smoking. I mean, if they smoked when they're 18, 20, 25, 30, 40, still smoking. So anyway, so that was it.

DWM: (13:00 - 13:01)
In 1962, you get this job at the ICU.

NS: (13:02 - 16:38)
ICU, OK. So then that director of nursing said to me, Nancy, would you like to join the faculty of the School of Nursing I just graduated from? So I said, sure.

So I was a clinical instructor, 1962, September 1962. And I helped the people, the young new nurses, students, learn about clinic. I showed them how to give a bath, showed them how to change the bed, showed them how to give shots, take blood pressures, all that early clinical stuff.

And I did that for two years. That was September 62 to September 64. And they began to ask harder questions.

And I thought, oh my gosh, I don't have much clinical experience myself. I better get out there and work. So I then said, OK.

So I scoured the Chicago Tribune looking for interesting jobs. And since I had kind of wanted to be an architect, I kind of liked the technical stuff. So I went to interview at two more ICUs.

Our little one was nothing, but the big hospital in Chicago. Two ICUs, one hyperbaric chamber. They had one unit just for wound care, hyperbaric chamber, and the dialysis unit.

And I said, look at this. Isn't this amazing? The blood comes from the patient and goes around and around in this machine, and it comes back.

Isn't this amazing? I want to work here. So I applied, and I got it.

September 1964.

DWM:
And what unit was that?

NS:
That was Passavant Hospital, which has now become Northwestern.

It's part inside Northwestern University. So I went there, and I was there. I was the second nurse.

It was a two station dialysis unit. They had two big tubs, stainless steel tubs. No, wait a minute.

First they had one. First they had one stainless steel tub, but we could put two patients on it, because they put two Travenol, I guess they were Baxter, called Baxter, twin coils. And when I first got there, I think we did one patient at a time.

So it was one patient and one Baxter coil. Then somebody said, let's try two patients. Oh, and we had a technician there who was changing the chemicals of the bath solution every two hours.

The patient was on for six hours. So every two hours, the technician changed the chemicals. So you drain the whole tub, put in new chemicals, get new water, every time.

And I'm the nurse, and I take blood pressures. And I became the head nurse of this two station unit. But we had a big flow chart that you had to do with all the blood work, all the pre and post blood work.

So I was in charge of all that data, and took blood pressures every one hour. OK, so then they said, why don't we do two patients at a time? So they still had one stainless steel tank.

They put two Baxter coils in, and they changed the water and the chemicals every one hour. So it was a lot of busy work. The technician was busy, busy, busy.

So I stayed there one year.

DWM:
And I want to ask you about that, some of the particulars about that. So when you talk about this two station dialysis unit in the hospital, you all are doing acute dialysis.

NS: (16:39 - 16:40)
No, it's chronic. It's chronic.

DWM: (16:40 - 20:43)
So you're doing chronic dialysis for patients.

NS:
It was in a little room, not quite as big as this. Maybe like up to that first chair.

So two patients on Barca loungers with the big tank in the middle, and the usual cabinets on the wall. So we call it the kidney room. It was the kidney room.

It was just big enough to be a room. Oh, it's just a little bigger than a closet. Yes, yes, really just a bigger room.

And we had all these coils in the cardboard boxes up against the wall. And the Baxter man, I used to remember his name, but he'd come and deliver 12 at a time. And he'd come like every other day.

He'd come and deliver those boxes. So let's talk about the roles of everybody. So as the nurse, your job is to monitor the treatment and to help prepare the equipment for the treatment, get everything set up.

And the technician is helping to set up. So what would the set up look like? What did it take to get ready for a patient to come and get started?

A nice, cleaned up Barca lounger. A little tray table here. We had to clamp off, must have been a hemostat, to clamp off when you disconnected the shunt.

These were plastic, silastic and silicone shunts, plastic. And that all came from the space age program. That's where they developed silicone and plastic.

So we just stopped the blood. We undid the, when the patient's in the chair, then we had this little sterile field. And we had the hemostat and we clamped off the blood and then put the artery onto the big tube that went into the machine.

And then when it came around, all around, then we'd connect the other tube into the patient's vein, plastic vein. So there were two connections into two big tubes into this that came from the coil in the bath water. So that was the initial stuff and also at the beginning.

At the end, we had to disconnect all that stuff and put the shunt together. So the shunt comes to you in external. So it has the external of the arterial limb and the vein's limb and it has a little loop that connects them together.

I think it was a straight piece of Teflon and we just put them together. Put them together. And hope they stay.

And the big worry was that if a patient at night is tossing around, they could dislodge this thing and bleed to death. That was one of the big worries. So we had to tell them, try to get a good sleep position, stay calm, don't toss around.

So all those prevention kinds of things. Don't get rattled and be very careful. Don't cut it, don't be anywhere where there's knives and things to accidentally cut it.

So that kind of stuff was always a worry. That it would become dislodged and they'd bleed to death. But then during the treatment, we just took the vital signs every hour and I had a chart for that.

And then when they came down in the morning, when they came to the unit, to the two-bed unit, two-chair unit, the blood work that had been taken last time came, so I had to put it on this big flow chart. And then draw blood at the end and send it to the lab. So as the nurse, I was responsible to get all that done.

DWM:
And you're sending labs at the end of every treatment.

NS:
Yeah, yeah, yeah. So the technician is filling up the tank.

DWM:
How did they fill up the tank?

NS:
A big hose, a big hose from the regular water. The big hose was regular water because they put all those chemicals in to change the pH and all the whatevers.

And then it was the usual osmosis, you know, diffusion process with regular tap water. I mean, we had no fancy water. It was, it holds from the tank.

DWM:
Filling it up.

NS: (20:43 - 20:44)

Filling it up. Draining it back out.

NS: (20:44 - 22:24)
And then drain it out again and put the new chemicals in. It was very primitive. I mean, when you think about it, what we do now,

DWM:
the tank is just wide open.

NS:
Yeah, yes, the tank was wide open. Not quite as big as this table, about this much. Yeah, it's just wide open.

Terrible stuff could have fallen in. The acoustic tile could have fallen in. We could have spit in it.

I mean, all kinds of stuff. It was primitive. And it was one of 12 clinical study units in the United States.

NIH had passed. This was before Medicare. Before Medicare.

This is 1960. See, the ....?.... was invented by Scribner in Seattle, Washington in 60. So that thing started to jump.

And so 63, I think, the PASAVENT Northwestern unit was open. And that was Dr. Doug Gorko and Dr. Simon. And that was one unit.

And then, and so it was just the two stations. Now upstairs on the second floor, this is my first floor at PASAVENT, they had, they were going to do transplants. I can't remember if they ever did any, but I was totally involved with dialysis.

Anyway, so we worked there one year because my husband was working for Food and Drug Administration in Chicago. He was with some big case, Crabiasin(?sp), that some guys were saying was going to cure cancer. Well, it didn't.

And they went to jail. But anyway, so Carl got promoted. And he gets promoted and goes to Washington.

So he'd come to Washington. And before you leave.

NS: (22:24 - 22:26)
Yeah, before I left Chicago.

DWM: (22:26 - 22:48)
Yeah, before you leave Chicago, I just want to add, so that one year that you're at the hospital in the two chair unit. There's your role, there's the technician. You're very involved with setting up machines, monitoring the whole treatment.

It sounds like you only had a couple of patients. You're doing maybe a couple of patients a day.

NS: (22:49 - 22:49)
Yes, two patients a day.

DWM: (22:50 - 27:58)
Two patients a day. And then you have a Monday, Wednesday, Friday group and a Tuesday, Thursday, Saturday group.

NS:
Or maybe, or the other two patients maybe weren't ready for three days a week.

