VOICE EXPEDITION INTERVIEW TRANSCRIPT
The Oral History of Nephrology
KATHLEEN SMITH
Interviewed by Dugan W. Maddux, MD
JUNE 17, 2015

DWM: (0:02 - 0:15)
So good morning. So today is June the 17th, 2015. And I'm at the Fresenius office in Washington, D.C. talking to Kathleen Smith. So Kathleen, thank you so much for being a part of the Nephrology Oral History Project.

KS: (0:15 - 0:17)
Thank you for doing this project, it's very important.

DWM: (0:18 - 0:32)
Great, so we're gonna talk a lot today, I think, about where you started and how you got involved in kidney disease. So I wanna just start with where you were born and raised and then a little bit about your education, where you went to college and how you got interested in nursing.

KS: (0:32 - 0:45)
Well, I was born not too far from where we're sitting right now in Washington, D.C. and grew up in the Maryland suburbs, just outside the district. Both my parents worked in Washington and on Capitol Hill.

DWM: (0:46 - 0:47)
Were they in politics then?

KS: (0:47 - 2:56)
No, well, my mother was. She came down and worked for her congressperson, who was a family friend, as soon as she got out of high school. And my dad came up after the Navy and had a patronage appointment, that's the way jobs on the Hill were done in the early days.

They were patronage jobs by the elected members of Congress. And Senator Estes Kefauver was a friend of our family, so he gave my dad a job on Capitol Hill on the police force and that was a non-professional police force at that time and during the course of my dad's career, he turned that into a real police force. He's still alive today and writing his memoir of that.

So Capitol Hill rat, whenever we were out and about. So then were you raised literally like part of the city here then? Just 10 minutes ride from Capitol Hill to where we lived in Maryland.

So where did you go to school, both high school and then where did you go to college? I went to Elizabeth Seton High School, Catholic girls school in the Maryland suburbs and then I went for a year to University of Maryland and then I was helping my mom raise the kids. So I did a year of community college to fill the gap and decided I would just stay there and get that finished and be working and then work my way through school after that.

So that's what I did. And when I got out of school, I thought that to round out my education, I would, I went back to University of Maryland and said, okay, I did what you told me to do, get back in and they had changed the curriculum completely and it would have taken me like two more years to function as a nurse and I had the AAD degree. So I started working and the way I decided I would proceed to work would be to work for a year or two in various specialties and gain my expertise that way.

DWM: (2:57 - 3:01)
So you had gotten your nursing degree through the community college system?

KS: (3:01 - 3:04)
After a year of regular studies.

DWM: (3:04 - 3:07)
So would that have been like a two year nursing degree?

KS: (3:08 - 3:08)
Yes, yes it was.

DWM: (3:09 - 3:12)
So you hadn't specialized in any way, you're coming out of school.

KS: (3:12 - 3:46)
Just coming out of school, right. So I worked in cardiology for a little while and then I decided to, I looked in the paper to see what else was available. And I saw there was an ad for training nurses to do dialysis and I thought, well, this is really what I wanted to do, to focus on different specialties and if they're teaching a course, that's the best way to get into it, so.

And what year was that? That was 74, 74, no, 75, that was 75.

DWM: (3:46 - 3:48)
And who was, who had the classes?

KS: (3:48 - 3:49)
And it was National Medical Care.

DWM: (3:49 - 3:51)
Oh, okay.

KS: (3:53 - 6:35)
And so I went over and interviewed and was hired. Interestingly enough, they didn't have enough other students for the course, so they said, would I mind learning on the job? So I thought, well, this wasn't exactly what I bargained for, because I really thought I would take the course and then get working.

And they promised that the very next training program they would put me in. So I don't remember how many months I actually worked on the job before I took the training course, but it wasn't all that long. And the interesting thing that I learned immediately when I started on the job was I was working with corpsmen.

Now, think about this, this is 1975, and many corpsmen, Army and Navy, two things. There were many clinical studies with regard to end-stage renal disease and dialysis treatment in major medical centers and in the military. And we have Walter Reed here, and we had the Naval Hospital here.

So technicians were coming back from Vietnam, where they had done significant medical things, amputations, et cetera, and some of them ended up in the dialysis units. And when they were finished in the military, they came out, and the timing worked that there was now an ESRD program and facilities were opening up. So it was kind of a match for these very skilled clinicians to go into what was really high-tech, but in the suburbs kind of dialysis centers.

So I was surrounded by, not all of the folks that were working there were corpsmen, but two or three of them were. So I felt very comfortable that I had, not necessarily RNs, but skilled clinicians beyond my skill level in the room. So I spent a couple days, I said, for a couple days I just want to observe.

And I was comfortable that I was the only RN there because I thought, I don't know what's going on with these machines, but if there's a code, I can handle it. So they're doing what they need to do and they know what they're doing, and I'm comfortable enough doing that, so I stayed after the observation and putting those pieces together. I was willing to stick around.

I think it was probably only about six months before I got to go to the training. And then I realized I thought it was better that it had worked out that way because I really knew the questions that I had to delve into in the training, which I think, I didn't want to monopolize everybody's time, but I think my asking some of those questions probably helped the people in the room who hadn't been in the facility yet but were going to be training.

DWM: (6:36 - 6:59)
So talk for a minute about, so these corpsmen are skilled. They've been in the field, they've done a lot of work. Talk a little bit about what the roles were, what the corpsmen

technicians would do as part of the treatment, what their role was, and what the expected role of the RN would have been in 1975.

What was the dialysis unit like?

KS: (7:00 - 8:19)
Well, that's very interesting that you ask because there was a shift supervisor and usually the day was two shifts of patients, so they were really the supervisor for the entire operation. I am not sure what nursing per the Board of Nursing was doing with dialysis at that point in time. Probably nothing.

My guess is probably nothing. They probably weren't all that aware of that treatment setting at that point in time. And so I don't know, and I was too young and naive to go immediately to the Nurse Practice Act in Virginia.

It wasn't too long before I was smart enough to do that, but I didn't do it initially. And so this one technician, who by the way is still a very close personal friend of mine, he was really in charge of the operation. So it was a small room, the building still stands, the office is still there.

I just had dinner with him and went to the theater and he couldn't believe it. He went to a doctor's appointment and it was in that same building. And when you walked in the front door, the unit was to the left in this not very long room and there were six chairs on either side of the room.

DWM: (8:19 - 8:20)
So 12 all together.

KS: (8:20 - 8:33)
12 all together. And we were using the RSP machines, big tank of water underneath the machine and a canister where the dialysate bubbled up and around the dialyzer.

DWM: (8:33 - 8:35)
Would it have been like a twin coil?

KS: (8:35 - 8:57)
It was a coil, not a twin coil, but a coil. So that was the crude situation mechanics-wise. And there were one or two of the technicians that were very well versed in how to fix the machines.

It wasn't much to tweak and turn at that point in time.

DWM: (8:57 - 9:01)
So the same technicians who were caring for patients are also- Were the technicians.

KS: (9:02 - 10:01)

There was no water treatment room. They had one large canister that filtered the water and made it as pure as you could make water at that point in time. And then we used the jugs of dialysate and mixed the dialysate in the big tank that was in the bottom of the machine, each individual machine.

And of course, a change over time. Always, you had the garden hose put in there and you'd go to do the next patient, the next thing you know, you'd hear the water overflowing onto the floor and realize you didn't get back to that hose in time. Happened all the time.

So there were towels on the floor all the time when you're cleaning up the water. And looking back on it, it's unbelievable, really. A friend of mine, another nephrology nurse, whom you may or may not interview, I talked to her many years later about the old days and she said, the patients died and the patients survived in spite of us.

Because it was really very crude what we were doing.

DWM: (10:01 - 10:08)
So there are these 12 machines there. The technicians are sort of managing the machines, tweaking them, and putting patients on, taking patients off.

KS: (10:08 - 10:10)
They were doing dialysis.

DWM: (10:10 - 10:20)
Yeah, yeah. So what could you do, what could you control about the treatment with regard to just the machine itself? Could you control ultrafiltration?

KS: (10:21 - 10:38)
Oh, okay. Interesting question. Yes, we controlled ultrafiltration with a screw.

And you tightened the C-clamp, or you loosened the C-clamp, and you had a manometer at the top. You saw what pressure level was and you adjusted it down, you adjusted it up.

DWM: (10:38 - 10:45)
And were you measuring your ultrafiltration as you went along? I mean, how were you keeping up with what you were...

KS: (10:45 - 10:48)
We didn't really know what the outcome of what we were doing was.

DWM: (10:49 - 10:52)
Okay, and you were monitoring blood flow rate?

KS: (10:52 - 11:05)
Yes, and that was pretty much it. All right. We tried to get, there was a blood pump and you knew what the speed was, and I think it was 300 cc's a minute that we were doing.

DWM: (11:06 - 11:15)
And so at the time of changing a patient, the equipment from one patient to the next, you were draining the tank, you were draining the dialysate out of the tank.

KS: (11:15 - 12:03)
It was pretty much done at the end of the treatment. So you gave it a good hosing and let that drain out, and then you started water again in a new jug. And just overflowing?

Didn't, there was no antiseptic or anything that you wiped anything down with. There was blood all the time because the coils tended to blow up. If you had the, with the C-clamp, you're increasing the pressure, and every now and then, more than every now and then, they would go pop and the ceiling tiles were always, you know, it was like artwork in the ceiling where the blood had splattered up.

So dialysis units in those days had, you know, whatever paint you could put on there that would be easy to scrub blood off of, and the tiles that were not quite as nice looking as the tiles today were always stained and would have to be replaced.

DWM: (12:04 - 12:08)
When a coil popped and there was blood everywhere?

KS: (12:09 - 13:30)
Sometimes in the nurse's face, sometimes in the nurse's mouth. Hmm, because you weren't wearing gloves. Oh yeah, we did wear gloves.

We did wear gloves, and interestingly, National Medical Care was becoming a large company and trying to put reins on all the facilities they had around the country. And I was uncomfortable learning to cannulate with gloves that didn't fit me well. So I found the sterile gloves that were in the, you know, we had a separate cabinet for sterile gloves and things we needed for shunts.

Now, not all the patients I treated had shunts, but we certainly needed sterile gloves for those, and not for the usual cannulation put on. So I liked the sterile gloves because they were so tight. So I found the stash, and I was always using the sterile gloves.

So the shift supervisor, my friend who was training me, he said, what are you using the sterile ones for? And I said, because I can palpate better and I can feel better, and those other ones are just so loose and got powder in it and makes my hands itch. So I said, I want to use those.

And he said, we're going to get in trouble at inventory time. I said, that is somebody else's problem and not my problem, and I continued to use those better fitting gloves. So we did see shunts in that, in terms of access.

There were some shunts, but certainly not all the patients had shunts. So we were a little bit beyond that.

DWM: (13:31 - 13:33)
What were the accesses you were seeing?

KS: (13:33 - 14:28)
There were fistulas, and I did not understand, I thought for a long time, and I didn't want to seem stupid to the folks I was working with. I didn't mind saying I didn't know a thing about dialysis, but the access under the arm, I was trying to figure that out myself, given what I learned in school, and I pretty much thought I had it figured out. They obviously connected an artery to a vein, but what happened to where you tied off?

That's what was my curiosity, and finally I asked one of the docs and got that explained. So we had, and we also had folks, it was pretty early on in terms of grafts. So they were the bovine grafts, and those were largely, the ones I had anyway, were largely in the thigh, and they were easy to find and easy to get into, but we had an awful lot of fistulas, and like I said, some shunts, but those were about, they were going away.

DWM: (14:29 - 14:38)
So in 1975, if you had looked around the room, what would your patients have looked like? Were they old, young, sick, well?

KS: (14:38 - 15:43)
Both. We had young ones, not children, but teens, and we had very, very old ones, and everything in between. But their color was awful.

They were a golden rod, often. And I studied and thought a lot about that. I remember in those very early days, I subscribed to dialysis and transplantation, and on my days off, because we worked Monday, Wednesday, Friday, or Tuesday, Thursday, Saturday, so I had days off, and I would read every article in D&T, and sometimes I'd skip all the process part and go to what they learned, what they were trying to do, and what they learned.

But I devoured every single one of them in those days, which I tend to do that still today. Took a lot of journals now, but that was like the one. So I learned a little bit from that about access, but there wasn't a whole lot being written about that necessarily.

So finally, I talked to some of the docs about what happened with corollary development of other vessels, and they said the body wonderful. It is wonderful, true.

DWM: (15:43 - 15:57)
So the demographic, if you walked into a dialysis unit today you wouldn't think that there was a lot of difference in the demographic that you see today. Older patients, some sicker patients would have been true for you in 1975.

KS: (15:57 - 16:04)
Yes. So their color wasn't good. Why do you think the color was not good?

I don't think, they weren't clearing as we do today.

DWM: (16:05 - 16:09)
What kind of treatment times were you providing?

KS: (16:10 - 16:16)
I think most of the patients dialyzed for four hours.

DWM: (16:18 - 16:24)
Were you measuring any type of adequacy or lab work?

KS: (16:24 - 21:36)
How often were you doing that? No, not initially when I started. I was probably in that facility for about a year when we moved into a larger unit that had been being constructed while I was working there.

And it was all exciting. We were going to this new building, and we went over and saw it a couple of times, and much larger, had two bays that were 12 chairs each, and we were in Northern Virginia. This facility, I neglected to tell you that we were in Northern Virginia.

So not only the age, but the racial mix was largely Caucasian there. Not all, but most in that location. And certainly, when we moved down the road, it was, that did not change at that point in time.

But in that new facility, I don't remember how long I worked there, and in that role, I was in charge of one of the bays. And not long after that, I was in charge of both bays, and in charge of the whole shift. But by that time, I was very trepidatious initially, so I didn't jump into any of those positions until I felt that I was really comfortable taking care of a patient, and then be able to be helpful as a nurse for these technicians to be able to do what it is they could do, and I was comfortable filling in what they were not trained to do, and had not educated to know.

And then it wasn't long after that, before I was the nurse manager, moved on, and I stepped up and said, I wanted to be considered for that role. As did that corpsman who taught me in May of 1975. And he thought, certainly, to go back to one of your earlier questions, there were not other nurses.

There were these technicians or unlicensed people who somehow maybe saw the same type of ad that I saw, and did not have medical background. Most of them did, but not necessarily all of them. So we get to the new facility, and we're working there for, I guess, the better part of a year, and when the head nurse, there was a nurse in charge of that other operation, that my initial operation.

I didn't see much of her, but she was in charge of what went on there, and then she was in charge of the new location, and when she was leaving, I felt that a nurse needed to take her place. As much as I loved Jim, and thought he was very good, I did see that as a nursing role, and stepped up and made that case. And by that time, I was also married and pregnant, and they thought I'd have a baby and not come back, the two docs who were in charge of that place, and I said, no.

