VOICE EXPEDITION INTERVIEW TRANSCRIPT
The Oral History of Nephrology
Nancy Armistead
Interviewed by Dugan W. Maddux, MD
June 26, 2017

DWM: (0:02 - 1:50)
Well, today is June the 26th, 2017, and I'm here in Richmond, Virginia with Nancy Armstead. Nancy, thank you so much for being a part of the Nephrology Oral History Project.

NA:
Well, thank you for asking me, Dugan.

DWM:
I'm looking forward to talking to you today. So I want to just start at the beginning, like even where you were born and raised and went to school so that we can figure out how you ever got interested or involved in the renal space.

NA:
Okay. I was born in Fairfax County. I lived up there in the Washington, D.C. area and went to Fairfax County High Schools, which were very nice. Did my undergraduate work at Longwood College at the time, which is now Longwood University. And at that time, it was all girls, so it was a strange environment. And after going to Longwood, I got married and came to Richmond and started working for a group called the State Council of Higher Education, and I had been a social studies major and had done a little bit of research work in college, and so they were looking for someone who could do some research for them for a health manpower study. So I did that and eventually ended up in graduate school and eventually ended up in the renal program.

DWM: (0:02 - 1:50)
So let's go back to the State Council of Higher Education. So what was their purpose or job?

NA:
Well, basically, they were sort of looking at the curriculum of all state colleges and community colleges and whatnot at the time. And so they were interested in what the programs were, and they actually had to give certifications for colleges and universities.

DWM:
So it was a certification body?

NA: (1:51 - 1:51)
Yes. Pretty much so.

DWM: (1:51 - 6:02)
And what was your role then?

NA:

Well, the General Assembly had given the State Council money to do a health manpower study.
DWM:
So what does that mean, a health manpower study?

NA:
Well, they were looking to see over the next ten years whether they would have enough dentists in the state, whether they would have enough physicians and nurses, and so there were various components to it. And what they were trying to do is make sure that there were programs that would be sufficient enough to train all of these individuals that they needed. So they hired a health economist who came down from Canada and worked on this. And John Wise needed to have somebody who'd be his little gopher and a research assistant, and so John hired me. And I was assigned mostly working with the dentists. And so we designed some surveys working with the Virginia Dental Association and worked with that group. And I found that working with providers was really interesting to me, and I liked that a lot.

DWM:
So what year would this have been?

NA:
That was 1973 and 74 probably, so it was just for one year.

DWM:
And do you recall at all sort of what the state of health care providers sort of was at that time in Virginia?

NA:
Well, people had concerns about whether or not, particularly since my area was in the dentist, whether there'd be enough dentists in the state and what those practices would actually look like, you know, and how many dental hygienists were going to be used. because I think back in that day, there weren't very many dental hygienists. You may recall the dentist actually came in and cleaned your teeth when you went, and it wasn't the dental hygienist. So it was an evolving change, just like nephrology changed, and having so many nurses and technicians and stuff. So they were going through some changes with that. So I stayed there for a year.

DWM:
And you liked working with the providers. What kind of contact did you have with providers and what did you like about it?

NA:
We worked with the Virginia Dental Association. And so we had task forces, and we would get a group of dentists together and use them as a focus group and get their opinions about things. And I just found that very interesting to do that kind of work, and then to be able to do policy work with these individuals and sort of take some of their ideas and take them on

up to the State Council of Higher Education and sort of translate that into a language that maybe the state could understand. So that was kind of fun.

DWM:
Very interesting. So you were there a year?

NA:
I was there a year, and it was probably about 15 months, really, because we completed the study and submitted it. And I don't know that I ever tracked it very much after that. But then I moved over to Virginia Regional Medical Program. And the Virginia Regional Medical Program was a federal program that really came into existence probably after the Medicare regulations or the regulations were put into place for Medicare. And they were tasked with looking at heart, stroke, and cancer. And this was in 1974 or five, they were tasked with looking at kidney. And so...

DWM:
And what, when you say tasked with looking at kidney,

NA:
Well, they were trying to figure out what was going on in healthcare and try to, they were funding programs to help prevention and education. They were basically the forerunner of the peer review organizations.