Because I don't remember working Saturday. So I think as they were beginning to get into this new dialysis world, John Bauer was patient number one. And Dr. Argyanes, who was a dentist, he was the second patient. So those two were Monday, Wednesday, Friday. I remember them and I remember their names. And the Tuesday, Thursday patients, you know, I'm thinking that was kind of miscellaneous.

Patients who didn't need dialysis right away, just needed to kind of get stabilized a little bit. Also, that's when we did the acutes. And there was another nurse, an ICU type of a nurse, I wasn't that, I mean, I wasn't a real ICU nurse, who would come down and do a lot of more stuff to the patient, you know, readings, this and that, and more procedures and stuff.

And they would fill in on the Tuesday, Thursday. So the two main chronic patients were John Bauer and Dr. Argyanes. Patients.

Patients, patients, yeah, patients, long term, right.

DWM:
So what was the role of the physician? How often did you see the nephrologist?

What was their role in managing the patient?

NS:
In the morning, always. Dr. DeGruca or Dr. Simon would be there for the first 15 minutes for the get on, the connect on. They'd be there while I'm doing the connecting. I'm doing, you know, take the shunt apart, connect, connect. And they would just be there and talk to the patient and ask us what we needed, what we did, and check the chemistries of the patient.

You know, oh, this is good, this is good. Your potassium's too high, blah, blah, blah. And then, the first 15 minutes, and then they'd go away.

Go do whatever else they had to do in the whole big hospital. They did come back at the end. We did the ending by ourselves.

But they were always on call. You know, always, we could call them in a minute. And they were just on the second floor, just up one floor.

So they would come quickly. If someone's blood pressure went really far down or, and I don't ever remember anybody bleeding, you know, bleeding out. Blood pressure's up and down.

DWM:
How did the shunts function? Did you have any trouble with shunts clotting?

NS:
Oh yeah, oh yeah, that's a big problem.

And either the doctor did that, the nephrologist, or a surgeon.

DWM:
So what would they do, do you know?

NS:
Oh, they would suck it out.

I don't know what they used, I can't remember, but a syringe to suck it out to see if it just came out. And most of the time it would, it would come out. I mean, because it had all those, the silastic stuff, the Teflon stuff, it almost bumps along the way.

You know, it wasn't a smooth thing. It was just bumpy along the way. And they had just had this procedure and they're going home and it was just had a tendency to clot.

That was a big problem. That's what the nephrologist and the surgeon did on Saturday. They declotted the shunts.

That was a big business, yeah. And I don't remember, see it would be dangerous to put them on an anti-clotting med. I mean, that'd be very tricky, dosage-wise, what to give and, you know, because of everything else.

I just can't remember that. I mean, I would have known it when I was there. If he asked me that question 50 years ago, I would have remembered, but I can't remember.

DWM:
So you mentioned that this was part of the, one of the 12 NIH. Oh yeah, yeah. So what did that mean to you, that there were these, that you were part of an NIH?

NS:
I thought it was cool. Very cool, exciting, different. It wasn't like those nurses who graduated from Augustana Hospital with a three-year diploma.

All they wanted to do was get married and have kids and stay close to their mama and work at the little home. I wanted to go out and see the world. So I go to Pasadena, Northwestern.

I find dialysis. Wow, this is really cool. I'm in one unit, and I learned that there were 12 units.

NIH, HHS, NIH had funded 12 clinical study units across the United States, and I'm working in one. It was just lucky. I mean, I knew when I was interviewed that it was on a grant program.

I knew that, and then my husband gets transferred and go to Washington, and Dr. Del Greco said, go check with Dr. Schreiner at Georgetown. He's got another, and he wrote me a letter of recommendation. So I went to interview Dr. Schreiner and said, here's a letter of recommendation from Dr. Del Greco. He says, I'm a good dialysis nurse. So Dr. Schreiner hired me. I'm in the second of the 12.

It was very cool. Very cool. It's a pioneer, an accidental pioneer.

DWM:
So you skipped a whole bit about how'd you meet your husband, and when did you get married, along somewhere in there.

NS: (27:58 - 27:59)
Oh, how did that happen?

NS: (27:59 - 33:49)
Oh, my nursing school roommate, Augustana Hospital, School of Nursing, was getting married. She asked me to be the maid of honor, and Jim asked Carl to be the best man. So she sets a date.

We're gonna have a wedding, small wedding. I was like, four people. My wedding was 14 people.

So the night before, we went out for pizza. This was pre-wedding. The next day, there's the wedding, they get married, and they go fine.

So Carl says, he starts asking me what I like to do and all that stuff. Well, lots of things, but oh, but I said, let's see, how did I put this? Was I gonna work in Chicago?

Oh no, I got things to go, things to do, places to go. I got things to go, which I didn't want him to think, I'm gonna, okay, you're a cute little guy, I'm gonna start dating, I'm gonna get married and have kids, no way. I got things to do, places to go.

So we started dating. The next week, we went on a sailboat in Lake Michigan. They have a lot of little sailboats.

And so that was the first date, and then we dated, and they dated, and then I was ready to get married, by the way, because he was a cool guy. And we set a date. Well, we didn't exactly set a date.

We talked about getting married. Yes, we're gonna get married. Okay, so I took time off from Augustana Hospital, School of Nursing, where I was teaching, because I thought, well, that'd be a good time to get married.

Well, he stopped talking about it. He stopped talking about it. So I went off to Hawaii by myself.

Had a wonderful time. When I came back, he meets the airplane. He says, let's get married.

He missed me. Too bad you missed Hawaii, too. So I went to Hawaii for two weeks.

So then we did get married. So we've been married 50 years. September 14, 1963, so 13, we had 50 years.

So that's him.

DWM:
So you get married, and then you take this job, and then he gets moved to D.C. So you came to D.C. without a specific job for yourself.

NS:
No, uh-uh, just with a letter of recommendation to Dr. Schreiner.

DWM:
Yeah, so what was, you know, one of the things that I do as I'm talking with people in these interviews is we've lost some people that were real other pioneers in nephrology, and George Schreiner's one of them. So tell me what you know about George Schreiner, what you remember about what he was like when you.

NS:
He was very nice, very good to the nurses.

He appreciated the nurses. He appreciated what we were doing. He knew we were all pioneers.

He's a pioneer, he was a pioneer, and he knew we were pioneers along this thing. And he probably, I don't know if he was, of course, not the only one, but he probably lobbied to get the grant money to HHS, you know, for these 12 dialysis units, you know, he and Scribner and all those old guys back at the beginning. And he was a very kind, gentle man, and he, like I said, appreciated nurses.

Not every doctor does, and some doctors are very nasty and mean, but they're not, there are far and few between, but they are, there are some, and who, you know, treat nurses with disrespect. Well, Schreiner didn't. And I think he conveyed that to the other doctors, all the fellows that came under him, Dr. Ted Lures, Dr. Carey, Jim Carey, because they all were respectful of nurses. They were very respectful of what the nurse's role was in the nephrology world. They would come and be speakers at meetings. Sometimes they gave a

little money, you know, for the coffee or the snacks or whatever, but that wasn't important, just that they were there to be, and give a lecture and take questions from nurses and just generally, just generally good people.

And I think for them, nephrology was a pioneering thing too. I mean, I even think, I think Dr. Schreiner was one who dialyzed the tiger or the lion or something from the zoo here and, you know, did all kinds of crazy stuff like that, but he did it, you know, to prove it could be done. Also they, Dr. John, Jack, John Marr, but they call him Jack, Jack Marr, under Schreiner was very, very famous with acute dialysis for toxins. I remember mushroom poisonings and other chemical poisonings, you know, so acute. So on the clinical study unit at Georgetown, that was 16 beds, eight rooms, two beds each. And then you'd go through the double doors, it was the lab, and that's where a bunch of technicians were doing lab work, and that's where they usually took the acute toxic patient back for acute dialysis and who knows what they did to them, you know, but many of them survived and lived and got the toxins out of them.