I worked hard to get through school. I like this job, I've been here a long time. I'm beyond moving on to other specialties.

I really enjoyed this. So I made my case and got the job. And moving on, I will tell you that not long after that, they came to me and asked me to move to the inner city of Washington, D.C., to run the dialysis unit there, that had been surveyed, and did not do well, and was threatened with closure, and they wanted me to go down and clean it up. I'd like to say a few words about survey and certification at this point. The law was passed in 1972, implemented in 1973. So the beginnings of dialysis facilities opening started at that point in time.

I come in mid-75. There were no regulations written yet pursuant to that law. But in 1976, June of 1976, out came the regs.

And by that time, I had figured out there was a law holding this whole thing up, and it was, you know, I knew that my patients had Medicare, but I didn't know how they had Medicare, so I figured that out, read that. And regs came out, I got the regs, and I read the regs. And that was, as I said, 76, so I had been in the field a year, exactly a year.

So surveys were beginning, and that, we hadn't been surveyed yet. I hadn't experienced it in Northern Virginia. But the D.C. surveyors found the facility to be in major trouble, and they asked me to go down. So I wrote up a little contract, and handed it to them, saying I could come back in three months, I would clean it up, I'd make it right, and I would be back. I want my slot, my new job as manager of the place. So we did that, and it involved some NMC folks, as well as the local docs.

And I made them re-sign that thing, that three-month thing, for a couple of years. It was down in the inner city, and at that point, the population, and not at that point, but in that geography, the patient population was much different than what I had seen in Northern Virginia, and they were all African-American, and almost all Medicaid.

DWM: (21:37 - 21:47)
So when you came to the inner city, and that facility had been surveyed, what were the big problems that the surveyors found?

KS: (21:48 - 22:07)

You know, I don't even remember what those were. It was just, I just knew I had to walk in there. And I didn't walk in saying, okay, let me see that document.

Let me see that survey document. If I did look at that, I don't remember that. I walked in knowing the way it should be, and making it the way it should be.

DWM: (22:07 - 22:12)
So what, as you walked in, what did you see, and what did you work on right away?

KS: (22:14 - 23:16)
I had to get to know the staff. You know, they didn't know me from Adam, so who is this coming in from the suburbs gonna make them all better? So I had to be sensitive to that, and make them want to work with me.

We had policies and procedures from National Medical Care. I just worked every shift with them, as if I were a glorified shift supervisor, and watched what they did, and then would have meetings and say, okay, here's how I wanna organize this. Here's how I think we should work in teams, or whatever it was, and staffing reorganized.

Just, I just picked up where it was, and moved on. I don't recall if there were one or two major things that had to be fixed within a time frame. I imagine that was true.

That's certainly the way it would be true today, with surveys, but I don't know then that the process was like that. I do recall, however, there was another survey after I was there a while, and they came in, and we had no dings whatsoever.

DWM: (23:17 - 23:26)
So when you came, do you think your biggest issue was that the workflow was just not organized correctly, or the staff had just not been held to the...

KS: (23:26 - 25:08)
Nobody had supervised them. The fellow who opened that unit for the company was one of the techs. The main facility in D.C., the initial one, and it's still a big one for national medical care, was in Bethesda, Maryland. So this little satellite facility, the one I first walked into, was considered like a satellite. I don't know if you can be a legitimate satellite in another state, but as far as the company structure was concerned, this little place that I walked into that wasn't much bigger than this room was considered a satellite of Bethesda. So the training was at the Bethesda facility, and all things were Bethesda.

Once we got into the bigger facility, things were growing as far as dialysis in the whole country, certainly in the area. So the Northern Virginia facility that I ended up managing was not a satellite of Bethesda. It was now one of the many and growing facilities of national medical care.

But this little D.C. unit was sort of treated like, it was small, treated like an offshoot. So this guy named Ron, who had worked in Bethesda for a very long time, they asked him, they said, go down and open this unit. He knew a lot about dialysis, another corpsman type.

And he set it all up and was managing it until I got there. And he just was a little loosey-goosey on the overall supervision. So I organized the work and just got them in a workflow that I think led to better outcomes.

And there were care plans and things that had been continued, put off. But it was quite an interesting patient population.

DWM: (25:09 - 25:16)
So how long were you working with the inner city D.C.? Well, I went there in 77.

KS: (25:19 - 25:38)
You're a woman, you have to think about when did you have that baby and when did you. So baby was little and born with significant cardiac defects. So that was 77, yeah, and I had her.

And I went, just as I went back to work after the maternity leave is when they asked me to go to D.C., so.

DWM: (25:39 - 25:43)
How did you balance out that new baby who had health problems with care at work?

KS: (25:44 - 26:03)
I had a nanny come to the house. It was the only way that was gonna work. Because I couldn't be schlepping her around and getting to the unit early hours and all of that.

So we had Rosa, and she was wonderful. So I was there until 1980, I stayed there until 1980.

DWM: (26:04 - 26:16)
So you've talked a little bit about the corpsmen that you worked with. What about the physicians you were working with? What was the role they had in the dialysis facility when you first came in 75?

How often were they there?

KS: (26:16 - 27:08)
Very similar to today. These docs, the docs in that very first place I went, that's where their office was. So not only did they round every shift, but they were frequently handy.

If they weren't in the hospital, they were there. Same thing, same two docs moved to the larger facility in Northern Virginia. And their office, their office was there in the unit.

So we sometimes got to meet back up. Patients who were about to start before they started. And I thought that's the way it was everywhere.

But that's not necessarily how it was. I learned later. So yeah, the docs, very similar to today.

Probably they didn't need the monthly capitation payment. They rounded on every shift, all the time. That was my experience with them.

And I think that was how it was in Northern Virginia.

DWM: (27:09 - 27:14)
And how was NMC as a company? Were you sort of aware of the corporate structure?

KS: (27:15 - 32:48)
Did you get support? Yes, they did not want me using those terrible. You really did get in trouble when the inventory came around.

They were growing as a company and we would get, one thing I would answer off the top of my head on that one was more missives from corporation down to the flock. Yeah, there was that. And sometimes we'd say, yeah, they can want what they want.

We gotta, you know, we know what we're doing. You know, I'm sure people do that still today. We try not to, I keep thinking that, remembering that.

That's how it sometimes feels down there. So the 1970s, so did you go back to the, when did you go back to the- Well, okay, so in 1980, she had had two, my daughter had had two surgeries. And I left National Medical Care.

I had taken like a month off for her surgeries. And there was a lot of political stuff going on, a lot of stuff going on in the NMC, DC metropolitan area. And I told my boss, I really didn't think.

And I had actually had phone calls with folks in the corporate office. And said, I didn't think I was gonna stay much longer. So I said, I think, man, maybe it's time for me to move on.

And I didn't know what I was gonna do exactly, but I remember, it's a funny story, twists and turns of a career. I had a friend, a nephrology nurse friend, who was, you know, she got involved in almost everything you could get involved in. And so we had Certificate of Need in Maryland.

And we had it in Virginia too. But she got herself on the State Health Planning Commission. Because in those days, this is worth noting, and you probably are aware of this, there were what we called closed facilities.

Do you know what that meant? Closed facilities meant if you were not under contract with, or whatever the connection was with National Medical Care, you could not admit patients to those facilities. So they just weren't facilities that, you know, somebody could make rounds and admit patients to.

So that was the way it was, at least in this part of the world in those days, were these closed facilities. So all of these facilities that were in National Medical Care in the DC metro area, I was aware of all of them. And through the ANNA local chapter, you know, got to know the nurses that were working in jurisdictions that were not far away from here, but not where I worked.

Wouldn't have known them otherwise. So that was very helpful. But there were, turns out that Holy Cross Hospital in, on the Maryland suburbs, had been trying for a very long time to have a dialysis unit.

There was a group of nephrologists over there. I think there were like maybe five members in that one practice. And they didn't have a, they did not want to go with National Medical Care, and they did not have a place where, to put their patients.

And they were internists slash nephrologists. So they were the family practitioners for these folks, and maintained relationships with them. They just couldn't do the dialysis piece.

So this was my first foray into realizing that patients still were, had an allegiance to sort of the family doctor that wasn't their kidney doctor, or was now their family, the whole family was going to that doctor, and they could, they were also nephrologists, but they couldn't treat the dialysis. So it took a long time for, NMC would fight these types of, there were ceiling battles all the time. And NMC was fighting anybody who wanted to open a unit, because they wanted to have all the units.

And I never went to any of the, I might have gone to one of those meetings. But after a while, and it was before I actually left the company, and I was working in the Bethesda office one day for something, and I heard two of the doctors that were the lead five doctors of the NMC business all around the D.C. metro area. And one of them says, they didn't realize I was working in an office down the hall, and they wouldn't have thought anything of it if they knew I was there.

One of them said, did you hear that last night they actually, that the State Health Planning Commission approved that Holy Cross facility after all this time? And the other one said, it doesn't matter. There's nobody over there that knows their this from that colorful language.

And I thought, hmm. So I go over to Holy Cross. I saw that they did have an ad in the paper, and they were opening a dialysis unit.

And I went over and met with them, and they hired me to do the startup. So then there was a big network meeting, and we all went around and introduced who we were, and I stood

up, and they knew I had just left the company. And I stood up and said, with Holy Cross Hospital.

A lot of heads turned, because they were thinking nobody knew anything, and that facility was probably in a languish, and it never happened. It happened. And it had a limited time to happen, because I was pregnant, and I said, you want this baby by the time, you want this unit by the time I have this baby, you're gonna have to work on my timetable, because Holy Cross had a very, I always said it rivaled the federal government to get anything done.

And I had to start from nothing, zero. So on I go in my career to startups.

DWM: (32:49 - 33:04)
That was a big switch for you to go from NMC and step out, and build something outside of the NMC, in direct competition with NMC. Correct, yeah. So how did that go?

And what year was that, 1980? Got your unit up and running?

KS: (33:06 - 35:14)
I did. I had the baby just before it opened. Now, I had hired a nurse, of course, from Bethesda, Bethesda NMC unit.

She'd worked there for her entire career. She was very good. And I needed her to be my assistant director of the facility, and once it was open, I didn't need that.

And she was engaged to one of the best technicians, who also was excellent on the equipment side, and water side. And he made it clear to me that he wanted to make that move when the unit was actually operational. So once I had the baby, which was Christmas time, and the facility was opening in January, they were, and I was talking to them when I was in labor, and while I was still in the hospital, getting the last of the things done.

And after that maternity leave, I decided not to go back there, because I lived very far away from Holy Cross Hospital. I lived out in the, I had a farm out in, beyond Manassas, so going 66 to the Beltway, and then halfway around the Beltway, really wasn't going to work. So I had Joyce and Guido in place, so nobody was gonna miss me by the time, by that time.

I'd written, I had written every policy and procedure. I went, I used the regs as the guide for the policies. I didn't steal any policies or take anything from anybody.

So I wrote policies and procedures, and there was no other way to do it, except to write it. And then I would give it to the secretary, and they would type it, it would go into a punch card, and that's how they could, so I thought, I can't even get over this. But I had terrible carpal tunnel.

Couldn't lift the baby, couldn't lift the frying pan off the stove. And that was because, well, I did three months of nothing but writing, it was amazing. So, I developed a new care planning plan, I outlined that as to how I envisioned was a good way to do care planning.

So I put that in policy so that it would be set, probably not the same way it is now, but anyway, I gave it a good stab at the beginning.

DWM: (35:15 - 35:34)
So within the six to eight month time frame, you left NMC, got everybody geared up, helped to build this unit, staffed this unit, prepared this unit, and then you never actually ran the unit. Correct. Yep.

So, I presume the unit did well at Holy Cross?

KS: (35:34 - 35:36)
Yeah, it's still there. It's still there. They've expanded it.

DWM: (35:37 - 35:37)
Good.

KS: (35:37 - 40:34)
I had a novel thing, there was a, I built in a small lavatory, but it was just for, it was just with sinks, and the patients were to scrub their arms. So it was sort of an initial, you walk in, and you have some things you have to do to take care of yourself. So they had to scrub up before they could go sit in their chair, so there were things like that I built in.

And the interesting thing about the docs was, these, that I learned, these physicians, I was wondering how the physicians were gonna get their patients to come back from Bethesda, they hadn't seen them in, who knows how long, they'd been on dialysis six years, they hadn't seen them in six years. Oh no, part of that family thing, they still had a relationship with the patients. And the patients knew that the doctors were trying to open a dialysis unit.

So they were the patients, some of those patients were just waiting to find out that there was a unit there, and they were gonna stick with their old family doc slash nephrologist. And those nephrologists, however, over time, one of them was the medical director. He knew nothing about running a dialysis unit.

So I'd have regular meetings with him, tell him what I was working on, and showed him the layout, they gave me the space, and I had to figure out how it was gonna be a unit, so I did various renderings and stuff, and would show him that. And interestingly, he says to me, that looks good, that looks good flow, yeah, okay, that looks good. What did he know, they hadn't even been in dialysis units, except in a hospital with two chairs or whatever.

So he said, where's the shunt room? And I couldn't believe it. They'd been away from it that long, they didn't even know that they weren't using shunts anymore.

So I thought, I've got a challenge here, these docs, they still know them from their internal medicine side, but they have not been, other than perhaps acute, dialyzing patients on a regular basis. So that was a whole new set of tasks, I was figuring out how we were gonna deal with that. And I made sure Joyce and Guido knew that situation.

Yeah, how did you deal with that? How did that work out? She just knew she had to, I looked, I told him, I said, look, there were like five or six folks, guys in that practice.

And I said, here's the deal, there are no shunts, things are very different from, I don't know what you learned on, but whatever. We're gonna take good care of you. We're gonna take real good care of you.

The nurses we've hired, they're good, they're really experienced, the technicians are really experienced, and you just, they'll make rounds with you, and you do whatever you need to do as a doctor, and you'll see what we're doing with dialysis, and everything will be fine in pretty short order. And I think that's how it worked out. But the interesting thing was, it was very interesting things, I learned so many things in this.

One, because that hospital was so bureaucratic. One day, one of the writings I did, I took a stack, I'm telling you, it was at least this big, of requisitions. I'm talking for C-clamps, for the machines, for from big things to little things.

But soup to nuts, everything I needed, I had to go through these big order books. And some of them didn't even have the things I needed. I don't even know how I scoured up other catalogs of what I was gonna need.

But anyway, had all these things, and I took them to Sister Patricia, who was my boss, and I handed them to her. I said, these are all the requisitions. This stuff needs to get in here so we can fill the place up.

And she took it. And I said, no, I'm not leaving it with you, because she, you know. I said, I'm walking these around today.