DWM:
So make that all come together for me. So they were interested in prevention and education.

NA:
They were giving grants. They were giving grants to universities. They were giving grants to associations. I can't even remember, Dugan, but there were probably some cardiovascular studies that were funded through MCV. They were doing prevention work. So they were putting on workshops probably for nurses and that type of thing.

DWM: (6:03 - 7:09)
Okay. And how did that sort of dovetail into peer review?

NA:
It was working with the physicians and eventually legislation was passed on Capitol Hill that did away with the regional medical programs and then separated it out so that they had health service agencies who were supposed to do the planning. And then they had professional review organizations who were supposed to do the implementation of the plans. Now, the funding for implementation didn't really ever come about, but they did do a lot of peer review so that making sure that Medicare beneficiaries who were in the hospital needed to be there, the length of stay, those kinds of reviews. But when I came to RMP, they were at that time assigned kidney. And again, it was probably because the enabling legislation came in about 72 and about 74 was when they really started to promulgate

regulations. And I worked with a group of nephrologists, really nobody else in the organization wanted to work with these kidney doctors.

DWM: (7:09 - 7:11)
So why were you willing to do that?

NA: (7:11 - 10:37)
I wasn't necessarily willing to do it, but I was low man on the totem pole and I was the newest hire. And so a dentist with the organization came in and said to me, here, you're gonna staff this committee and here's the information and go work with them.

DWM:
And why were people like a little hesitant to work with the nephrologist?

[Speaker 2]
I think they just didn't know anything about dialysis. It was a very new program. They didn't know any of these people and it didn't have the sort of sex appeal that working with cardiologists had. And so it was just, and everybody was probably overwhelmed with the work that they were doing. And like I said, I was sort of low man on the totem pole. And I remember the first time sitting in on a meeting and I was a little aggravated because I thought the guy who had assigned this to me was really making big bucks and I thought, well, you know, that's his job. Why am I doing his job? And after about a half an hour, I thought, well, this is pretty interesting stuff. And these are pretty interesting people. And they were all Virginia nephrologists, Fred Westerfeld, Dwayne Wombold, Norman Sporn. I think there was a transplant surgeon, Les Rudolph from UVA. And this was shortly, I guess, after David Hume had passed away. So that was a big topic of conversation among the group.

DWM:
Yeah, so let's talk about all this group just a minute too. So first off, what year would this have been?

NA:
This was probably 74, 75. Okay. And these are some, I wanna talk, one of the things that, You know, I think this interview process is about, this project is about, is to talk about people that have lost. We've lost, like David Hume, who were, you know, obviously really important in early renal care. And so I like for people who were involved in knowing about the work of these people to talk about that. So if you could just talk a little bit about some of the, Fred Westerfeld, Dwayne Wombold, these are names that we've all certainly heard. And also then what you remember, they, was the impact of sort of David Hume's legacy at that time.

Well, I guess Jean Pierce was in that group too, because Jean Pierce was, had worked for David Hume. And Jean was set up Southeastern Organ Procurement Foundation. And Bill Stacy, who was at the VA, was a nephrologist there. So these were people that all knew David Hume. And they just felt the loss of his expertise very significantly, I think, because

they would spend a lot of time talking about what was gonna happen to the transplant program and what was gonna happen to the renal program, because he was apparently a very forceful and dynamic leader, and who had a very tragic end, you know, from what I was told.

DWM:
What happened then that you recall?

NA:
I had heard that, well, he was in California, I believe. And I had heard the story that he was told, he was a private pilot. And I heard that he was told that the weather was too bad for him to fly out. But he apparently didn't follow that advice. Now, I don't know if this is true or not, but he did fly out and he crashed his plane and was killed, so.

DWM: (10:38 - 10:44)
And he had started transplant, were they concerned that they would lose momentum?

NA: (10:45 - 13:30)
I think that, yes, they were concerned that they would lose their program, that they had this dynamic leader who has, you know, had a good national reputation. And I think they recognized that it was gonna be a competitive field. Everybody's gonna be vying for, you know, the patients and the glory of all this with transplant and stuff. And that it was very significant to them that they had, you know, lost him, so.