So they were, he was very nice, a very nice man.

DWM:
So when you came, it must have been about 1965.

NS: (33:49 - 33:50)
Yeah, 1965.

DWM: (33:50 - 36:59)
So did you have to interview with Schreiner? How did you, did you show up at the hospital?

NS:
Yeah, I called up to his office and made an appointment that I was a nurse from Chicago, and I had a letter from Dr. Del Greco who said that I would be a good fit for this other clinical study unit. They're all called clinical study units. And so he said, well, we set an appointment, so I went in for an interview. And also his director of the unit, the nephrology is in charge of everything, but the director of the clinical study unit was Anne Peterson, MD.

And she was lovely, too. There's another one who respected nurses. And so she was the actual one who signed the paper for me to have the job.

You know, Schreiner didn't sign the paper, but he interviewed me and got me set up with Anne Peterson. And then she said, well, there's an opening, da-da-da, you can start, da-da-da. So our first two weeks, I played tourist, because I, oh, I've never been to Washington.

So I went to the Washington Monument, I went to the White House, I went to the Capitol, I went all around to see the stuff, you know? So that was fun, too. And then I went to work.

And on a clinical study unit, it was more than staff nursing. We had nurses' aides to do baths and beds, but we had endocrine studies going on, and renal studies, I can't remember anything renal except dialysis, oh, and transplants. We did the transplants.

I mean, they did them in OR and brought the patient down immediately to the clinical study unit. So we were post-transplant. We put the patient in reverse isolation.

But the endocrine studies, we had one study where the patients were very obese, like four and 500 pounds. So we had, and so they were on a liquid diet. And we had a special scale, or they had to go someplace special.

I forget, they went to another department at Georgetown to be weighed, and they did that every day. And we, so we, we didn't even give the drink, the diet food solution. The dietician did that, an official dietician who I still keep in touch with.

And she stirred up some kind of a smoothie kind of a thing, you know, and took it around to the endocrine patients. And it was like a psychology there. Some of them were very angry, and I don't know how they got there, you know, who put them there.

But, and there were no locks on the door. The doors were open. They could walk in and out.

But they stayed, they lost weight, and I lost track of them. I don't know what happened. And then other endocrine things, oh, I can't remember any specific diagnosis, but other endocrine things, you know, so.

DWM:
So how many dialysis patients were there? Were these also chronic outpatient dialysis?

NS: (36:59 - 37:01)
Yes, yes, so, so.

DWM:
Treatments, and how many?

NS: (37:02 - 46:19)
So then we had, I would say, let's see, two, four, six. Six patients, one, two, three. I would say we had about 12 patients.

So it could be six patients on Monday, Wednesday, and Friday and six other patients, or maybe just three, on Tuesday, Thursday, Saturday. So nine, 10 patients, something like that.

DWM:
And what was, what equipment was being used here?

Was there a lot of difference between what you had seen in Northwestern to what you were using here?

NS:
When I first got there, there was the big tank with the two Baxter coils, or one Baxter coil. Then there was another huge thing, like a freezer.

A big, square, stainless steel box. And the water was inside, and the chemicals, and the dialyzer, was that, it may have been more tubey-like. It wasn't so big, like this, like the twin coil.

It's more like a tubey-like thing. And then, and then there were some keel. Kiil was a flat thing.

And we didn't have to build them, but the technicians beyond the two swinging doors, they had to put that flat cellophane down very carefully, and watch them, and watch them down, and then put the boards on top of that, and another cellophane, and more boards, boards, cellophane. So they had to build that, so we didn't have to do that, thank goodness. And again, the baths were separate.

So it was called a kiil. And the big, big stainless steel thing, I don't remember what that was called. And then the travenol, the stainless steel tank.

Was there anything else? No, I left there in 70, so, or maybe it was 72. Yeah, I left in 72.

So, 72, 82, 92, 02, and 12. That's 40 years ago, so a lot more has happened in 40 years. But that's what was there when I was there.

DWM:
Did it look pretty familiar to you from having been at Northwestern, to the treatments, the type of treatments they were doing in here? I mean, it was pretty similar when you moved along to having a better dialyzer, I guess, the keel was being considered.

NS:
And, you know, all the doctors were concerned about the chemistries, pre, pre and post.

In fact, I got so good, when the patient walked in, I could estimate, I was there six years, seven years at Georgetown, I could estimate what their, well, what their weight was, how much weight they had gained. B-U-N and creatinine, but also, what was the other one? I think it was potassium that I could estimate with.

Just by how they walked in and how they behaved. Because every day, every day, every day, same patients, you know. And, oh, they had bad neuropathy.

They would flop their feet. I'm diabetic, and I have some neuropathy, and I try to pick up my feet so I don't flop, flop, flop.

DWM:
Why do you think, so were they typically getting treatments three days a week?

Would that be typical? And about how long was their treatment time?

NS:
Six hours.

Three days, six hours, yeah. So, the nurses who had those patients, that was definitely an eight hour day, but often, you know, longer for more, you know, after work, different stuff.

DWM:
And were they getting transfusions?

NS:
Yeah. Yeah, some people had transfusions. It wasn't a big deal.

DWM:
And were you all worried about calcium and phosphorus?

NS:
Oh yeah, oh yeah, yeah. And the dietician got into all that, calcium and phosphorus, and how much they should have and how much they shouldn't have, and all that, yeah.

Just, she was busy with the endocrine patient, but she was also busy with the dialysis patient, and the salt, and the protein, and all those early things, you know, that everybody worried about.

DWM:
And still using the Scribner Shunts, or began to see fistulas, and?

NS:
Not Dr. Rahilo, see, from New Jersey. He was a fellow, comes from New Jersey, big hotshot. Well, he thought he was a hotshot. Anyway, he comes in, he's got this new thing, a fistula.

Well, he tried, he and the surgeon put it in this unfortunate patient. They chose not a good patient who didn't have good fistulas, and it was a mess. Oh my God, and they put the fistula in her, and they thought it was wonderful, the surgeon.

But for the nurses sticking the fistula, it was not so wonderful, you know. It was very hard. So then there was a whole process of learning how to stick fistulas.

Oh, that was, wow, that was 70. It was Dr. Rahilo, see, from New Jersey. And I can't remember the year, but it was while I was still there on the staff at.

DWM:
So even as troublesome as shunts were, getting clotted and everything, they were definitely easy to access.

NS: Easy to access, click, click, you know, just put it together.

DWM:
And now you've got to stick a needle into your fistula.

NS:
Yeah, stick a needle into it, and you hope that the connection is good, you know. Yeah. Yeah, so that's when I was phasing out, yeah.

And I phased out because it was really, I just, I couldn't take it anymore. I couldn't take the renal patients anymore.

DWM:
Why not?

What was fatigue, you were fatigued.

NS:
I was fatigued in motion. The thing that broke the straw, the straw that broke the camel's back.

Okay, this lady was on dialysis. And we called her, there was a kidney for her transplant. And I think I was either on the evening shift or the night shift, I can't remember.

Maybe it was on the night shift. So there's a kidney for her. Come in, come in quick.

So she and her husband came in and, or he brought her in, but then he went back home because he had a little girl, a six-year-old girl that he left alone in the apartment. Right somewhere here, downtown D.C. And she has such leg problems. So she got her kidney, she got her transplant, but she had such bad, bad, bad restless leg syndrome and all of that stuff, bad.