So I only came here to ask you to tell me, in what order do I go to the business side and get these? And she said, oh, okay. And so she gave me this list of like six people in order.

So I go to the one guy, elderly fellow, accountant, accountant, or I don't know what he was. But he was the first approval. So I walk in.

Now, this time, I'm pretty pregnant. She hadn't always been pregnant when she interviewed me, but she didn't say anything about it. So I put this thing, I handed it to him, and I said, you know, I made appointments with them all, 15 minutes apart.

And I said, I need you to sign these requisitions. This is everything we're gonna need for the dialysis unit. And they were all excited that we were gonna have dialysis units.

And he took it like this and put it in his inbox. And I leaned over, took it out of the inbox, and I said, no, this is for now. I have a 15 minute appointment, and I'm taking them to so-and-so, and then so-and-so, and then so-and-so.

These are all gonna be done and out of here today. Oh, like, how can I be in charge of him? It's one of my experiences that if you are in charge, if you act like you're in charge, most people like to be in charge.

I do it with policemen, I do it with whatever, doctors. But so I walked him through. Never happened in the history of the hospital, I don't think.

Went back to sister, and I said, they are all signed, and they're out of here. She couldn't believe it. I'm telling you, in that hospital, if I said beans, they, you know, they jumped.

It was just something new, and they didn't know anything about it. So if I said this, they'd go, okay, that's fun.

DWM: (40:36 - 40:36)
Well, it's sort of.

KS: (40:36 - 44:19)
Oh, but the most important piece is this. This is the interesting political piece. I was getting calls every day by patients.

And I learned something. You know, they always ride in cabs, groups of cabs. I assume that's still the case.

And the group that's in that cab, two or three people together, they're taking the same shift, you know, so they're really tight. And so they tell people things. So they were, these folks, the ones that were linked to the docs that they'd been separated from, they were definitely coming.

But they were talking to their friends because they live in the same area because the cab's picking them up, right? So their geography is pretty similar. And Holy Cross was closer.

It's on the other side of the beltway. And so I'm getting these phone calls. We had six days a unit.

And I was gonna open two shifts on Monday, Wednesday, Friday and two shifts on TTS. I got so many phone calls. We were getting to three shifts.

Mind you, there was not a unit yet. Three shifts, Monday, Wednesday, Friday, and then, TTS was always, nobody really wanted to be there Saturday night, but enough were coming on the phone to be, okay, we have, we're gonna have, I said, went to sister and I said, we're

gonna have a completely full unit before anybody walks in here. We need to submit a request, go back to the shift or whatever it was.

We have to go back and ask for three more stations. Now, when we built it, we had enough space. And I said, you know, they had already gotten, the approval they got when I heard that they got it was for the six stations.

But we had enough space that I said, you know, we'll be expanding. So it's good we have enough, you've given us this much space in the basement to have nine stations. So I said to her, we need to apply now for those nine stations.

So I had to work on that application. And I'd get that in. And, because we had, we were gonna open that unit full.

So along comes the meeting time for that. And I go to the meeting. And the doctor from the Northern Virginia unit that I was very close to at first, he was in the little building and gave me the job in the bigger unit.

And he had risen in the hierarchy of the NMC docs by that time. And, I mean, we were both very fond of each other, but things were a little, I mean, he used to come down and visit me at the Capitol Hill unit after. I mean, he had no reason to leave Northern Virginia, but he'd come down, he wanted to make sure I was okay, or I don't know what, but, so we stayed close.

And all of a sudden, he's at this meeting. I'm like, what was he doing over here in Maryland on this meeting? And he was just one of the NMC docs that was opposing it.

And I made my case that these, the unit hadn't even opened yet, and it was full, and we needed to be able to accept other patients. Not only that, part of the unit was the acute unit. It was separated so that it was separated from the outpatient and the structure, Medicare structure of the outpatient.

But, you know, part of what I was building was a space for the acutes, to fit for acutes. So anyway, that, and it was shifted, though, they didn't regulate that. So, here's the meeting, and we got, not that night, but shortly thereafter, we got the letter for the three seats.

So it opened. Now, they didn't open with those three chairs, but they were, they clearly were gonna fill them up in no time. So that was very interesting.

DWM: (44:20 - 44:37)
That is interesting. Why do you think, what was the main reason that patients were willing to come? Was it because this unit was geographically closer to their homes, or because they still had this relationship with the docs, and they wanted to be back under the full care of the docs?

What was the main reason?

KS: (44:37 - 45:06)
It was, for the ones that still had the relationship with the docs, that was it. For the ones they told in the cabs, they wanted to be closer, or they wanted to stay with their friend. But, as I said, the cabs were coming from the same neighborhoods, and so, if Sadie and Jack were in the cab, and Dugan was in the cab, Dugan didn't know anything about that.

But, well, I'd like to go there, too. That's closer. They probably stayed in their same cabs, only went there, for all I know.

DWM: (45:06 - 45:24)
So, were patients, do you think any of them said, well, this is a new unit. I don't know whether they can take care of me the same way that unit can, or did they say, you know, I'm not really happy with the care I'm getting here. Maybe this care will be better.

Did the quality of care, you think, influence the decisions, or was it really much more about the geography?

KS: (45:24 - 49:04)
No, I think the patients felt they were taken care of in the dialysis unit, fine. And they probably thought, you know, the other one would be just as fine. I don't know how many of them had to change doctors.

But, I wasn't involved in that at all, but some of them probably did have to change doctors. But it was like, the cabs are, probably still today, powerful. The people that, and I have, we'll go on with my career, I'll tell you more about the cabs.

That's probably still a little bit the case. So, I learned some lessons along the way, and more I'll talk about further, again, down my career, but nephrologists think they have a relationship with their patients, and they do with, let's just say most. With others, not necessarily.

So I'll tell you something that Louie Diamond used to always say, please will you stop saying this in public? And that is, I learned that, just because, for this very reason, patients willing to change dialysis facilities. The doc thinks, like I just said, that they have a relationship.

And I used to say, I used to do quite a bit of public speaking, that's what I would say, to the audience, I'd say, do you know how it is that a physician bills for Medicare for what they do in a dialysis unit? This was before the MCP. And they would all just sort of draw a blank.

Nobody ever raised their hand with a potential answer. And I said, it's so easy. If they're the first one to get a claim into Medicare for Sadie Jones, they win Sadie's Medicare money that month.

That is it. And Louie would say, can't you find a more sensitive way for saying that? I said, that is the truth.

It's important for the patient side, that they don't necessarily feel linked to their nephrologist. Especially if they came out of an internal medicine practice and still go to that doctor for non-kidney things, which those doctors are usually not real happy about because they're not all that plugged in with the renal side. They'd rather, since it affects everything.

But anyway, I think that that probably was not a terrible challenge. The cabs and your friends and geography and the time you spend for dialysis is bad enough, let alone the traffic time, the extra traffic time. From Holy Cross to the Bethesda unit, if it was bad traffic, could be at least a half an hour on top of whatever the ride would otherwise be.

And those are just things that, from the inside of dialysis, we never gave much thought to. So in positions like that for me, now when I was in the inner city, no problem. Cabs were picking them all up.

Medicaid paid cabs were picking them all up. Here's another interesting story. In the Medicaid paid cab, one of my patients from the Capitol, it was Capitol Hill Southeast facility is where I was located, she won the lottery.

So in the paper, I read, and she came in, Mary Bell. I said, Mary, are you kidding me? You won the lottery, blah, blah, blah, blah.

So here's the article in the paper. She tells the story of how she won the lottery. Well, on her way home from dialysis in the cab, she stopped at the liquor store.

And bought her ticket there. I'm waiting for Medicaid to come knock on my door. But there was a lot of fraud with the Medicaid medical cabs.

And that came to a head anyway, but.

DWM: (49:07 - 49:15)
So you helped this unit get launched at the Holy Cross, but you, our own attorney leave it, don't ever go there.

KS: (49:15 - 51:59)
Right, right. I was talking to Joyce and Guido every day, and it was gonna be fine. So, God talked to me in the U.S. mail. So while I was home, I'm attorney leave. Now, I was very active with the Renal Network, and I did some consulting with the Renal Network. So I was busy at home when I was on maternity leave.

Now here's the, so I've had this one healthy baby, and the other had had two open heart surgeries just before I got pregnant with this other kid. So the home situation was that. But I was doing things at home.

I was writing things for ANNA and doing various things for the network. So I was thinking, I'm with this baby and this other child. I don't think I'm gonna schlep all the way there.

So, but I hadn't figured out what I was gonna do. I hadn't made any firm thoughts. But I opened the mail, had to go out to the big mailbox way at the end of the lane.

You probably relate to that. And I get this notice from the Washington Hospital Center. Don't ask me why.

I guess just because I was a registered nurse. And they began the weekend alternative. Do you remember that?

You got paid full time as a nurse if you worked Saturday and Sunday. And I thought, wait a minute, that's pretty good if I just worked weekends. So I called the hospital and I said, so I got a recruiter, and I said, look, I am like worth nothing because all I know is dialysis.

And they had a big in-house patient unit so I knew the head nurse from A&A Connections. But they didn't do any chronics. And so I figured Saturday and Sunday was only a few acute.

But that wasn't gonna be one of these all day, 12 hour Saturdays, Sundays. No way, the dialysis unit's gonna be working like that. So I said, I'm like useless.

I don't know, maybe I could do new babies, the healthy ones. Not the sick ones. I don't know what I could do.

But anyway, just thought I'd talk about this. So I guess at the time I might have even been willing to do regular nursing, floor med surg even maybe to do that. Now mind you, that was gonna be an hour commute, only an hour because it was gonna be in the middle of the night that I'd be driving down to D.C. from where I lived. And I could make it in an hour. But any normal day with cars on the road, I would never, it would be much longer than that. So I knew I was going in really early and coming home really late so that was gonna be fine.

They said, oh no, no, no, no, we have a job for you on the transplant unit. And I just went ding, ding, ding, what's the matter with me? My patients were being transplanted.

A few of my patients from the unit from D.C. were getting transplanted there. So I thought, wow, what a way to round out my nephrology experience. So that's what I did.

DWM: (52:00 - 52:10)
So what was, so this is 1980 or so. Yep. What was renal transplantation like in 1980?

How many patients were you seeing? What kind of meds were you using?

KS: (52:10 - 53:12)
And how healthy were they? Very interesting. I mean, this career I've had has just been all accidental, not really orchestrated.

You know, I tried to organize my education and that didn't work. But this was, now remember, I'm still doing consulting. During the week, I was still consulting and doing work with the network.

I could actually drive into the network. My grandmother lived right near the network office and I would just take the two little ones to my grandmother's and go over to the office if I had to actually be there physically. I certainly didn't have to do that every day, but I probably did it every week.

And then I got other consulting jobs as well. One was, so before we talk about transplant, we'll talk about my working from home during the week. One was the very first study, which I think is still relevant today, the paid aid, there was a paid aid demonstration project.

DWM: (53:13 - 53:14)
Oh, say that again?

KS: (53:15 - 53:19)
Paid aid. Paid aid. You have an aid that is paid to dialyze you at home.

DWM: (53:20 - 53:22)
Really? So who was sponsoring the paid aid?

KS: (53:22 - 55:20)
Well, this goes back to the history of, it's very interesting too, the history of dialysis in the, and you probably know this. Cut me off when you want to cut me off. The history of ESRD treatment in the Pacific Northwest and all the developments that came from the docs there is very different from the development of ESRD care in the northeast part of the country.

Obvious right off the bat, far more rural, different geography, very urban. And when I say northeast, that extends down to here, because the link between Boston and George Schreiner at Georgetown was huge. So that was, northeast wasn't just Boston.

So in the Pacific Northwest, I learned this again through a colleague from ANNA who worked at the Northwest Kidney Center, they would train, the patients were coming from Alaska, Montana, Idaho, you name it. And they would train them, I knew we could keep them alive, so they would train them and send them home. And they had to find a partner.

And I mean, they were asking their next door neighbor or the person three houses down or whatever. And that's how, that's what it was. They would find somebody willing to do that.

And you can imagine the technology at that time, even getting the machinery ready had to be a job, let alone then sit through a six hour treatment. But that's what it was, that's what they were doing. And they thought that was the best thing ever.

And they would train these people and they'd be so far away. I mean, phones weren't even all that reliable, but anyway, that's what they were doing. I don't remember what the impetus was.

I know that the Orkand Corporation did, was commissioned by the government to do this payday demonstration.

DWM: (55:20 - 55:21)
What corporation?

KS: (55:21 - 55:23)
Orkand, O-R-K-A-N-D.

DWM: (55:23 - 55:23)
Okay.

KS: (55:24 - 55:57)
I got involved in it after I had the baby and was on maternity leave to do, actually, I was going to go interview the patients and they realized that was gonna cost too much money. And so they developed a different tool that would be a phone interview with these patients who had been at home, dialyzing at home. And I met John Newman and had a wonderful time interviewing these folks about their experience with home dialysis with an aide.

DWM: (55:58 - 55:59)
So how common was this?

KS: (56:00 - 56:39)
It was just pockets. But the government, somebody decided they should look at that model. And it could have been Chris Blagg and those making noise about that and got that.

I wouldn't be surprised at all if Chris wasn't the impetus because he came to Washington a lot and dealt with the Washington delegation and there's still a tight relationship with that because of what he's built over the years. And certainly the senators and certainly the congressperson from where the Northwest Kidney Center is located is well aware of that organization and what it does in general and they're folks to go to on Capitol Hill that understand the SRD pretty well.

DWM: (56:40 - 56:45)
Do you wanna talk about meeting John Newman then and about John Newman?

KS: (56:46 - 56:49)
I love that man. Knew him all the way up to his death.

DWM: (56:50 - 56:53)
So how did you first meet him and what was he doing?

KS: (56:53 - 57:14)
On the phone, actually. But I knew his name. I knew he was an outspoken patient.

And after the phone call, I remember where I was sitting in my house and I remember where the baby was during my interview with him. And he said, well, you know, I come to Washington and blah, blah, blah, we'll have to meet. So we made like a friendship right on that first call.

DWM: (57:15 - 57:17)
So he was dialyzing at home at the time?

KS: (57:18 - 57:37)
He was early dialyzed at home in Boston. He was in Boston at that point in time because I think that's where he got his PhD. So he had his family, his two girls were young then when he developed the SRD.

I'm pretty sure he was in Boston because of where he was going to school.

DWM: (57:38 - 57:39)
And he was doing home hemodialysis?

KS: (57:40 - 57:51)
And he was in the very, very early days. And Mike Lazarus was his doctor. And I knew that.

I never knew I'd end up so close to Mike either, but I'm telling you, I've had a blessed career.

DWM: (57:51 - 57:58)
But what was it generally about him that made him stand out? Why do you remember him still today? Why did you get to be friends with him?