DWM:
So what do you remember about this early? So you said one half hour into it, you thought this was very interesting. What in the world happened that made you excited about it?

NA:
Well, they decided that they wanted to do a survey of all the dialysis programs. And they didn't really have a whole lot of information about, you know, what they wanted to collect and stuff. And that was really an area that I had some experience in, because I had done some surveys and stuff. And so I just thought it was fascinating to sort of see how their minds were working about what information would they need to collect and how they would collect it and then how they were gonna display it and what they were gonna do with that information. And I think it was just sort of getting an inventory at that time. And as I recall, there were probably only about 15 programs back then. And most of the people that were sort of involved in those programs were represented on this renal advisory committee that, you know, was that regional medical program. They, I think, nephrologists are sort of a unique breed. I think one of the things that I found with this group is that they had the medical background, but they also had almost an engineering background. They really did understand the technical aspects of how everything worked. And I thought that was pretty interesting, that they knew they were doing something some real groundbreaking work. They knew that their work was bringing a quality of life to patients that they wouldn't otherwise have. And I just think it was their level of commitment and their passion about the work that I really appreciated. And they were just interesting personalities. The

dynamic between the various people and stuff with the various programs and whatnot, and the sharing of information about things. It was really kind of interesting to me.

DWM:
Yeah, let's talk about that a minute because I think this was a small group of people really doing dialysis in the mid-1970s. So was there a lot of sharing of information? And what kind of information were they sharing? Were they ever protective about their little part of it? Or were they much more open in trying to share?

NA:
I always felt they were very open. The conversations always seemed to me that they were always willing to share about their reverse osmosis machines and their baths that they used and how they were managing patients and stuff. They seemed to have a lot of conversation about that. You know, when we weren't talking about what the survey results were and stuff. I don't think, and I could be wrong, but I don't think they had the idea that this program was going to grow to the magnitude that it did. So there weren't many facilities that were being opened at the time. And so I think it was a lot of discussion about how do you actually manage the people that were coming into your program? And what kind of staff do you use in your programs and stuff? There was a situation at Richmond Memorial that became kind of tragic. And a number of patients died as a result of some mistakes that were made. And so Richmond Memorial decided that they would only use RNs in their units and they got rid of all their techs. So there were discussions about that, you know, whether techs could do the kind of work that needed to be done or whether you wanted to have RNs do the work.

DWM:
Do you remember sort of what that event was and why that would have led them to be more RN-focused and less tech-focused?

NA:
I think that what happened is a tech actually put a patient on incorrectly. And so the venous and artery were reversed. And basically the patient died as a result of that. And it was human error. And it happens, but I think that it just sort of scared everybody. And there were, you know, there were a number of situations over there. And I'm sure you could recall them too. But, you know, chlorine getting in the water and things. And so those were kind of sad things that just, you know, happened. And sometimes you couldn't really prevent it with the systems that were being used at the time. So there were system issues where it's just really hard to control and to standardize.
DWM:
Do you remember in those early days then when you first started working with the group, any of the, you said they were sort of, had personalities and all that. Do you remember, how important were the personalities? And were there some people that were more persuasive than others in trying to influence what happened?

NA:

Yeah, I think clearly there were. Fred Westerfeld was very influential. He was sort of the designated leader of the group. And he became my mentor for many years.

DWM:
And what made him influential in the leader? What was it about him?