And she begged us constantly to rub her legs, rub her legs, rub her legs, which we did. In fact, I think I called in another nurse on that night shift to help rub her legs because she was just, it was unbearable for her. And then her husband came in after the transplant, he brought her there and then he went home.

Then he came in after the transplant and I said, where's your little girl? Did you bring her? Because we would put her somewhere and give her some coloring books or something.

You know, we'd babysit her as best we could. But he said, I left her home. I said, you left a six-year-old girl at home in the dark, no mother and father.

Somehow, I was a mother and I had two children. That just blew my mind. I said, I can't deal with these problems.

I can't help him, I can't help the little girl, I can't help the lady with the leg. I can't do this, I have to quit. I gotta get out of here.

I just can't take this anymore. So like the next day, I resigned. I said, I just have had it.

I've had it up to here with real good. And we had the lady with the shunt, it was so hard. I mean, with the fistula.

And then Rudy Dervichelli, he came from some other country, South America. He came and had a transplant and it failed. And then they did another transplant and it failed.

And I think they talked about doing a third and that was very bad. And he was so skinny and he was yellow, you know, jaundiced color. And then there was Robin, the boy who was about 16 and his mother was like, she was properly so protective mother, but a little bit on the overprotective side, but it was still okay.

So he was on dialysis and he was so skinny little thing. And he had the shunt, but he, I think he had, yeah, he had one transplant and lasted for several years. I heard about that, I had gone, but I think it's, oh God, these kids need transplant.

And I just, it was burnout. I just burned, I couldn't take, I was, at that time I was supervisor, head nurse. So I had to worry about staff and I had to worry about hours and cover the shifts and my own children at home.

And I said, I can't do it anymore. I'm leaving nephrology. I'm going to work.

I'm going to sell furniture at Scan Furniture. Scan Furniture is a modern Scandinavian place. They've closed now, but that's, I had some in my house.

I'm gonna go sell furniture at Scan.

DWM:
A simpler life.

NS: (46:19 - 46:20)
Yes, simpler life.

NS: (46:20 - 1:02:59)
You don't have to worry about these patients who are so sick.

DWM:
So how did that go for you, selling furniture? Well, I never did, but what I did go do, I went and got my master's degree at Catholic University.

So first I'm with the Lutherans and then I go with the Catholics at the Catholic University.

DWM:
So what year was that?

NS:
It's 1974 to 76.

What did you get your master's in? Med Surgeon Nursing and the educational thrust into it. So, and that was a government grant too.

You know, back in the old days, I got my whole master's degree. I don't, it was thousands of dollars. I don't know, 10,000.

Sounded like a lot then, you know, not 74, 40 years ago. 10,000, I think it was 10,000 a year. So it was two years, $20,000, a lot of money.

So I got my master's degree. And then, and while I was getting my master's degree, Dr. Schreiner's office nurse needed a splenectomy. So they called around, could you help out in the office?

So I did. Okay, I did that. Then also while I'm getting my master's degree, the kidney disease program of the state of Maryland started and they wanted nurses to inspect dialysis units.

So I became a nurse surveyor. So I started that between 74 and 76 when I was a student.

DWM:
So why was that starting up, that nurse, that surveyorship?

So, I mean, in 1972, the- 72, the- Act was passed and Medicare and I guess the law is there. So why did they finally get around to starting the survey process?

NS:
Well, I guess, you know, when you make a law, you know, somebody has to make regulations and there's regulations.

You better go around and check these dialysis units and transplant units, see that they're complying with the law, but there were silly things in there. There were like, one is not so sad. They had one about they had to have so much square footage for a patient.

So patients were not jammed together. I forget what it was, eight by 10 or something. No, that's too big, whatever.

And the refrigerator that held stuff. I guess it was, well, maybe it was the blood refrigerator or the chemical refrigerator. It had to be a certain temperature.

So we had to check that. And I said, we're not checking the patients. We're checking the square footage and temperature of the refrigerator.

This is crazy, you know, but I was paid. It was a job. So I did it all over the state of Maryland, dialysis units and then in DC, dialysis unit and transplant units.

There weren't any transplant. Wait a minute, maybe there was at Hopkins. Maybe at Hopkins.

I don't know, whatever, but it was mostly dialysis units. So I got to go over around the state.

DWM:
So what, did you see a lot of variability?

I mean, was there, or was it pretty consistent that people were doing-

NS:
It was pretty consistent. Yeah, they were trying to do the best. I mean, like we had the little kidney room for two stations.

Everywhere, they got one little space for that, you know, one little space for the kidney stuff. And they did what they did by whatever space they had. They said, well, we have room for one more bed.

We have room for one more Barcelona's chair. And they just did what they did. I mean, they, well, I also, because I was involved with the Maryland Nurse Association, I also sat on the Health Systems Agency Board.

And so eventually, the dialysis unit came through. They have, you know, we need one here. We need one, this community, this community.

And we, the Health Systems Agency Board, would vote on if that dialysis unit, they would come to us with a proposal. We wanted to do a 16 station unit, or a 10 station unit, or a six. But it was based on what they had, you know, space and so.

But, you know, we have to go back to 1972. 1972, when the amendment was passed to Social Security and Medicare. I was outraged.

72, I had already left Clinical Study Unit, Georgetown. But I said, they never asked us. We are an nephrology nurses.

We take care of dialysis and transplant patients. We're here at Georgetown Hospital. It's just down the street from the U.S. Capitol. Nobody asked us. So I got my ANNA buddies and said, we gotta do something about this. We have to do something.

We have to go to Capitol Hill. We gotta tell them about what we think about ESRD and the dialysis world and all that. So Kathy Smith, Julie Matamor, Carmela Bocchino, we made ourselves become the Legislative Committee of ANNA.

We said, okay, we have to find out what to do. So we made some phone calls. We found out that that law had come through some committees, Senate Finance Committee, House Energy and Commerce Committee and House Ways and Means Committee.

And on the Senate Finance Committee, the Health Subcommittee, there was a nurse, Sheila Burke, RN. She worked for Senator Dole and he was chairman of the Senate Finance Committee. We called her up, Sheila, we wanna talk to you for a nephrology nurse.

We wanna talk to you about the ESRD problem. 72, you pass this law, Congress passed this law and nobody asked us. Now the doctors had had some.

I don't even know which doctor. I'm sure Schreiner, because he was here. Scribner, I would have called him.

The big names, you know, in 72. So we went over there to Capitol Hill. We met with Sheila and she said, well, we're having a hearing coming up on such and such.

Would you like to testify? Absolutely. So we got a bottle of wine.

We sat on Julie's floor. I think Kathy told you a little bit about that. And we wrote the testimony.

And we presented it to the ANNA board, said this is what we're gonna present for all of you guys that are out there in the world. But we're right here in DC and we wanna say something. We're not gonna let this go by.

So we testified before Senator Dole's, it was Senator Durenberger's Health Subcommittee of the Senate Finance Committee. I have a picture somewhere in my world, world. And we did that.

Dr. Sadler's behind there from University of Maryland. His eyes were digging into me. I could feel his eyes digging, scared that I would say something bad about doctors.

I wasn't saying bad about doctors. I was talking about the patients need da-da-da-da-da-da. So that was the start of the legislative committee.

DWM:
Well, let's talk a minute about how ANNA ever got started. I mean, who got that organized and where did it start?

NS:
In 1969, I heard there was a woman named Bernice Hinckley.

She worked for the VA and she was doing dialysis. So this must have been 1965. She must've been working for the VA.

She was much older than us. And she talked to her friends and there was an initial meeting in Atlantic City, New Jersey. I think it was alongside a doctor meeting, because that's how they used to be, nurse and doctor meetings side by side in the same hotel.