KS: (58:00 - 1:00:02)
I guess because he was already an outspoken advocate at that time, so I recognized his name. And I thought, wow, I'm talking to John Newman. You know?

I just knew that he was outspoken. He was active in a NAFT, National Association of Patients on Hemodialysis and Transplantation. That was the only patient group.

And I had made connections with folks at that, at NAFT. And I knew he was one of the early folks. And I just admired everything he said.

You know, the kids were really little. He tells a story that when the kids went to their friend's house, they asked where was their dad's kidney machine? Because they thought that's what dads did.

It's two kids or one, but it's two daughters, but one's a physician. And I will tell you that my sister-in-law was his transplant coordinator on the kidney that his daughter gave him. And he told Julie not to tell me.

It was gonna be a surprise. That was his second transplant. He had had a transplant where he actually was a patient of mine.

We'll get to that later. But beyond that, he lost that kidney eventually. And then, you know, he would always tell a story about when he was diagnosed, you know, would he see his girls grow up and go to school, graduate from school.

And when his youngest graduated from college, she, and he would tell this story. So when my youngest graduated from college, she said, dad, I'm giving you my kidney. So, lived to see all that.

So anyway, I was doing all different kinds of consulting during, you know, and even when I had the weekend job, I would do stuff during it.

DWM: (1:00:02 - 1:00:05)
How long did this paid aid program last?

KS: (1:00:06 - 1:00:22)
The one in the Pacific Northwest? I don't know, because that was unique to there. People knew about it.

It's how it was done. So it just, I think, perpetuated itself. I doubt that's still the case.

I doubt that's still the case. But then on to, I wanna tell you about what was going on with the transplant then.

DWM: (1:00:23 - 1:00:23)
Absolutely.

KS: (1:00:23 - 1:09:19)
So again, working at the network, working on data. And let me tell you what that was like with no computers. They had a computer.

I don't know what in the world they did with it, but it wasn't anything like that. There was one person who knew how to do whatever they did with it. And I'd have to prepare reports for the medical meetings and stuff.

And I literally had to use, you know, yellow paper and make columns and put diabetic or age or whatever on one axis and the other, have the other axis and fill in the blanks to say, you know, is that crude? And my math skills don't go far beyond that. So once the technology came out, I wouldn't be able to do this anymore.

J.R. could do what he could do, right? But mine was all, you know. So we'd say, you know, how many diabetics lived through whatever or how many years they were on or how long, whatever the measurements were, you know, it was all very, very, very crude.

But I was learning an awful lot about, you know, looking now at a population. It also gave me the opportunity, because of the other part of the job that I had, was the workflow, all the forms that the facilities had to complete, which I imagine there's still some today, but that's not electronic. But they actually had to fill out a number of government forms, right?

There were blue, one I know was blue and one I remember was yellow. So I had to call all the head nurses and either say there were some blanks on one or I had to validate something or I didn't get, it didn't match the roster they sent of patients. And so if they weren't, the ANNA chapter wasn't all that active.

So if I didn't already know them from an ANNA meeting or something, I got to the point where I knew every head nurse and every dialysis unit's phone number by memory in the entire DC metro area. So that was helpful in terms of outreach, which led to further down my career. But part of the data was transplant data and there wasn't a whole lot of that and I had nothing to do with that, but I was starting to track that stuff in the network.

So I go to work at the hospital and I'm thinking, I'm gonna see some of my patients even back from the unit because they were waiting four to six years and it hadn't even been that long since I left the southeast unit. So I forgot to tell you that while I was in that southeast unit, we moved from the little townhouse that I walked into the first day I moved to the district to work, which by the way was a row house and my office was in the basement, which had no egress. So if there was a fire on the main level, there was no way.

So that's what the staff lounge was downstairs, supplies and my office with dead rats in the black boxes that the techs would be kind enough to take the black boxes out for me when I started smelling something under my desk. And I'll tell you a quick story that's funny. My brother was a firefighter in DC and he had had an injury.

So for a while he was doing the responding to the calls and there was an alley in the back of the dialysis unit and we'd had some issues with people starting fires in the big dumpsters. So Saturday night and I get a phone call from Claudette. She's closing down the shift.

They had a night shift. We had three shifts a day. So it was kind of late and she calls and she said, I just wanna let you know we had another fire in the dumpster and I didn't realize it because they never came in through that alley.

She said, I didn't realize they had pushed that trash cart closer to the back door. So they were starting to put out the trash for the last shift and she opens the back door and this thing is in flames practically right by the door. So she called the fire, and I'm thinking, oh my God, there's a fire in the unit, she says.

So I called the fire department and I gave them the address and said it's the dialysis unit and this is the address. And this person says, is that Kathy Smith's dialysis unit? She says, yes.

And he said, oh, I'm her brother. And she said, I don't care who you are. Are you sending a fire truck?

This is, I'm looking at flames coming at me. So anyway, anyway, so the transplant day. So I go in working on the hospital center.

I'm not seeing anybody I know, nobody. I'm trying to find out what dialysis unit they came from. I might know some of the nurses that they know and I can mention that to them, make them feel like there's some connection here.

And I'm thinking, and not really. Most of them were from Arab states. I'm thinking, where are my patients?

Why aren't they on this unit? And I investigated that a little bit. I called Georgetown Hospital.

Name shall be deleted. And said, what is going on here? This nurse had worked at Georgetown forever.

And she said, I said, all I'm seeing, I don't have any prejudices here, but all I'm seeing are people from foreign land. And she said, oh, you haven't seen the suitcases of money, cash? I said, I'm gonna work weekends.

She said, oh, well, I'm gonna walk him right into the president's office and give him, not the president of the United States, but the hospital, and give him cash, and get a suitcase full of money. I said, oh. So I started talking to the docs about it.

So I went to the chief, occasionally worked weekends. And he knew me from the network, so he thought it was a big deal that I was working on the weekends. I was like, I don't even know anything about transplant, but if you think it's a big deal, fine.

So I said, so Charlie, what is up? Why aren't my dialysis patients here? And why are these people getting all these kidneys?

And he said, they, they are willing to accept organs that we do not on our matching system. So the kidneys that we wouldn't give to people on the list. I paid a little bit of attention to what was going on in Richmond with UNOS, but not much.

So I got a little data, I had a little data, I didn't steal it, I already had this data, a little bit of data on transplant. And Al Gore was a congressman, as you probably remember. Were you in Tennessee then?

I wasn't then, but I certainly remember. Well, he had a wonderful guy who ended up being a very high level FDA person, was his health staffer. And I didn't take a handful of data or anything like that, but I made an appointment and went to his office and started talking about it because he was already on the news, I don't know if you remember, about this little boy and his mother and the little boy needed a liver and he just got turned onto the whole issue.

And he actually wrote a bill. Gosh, I thought I'd never forget the acronym for that long. It'll come to me maybe.

So I knew he was working on, because there was a lot of press coverage of that mother and the child and Gore being involved in this transplant issue. So I went over, met his health guy, and I said, you know, I work, well, when I called, I said, you know, I work in transplant in D.C., which is like talking to you about what you're doing with transplant. So that's how I got the appointment.

And we started working on the bill. He was giving me drafts of the bill. I don't think I knew anybody in transplant really.

My sister-in-law wasn't my sister-in-law yet. But I was still, you know, they asked me to just draft what you think, here's a sketch of what we think would be good, you know. And sometimes I would go over to take what they'd give me, and I'd go over to my dad's office on Capitol Hill, the police office, and they'd give me a seat and a typewriter, and I'd work a little bit with the language on that, because I still lived out in the country, so if I was in town for a visit, I wasn't, I had to stay here for a while.

So worked on that. That went on for months. By that time, I took a part-time job two or three days a week at a dialysis unit in Northern Virginia, easing my way out of the weekend job.

So I'd been doing the weekend job for about two years. But I'm now working part-time in a dialysis unit during the week.

DWM: (1:09:19 - 1:09:21)
This would have been the early 80s?

KS: (1:09:21 - 1:10:37)
Yeah. And he called one day, and we were on the phone in my office, and there was a code in the unit. And I said, I have to put you on hold, we have an emergency.

I went out, it was a full-blown code. I did the code. I go back to my desk, and here's the red light blinking.

So I didn't just push the button. He held the whole time to finish this conversation with me, whatever it was, every time I translated. Anyway, they passed the bill, and then there was

some controversy, I forget what it was, but it made the news, and Al was gonna be on TV the next morning, and he told Jerry to call me and come over.

So we could talk, so he wouldn't be saying any wrong things. So I went over for that. Surely, he had real transplant people talking to him about all this, too, but anyway, I was in the fringes, but I was, you know, I'd made, there was one night where, one evening news, where I was in front of the TV, and they had two factoids up there about transplant that were data from the network, but it was broad data, like the number of transplants that were done last year, something safe.

But it was clearly something I'd given him. I got a little nervous about that. So that was a little foray into fun, you know?

DWM: (1:10:39 - 1:10:43)
So what happened with that bill, and what happened with this sort of transplant issue of?

KS: (1:10:44 - 1:11:13)
Well, it gave birth to, did it give birth? There was something before UNOS. I don't remember if it created, it created the transplant registry.

I think UNOS had already been an organization, it was probably in Richmond. So I don't think he actually created that, but the whole transplant program as we know it today, although it's been refined, it really is based in that law.

DWM: (1:11:13 - 1:11:18)
So the waiting list, and priorities, and all that was really established. Yeah, and of course, those have been changed.

KS: (1:11:18 - 1:13:04)
Yes, yes. But that was? The beginning of the structure, okay.

I can't remember. NODA, the National Organ Transplant Act, N-O-T-A. I don't remember the year that it was passed.

I know that it had to be reauthorized every three years, and it would be one of the many bills that would be late in the, so we would lobby, we would lobby all the time for it to be reauthorized within the timeframe. Because you don't, you're not supposed to get appropriations if your law is not active. And so if it's passed, it's time for, you know, it's not supposed to get the money allocated.

But Congress wasn't paying attention to that for a long time. And I think when Newt came in, he tightened up those screws and processes, and by that time, I had yet another job, and I paid attention to that to make sure that nothing bad happened with NODA, because they had been letting it languish for, then I think they actually extended it. I don't think it has a three-year authorization anymore.

I think one of those times, they expanded the authorization for maybe every four or five. I'm not entirely clear about that. But anyway, I, you know, I fooled around on the edges of NODA.

For somebody who wasn't really much of a transplant nurse. But I wouldn't have gotten involved in that at all if I hadn't been working in transplant and seeing the larger policy picture of the whole kidney world and getting a bigger sense of that. It worked for a long time on, he carried forward, even after that law was passed, for what we might do to improve organ donation.

So we had hearings just on organ donation, and talked for a good while about whether we should launch in the United States presumed consent.

DWM: (1:13:06 - 1:13:07)
For driver's license.

KS: (1:13:08 - 1:13:11)
No, you have to say no, as opposed to you have to say yes.

DWM: (1:13:12 - 1:13:12)
You opt out.

KS: (1:13:12 - 1:21:43)
And Europe, companies in Europe do, and we had people at the hearing that testified to that, told their story of how it was in their country or whatever. But the United States still isn't ready for that. If somebody made a big push again, and it was big talk for a long period of time, people might think, oh yeah, so when it came time to oppose it or not, no, no, no, that would be okay, but there's too much else going on for that to rise.

So that was fun. So then what did I do? Left there, okay, so then I went full time running the dialysis unit that I'd been dabbling at.

A friend of mine was a nephrologist, a friend of mine, well, colleague, we were colleagues then, we're very close friends now. He'd opened a unit in Woodbridge, Virginia, which was not that far from where I was living in the country. Woodbridge.

So that would have been perfect. I could get away from the long schlep on the weekends. And I'd had two good, two solid years at least of the transplant job.

And when I started dabbling at the unit, it was like for two or three days a week. The consulting was winding down and I was doing the two or three days at the unit and was really sharing the head nurse job with another nurse. So one of us worked two days a week and then three and then two and then three and it wasn't a huge unit.

So it was all manageable. And then she didn't really, she lived in Maryland, kind of far for her to come. So after a while, I was the only mom at the head nurse.

So I did that for, until 1986, I believe. And then here was the best. No, because this is the best, but I got a phone call from John Newman and he said, Kath, we have to talk.

I said, okay, John, what do you want to talk about today? He said, no, there's this doctor in Florida who has a program where he puts patients at home and he provides them with an aid. And everybody would go home if they have an aid.

So I went down and I talked to him because I'm really very interested. And he said, he told me, he said, he's already written a letter to, I can't remember who was the head of HICV at that time, but he wrote a letter to him explaining the program and the guy said it sounded legit to him. So he was expanding it to other cities.

Because the way he was doing it initially was really just his practice in his unit. So if he was putting people home and putting an aid there, who cares? Because Medicare was paying what they were paying and it wasn't gonna cost him anything else except it was coming out of his pocket.

He didn't really figure that out. So John said, I told him I could be probably a consultant to him to help him get people around the country. And I told him that Washington DC was completely taken care of, or it would be after we had a little phone call.

And I said, thanks John. You're always thinking of something else for me to do. But I wasn't trained enough to, he said, is it okay with you that I give him your phone number?

And I said, okay. So I made this appointment to talk and it was very brief. And he said, really, you need to come down here.

I said, yes, not only do I need to come down there and talk to you about your program, but I want to look at at least three or four patient charts. And he was like, what, this is an administrative job. He said, okay, if you want to look at your patient charts, you can.

So I go down to Florida, to Miami, and I meet with this physician who had started, the company was called Home Intensive Care. And he came out, he described it that he came out of nephrology, I know he came out of research on bone diseases, if I recall, he was a nephrologist. But that's what he'd been doing.

And he came out and what do you do? You start a unit, so he had a unit. And he thought, well, these people aren't really doing as well as they could.

I think they'd probably do better if they were at home and did some work or whatever. I guess he thought it was kind of depressing because rounding a dialysis unit, he hadn't been doing that. He didn't do that typical nephrology thing.

So he decides they should dialyze at home. And so he told them he'd have an aide that would come and do dialysis for them. And all of them were better, clinically.

So he thought, well, this is such a good model. So it took him a while, but he thought, I think I'll expand this to Tampa. And that's about where I came in.

Because that's why he wrote the letter to Strymer, who was the head of HICVA, Bill Strymer. And he described what he was doing. And Strymer said, go ahead.

And I didn't see that letter. I didn't know exactly what he said. But Strymer said, okay, go to Tampa.

So he went to Tampa, hired a nurse, and did a program. And at that point, he realized that he wasn't paying attention to the math back at the ranch, or he would have seen that it was doing well and finances were good, but it was feeding off of the income to the unit. That was covering the floating everything.