NA:
Well, he's smart. He's a very smart guy. And I think he just has some natural leadership skills in people. And he had some interest in sort of bringing the group together and sort of working with the feds and whatnot. And that was another thing as the program sort of advanced a little bit. And we found that the federal government really didn't know what to do with the program. And they had to rely on people like these leaders because they had to have regulations and they didn't understand the program. And they had to have survey and certification requirements. And they had to know who the players were and what needed to be done. And without having any of that expertise, it was a natural that they would go to people who had an interest in this. And I guess one of the reasons, I mean, we're so close to the Washington area that we sort of tapped, we were tapped into some of this. And so Fred was interested in that. And Bill Stacy, who was at the VA, was involved in his leadership with the VA and stuff. So I think it's just, some people are just natural leaders. So it was an interesting group. The story that I do have about, there was a doc down in the Tidewater area, John Setter, who was just a really wonderful guy. And he was associated with the Portsmouth Naval Hospital down there. Eventually, I think started his own dialysis unit. I can't recall about that. But John would come and had the same thing on every time, a white shirt and black pants. And he said, that's all he had in his wardrobe because he didn't want to think about changing clothes or what to wear. And I thought about this when Mark Zuckerman did an interview recently. And apparently he has grey t-shirts and jeans. And he just doesn't want to think about the mundane things about what to wear every day. And it made me think about John Setter because that was sort of his philosophy of things. So it was kind of fun. So there was a lot of competition. And I suspect there still is between MCV and UVA at the time. UVA had an up-and-coming transplant program. And the transplant program at MCV, they're vying for the same patients and stuff. So there was some competition among these guys. But I didn't really feel that very keenly. I felt like they were all on the same page pretty much.

DWM:
So you're brand new and are sitting in this meeting. And so how did it all unfold with the survey and the plan?
NA:
Well, we finished the survey. And it was like all surveys for the next 40 years. It was like pulling teeth trying to get people to complete them. I don't think some things ever change. But we got all the data in. And I remember trying to talk to people and explain to them why we needed this information. And there was really, we didn't handle the information in any kind of confidential way. We would get information and just, it never occurred to us that this should be confidential. And I don't think we were thinking along those lines. So we put together a program, I mean, a booklet called The Renal Program of Virginia First Edition. And it had a listing of all the dialysis centers and the number of patients they had and the

number of shifts they ran. I think we even had a listing of the staff, maybe had nurses and that type of thing. So the regional medical program paid for that publication. And I don't, we gave it to the state. We were mostly interested in making sure the state knew. Because at that time, then they were thinking about certificate of public need and what they were gonna need. So we did a second edition. And around that time was when the government decided that they would do away with regional medical programs. It was about 75. And that they would do this breakdown between health service agencies and PSROs. And so the guys were sort of sad to see their little group break up. They didn't really like that. And so somebody, I don't remember who, but somebody went to the Virginia General Assembly and said, we need a state program. And it needs to be housed in the health department. And because there were several states that did have state kidney programs. And I think they got a little bit of money for it. But I can't really recall. But I, and I probably, it was Fred who probably went over there and did the lobbying for it. But they did get the state health department to take it on. And so I moved over to the state health department. So I don't even think I was a state employee. I think I was hired in as a sort of a temporary position or something. And at that time, the state was really gearing up with Certificate of Need. And they knew that they were going to have these renal programs coming in. So again, I sort of got dumped with this, doing the Certificate of Need work. And I remember feeling really overwhelmed having any information about how to do this. And there was no way of assessing. We had, I mean, we hadn't even thought about assessing need. And so we started thinking about, you know, with this group again, we sort of kept them intact. And we started to develop some criteria for things like how far should a patient travel to receive dialysis? You know, should it be 20 miles? Should it be 120 miles? What was the minimum utilization rate? You know, how many patients could one machine take care of? You know, at the time, people were, I think, trying to get patients to dialyze a little bit longer than they were, than they are today. And so, you know, you could, could you run two shifts three days a week or, you know, so doing all those calculations about, for need assessment and crunching those numbers and sort of saying, okay, you do or don't need this. And what the staff would do would be to make recommendations. And there were local health service agencies that would make the initial recommendation and then it would come to the state. And the state would make the final recommendation about whether or not to approve a new facility. And most of the, most of the certificate of need work up to that point had been hospitals and nursing homes. And basically what it was designed to do was to look at the big ticket items so that you didn't have two big programs in the same community or two, you know, MRIs, you know, in the same community and stuff. So the renal stuff sort of, just sort of came in. And the first really big program that I worked on was a center that Ed Baer, who was a nephrologist at the VA, wanted to open a dialysis center in Gloucester. And so his was, his was the first real program that came through the certificate of need. And I remember a lot of people thinking, thinking at the time that this would not get approved, that the state was not going to allow new dialysis centers. And it was very clear that there needed to be a dialysis center in that area. I mean, we knew that there were patients in that area. They were traveling down to Newport News or coming up to Richmond. And so Ed's center was approved and it sort of opened the door for a lot of other people to start coming in. So I stayed there and did that kind of work. I don't think I did anything but renal for the whole time I was there. And we were still having committee meetings, you know, and talking about