And she found, she went there and that's, I think it was called American Nephrology Nurses and Technicians at the very beginning. And as I remember, it was formed in 1969 in Atlantic City, New Jersey. That's the first meeting I remember.

And I wasn't a member and I didn't know about it. I found out, wow, how come, again, nobody told us. And I was a nurse at Georgetown.

How come I didn't hear about this? I would have gone, you know, because I was already rabble-rousing and wanting to get involved in doing stuff like that. So I eventually, I was president of ANNA in 1982, but that was long after all that beginning stuff.

DWM:
And what do you think in those early days, so even if it started in 1969 and you all sat in the floor and became the legislative committee in 1972, what was the purpose of ANNA early on?

NS:
Education, continuing education for the nurses. Yeah, continuing education.

It was not to be a lobbying group. It was continuing education of the nurses. Because there was always something.

There was a, you know, first there's the shunt and then there's the fistula and who knows what's next. You know, and then there's this machine and that machine and this machine. And then, you know, this calcium, phosphorus are a big problem and next year there's another problem and this is a problem.

So you have to keep up with all this stuff as the educational needs, you know, continue constantly. There's always something new or something different or something taken away, something they say you don't need to do that anymore. So it's lots of change, constant.

Always something, it's always something.

DWM:
All right, so you all, in 1972, you finished working for?

NS:
The state of Maryland.

Yeah. Yeah, 70, let's see.

DWM:
So your surveyorship, how long did you do that?

NS:
That, let's see, I got my master's in 76 and I was doing it part-time while I was going to school. So then when I got my master's in 76, oh yeah, then I did full-time, one year full-time for the state of Maryland Kidney Disease Program, which was the full-time Medicare surveyor. So then I got also into some education, you know, education programs and what surveyors did and what they wanted to do.

And then I started going to other meetings, other big meetings.

DWM:

Like which one?

NS:
Well, even like the Kidney Foundation and KCP wasn't started, of course, then.

Maybe some of ASIO, ASIO, that was an early, is that still in existence or has it been blended with other stuff?

DWM:
I think it's in existence still, but it's largely focused on cardiology and cardiac.

NS:
Yeah, well, whatever meetings would be together, you know, closely allied with the nursing groups, just kind of constantly keeping up.

It was only because we were here in Washington and the amendment passed and nobody asked us about it that we all got riled up. So then there was no stopping us. So then we started our legislative workshops and let's see, now we're up to 76.

Okay, so 76, let me look here, 76. Kidney disease, oh yeah, American, oh, nephrology, 70s to 82, I just have a big bunch of years here because it was just nephrology.

DWM:
And you stayed in the DC area?

NS:
Yeah, yeah, we've been here the whole time since 65, since Carl and I moved here. But what was I gonna say, 19, oh, wait a minute, 85. Oh, wait a minute, I gotta be here.

Oh, 82, okay, 82, so I had been with the kidney disease program until 77. And then-

DWM:
As a surveyor.

NS:
As a surveyor, yeah, and then I left.

The reason I left there, we had this little Pinto station wagon car with no air conditioning. And I lived in Bethesda and had to go to Baltimore on the BW Parkway. This was even before 95, Highway 95, the big speed thing was, oh, that little Pinto was so hot, there was no air conditioning.

And I said, okay, I've done enough surveying, that's it, been there, done that, don't wanna do that anymore. So, what did I do from 82, I was just busy with the nephrology stuff, but 82, the more nephrology stuff, oh, I hear 80s. In the early 80s, this is under political nursing, okay.

In the early 80s, the sleeping giant of two million member nursing community, that's ANA, is waking up and thinking, oh my goodness, 82, we gotta get involved, more involved, more involved in Washington, with legislative stuff. So, there had been before, but not enough. So, here we are in Washington, there's four hot nurses here ready to rumble.

And we had this committee, Kathy's on the committee. And so, the specialty nurses, nephrology, oncology, orthopedics, pediatrics, gerontology, maternal child health, we all decided that the nursing community needed advocacy skills so they could learn how to contact and influence members of Congress. I'm leaving this here for you.

And they had to be able to speak to the leadership of federal agencies, where the nurses had some concerns with the patient concerns and the patient. So, this little committee of six, we established Nurse in Washington Internship. That is my legacy to the nursing world.

We established a six day educational program here in Washington. We invited nurses from the specialties. We didn't go through ANA, because ANA didn't want us.

They said, no, we don't want you specialties involved in advocacy, in legislative stuff. You stay away. So, we said, we're gonna teach nephrology nurses and others how to do this.

So, Nurse in Washington Internship, six days. They came here, stayed in a hotel. We had speakers from the Hill.

We had Senator Dole. We had other people like that. Speak to the nurses.

This is what happens in Washington and you have to learn how to do it. So, speak up for yourselves as professional nurses and speak up for your patients. So, we created this six day thing.

We had, the first day was how a bill becomes a law, how legislation happens, how it occurs. And following that on Tuesday, we had, and then come regulations. So, you have to go, right.

So, then we said the nurses, okay, oncology, you need to go visit in HHS, whoever takes care of oncology regulations. Nephrology, you go to CMS in Baltimore. Well, it wasn't CMS, it was HCFA.

And tell them what you think. You're a dialysis nurse on such and such a unit and you think that Congress or the regulation should say blah, blah, blah. So, we talked them up.

Wednesday, they go to Capitol Hill. They meet their own senators and representatives and, again, make their spiel about whatever. Thursday is state day.

Okay, when you go home, you do this in your state. So, learn how to do it in the state level. So, state.

And then Friday was like PR, media, different kinds of stuff like that. And so, they learned, they came in on Sunday night. So, the first year, the leadership of the nursing associates, oh, they'll never come.

Nurses will never come for six days in Washington. How can you do that? It's too expensive.

Where are they gonna stay? Blah, blah, blah, blah, blah. We said, well, let's do this as a pilot study.

First year, 20 students came. They loved it and they raved about it and they paid their own way. The next year, they said, we said 50 students come.

50 came and they raved and raved and raved. The next year and every other year after, 100, 100, 100, 100. This program has been going 30 years.

30 years they've had this nursing Washington internship. Kathy and I and Julie and Carmela and the orthopedic nurse and the MCH nurse and the NAPNAP pediatric nurse. We started this little thing.

And it's an educational process to get nurses involved. So, whatever your patient population is, get to it. So, that's what we did.

DWM:
So, let me ask you about that. So, why do you think ANNA was not that enthusiastically supported? ANNA, you mean ANNA was not enthusiastically supported?

NS: (1:02:59 - 1:03:03)
Oh, the nursing association, ANNA. Yeah, American Nursing Association.

DWM: (1:03:03 - 1:05:43)
Because they were doing it. They thought they were doing it. They spoke for all nurses.

It's like the AMA for doctors. They probably say, I don't know what they say, but they probably say, we're doing it all for you. We're doing everything.

We're doing all your education. We're doing all your lobbying. We're doing all your this and that and this and that.

It's just like ANA has said, nurses, specialty nurses, you don't need to do lobbying. You don't need to do lobbying for your patients. We're doing it for all of you.

We're getting all the educational money. We're getting educational funds. We're getting grants to your schools of nursing, blah, blah, blah.

And we're lobbying for all patients, and we're lobbying for all nurses. And we're doing it. And we, Nephrology, ANNA doesn't know ESRD.

They have the foggiest nurses. Maybe they have a staff member who once worked in a dialysis, I don't know. But they don't know ESRD.

Oncology, they don't know. ANNA doesn't know what it's like to deal with a cancer patient. And Pediatrics, they don't know what it is, a little cancer patient, a little child.

There's so much that ANNA doesn't know. And we want to help. We want to get our voices up there.