So if you want to do that and float that, and he's, I guess, was paying himself enough, paying everybody else, that could be fine. But you can't grow that somewhere else. So then it dawned on him.

So years later, when we're in federal court, he tells this story to the judge, and I'm sitting there. And so the judge said, so when you opened Tampa and you realized the finances were what they were, what did you do? And Alan said, I read that book.

And the judge said, which book? That book, the book that was on the table of the Hick the lawyers, it's the manual. I read your manual, and I did what it said.

And it was method two. And when method two came out, when that rule came out, everybody assumed method two was for PD, and everybody assumed that Baxter's the one who got that in there. I mean, who the hell would have thought of a method two?

So everybody always said that was Baxter, and they never ever indicated that. And the folks who would have were long out of nephrology by now, so we'll never know that. So it didn't say anything, it didn't say anything about PD, but that the patients don't have to get their supplies from a dialysis unit, get it from the vendor.

So he said, well, I can do that. So that's what he did. So he, Tampa was the only one he had opened, and that's why he was talking to me, because he wanted to do DC, and he wanted to hire someone, wanted to hire someone who could not just do the next city he was gonna do, but do that and then do other cities.

And that's what John had told him about me, that yes, A, I could do it, yes, and B, I could manage the business. So, I don't know, 1986, I guess, I was ready for another change, and I said, yeah, I wasn't making very much money in that little dialysis unit, that was my friend's

dialysis unit, it was just pittance, really. And so he was gonna give me, I won't even tell you what he was gonna give me, that sounded like a lot of money.

But I thought, well, this sounds like fun. Now, I had never done home dialysis in the units, the two BMA units that I did. They didn't have home programs, and holy cross, they might have one now, but that wasn't part of what they were gonna do when they opened up.

So I thought, oh, well, I haven't done that yet. So, well, I know John did it, I could do it. So that's what I did.

And it was a wonderful, wonderful model. And it was a wonderful model for nursing as well as for patients.

DWM: (1:21:43 - 1:21:43)
Why?

KS: (1:21:44 - 1:29:46)
First of all, he respected, he, a doctor, his model was, hire a nurse in these cities who are well-known in their cities. Now, you've heard my story. DC, Maryland, Virginia, network, transplant.

I knew every doc in this town, and I knew every head nurse in this town. And I had seen a lot of technicians coming and going, and staff nurses coming and going. I knew exactly who I would not hire, and I knew every head nurse well enough that any technician that came before me, and this is what I would say when I interviewed them, I know every head nurse in this town, and I know Ellen, which the head nurse he was currently working for, or whatever.

And I'll be talking to Ellen, because we can only put the cream of the crop in people's homes that we're not observing directly. So, you know, we're picking the cream of the crop. And so I said, if you're not the cream of the crop, tell me now, because by tomorrow I'll know it anyway.

So it was a nurse's ability to pull it all together and have docs who will give you referrals, trust you, and give you referrals. And that was Ellen's idea, that, I guess, as a doctor, you know, he probably thought to himself one day, you know, would I do this? Well, I would if Sharon told me.

You know, probably something like that, because that's what he thought. He wasn't sure if they were going to be very good at finances, so we had a chat about that years later when I said, isn't it funny, he said, you know, they understand these P&Ls, you know, I would go over there and P&L with them every month, and it would be an interesting, an interesting learning, because they'd say, look, Kath, look, look at my bottom line this month. And I'd say, yep, but you gotta read the whole thing, Mary.

They didn't post your rent. Oh, so it was simple things like that, you know. And I said, and he said to me, it's amazing that these women did that.

Well, he said, I knew you were hiring only good nurses, but I wasn't really sure how the finances, you know, if they were going to be sensitive to that. I said, Alan, yes, they're all women. They're almost all divorced women raising children.

You know what, they have a checkbook, and they know money in and money out as good as any financier in New York City. They know money in and money out. So they got their little checkbook, money in, money out, and they've got the business thing, the money in, the money out.

Same general, basic math, it's as far as I can go as far as sophistication, and it's working for them. And they were, you know, we would go, I'd go to some of the other cities with some of the gals I would hire, and we'd talk to some of the docs, and they'd say, they didn't necessarily know that I was a nephrology nurse. You know, they sort of thought, they knew this nurse, and they thought I was a business person.

And they'd say, so, you know, when did you start this business? I'd say, well, no, the company's based in Florida. This isn't your business?

You know, they thought we were, oh, we thought you owned this. This is terrible. So anyway, you know, we were, patients were coming in droves, in droves, I can't even tell you.

So my experience here in D.C. was, back to NMC, patients would call, patients found out about us. I sent a lovely brochure with letters and explaining the program to every doc in the city, every nephrologist in the city. And I figured they were all going, right in the circle of, well.

The woman I had hired, she hadn't come to work for me yet, because I was still just doing foundational stuff. I hired her, and she worked in the big NMC unit in Northern Virginia. And I had worked with her a shorter while in that Woodbridge unit, just a little further out.

But so I knew her, and I knew she was very strong clinically. I had a good head on her shoulders. And she called me one day, so I'd already really hired her, but we weren't at a point yet to bring her on.

So she's a charge nurse in that unit. And she says, after the material went out, she said that the same doctor from the unit, the first unit I walked into in 1975, that was so close to me when I was in the inner city and would come visit me regularly. And then at the Holy Cross thing, when we asked for the extra chairs, and he was in that room, I didn't finish that story.

When we walked out, I walked out with the nun who was my boss and running the program. And I thought, well, this is a little tense, but it was just him walking to the car and us walking

to the car. So I said, Barry, I'd like to introduce you to sister, Barry's Jewish, I'd like to introduce you to sister, and sister Patricia.

And I told her who Dr. Strouch was. And he shook her hand, shook her hand, and he said, I must tell you, you couldn't have picked a finer person for this job. I'm sure everything will go very well.

Okay, that was that job. When it was home intensive care, he was even bigger in the structure here. And he went to, I guess, every dialysis unit, but the one where Linda was, he had a staff meeting after, staffs that were there, and said, you know, showed the material, and this is something, we could lose patients to this program.

I know this person, some of you know this person, my name's on the bottom, and she will be successful in this job. And this will be a program that, I don't know what words he used, but legitimate, safe enough, this is going to be something. And we're going to have to make the patients happy.

So she calls me. Barry's saying we should make the patients happy. So at the same time, corporate comes down with, no more choice of reuse or not reuse.

We're reusing. Bad timing. Very bad timing.

So back to my, so what I learned. They don't, patients don't necessarily feel a tie to a nephrologist. Many times.

I'm sure there are many who are wedded to them, but I mean, my experience is what it is. And they have, they do have some sense that they should have some choice of some things. And what they know or don't know about reuse, whether they know that there's, you know, toxic chemicals involved or not, they still think they should have a choice.

And they didn't like that they weren't going to have a choice. And they're not stupid because they're not educated. So one of my really good friends was running one of the units in Maryland, just over the Virginia line.

And I was getting a lot, there were a lot of active cabs in that facility, let me tell you, because I was getting phone calls all the time from that unit. So I came in one morning, phone rings, I pick it up. It's Bob.

I said, oh, hi, Robert. We've worked together. Hi, Robert, what's up?

And he said, oh, I'm Kath. Are you almost done? I said, done with what?

It's Friday and I just got here. He said, the last fax you sent requesting records? I said, yeah, yeah, yeah.

And you got them ready for me? He says, she's the last patient on my morning shift. That was in the two days that I think was at least, if not 25, maybe 30 stations.

Call shift. I knew I was getting patients right and left, but I didn't picture that. That's what this program did in a city where it was.

This is like lots of patients. Always lots of patients.

DWM: (1:29:47 - 1:29:49)
Where were you finding the aides to help with this?

KS: (1:29:49 - 1:30:19)
Oh, they loved it. The technicians loved it. I don't even remember if we ran ads.

Well, maybe Linda ran some ads. I don't remember. I think it was word of mouth.

There were some I called, but not many, because I had been out of facilities by that time. The ones that hung in with me for years, some of them, I had a couple of really good technicians. We'd walk on hot coals for you.

Some of them came as soon as they heard I had this job.

DWM: (1:30:19 - 1:30:21)
And how many patients could one aide?

KS: (1:30:22 - 1:30:44)
Well, we had to put a limit on that, because some of them really wanted to make more money. So we had to be very careful about that. We thought three treatments in a day was enough.

And some of them wanted to pick up an extra one if some patient wanted dialyzed late at night. And so we didn't allow that.

DWM: (1:30:45 - 1:30:48)
So how many years did this go on?

KS: (1:30:50 - 1:31:30)
This went on, and this is what's very, very applicable today. 86 it started. I think it was in 91 that it didn't.

There was something in the statute that folks who wanted us gone away tweaked in Medicare, regarding Method 2. And I'm pretty sure that happened in 91. No, it wasn't that early.

It wasn't that early. It was 91 or 92.

DWM: (1:31:31 - 1:31:46)
The business model was that the patients would, you all would supply an aide and equipment. And the equipment and disposables were billed. You all became the provider for those, the equipment.

KS: (1:31:46 - 1:34:11)
Yeah. Well, they had no provider, really. Right.

They had no provider. That's, see, CMS was left with what in the world? Because they thought that Method 2 language was only for how a patient would get supplies, that they weren't linked to the unit.

They could choose a machine different, which is probably Baxter fighting Fresenius competition. So if Fresenius had units, and they would send all their patients home on their products, and here's Baxter trying to sell PD. That's probably what it was.

That's what everybody assumed. So I hope this comes out of this interview. So the patient, actually, we did studies as time was coming, and we knew that there was a lot of work to try and close this loophole.

We did a test run and said, all right, we're going to pretend that I'm a patient, like a John Newman. And John Newman did this to me. He wanted some kind of machine that started with an M.

I can't remember what it was, but it was the latest and coolest. And he had to have it, and I had to get it for him. It cost a fortune, but this time, he's living in Reston.

So he's in my home. I'm getting back to John. He was in my dialysis at home program, so he's living in Reston.

So I had to get him this machine. That's when he got his first transplant, was when he was with me with home intensive care. So they could buy, so we did, OK, here's, we pretend a patient, and they ordered needles from here, and dialysate from here, and machine from here, and all the way through.

And that came to $10,000 a month. So that's really the loophole that they had created with this method two. It didn't play out that way, but that could have played out that way.

And what we also learned was that by operating under method two, we weren't connected to a facility. Nobody surveyed us. We had to survey ourselves.

So CMS is like, which, if I were at CMS today and I found that, I'd say, under no oversight whatsoever, in homes being dialysed, they could die, and it would be wrong. We have nothing over that, because we didn't realize we should. We weren't surveyed by anybody.

We were doing it in nursing homes.

DWM: (1:34:14 - 1:34:20)
So Medicare's foot in the bill. So the patient's ordering from you all, and the bill goes to you.

KS: (1:34:20 - 1:36:03)
So they didn't order like I told you. That was just an example that we used for the court case, that you don't even realize what problem you had. If they did what you said they could do, our example was $10,000.

You're giving us the same thing you're giving John Sadler, per patient for PD in Baltimore, you're giving us. And we're managing to put a machine in the house, water treatment in the house, and we're And a caregiver, because John cornered me one time at a meeting, he would never give us a patient. I opened a Baltimore program, he would never give us a patient.

So I saw him at a meeting, and I said, John, we're not killing anybody. I'm sure you have a few patients who would like to do this program, your PD patient. I mean, he was big on PD, your hemopatients.

What's the matter? You can't throw us one bile and give us one patient. You won't be unhappy.

And I'm quite sure you've talked to some of your TC friends who told you it's going fine for their patients. And you'd say, no, no, it's just not right. It's just not right.

It's just not safe. And he said, the financing, I'm just really worried about that. I said, John, don't go too far down that road, because you're getting the same amount of money as I am.

Only I'm paying the caregiver, and I've got a machine in there, and I've got water in there. So it's like the ad today on TV. What's in your pocket versus what's in my pocket?

Come on. And he just shook his head in the hallway and walked away. It was an ASN meeting in the hallway.

But that's what it was. It was the same amount as PD. How did you make that work?

Well, then we were using John, what's his name? The nephrologist who had the, you know what I mean, southern accent from Mississippi.

DWM: (1:36:03 - 1:36:05)
Oh, Bauer. John Bauer.

KS: (1:36:05 - 1:37:32)
He had that supply company. Actually, it was his son. Remember that?

That's who we had a big contract with. He stopped me. Well, I think we were at a network meeting, national network meeting.

And I'm sitting in the room, and he didn't really know me. And they had just said that the Florida Blue Cross Blue Shield had gotten the contract for a demonstration project for something else. And he said, and that stupid Florida, given that contract to that Blue Cross Blue Shield company, just like they allowed that home company to do home dialysis.

And he said, and that's, and he kept saying, and that is the worst thing that ever was. That is the worst thing that ever was. And I thought, you know, there were too many people at this table, big people.

I need to start a fight with John Bauer across the table. And some knew me, some did not know me. So I thought, no, I'm not going to look bad for the company.

I followed him out of that room. And I said, what exactly is the worst thing that ever was? You're making money off every one of those treatments from your supply company.

How can you sit in there and say what you said? Give me a break. He said, who are you?

I said, we can all have opinions, but you know, you've got a little more truth behind it. Come on.

DWM: (1:37:34 - 1:37:55)
So this was a very, it sounds like patients were very engaged with this program. And it was financially viable under the method, too. And then, so why do you think that, was it CMS that really just said, this is all not, this is just unsupervised, and this won't work?

KS: (1:37:55 - 1:39:12)
They didn't say that. They didn't want to admit that. So that wasn't going to be any big in their life.

They just eliminated method two, and we would fall apart. We saw this coming for years. And so the company, and I didn't much like this.

I didn't have much to do with it. But they started, they turned the company around, OK, sounds familiar, turned it around to be an infusion company. Because it's sort of an infusion.

We're not putting things in, but we're putting needles in. So we bought some infusion companies. It was big then, home infusion.

I don't even know if that's still a big market now for x, y, and z things. All the different kind of things. So all of a sudden, these nurses who had built this business have these other nitwit nurses, who all they know how to do is IVs, come in and manage the new company.

Because dialysis was still going to be part of it, but obviously it was going to be less for the private pay patients. And we did have private pay patients. And they could continue to use their insurance.

So they were like falling, again, my folks were falling away like flies. I don't know how many cities I opened. Probably six or eight of them.

So they were all gone. What did the patients do? They had to go, you tell me how they had to go back and say.

DWM: (1:39:12 - 1:39:18)
I know, they've had this home with assistants, dialysis. They have to go back.

KS: (1:39:18 - 1:46:46)
And the stories, so what I learned from that program, this is another conversation, compared to all the yap about home dialysis today, I am very opinionated. Not everybody wants to hear it. Look, the Home Alliance got a bill, got a legislator two years ago to request another GAO study on home dialysis.

It was the Washington folks and a Washington rep, Washington state, to get that in there to request the GAO study, which was supposed to be out by now. And it's not really yet, but it's close to being ready. And so I thought, OK, great.

We'll see what yet another study from the GAO on dialysis has to say. And the guy from GAO, he's done all the EPO studies for GAO. My ex-husband used to be a GAO, so I know well.

We've had many a meeting over different studies. So he came. I set up a meeting at one of our training centers last spring, a year ago, May.

He comes in with his team. And he has this one piece of paper and he's saying, and they're going to interview a patient. They're going to spend a good bit of time there.

We sit down in the conference room. And he says, well, the first thing I would like to know is, and he holds this piece of paper and he says, does this mean anything to you? I almost, I need to hear this.

So here's this graph. I hope, I'm hoping that that graph is in this report when it comes out. So here's this graph.

And it's a home dialysis graph, patients at home. 1986-ish, 91, nothing like it, way like this. The rest of the noise of home dialysis is here.

And here's 86 to 91, and then the drop off. And he said, nobody knows what this is. I said, honey, that is my life in front of you right there.

He said, what? And I said, from 86 to 91, 92, I know exactly what that was. This has been tested and proven, how to get patients home.

So I told him the story of home intensive care. And I said, go back and look. There have been two other studies about home dialysis, and the early one on paid aid.

The Orkand one was not GAO, but the original one was GAO. I said, we know what it takes to get people home. Somebody to take care of them.

And the country can't afford it. So if that chart is not in that, and a little bit of history of home intensive care, or staff-assisted home dialysis is what we call it. So I did get a degree in nursing management, and I used the PD training program, because we ended up doing that with dialysis, because some of the patients wanted to transition to PD.

They didn't need a helper, but we still did the PD. So I wrote the manual for all that, and the marketing. Or I might have used the other one, which was nursing home marketing for home hemo.

And then there wasn't a next stage machine then, so I wasn't using it. One of the others I submitted. I had taken all the classes, and then I just couldn't get around to writing a paper.

And I had this assistant, and she kept saying, Kathleen, it's been like a year since you've been taking any classes. And I said, it's been a year and a half. And she said, I called them, and he said, if you ever turn that paper in, you'd still get your degree.

You're probably closer to this guy. I don't even know his name. So she came to me, and she said, look at these.

Pick one. Either one. You did both of these.

All I did was type it, and we had some graphics and stuff. Oh, there was another one. We did a prison program.

And then we started marketing in jails and anywhere. We started marketing anywhere. And so for the booths, we made this.

So this became a nationwide thing. We put any place they called home, we'd go. And they would crack up.

But particularly jails that only have them for a short period of time. Like we had a patient who worked at National Airport, and he ran over, and he did the luggage cart. So anyway, she just took one of them and sent it in.

But the prison thing was really interesting. One of our offices, Home Intensive Care, gets a phone call from a jail. It says, wait a minute.

So you do dialysis. This guy's only going to be here a few days. Can you come over?

Can we do that? So all of a sudden, it's a buzz across the country that that's another thing that we could get involved in. That would be better than schlepping them with guards, which I lived through quite a bit at that Woodbridge facility.

That would be much better. So we got all excited about that. And I thought, let them flitter around with jails.

I'm going to the federal government. I'm going to get some big contracts in, all right. So I go and phone a call to the Assistant Surgeon General in charge of, not dialysis, but what was it?

In charge of the federal prisons with hospitals. So I go down. I have two weeks.

I have an appointment with him. I go in. I sit down.

Turns out, funny story, do you have time for this? When I was working in the inner city unit and pregnant with my daughter, she says to me, this doctor that used to round, she didn't admit patients, but she would round. She says to me, well, I said I'm going to need a pediatrician.

I'm about to have this baby. I guess I better think about a pediatrician. She said, well, bring the baby to me.

I said, why would I bring the baby to you? It comes with rounding in an adult dialysis unit. And she said, I'm a pediatrician.

I said, then what the hell are you doing here? She said, I'm a pediatric neurologist. I'm making rounds for my girlfriend.

One of the Georgetown guys was a friend of hers. She ends up being Surgeon General of the United States, just so you know, for real. So I said, OK, I'll bring the baby to you.

So that's why she was two years old, and I took her to her. And she listened to her heart. And she said, bring my daughter to Georgetown right away.

What? She said, maybe a little VSD. I'm driving home, VSD.

What is that? I was trying to remember what it was. Anyway, so she was then moving up.

She wasn't Surgeon General yet, but she was moving up. So I started talking, anything to get a contract. So I say to him, do you know Tony?

I forget her last name. And he said, oh, I've known her for a long time. I said, oh, yeah, well, I've known her for a long time, too.

Blah, blah, blah, blah, blah. I said, she can vouch. She's a nephrologist, and he knew that.

So it turns out he had already donated kidneys from his dead wife, I think it was. And so we just bonded immediately. And he ended up being Surgeon General.

So within two weeks, I had a contract for the Federal Women's Prison in Cincinnati. And I had opened an office in Cincinnati. And I really liked the nurse that I hired there.

So we did women. We dialyzed women in that prison. But we did the Baltimore down the underground.

And they only see the light of day for an hour. We did that. So that was part of the thing that I think I got my degree on.

I don't remember which one it was, where we did the photos and everything about this prison system. You name it, where they do dialysis, I've been there at least for a few minutes. It's cool.

DWM: (1:46:47 - 1:46:56)
It's cool. And it makes sense, right? That's interesting.

So when that all closed down in 1992, what did you do?

KS: (1:46:58 - 1:47:11)
I got a phone call from the folks who manage A&&A. No, I didn't. Here's what I did.

I thought, I don't need a coach, but I'm going to do it. So my grandmother.

DWM: (1:47:11 - 1:47:16)
Did that warn you out? Had that whole process of the legal battle and all that, did it warn you out?

KS: (1:47:17 - 1:56:51)
No, I enjoyed the legal battle. I sat through every minute. Well, by the way, OK, so we won that case.

We won that case. We did not do anything that the book didn't allow. So we go back to work.

But then we realized we were going to have to do something else, so that's when the infusion thing started. We called it the confusion people. And the folks at the corporate level were changing, too.

And there was no reason for me to go anywhere. I still had things to do. But I thought, this is really shifting quite a bit.

So next thing you know, we find out that NMC bought the company. Because here was the deal. Gus Hampers could not kill us.

Tried every way possible. And after the court case, didn't kill us. He bought us.

And I knew that, so we won the first case. Let's back up a second. We won that first case.

The HCFA appealed. So the appellate court determined that, are you ready for this? The judge in the first case, no, that's federal court.

It's not like you pick which court you're going to. He didn't have jurisdiction over this issue. How could that be our fault?

If you put the wrong man in the chair, what's that got to do with us? I don't understand that to this day. Every now and then I mention it to a lawyer.

So the determination of that was, we owed the government $15 million. So next thing you know, I go on my annual vacation to Florida with my nephrology nurses, Nancy Sharpe, one of them. And I get the phone call, Nancy was with me, I get a phone call saying that NMC just bought the company.

I can't freaking believe this. They bought the company. So funny thing I said to myself and myself only, Gus couldn't kill us, so he bought us.

There's no way he agreed to pay that government $15 million. There was a deal done. He must have done a deal with the government and got it lowered.

And once it was lowered to where he thought he could do, he'd buy us. That's exactly what happened. So after I have this job and I meet people every now and then I meet people and something would come up like that.

They'd say, oh yeah, I did that deal. I've been waiting for you for years. So I would tell them what I just told you, that part.

So is that the deal we're talking about? Just tell me, because I've been waiting for years to know what it got down to. So he bought us and killed us.

I knew he couldn't sleep at night wondering that he'd, that he didn't find a loophole in law or reg that this upstart doc in Florida found. I'm sure he kept him up at night. So I got a phone call from Jeff Sweat, funny thing.

Jeff had been the regional administrator of the DC metro area, NMC, which by that time was huge. And he was the regional administrator when I was doing home intensive care and apparently closing entire shifts. When I think about it now, can you imagine if something like that was out there?

Doing that? Oh my God. Huge, no wonder, people didn't talk to me for years.

Anyway, my grandmother died right at the time that NMC was, that we were going to, NMC was buying them. Jeff had called me a few times and said, I think Ernie, and I knew Ernie. Not from Northern Virginia, but once I was in the DC unit, I saw her a number of times.

And when there were issues toward the end when I was leaving, I was dealing with her with the folks here. And she had me pretty well covered. But I said, if the folks here feel like I need to go, Ernie, don't make it that I have to stay because I don't feel that way.

I just went through this thing with my daughter. I don't really care that much anyway. Of course, she didn't know I was going to end up going over to a competing company, another unit.

But anyway, she held up her end of that bargain because of the information I had given her. She appreciated that, so she let me know. But anyway, so I thought, well, maybe she's thinking back to the old days, and maybe he's right that she might want me for three or six months.

And if she just wanted me for that, for the close-out and answer questions about certain things, I would consider that. I didn't think they'd offer me a job, and I didn't think I wanted a job. But anyway, we're going to Israel, the whole family.

So I'll call you when I get back, Jeff. So off I went. And when I came back, he said something like, well, I don't know, I'll call you or whatever.

And I thought, I don't even care. So the ANNA folks, the folks who manage the ANNA group, and I had been very active in ANNA, and I'd been on the board of directors, and I got to know the guy who was the owner of the company that managed many nursing organizations and started out in publishing nursing journals. But anyway, so I knew Tony for years and all that.

So I go off to Israel, and it was springtime. So here is the ANNA meeting with no booth, because we had just got bought by, so nothing was going to happen there, so it was an empty booth. And there was this big drew-ha-ha flare-up with the nurse who was assuming the presidency, having a huge fit with one of my colleagues, a former president of ANNA, who for the last couple of years had been lobbying for a company called Nursing Economics.

Nursing Economics was a journal published by the guy who manages ANNA. He started out as a publisher, realized he could do more for the nursing organizations besides just publish their journal, and ended up doing management for all kinds of nursing organizations. So he's totally plugged in with just about everything in nursing and health care.

And he's in Jersey, so Tony I've known for years. So here's this meeting going on. Everybody sees an empty booth that would have been Kathy Smith's booth.

And then she's somewhere, and she doesn't have a job or a company anymore, so I'm all having a great time. And the president did not like this nurse who was working now. Tony had decided that the one service he wasn't offering nursing groups was representation in D.C. And ANNA is so bland in representing nurses, and it's practically really just only a union, so there really isn't a good voice for the specialty nurses. So he thought that was a good avenue for him to add to all his organizations and maybe bring in some new organizations if they realized that he could do government affairs. So he called the Office of Nursing Economics, like his journal, because he thought that made sense. So he hired this previous past president of ANNA that he'd been close to for years, and she moved to D.C. and was doing lobbying. And I knew she was, and I would see her and have lunch with her and all that, and she'd love that job, and blah, blah, blah. Cool. So while I'm gone, the president pitches a fit and says, I'm not taking the gavel, the new gavel in becoming president if you don't get rid of her in that job because I don't like her.

So they said, okay, we're not going to fire you. They told her, we're not going to fire you. You've got the other nursing clients.

And when Kathy comes back from this trip, we'll see what she has in mind. So I came back to her job. So it was in D.C. It was representing ANNA. So I knew what their issues were. I'd worked on state issues for them, just because things would come up. So I said, that sounds good.

Go to an office like normal people in Washington. That would be cool. So that's what I did.

I got into a Hopkins program in health policy and management, started doing that, and then my friend and colleague Carmela, who was working with me, says, well, just so you know, I'm not going to stay but a few months. She was going when the two major insurance associations merged. She was going with them.

And managed care was just coming online, managed care plans, and she's been there ever since. It was a good move for her.

DWM: (1:56:52 - 1:56:53)
And about what year was this?

KS: (1:56:53 - 2:05:31)
So this was in 93. And I came home to her job. So I said, I know ANNA's issues.

I've dealt with boards of nursing across the country, dealt with state issues with how intensive care, various things would come up. And I had, since 84, when Nancy Sharpe, who you will interview, was president, and Carmela, the woman who I was going to be starting to work with as she moved on, she was right behind her, right after Nancy as president. So that's how we all got to know Carmela really well.

We had done, starting in 84, when Nancy was president of ANNA, you'll hear about this, she felt that there needed to be a government affairs committee within ANNA and pay attention because we were all about regulated. So she wanted her two best friends in D.C. to help her make this happen, to have a committee. Here she was president.

But she and my friend Julie and I, the Florida vacationers, we sat on Julie's floor and wrote a position statement on the policy issues of the day for ANNA, for nephrology nurses to stand behind. We took a position against closed units and all kinds of whatever the mess was at that point in time. We thought through it and thought that this should be what nephrology nurses thought was best.

So as a volunteer from 84 on, I got increasingly more involved in that committee and what ANNA did. So stepping back into it, I didn't have time for that during the home intensive care days, but then when I went to that business full time, I had written lots of ANNA's position statements and other things, so a lot of them didn't know, a lot of the membership did not know that about me, even the board didn't, because I'd spent like seven years, I'm not quite that many years, but a good number of years at home intensive care, which was this renegade, crazy, not quite legit business. So some of the board had to really, I'd say in an A, they'd know me.

Well, the board didn't necessarily, so we got past that. And then I took on other, then when Carmela left, I had other clients. So I had orthopedic nursing.

So it's another aspect of this nephrology nurse's career, like orthopedic nursing, pediatric nursing, which after one of my daughter's pediatricians put her on erythromycin, I was out of town, put her on erythromycin for some, I don't know what she had, and she ended up leaving all over the place, because she was on Coumadin for a metal heart valve, and I kept telling the, what do you call it, not the publisher, the editor of the Pediatric Nursing Journal was on the faculty at George Mason University, another university where I took courses, and we sort of became friendly when we were both working under the genetic umbrella of the nursing company, and I said, you know, there really should be more stuff in the pediatric literature about kids on Coumadin and what drugs, because if you're not a pediatrician or whatever, you might not know that. Here was a pediatrician who didn't know that.

And I actually was at a meeting in Utah when this happened, and I had to fly home abruptly. She got an article in real quick after that. But anyway, so that was just sort of a whole lot of fun, and I took on a number of associations that they already had, and then I thought, I might probably grow this a little bit.

So I brought Natko in, the transplant coordinator group, and I brought in the big contract that Tony said, no, don't go there. I know he was very close with the executive director of the Oncology Nursing Society. Big money, they have big money, because the drug companies.

I mean, I'd never seen a nursing organization that had that kind of money. And he said, no, don't bother with parole. If she wanted anything from me, she'd let me know.