So, we're here.

DWM:
So, and most of the nurses who come through this program are paying their own way?

NS:
Yes.

Well, lately, lately, now the associations, they did at the beginning. But the association can see how that nurse learning the process benefits. And they pay, they give a scholarship.

You know, the association, Oncology, Nephrology, they give a scholarship for the whole expense. And now it's not even five and a half days. It's two and a half, I think.

So, I don't worry about that.

DWM:
So, do you still get support? Bob Dole is, you know,

NS:
those kind of people still do.

They still do. Yeah, they're all very busy. And you just, scheduling is a nightmare.

But you just do it. Yes. They can help.

No, no, as a retired nurse, I'm getting into quilting. And I'm getting onto the program committee. And you know what?

Scheduling is a nightmare. Just like it was back when I'm making these nursing wash . No, I'm in the scheduling.

I've got to talk to this lady from Florida. She's a big hotshot quilter. You know, famous, world famous.

I'm trying to get her here next May. Oh, I've got to talk to her Thursday about the plane. Where's she's going to stay?

Oh, God. Why am I doing this? The details are always the...

DWM:
The details. The big concepts are really the details.

NS: (1:05:43 - 1:05:43)
Oh, God.

NS: (1:05:44 - 1:11:00)
And of course, they worry about there's not enough money. You know, how much money the little quilt guild has. Oh, Lord.

Oh, Lord. Same old, same old, same old. Just different people, different area.

DWM:
So, you get very involved in advocacy and work in Washington. What's paying your bills? What work are you doing to pay your bills?

NS:
This, when I worked, let's see. With nephrology, when I was president, I got a stipend. I got $500 a month, I think it was.

So, that was a little bit.

DWM:
Stipend of ANNA?

NS:
Yeah, from ANNA.

So, that was a year and a half or so with ANNA. After, when I left CSU and the department of, the State Department, the State of Maryland Kidney Disease Program, I was paid there. 82 was, this year when I was ANNA president, was kind of lean here.

But then I got a job here with nephrology, obstetrics. This is the Nurses Association of the American College of Obstetricians and Gynecologists. And ACOG, you probably know ACOG.

Well, this was an ACOG, okay. So, this was 1982. I'm hired as staff to NACOG as Director of Practice and Legislation.

And so, that was a nice job. I was their lobbyist, so to speak. Even though ANNA said, don't do this.

Don't get involved with advocates. NACOG hired me. And the nurse midwives already had a full-time office and nurse anesthetists already had a full-time Washington office.

And who else was thinking of them? Midwives and nurses, and others were thinking about it. And here NACOG hires me.

So, here I'm starting to be paid again. There were a few lean years here. But here, this was paid, nice paid job.

So, I stayed with them for eight years with NACOG, Director of Practice and Legislation. And let's see. And that's when NIWI, we called it NIWI, Nurse in Washington Internship, was active, okay?

Okay, then we go to, let's skip to 1993. Let's see, I was with NACOG until 1990. Then I worked for, 91 to 93, I worked for Capital Associates.

And that is a lobbying firm here in Washington. Deb Hardy Havens was President and Chair, and Terry Learman. And that was a good job for two years.

And that was, I was the education component of that lobbying firm. 93, I left there, and 93, another big stepping stone. The American College of Nurse Practitioners.

The faculty of Nurse Practitioners, what was that? The Nurses Organization of Nurse Practitioner Faculty. They seeded, they gave $5,000 seed money to organize nurse practitioners into a Washington meeting.

At that meeting, the group decided they wanted to start a national organization for all nurse practitioners. All specialty, nephrology, oncology, all kinds. And they needed staff.

I was available, because I just left the NACOG group, and the Capital Associates. So I was hired as the founding Executive Director of the American College of Nurse Practitioners. And the purpose of that group was to be a coalition group of all the nurse practitioners.

The pediatric, the dermatology, the nephrology, the all kinds of nurse practitioners. So again, I worked very hard. And again, in four years, I had another burnout.

It was like the dialysis patient burnout. I can't do this anymore. I'm working 12 hour days.

I'm going on the hill. I'm testing, I'm teaching, I'm running these workshops. I can't do it, four years.

So I'm riding on the metro home with the president. I said, I just need a break, I need a break. She said, how about three months?

You know, it's fine, I'll take three months sabbatical. I slept 12 hours a day, I'll try to recover. But I founded this organization, which was a coalition of nurse practitioner groups.

It now has merged with one of the others. There are 205,000 nurse practitioners. They have just celebrated, there are this year, celebrating their 50th anniversary as a profession.

And there are like 55 or 60,000 members of this nurse association that I helped found. So I'm tired. I'm going to take a rest.

DWM:

So you took your three year sabbatical. Yeah. And what year would that have been?

NS: (1:11:01 - 1:11:01)
97.

DWM: (1:11:02 - 1:16:07)
What happened after that? What did you do after that? Well, I got a phone call from, his name escapes me right now.

Lives in Reston, Virginia. Tom, Tom, Tom, Tom. And he was starting an organization called Med Scholar Digital Network.

Med Scholar Digital Network. And he was proposing to the cable industry that we put continuing education on cable and the internet. This is 1997, so early internet.

So would I come and work for him? Well, I said, sure, this sounds cool. So I worked for him for four years.

I worked for Med Scholar Digital Network. And my responsibility there was to gather all the nurse leadership from all the specialty groups and get them to sign on to this cable venture, which would be CE. They could lie on their couch in their living room at home, like we do now.

Because this is 1997, this is 20 years ago. And it was a hard sell, but some of the nurse organizations did join up. They signed up, oh yeah, we want this.

And there would be some profit to them and profit to the company. And the big name in that world of cable was John Malone. They called him the cable cowboy, John Malone.

And he was out in Denver, Colorado, and he started cable way back 1,000 years ago. I never met him, but I worked with other visionaries here at Discovery Channel, TV Channel, Cable Channel, and met some really cool people who just could see things differently. The old teacher with a pot and a plant, that old term that you just give a lecture to a million students, it's so different.

I mean, now we have what they call online teaching that everybody's doing, but this was 1997. And this was cable and TV and Discovery Channel and Tom, whatever his name was. And I did that for four years.

That was fantastic, fantastic. Now, MedScholar Digital Network itself fizzled. We didn't get the fizz.

We didn't get the rush that we wanted for that particular. But other things were happening. But it was 19, it was 2007.

I said, okay, enough, enough. I've been in the world nursing enough, 2007. I'm out, 45 years, let's go.

I'm out.

DWM:
So did you retire?

NS:
I did retire, I retired after MedScholar, yeah.

So, and I've helped out with a little bit of stuff, you know, writing for this one and that one. And ANNA called me for some things. Oh, another thing with ANNA, we got CMS people to go into the dialysis units.

That was the first, they had not done that. And again, Kathy and Island Julie, it was like our idea. But I met the CMS people over there in front of 200 independents.

And I got the taxi, and I took them up Georgia Avenue to one dialysis unit, which was a sight to see. It was, there were guards there, and they had unlocked the doors. It was a bad neighborhood, so they unlocked the doors.

But inside was dialysis, you know? And they go, oh my God, look at the blood, they're going here and there and going around. That was interesting, it was like a 12 station unit.

But then I took them to the Washington Hospital Center, where they had 30 stations. And it was run very smoothly and calmly, and you know, 30 patients on that, calm staff going around, nobody bleeding, everybody talking and watching TV. And these CMS people, they never saw that before.

And so now, again, that's the first time I get them in a taxi, I take them, and I pay the taxi to take them to the dialysis unit. So that's, now ANNA has these educational programs. They have Education Week, I think it's in August, where they invite CMS staff and congresspeople to their dialysis units. So we started that here.