We've been friends for years, blah, blah, blah. I ended up at lunch with a friend, and a friend of Pearl's was in town for some meeting, and she said, oh, Pearl's going to join us. And I thought, this is swell.

But she was sitting right across from me, and I said, did you fill that position yet for government affairs? She said no. And she knew I was working for Tony, and we talked about Tony, and then I said, well, good, I'm glad you didn't, because I think you should hire me to do it.

And it was. So anyway, I took it, and we had such a great time. It was wonderful working with them, too.

I think I was up to like seven or eight clients. So that was five years that I was doing that. And going up on the Hill, going to CMS, all these various associations.

There's the big, the physician, the Stark Law, the Stark Law regs were written. And I thought, oh, I know this is big for a lot of these doctors, particularly the oncology nurses that worked. The infusion centers are really part of the, it's very, well, here's the thing.

I had to make corollaries to something I knew. So the rule came out, and I went right to the rule, and I saw who the staff person was for the rule. Her name was Sensimer, something Sensimer, strange name.

I called the number, and I'll be damned if she didn't pick up the phone. And I said, here's the deal. I'm representing the Oncology Nursing Society.

They need to understand this rule. I need to understand this rule. And here's my deal.

My background is in ESRD. So if you have any friends who know ESRD or whatever, I mean, I'm all over that, and somehow I have to translate that to this. She said, honey, I did a little bit of a stint in ESRD.

If you know ESRD, you know Medicare. She said, I'm going to come to your office. She worked at Baltimore.

I'm going to come to your office, and we're going to have a meeting, and you're going to understand this rule. She did. So after we did that, Joanne Sensimer was her name.

So after we did that, I said, for the benefit of my client, I want to have a meeting, because this is huge, and the docs are all going nuts. And there were a few doc organizations in oncology. And I said, I would like to host on behalf of my client, to have the nurses host the meeting about this rule coming from the nursing group.

And she said, you just let me know when it is. So I convened this meeting with all these doc groups, and the Oncology Nursing Society was there with their staff, and she acted like she was my best friend forever. I learned a lot from that experience in going through that rule.

So after five years of that, I loved it. I went through, as far as my education, I went through the Hopkins courses, and by this time, I was married again and had another baby. And I had, like, 16.

They only let you, you can only take 16 credits without matriculating. But I was doing a straight A's, and I thought, there was one more course I wanted to take, but it would throw me over to 17. Is that legit?

Can I take that course, and even though I'll be over one? Yes. So I did that.

I had the baby. I went back to the program and looked. And I thought, what was I thinking?

I called them and I said, I'm looking at this brochure. I think it's time for me to matriculate, and I'm thinking about doing this program, but it's 70 credits or something. It was way more than usual.

What's a master's usually? 30-some credits? Yeah.

So it's 70. I said, I thought I was in, like, half done, you know. No, no, no, it's 70-whatever-it-is credits.

And I said, why? Well, because when you're finished, you only have, like, a paper to do for your Ph.D. I said, I don't want a Ph.D. And that was it. And so I thought, Hopkins doesn't care about turning out people with master's degrees.

Right. So I thought I was good to that. I never went back.

Well, it didn't sound like you needed it. It was right up the street. I loved it.

The courses were fabulous. I really loved them. And it was right in the middle of Clinton's health care reform.

Couldn't have been better to sit through those classes.

DWM: (2:05:32 - 2:05:32)
Yeah, yeah, yeah.

KS: (2:05:32 - 2:13:09)
Very cool. Very cool. I've been very, very blessed.

So I get this phone call. Somebody tells me-no, a colleague called me and said, National Medical Care is looking for a lobbyist in Washington. And I said, no kidding.

What's going on in there? And I hadn't given it a minute's thought. Even though I still was representing nephrology nursing, so I was staying aware in that space.

And she said, would you prep me for going up for an interview? And I said, yeah. I took her to lunch.

I did that with two people. Told them what I knew about Ben, told them what I thought they should know for the interview. And the one I prepped the most, she came back when we went to lunch again, and she said, well, and I thought maybe it didn't go very well because she could get a little off.

And I said, how did it go? She said, well, I made a decision long ago. I would never work for a man who was shorter than I was.

She was a big woman. So I thought, okay, she would never admit it was a bad interview, so I figured that's what it was. Next thing I know, I get a phone call.

I get a phone call. Would I be interested in going up and interviewing for that position? I burst out laughing.

Are you kidding me? So it was a total lark. I got on the plane.

I didn't make up any questions on the plane. I didn't do anything to prep for an interview. I just thought this was going to be a fun experience.

I don't even know why I went. So I get there, and they hand me the list of, like, six people who were going to be interviewing me for the day. And the whole thing was just a joke.

So I said, okay. And I go in, and the first interview was at Jeff's Web, who was the regional administrator. And he knew me and I knew him, but we had never, I was well into home intensive care or even whatever I was doing before, maybe the transplant.

I don't know when he came to town, but I didn't have anything to do with NMC anymore, and I really hadn't kept up with the politics or who the players were, except for my friends who were still working. So anyway, we never really knew each other, but I remembered that I had taken a whole morning shift, and probably from more than one unit, whose managers didn't know to call me and tell me I took the whole shift. So anyway, I thought, oh, my God, Jeff's way on this list.

Oh, Lord. So I go in, sit down, and I'm like, hi, Jeff. Hi, Jeff.

So I don't know what he asked me, but at the end, he said, this is kind of funny, isn't it? And I said, yeah, it's more than kind of funny, whatever. We did a little talking about the folks from the D.C. area. And I don't remember how the interview went, but I said, he said, we did have a meeting the other day, and we asked, does anybody know her? Could we share

what we know? And he said, I did speak up and tell him that we crossed paths in Washington.

And I said, okay, that's what I was sort of getting to. So how'd that go? And he said, you want to know the truth?

He said, what do you know about me? And I said, I don't really know anything about her, except for the fact that she didn't get a job done. Because he was hiring somebody to get the bundle passed.

He wanted somebody on the Hill all the time, beating that drum, because he had decided that we needed to do that. And in the meantime, he had taken himself on the road to all the associations that existed in Renal. Probably not pharmas, I'm not sure, but he went to the Renal administrators, and he did more rounds, because he had done some rounds before he hired me, and then after he hired me, he took it on again with the law firm that I was going to be working with and him.

So then he did that again, in good faith. So the first round, because he wasn't always the best with people, so the first round I missed. The second round I didn't miss.

But it was the second planting of seeds and new business, and all those people knew me from the Renal field. Not all of them, I guess. Some who were newer and missed my time didn't know me.

But I knew most of the people that were still involved in various associations. So we did that initial dog and pony show. So I walked in to meet Ben at the end of the day, and he looked up.

He always does more than one thing at a time. And so he had piles on his desk that he was reorganizing, and so he's leaning over his desk, standing up, standing up, doing his piles like this, and he looks up and he says, Oh, I know you. Come here and sit down and tell me how you know me, because I know I know you.

And so I told him a few times that we had crossed paths, and he said, Yeah, yeah, yeah, yeah. So he describes the job. And he's going through all this from this settlement of the case with the government, and I've learned a lot that way.

He said, I really don't know anything about how we get paid or any of that, but I learned a lot. As I described it later, he learned it all by going through the underwear drawer, because what he learned from the case was everything foul that somebody could do. So it's like, I could say backdoor, but I don't know, a little crude.

So that's sort of how he was learning it. So, you know, he said, you know, some people told me. So I said, Have you ever?

You know, that was my exit speech. So I said, So you're familiar with the payment now. You had the company for a while.

He said, Yeah, yeah, I get it, I get it. But, you know, it's going to be just easier if there's one payment. He said, What I've learned is they have all these invitations for fraud.

Not that people should be taking it up, but why even have a system that, you know. So this just makes much more sense. Better for us.

Better to manage. Better for the company. Better for growth.

Better for the products. Blah, blah, blah. He goes, No, no, no.

And I said, Yeah. And he said, Okay, okay. He said, So you think you'd have fun doing that?

You think you could do that? And I said, Well, I'm sure I could have fun with it. It takes a long time to get a bill like that passed.

It's huge. And seven to ten years to get policy like this passed. So, you know, if you think I'm going to do it next year, maybe I'll have a fun year and you'll tell me to leave, but it's not going to happen in a year.

And he said, Well, I've got this attorney in D.C. He said one of our guys, one of our lawyer guys went to school with him, and he's a disability advocate. And everybody knows him. And Ted Kennedy says he's the best thing since Post Hosties.

And so you're going to work with him in his office. He's, you know, and he's going to, you know, lead the charge. Because I want you two to be separate teams.

Separate teams. You're going to wear the white hat. You are not going to go to Capitol Hill the same way that we go and keep the Massachusetts delegation up to snuff on the deal.

And I said, Fine. I'll go to whatever offices I need to go to. So let me get to the door.

That's why I have the job. So we didn't talk details. We didn't talk salary.

We didn't do anything. We get to the door, and he opens the door, and he said, It was really good to see you again. Blah, blah, blah.

And he said, This is going to be a lot of fun. And I said, Oh. Now, I hear myself.

I do not think these things. I hear them when you hear them. And I said, So we're this close.

He's opening his door. Oh, he was telling me he was packing up because he had to go to board meeting. I said, One thing, Ben.

Have you figured out this is not about widgets anymore? Because I'm not from the widget business. I'll be of no use to you there, and that's not where I'm coming from.

And he said, Well, I don't know. You know, Ben? Yeah.

Oh, people tell me all the time. No, I'm getting it. I'm getting it.

It's pretty good. No, I know this is the whole lot part. I don't know a lot about that, but I can.

You know, it's going to work. That was it. That was it.

Should I really do this? But then it was just wonderful because, well, it was more.

DWM: (2:13:09 - 2:13:11)
So who were you working with? Who was the lawyer?

KS: (2:13:11 - 2:14:41)
Well, the attorney is Peter Thomas. And he's with a firm called Powers Piles. What's the middle name?

Sutter and Verbil. Sutter and Verbil. And he's wonderful.

And he's done disability advocacy since he was a teenager. And he did go to school with one of the guys in the law department. He's not there anymore, but he heard what Ben was looking for, and he went in and said, You're describing a friend of mine.

And Ted Kennedy would always say he is the go-to guy for disability. Very highly respected in this field. And he was just great.

He did go with the delegation from Boston who would come quarterly and brief the Massachusetts delegation about the case. I would love to have sat in on those just to get briefed on where the case was because I really had nothing to do with it and didn't need to know anything. But I thought that Ben was correct, that my face was never part of that.

Not that we were only going to the mass delegation to promote the bundle because that wasn't the case. But I didn't even really need to know all of that. But as time went on, I, of course, learned what the key issues were.

And this was the right policy. So I taught him 7 to 10 years. It was exactly 10 years.

From 1998 when I was hired to 2000.

DWM: (2:14:42 - 2:14:47)
To getting the bundle. So are you still convinced the bundle is the right thing?

KS: (2:14:47 - 2:14:54)

Yes. No doubt. Despite how CMS has translated it.

DWM: (2:14:56 - 2:14:57)
The concept is correct.

KS: (2:14:58 - 2:15:30)
Oh yeah, and throw the quality in. So we did that. They would look at us very strangely, Peter and I.

They would say, you've got to be kidding me. Big company. You want one payment?

And you want to get in the pay-for-performance deal? And we said, absolutely. This is a single process we do.

While it's very complicated. Easy model for you guys. You're talking about pay-for-performance all over the place.

You can do it. Who thought they'd make that messy QIP, but whatever.

DWM: (2:15:32 - 2:15:41)
So how has it been being in Washington, being a lobbyist for several decades? What is life like?

KS: (2:15:42 - 2:20:55)
I enjoyed my role in that. A couple of things that you learn. First of all, I'm here with a phone.

There's a corporation up there. So it was very interesting finding the people I needed up there. Developing relationships with them.

Because there wasn't just the bundle. There were innumerable regulatory, everyday, frequently billing-related, not billing itself, but finding the right people who knew. Well, see, I envisioned, I knew getting a law passed was a huge thing.

I also knew it took a long time. So it didn't take all day every day of a long time. It just took, the process takes a long time.

So just working on that was certainly not enough for him to pay me what he's paying me. So I had to scour that, and the real blessing was I got to make all this up. Because there wasn't anybody there who had that scope in their mind to write my job description.

I had to do that myself. I had to determine what I thought the company needed and get it and do it. If I didn't do it, they wouldn't miss it.

If I did do it, they probably wouldn't notice either because it wasn't necessarily headline news, but it was stuff that had to happen. So who gets to do that? I got to do that.

So that was great. But it was all long distance, phone calling. I didn't know very many people up there at that point in time, a few key people, nurses.

But one real gift was Jocelyn Romella in the billing department. How did those people up there even know I had this job? Very few people did.

But she did, and she would call me as a billing person on all kinds of really tedious, remote kind of issues. But she knew what the problem was. She could tell me what the problem was in a way that I could go tell CMS, this is a problem, this is what it is.

So I think of the next, okay, regulatory. Let's talk about how are the surveys going. I had all kinds of connections with the people in the Survey and Cert.

One thing I left out for you was very early on after the regs came out, the woman who had run the DC network went back into CMS. She had come from CMS. She went back to CMS, and she was on the Survey and Cert. So I had a really good friend. She's still there, but she didn't have to be that friendly anymore.

But for a long time I had strong relationships there. And, you know, just one thing after another that I was trying to chase down and make sure we had relationships with. But I didn't know all the folks up there.

But I started with one, and then she would talk to people, and, you know, eventually. And then John Marcus came into the role. So he was on board not too much longer after I was, but completely consumed with the issues of the case initially.

So he knew that he was responsible for me, and he never heard from me, and everything was apparently going okay. And so, I mean, I don't even – it was months before he even rang my phone. And then once he – it was very funny.

It was very funny. The first time he called me – I don't know. I think he might have been there a year.

He called me one day to talk, just to chat or whatever. And he said – I think we had – he had made an appointment call. And he said, sorry, I – I think he was a little late.

He said, I've been dealing with – I'm going to flip after what I've already told you. He said, I'm spending all day on this Part B thing and Method 2 stuff. And I said, are you kidding me?

And he said, no, why? I said, I am the queen of Method 2. You don't even know what you have down here in me.

You should get to know me. I can help you. And he just said, are you kidding me?

And I forget what his question was. It was how to do with the case. And he's, you know, asking me this and this.

I was like, okay, he's educating me. I can't even believe this. He said, nobody up here even knew that in the laws.

We were like this ever since then. But – so that was sort of building a department, a department, long distance, on phones. Email was just coming into being a regular mode of communication.

When I look back on it, I think I should have thought it was challenging. I didn't think of it as challenging at the time. It was just what I was going to have to do.

Because all day, every day, you don't go up there and lobby for something. You've got to wait for the right timing for things. And you have things that have to fall into place.

And you have to plant seeds that take months or years to, you know, come out of the ground.

DWM: (2:20:55 - 2:20:58)
Now you've had this job far longer than you've had any other job.

KS: (2:20:58 - 2:24:43)
Right. Yeah. And once the law was passed, I really did have no desire to continue.

But first of all, lobbyists up there, you have to be 40 and willing to drink every night. And act like you like people that you don't like. And, you know, I was on a mission to educate people as a nurse about dialysis.

And here this is. Very simple and straightforward, while very complicated undercovers. But very simple and straightforward.

Separate part of Medicare law. Blah, blah, blah, blah, blah. Easily measurable.

We've been way ahead. And in all my network work and everything else, part of every step of the quality attempts that CMS has made over the years to measure or look at or collect data on, even from my early forms from the networks coming in, that little bit of job that I had with the networks, you know, just watching all that come together and trying to shape it as you move forward and then going to meetings where they're hinting at we're going to have to start putting some things on claims.

And everybody's saying, no, we can't do that, we can't do that. Doc's going, no, no, no. And I'm thinking, we're pioneers here.

This is good for our industry. Let them have that kind of information. It would be good for patients down the line.

And it's, you know, someday we'll be able to wave that flag and say, you know, we were pioneers on this and this. And then we were. We were the first to report any kind of data on claim forms.

And many of the other things that we've done. So very simple, same thing for me to go to Capitol Hill and say, look, this is dialysis. This is straightforward.

This is an easy one to do. We have a number of measurements that the industry itself has put itself. I can't tell you how many, and maybe you were at some of these meetings where the docs would stand up and when they would start to speak about quality, if only we knew how to define quality.

If only we knew, I guess they wouldn't have said something like the elements, because even in the earliest of days, we'd look at the BUN pre and post, and if it was cut in half, we did good. In half. That's somebody right out of their head, half is enough.

But it was the early struggle for what measurement tells me something about what we're doing. And so that's a part we haven't talked about in my career, but I have had the pleasure or whatever of watching the crudest thoughts and hearing at large meetings, if only we knew this or that. If we had measurements, if we had this, if we had that.

So I watched all that. So I think I brought a lot to the table in educating people on the Hill about the deal of many things. I was dealing with folks who mostly deal with health care, but dealing with health care in general and dealing with dialysis is a little bit more refined.

And so I could explain it, I think, in plain English, and as a nurse, educator, always, we always are, a way of providing the information in a way that you really delivered it. And I'd have to take a few more meetings with those people to realize if I really got it in them or not, you know, really gave it to them or whether they understood it or not, or we had to have another chat. So that part was what was fun about making the soil fertile for, after enough time goes by on Capitol Hill the way it works, that there's enough comfort to say we can do that.

DWM: (2:24:44 - 2:24:52)
So if you look back over all this long career, I mean, from direct patient care, which you stumbled into in the 1970s.

KS: (2:24:52 - 2:24:53)
I had the paper.

DWM: (2:24:53 - 2:25:29)
You had the paper. To this work you do today, I mean, having been from direct patient care, corporate management, to now lobbying for change, slow change in the government, where does your heart lie? And where do you think the most important work is done?

How important is the work you do today compared to the work that patient care takes?

KS: (2:25:29 - 2:26:15)
My mind has never left that room I walked into in 1975. Why? Because that's where the rubber hits the road.

That's what it's all about. That's why we are employed by who we're employed by, and it all comes down to that. At the end of the day, it comes down to what's happening in those units right this minute.

That's the picture in my mind always, always. So when I'm telling that to somebody on Capitol Hill, hopefully because I see a clear picture and I use simple words, I hope that's meaningful or helps them get the word across. And I do explain things.

I'm not good at math at all, but I do reduce English to its simplest terms, like with fractions. Fractions was the only math I could ever do.

DWM: (2:26:15 - 2:26:28)
When you're talking to people in Congress who, I guess many of them, have never stepped foot into a dialysis clinic, do you use stories? Do you talk about patients?

KS: (2:26:29 - 2:29:20)
I do. I do. And, of course, I've taken many to dialysis units.

And, you know, I explain how the kidneys work very simply. I talk about leading causes first because often they'll say somebody in their family has diabetes or I don't want to blurt out that diabetes is the leading cause. He tells me he's diabetic or he doesn't tell me, but I find out he's diabetic, you know, whatever.

So I try and do the kind of things you learn in nursing with regard to communication when I'm dealing with staff. Most of you are dealing with staff, but I've dealt with many a member. Well, for example, I was at a meeting one time with, this was still when we were talking about the bundle, and we were, Ben was here, so we were doing, we were seeing a lot of the mass delegation, but it wasn't about the case.

I think the case might have been settled by then. And one who is still a member, and I was sitting next to him, he was there, he was at the table like this, and I always like to ask, as nurses do, whether the person has any experience with what you're going to talk about. So I said, have you had any experience with dialysis or someone with dialysis in your family?

And his eyes welled up. And I don't know if they noticed, but I noticed, and he said, well, my dad had heart surgery and he had a few dialysis treatments before he died. And I reached over and touched his hand, and it's not in a way that would have been inappropriate to touch a congressperson, and he gave me a little squeeze of appreciation for that.

So, you know, it all goes back to nursing. I mean, it's the human interaction. And so everybody should go to nursing school if you want to learn how to really be with people and help people, no matter what it is that you're helping them with.

In this case, he had a moment. He needed just a little bit of help. And I'm still glad that I asked that question before I launched into assuming he didn't know a thing about it.

I don't think that's the right way to do that. And I don't like to just blurt out, you know, people with high blood pressure and diabetes. I prefer to try and back up on that a little bit.

Even if it's just a quick encounter. You don't have much time. But I always say those kind of things first just to cover my bases before I launch into something.

So I took Senator Cardin's staffer to a facility probably just about a year ago now. We couldn't get—we wanted him on the Senate bill, and we didn't get a Senate sponsor for the bill last year. This year we got it, and Cardin was on it.

And the staffer he sent to the facility—well, I didn't see Cardin, but his staffer was there, and I started off the same meeting at the facility with, do you have any experience? Yes, my dad was on peritoneal dialysis all through my high school.

DWM: (2:29:21 - 2:29:51)
Wow. Good place to start. So we're going to wind up here and finish up, but I want to know if you look to the future, the next 5 to 10, 15 years for kidney disease.

In your position today, the work you do today, what do you think might happen? What would be some of the good things that might happen, the important things that might happen in the next decade for kidney disease?

KS: (2:29:53 - 2:35:33)
I don't know what's on the horizon. You may know better than I what might be on the horizon for them treatment-wise. Certainly I'm not.

I've gone to all the major meetings for the last umpteen years, and I haven't heard of any, so I don't think there's any big secrets about any new magic or anything right now. I do think that we are not—there is no new money, and there is not likely to be any new money for a long time, if ever, probably never, to treat this population and growing population. Although I did read that in—I think it was in the last USRDS was the first time that the annual growth, the number coming in was flat.

I think it was less. It was flat. And I thought—I wasn't sure I'd live to see that.

So that's maybe a good sign. I think the country is—we're going to have—we're struggling already, and we're pretending we're not, I think, to some extent. But we're pretending it's never going to get any better.

It's never going to get any better, unless we can just print money. So it's a costly population, and dollars are limited. So we're either going to have to get more creative, and Nextage is very creative, but they're not going to pay for more than three times a week in most cases.

I'm very surprised that some of those MACs have identified— they're pretty significant diagnoses, not too many people have them, but it's interesting that they came up with some anyway, that they've agreed that they'll pay more for. Hopefully the—maybe they can come up with some equipment that would be as easy as Nextage and still be sufficient therapy. But we don't appear to be there yet.

So I think we're going to struggle. I think it's going to be less money and become—we talk here in the office, is it a commodity or a utility? One or the other.

Pick the right word. It's probably what it's going to look like. So I'm not sure it's always going to be big business, be more bare bones.

Good and safe, but I'm trying to—I drive people crazy with the use of words. There'll be a very detailed letter, and we have to review the letter. And I first—this is a flaw of my own.

I first review the letter because I see the flaws in the English or the punctuation or the choice of words or whatever. We're getting the message across, but I can't help it. It's Catholic school.

So I do all that, then I go back and read it again and just focus on the substance. But whoever drafted the letter always—I'm sure they all hate me because they get the big track changes of my suggestions. But I also think that words matter.

And in a lot of our letters, something minor. You want significant feedback on a letter, and I'm giving you, say, beneficiaries, not patients. You're writing to CMS. These people are not their patients. These people, from the reader, they're responsible for the beneficiaries. Use that. We're only—they're only patients to us when we're treating them.

So we shouldn't throw that around all the time because, you know, we're not— maybe they're not our patients. But so the word I'm worried about now using, and I haven't edited any letters with this yet, but maybe when the rule comes out, I think we should stop referring to ourselves as an industry. I don't think that probably sits well.

Way back in the minds of the people at CMS, this benefit was not designed to create an industry. So even though we can say, well, it is as we view it, we shouldn't paint that picture of it because Medicare wasn't set up, period, to spawn industries. It was to take care of the citizens.

So I think we need to be careful about the words we choose in our conversations with each other and certainly in our written material. So I don't think I've thrown that one out yet. But as I said, we use it a little bit too much.

I think that when we refer to—like KCP letters, for example, we refer to the industry meaning we have everybody at the table. There are other words that we can use. We are a community caring for kidney disease, that kind of thing.

Because I think that we have sent a message that we're big business, and that's not good in the long run. Nobody's listening to that, but I'll keep saying it. That's what I'm worried about.

DWM: (2:35:35 - 2:35:47)
Is there anything we have not talked about that you think is really important that should definitely be part of the oral history? You've covered a lot. You've done a good job.

Oh, thanks.

KS: (2:35:48 - 2:35:51)
You have a very fortunate career, don't you think? I mean, I've stumbled into all of it.

DWM: (2:35:51 - 2:35:54)
Yes, it has been a fascinating journey, for sure.

KS: (2:35:56 - 2:39:06)
And yet, I mean, sometimes I think, oh, I wish I'd been in ICU. I'd like to have those kind of skills back. Because I remember when I got really good at dialysis, I felt so confident.

I had a nurse that I couldn't stand. This woman just—she was fairly early on. Even in that first unit, she came just before we moved to a bigger unit.

And she just didn't like me. Or she had no personality. I couldn't figure out which it was.

And then we moved to the bigger place, and then I became the manager of the whole facility. And one day she was off work, and I forget why we ended up talking on the phone. And then I forget why we got into—I just blurted out, you know, what is it that made us really never get along?

And I couldn't believe she opened up like this. And she said, I was so—and I trained her. She said, I was so afraid in that room.

And you were confident, and the patients loved you, and you joked with them, and you were relaxed. And she said, I just couldn't—I could not do that in that room. Well, she didn't have much personality to start with, to tell you the truth.

But we used to play trivia with the patients and all kinds of games. Like that very first room with the water on the floor that spills all the time. We weren't supposed to have any electronic equipment.

Well, for a long time I had Tuesday, Thursday, Saturday evening shift, and what fun that is. I made sure there was a cord that went far enough without draping on, you know, looping on the floor. And the wobbly tray table, charge nurse setting it up so we could watch.

To name that tune. Yeah, it was really—we were really close to the patients. I hope that still exists.

I visit the facilities around here as often as I can. I take people to visit the facilities. Anybody I—anybody new I meet or who is going to be involved in the business at all, oh, let's go to the dialysis unit.

And I usually take them to the Dupont Circle Unit. I'd like to take you there, actually. It's very unusual architecturally.

I'd like you to see it. It's in a basement. I'd like you to see this basement facility.

But anyway, I don't—I'm not in there long enough to see if there's the kind of banter with the patients. Probably not now because they have their own TV and a thing in their ear. But it's not the same.

We used to play dialysis trivia and we'd make up questions for the patients to know. So what is your BUN supposed to be, you know, and potassium and— and something else about that patient population back then that I used, again, not clinically, but with people that I talked to on the phone and do emails with these days. And that was when the label changed, then the warning was on the label for EPO.

And nothing higher than 10, not to—is that what it was? Yeah, not— Twelve, yeah. Without—how did that actually read?

We shouldn't target for more than 10. They didn't even want to target it at all, right?

DWM: (2:39:06 - 2:39:06)
10 to 11, yeah.

KS: (2:39:08 - 2:42:35)
So I felt very worried for the patients for the following reason. Because I think that the physicians rounding today, most of them today— and I have asked a couple of older docs this. Am I—if I do say this ever when I have to say it, am I supposed to write, the ones rounding today, by and large, have never treated the anemia or renal failure like we did.

I'd get phone calls all weekend long that the labs from the week were 15 and 16, you know, hematocrit. So I think that I didn't know how they were going to deal with that and the patients be okay. But here I am sitting in that office, nothing I can do about that.

Because in our day, we knew those early patients, the very first patients I'm telling you I set my eyes on, we'd set up—I'd set up a deal with them. You tell me, what do you do—what do you do the most that's like exercise? You know, move your body, make you tired.

And for this woman, it was grocery shopping. So if she told me she couldn't get past the third aisle, we knew she was going to need blood that week. I don't think that kind of chat goes on today.

So how would they know? Because you haven't even set the patients up for describing how they feel so that you can have some idea that you need to do something clinically. So I do worry about that with today's changes and wonder.

You know, what we had back then is almost better than what we have now in some respects. Talking to the patient versus waiting on a lab. Yeah.

Really understanding the patient experience. Right. And one, another one, she and her husband liked to do—it was like clog dancing.

And she would tell us on Wednesday. She would know by Wednesday if she was going to be able to do that on Friday night. And she was at Wednesday—Monday, Wednesday, Friday afternoon.

And so she'd let us know so that we could have blood for her on Friday morning. And it wasn't willy-nilly. I mean, it was almost like a scientific thing.

She wouldn't play with it on her end. And this was as much science as she knew. And they can measure themselves better than, you know, a test maybe even.

And we used to do the hematocrits in the units in those days too. So I just think it's been a wonderful field to specialize in. I often think if I specialized in something else, like I would love to be so skilled like a neonatal nurse.

And they put these teeny-tiny hair-sized needles in a scalp, and they actually got it in the vein, and they're just dripping in. I mean, I can't even get over it. But I don't know that that worked.

This is about—so much about life dialysis is, and kidney disease. There's so much more to it, which is probably what's kept my interest, as well as not being stuck in that room the whole time, but being, you know, really— I think I've experienced every aspect of it that you possibly could. I'm really glad I did that.

Those two hard years of transplant.

DWM: (2:42:38 - 2:42:44)
Well, Kathleen, this has been great. It's been wonderful. I really appreciate you taking the time to talk with us for this project.

KS:
Happy to do it.