DWM: So did it surprise you, at the time you started all this, that people at CMS, who are making regulations, they're making regulations for you. They're making regulations.

And they've not been to a dialysis?

NS:
They have not been to a dialysis. It appalled me.

Again, I'm outraged at the amendment, and I'm appalled that these people write regulations, they've never been in a unit. They had no idea, no idea. And we said, you can talk to the patients, ask them how it is, ask them how it is to be a dial, how do they make it here?

I mean, taxis, shuttle service, bus, you know, talk to them.

DWM:
And did the CMS folks, did they talk to patients?

NS: (1:16:07 - 1:16:08)
Yes, they did.

DWM: (1:16:08 - 1:20:46)
What did they think about it?

NS:
They were impressed at the, I guess, the courage, that's not the right word, the courage of the patients. How much they have to go through.

To get there, to get there that morning, for their dialysis, that's number one. And how long they live on this. And this is life.

Three days a week, they come in here. This is life. What else do you do?

Very few people, they ask them, you know, do you work, do you have any time? Some people say, well, you know, I put in a few hours here and there. You know, like it is, you know.

It was just, it was, I would say their eyes were like bug-eyed. They were so impressed by the blood, the blood going down the tubes. Blood going in and out, spinning around.

That, that just blew their eyes. And to me, it's nothing, you know. The blood goes around and around on the machine.

But they really, they, but they did talk to the patients.

DWM:
Do you think things are better today for CMS compared to that time when you all first started bringing people? Do you think CMS has more sort of awareness and specific knowledge about ESRD than they used to?

NS:
I think so, but most of it is just due to time. Time has passed, so they've learned a lot more. And they understand more than they used to at the beginning.

It was such a mystery at the beginning.

DWM:
Are there people there that have been there a long time, or?

NS:
Well, you know, Kathy and I were at a craft fair.

We went to a craft fair in Baltimore. And she recognized Linda Fishman, who had been in this program a long, long time. And she had, that Linda Fishman had just retired.

So she had been there a long time, you know, 30, 40 years, whatever. And that's the only one that I know that, and that was just a chance meeting that Kathy had at the craft show. I don't know, oh, there's, you know, I can think of another guy whose name I can't remember who was there a long time.

They're government employees, you know, that go in, like my husband went to food and drug when he was 22 years old, and they stay. And, you know, so there are people like that, and good people, you know. My husband was a good guy.

30 years, he worked food and drug. He didn't have to do regulations, but writing regulations is horrendous. Yeah.

What a job.

DWM:
So, and how do you think about, how do you think the awareness is on Capitol Hill about ESRD in particular? How much, have we gained some ground in helping members of Congress understand about ESRD?

NS:
I think they understand, but there was a period of time when they were, they were outraged that it was costing so much money. You know, those initial amounts of money, like probably Schreiner and Sprechner said at the beginning, you know, oh, it's only gonna cost $50,000 or something else, 50 billion or whatever it is, you know, it's just, everything's, there was a lot of concern on the Hill that the program was costing so much for so few patients, you know, in terms of the whole Medicare world, you know, there's millions, and for ESRD, it's just this many. And so that program costs a lot of money.

But, and then there's been a lot of tightening, tightening lately with all the legislative changes. And I haven't kept up with them. I was, I've also seen, or I should say, I haven't seen in the paper, things have been quiet in the papers about scandals and people dying on dialysis because of the baths is mixed up, or somebody made so much money because blah, blah, blah.

You know, that kind of scandal stuff has is, I don't see it anymore. Maybe it's happening, it's just not in the Washington Post, I don't know. Or in New York Times.

Julie, you're, reads the New York Times, so she sends us information when she sees that. That's our friend that we go to Florida with, yeah. We're still good friends from way back, way back when.

DWM:
Oh yeah, I've been through the fires.

NS:
Yeah, I know! Yeah.

DWM:
Yeah, yeah, yeah. So, if you look, think back to the 1960s when you first started taking care of dialysis patients, what surprises you the most about what's changed for dialysis today? I mean, could you have imagined back then what dialysis would be like today?

NS: (1:20:46 - 1:20:47)
Never, never.

DWM: (1:20:47 - 1:29:17)
And what are the biggest surprises you've seen?

NS:
Well, the growth and the hugeness of the dialysis clinics, how big they are. But very, but that's economical, you know, to have bigger units in terms of costs and things, you know, supply costs and space, real estate costs.

So that, with my little two-station unit, you know, it was, I just never thought of it. I just wanted to get through the day and hope the patient lived, their blood pressure didn't go down. And now it's these big, big, big places, and I go to this diabetic support group, because I'm diabetic, and there's one patient on dialysis.

And he's amazing. Not only does he do dialysis, he's in a rock band, he does karate. He plays, he's moving up in the belts, you know, in karate.

He's about 60. He and his wife go on cruises. They love cruises, and they love Las Vegas.

So once a year, off they go. And he just does everything like a normal person. He has no time to work, because he's doing all these other things.

But I don't, I don't even know what his work was. But he's, he's just so regular. He's so ordinary, so regular, just doing regular stuff like everybody else does.

And we're all amazed. I can't hardly stand to get on a plane. He goes on a plane to Las Vegas every year.

Oh my God, that would be punishment. I couldn't stand.

DWM:
And it sounds like when you were describing some of the patients you were caring for in the late 60s and 70s, they didn't look too good.

NS:

No, no, they didn't. See, I think nephrology treats all the issues that they used to just let go, like the neuropathy. I don't say anybody, well, I'm not in a dialysis, so I don't.

But I think that has been probably, and the funny skin color, what's that, hemochromatosis? Yeah, hemo, where the skin gets yellowy. It's too much iron, because of something.

They used to be yellow, the yellow gray. But I think a lot of those nephrology physiological issues have been corrected or dealt with, and the patients are doing better, I think.

DWM:
Now, one of the reasons I started the Nephrology Oral History Project was to, I finished my fellowship in 1989, and totally took for granted the technology that we had for dialysis then, including the fact that we had erythropoietin to treat patients and all that stuff.

And I began to hear about dialysis in the 1960s and 70s and realized how far we've come, and how far we've come yet again since 1989. So it is pretty dramatic, the change.

NS:
The change in the physiology, the treatment of the disease, yeah.

DWM:
And certainly the vast number of patients who now can be treated, compared to the ability to, you know, the capacity to treat patients before. I mean, you can, building a kiil dialyzer manually took up a lot of time. It's very different than just hanging up a disposable hollow-fiber dialyzer today, which makes it possible to dialyze more people.

So the technology changes have been significant, for sure.

NS:
Yeah, that really has helped.

DWM:
But the nursing, the nursing, the role of the nurse, has also changed a lot in the last 50 years as well.

What do you think about the change? I mean, you described your nursing experience, which involved a lot of direct patient touching, massage, and changing in the early days. What do you think about the change in nursing, the nursing role today?

NS:
Well, I'm so far away from it now, I don't know. It's very much more technical in terms of electronic medical records and posting everything you do with the patient, you know, on the record and the internet stuff. So I don't, and they, I read, I read about how those nurses that are practicing out there complain about how much there is in terms of documentation.

I don't know that because I haven't been there. I've been so far away from it for so long, so I don't know, that may be a terrible problem. I don't know.

And the technology, they do write a lot about it in the nursing journal, alarm fatigue. These dialysis machines certainly have alarms going off all the time. Alarm fatigue so that you just ignore it.

You don't, and so if a patient's bleeding out, they could bleed all out and their beeper's going. You know, that's certainly a problem.

DWM:
Do you think that nurses today have the influence they should have on regulations and legislation?

How is your voice being heard?

NS:
Well, I think the nurses who work in hospitals and the, what we call floor nurses, staff nurses, I think they're trying through their organizations, through their director of nursing, trying to get more input into policy, hospital policy. On the other hand, the ones that do have a lot of influence are nurse practitioners.

They have influence, and they are making changes, dramatic changes. 2014, I can't even remember the thing, that four big things happened, I remember, but that makes it, the practice authority for nurse practitioners is getting better. All, you know, the state law for nurse practitioners, many of them still have restrictive things in there that they can or can't do such and such, and a lot of those are being, the laws are being changed, and it's because other entities are seeing the ridiculousness of it.

For example, the Federal Trade Commission, the Institute of Medicine, the Robert Wood Johnson Foundation, those big people that make big studies see the ridiculousness of, you know, I don't know, Illinois saying that nurse practitioner can't do this or can't do that. It's just so stupid, it's just, so the light is coming on to more things happening good for nurse practitioners than the light coming on for nurses still in the hospital bureaucracy kind of a place. The nurse practitioner is more like in primary care, has more independence than the, so a patient comes in and does this and this and this and this, and a diagnosis is made and medication, so, but if they have a brain tumor, they get, you know, they get referred out to the brain surgeon.

So it's more of a, it's not a more professional role because the hospital nurses also have a professional role, but it's different, it's a different, more autonomous role than the hospital nurse has. The hospital nurse doesn't have an autonomous role, very, this is very much more of a chain of command kind of a thing, where the nurse practitioner is taught to do primary care and whatever referrals need to be made, need to be made, and they want to be in a team setting. The nurse practitioner wants to be in a team setting, but some people don't want to be in a team.

They want to be in charge, so.

DWM:
Leah, we talk a lot today actually in the work I do about the importance of the multidisciplinary team. That's so good. Do you think, if you look back to the late 1960s, 70s, did you feel like you were in more of a hierarchical situation or?

NS: (1:29:17 - 1:29:17)
Yeah, yeah.

DWM: (1:29:18 - 1:35:01)
When did the team components, did you start to see that at any point along the way?

NS:
Yes, and that's why when I say Dr. Del Greco, at past events, dialysis, he treated me like an equal. I'm an equal, I'm in charge of this, and Nancy, you reported on this, and I have this to do and I can do it, but we're two people, and we have our roles, and we work together.

And again, with Schreiner and the dialysis unit, he respected the role of the nurse and what you could do and was very appreciative of the work that they did. And that doesn't always come through, but I think on a multidisciplinary team, I think that it should be natural, but it may not be. And I know there's also efforts in the academic world to teach people and psychologists and pharmacists and nurses and doctors all together.

They all get the lesson on anatomy of the leg or the whatever, or the side effects of Demerol. I don't know, they all get the lesson because they all should know. It's not just the silo teaching.

Yeah. Yeah. You might wanna help some too.

DWM:
So you started out by thinking about architecture and doing technology and all that. So have you had, did you achieve something?

NS:
It has dawned on me.

After these 45 years, it has dawned on me. I really did build things. Architecture, design, and build.

I built the legislative committee on ANNA. I built and designed the Nurse in Washington Internship. I designed and built the American College of Nurse Practitioners.

I've been involved in designing and building. So I've done architectural skills, but I don't have a building. I've just done it, I don't know, visually or something.

DWM:
But you built systems.

NS:
Systems, I've built systems. Yeah, yeah, yeah.

That is quite an accomplishment. So I feel good about my career, my professional career. And I don't, and those nurses that stay on a hospital unit for 50 years, I'm telling you, I admire them.

I couldn't do it, I couldn't do it. But they are happy. I've met nurses who are happy, who have been taking care of patients, especially in OB, that nurses love OB, babies and mothers and babies.

But they also love other kinds of things. I mean, occasionally there'll be a dialysis nurse who's been there 40 years or 50 years. Holy smokes, how can you do that?

I mean, how can you do that? Even my husband, he worked for Food and Drug 33 years. How could he do that?

I mean, he kept getting different assignments, so it wasn't doing the same thing all the time, but I just, I kind of jump around a little bit.

DWM:
So what do you think will happen with nursing in the next five to 10 years? What do you think will happen down the road?

NS:
I don't know, I'm a little bit nervous. I'm a little bit nervous about what's going to happen in nursing because a lot of other technician types are coming along. For example, coming on the Metro today, there was a young lady in front of me, she had a navy blue kind of scrub clothes on, and her thing said, Medical Tech, Med Tech College.

And I almost asked her, so what do you do? You know, does she draw blood, does she? I mean, when you go to have draw blood, you have technicians who have been to Med Tech College.

And so there's that, and back in the old days, nurses used to even draw blood. So there's that technician who takes care of that. I was at Washington Hospital Center, no, it was the Holy Cross, and I saw someone else who had a very specific job.

I can't remember right now what it was, but it was something specific that I thought, oh, nurses used to do that. So maybe, maybe not five to 10 years, but maybe long term, nursing, per se, as a bath giving, bed making, medication administering, blood pressure taking, because Med Tech College people do that. Maybe, maybe there won't be any, I don't know.

That's kind of sad, but maybe, maybe that's how it goes, I don't know. I mean, dialysis, think of dialysis, used to be all nurses. Oh, the regulations, they used to say how many nurses you had to be in.

I don't know what they say now, but think of that. And Julie and Kathy, they used to train thousands of technicians who were really good. And they, when we go on vacation, we've been 30 years on vacation, oh, remember so-and-so and so-and-so and so-and-so.

And they would say, oh, I would have him be my technician in dialysis, he would dust the bed sticks. Good grief, you know? Maybe, I don't know, maybe one nurse, because the nurse has a license to hang blood, I don't know, maybe technicians can hang blood, I don't know, I don't know, what do they do now?

NS: (1:35:01 - 1:35:02)
Yeah, I don't know.

NS: (1:35:04 - 1:38:11)
On the other hand, things change, and you gotta roll with the flow, yeah. I'm not moaning, you know, I just, if it happens, it happens. The technology is just there, technology does so many things, so much.

But I always want somebody, even the technician, to be nice to the patient. If you see the patient is scared, hold her hand, touch him, touch. I think that's what nurses are, at least could touch the patient.

DWM:
I wanted to just ask if there was, in all the work you've done, if there are heroes that you would consider in your professional life have been sort of your mentors, your heroes.

NS:
Just one, but of all the nursing world, oh, I should say more than one, two or three or four or five, I don't know, but just a few, just a few that have really like embodied the nurse persona and really been, I was really not meant for real nursing, you know, patient care and nursing. I like this other building stuff, you know, that's what my skills are.

I mean, even in high school, I was president of this and president of that, but I like to lead stuff. So I'm not a good touchy, although I do, when I'm with someone and they're upset, I do touch them. That I know is a nursing thing and we should all do more of that.

So your heroes are these nurses and I guess they've been women largely. Yes, they largely have been women, although as I have risen through the ranks in administration and in the nurse practitioner world, oh God, in the nurse practitioner world, I know 10 or 12 wonderful men nurse practitioners and they've risen in the leadership too, but they're wonderful, they're just wonderful. In the nursing world, I never worked with a male nurse in the regular nursing world, not in my day.

And in dialysis at Georgetown, at Passbent Northwestern, it was a technician was a male and at Georgetown, yeah, the technicians were male and they worked in the lab, so they weren't out doing nursing things. Yeah, I wish more men would go into nursing, that would maybe change things, raise things, elevate things, I don't know. But that's not my cause.

That's not my cause. My cause is get nurses up on Capitol Hill. Speak your piece, silence is not golden.

DWM:
Well, Nancy, thank you so much for spending the time with me today to talk about your history of nephrology, this is fascinating.