this criteria and stuff. And by that time, around 75 or 76, we started getting wind that the feds were going to fund these network coordinating councils. Yeah, let me just ask you then, just stepping back to the certificate of need, you mentioned that, so the 75, 76, when you're working in this group, that you kept that physician group intact who had been sort of the renal advisory committee.

DWM:
So how, when they were developing this criteria, which sort of makes sense, like how far do patients have to travel and that kind of thing, were the physicians really influential in developing these criteria? And then did the local and state people really rely on the criteria? How much of it became sort of the government deciding what they wanted versus really being influenced by the providers? No, I think the providers were instrumental in this. I mean, I don't think that these localities understood this program.

NA:
They didn't have any expertise. There were very few people who really did at the time. And so I think they wanted to have sort of an arm's length. I mean, I think that they were, I'm sure that the certificate of need people that I worked with really didn't want to hand it all over to the provider community. But it was being vetted by the people that I worked with. And it made sense. I mean, it wasn't that they were coming with these harebrained schemes about criteria. This was all very logical and very sound kind of advice that was coming from these guys. Because I think these were the real issues that they were having to deal with. And think about. And so they were very conscientious about their charges. I never felt, at that time anyway, that there was a lot of self-serving stuff. I mean, I think they were really interested in coming up with sound guidelines that could be followed down the road. And I think that's what we did.

DWM:
So with certificate of need, because you're going to move away and talk about networks, because that's where you went. But do you recall sort of what happened with certificate of need for renal, for dialysis facilities?

NA:
Yeah, and it does sort of fall into the networks. Because that's what the networks did in the early years, is they provided the data for the certificate of need program all over the country. And so when the networks came into existence, I think a lot of people left these state programs. There were a lot of people like me who were working in various state health departments. And they left to work at the networks.

DWM:
So how did the network concept ever come about?

NA:
Well, in the original enabling legislation, there was a clause, as I recall, that said that there should be some peer review. And that there would be medical review boards. I don't think they called them medical review boards. But there was the concept that there would be a

group of local people who would come together to sort of look at the quality, look at folk rehab. And so, as I recall, it was the National Kidney Foundation came up with a position paper. And that was sort of adopted. And in that position paper, they had this network concept that there would be a medical review board, that there would be, they would set standards and goals. That there would be a board and they would do administrative stuff.

DWM:
And what year was, was that NKF position paper?

NA:
Probably that came out, I think, in about 73 or 74.

DWM:
Okay.

NA:
And so networks were just sort of put out there. Originally, there were, I think, in the first regulations that came out in 75, I think there were 30, excuse me, 23 networks that were designated. And then there was a little, a lot of political jockeying because people were put together, didn't really want to be put together. Virginia was put with North Carolina. And North Carolina didn't want to have anything to do with Virginia. And I think we were put in with Northern Virginia. And then they, and they were supposed to be, the boundaries were supposed to be drawn on referral patterns. And so, by the time it was all said and done in 1976, when the final regulations came out, there were actually 31 networks. And so we were Network 30, because we were one of the ones that was carved out. And we were Virginia with minus Northern Virginia and West Virginia. And Northern Virginia was in a network with D.C. and the metropolitan Maryland area. And then there was another network for just Maryland. These networks were pretty small. And at that time, I did look this up. We had 28 facilities and 900 patients in our network area. I mean, it's just really incredible to think. I think we had index cards on all the patients. But networks were sort of left to sort of creating themselves. There were certain requirements that you had to go through. You had to get 75% of your providers in your geographic area to sign on and agree to work with you and sort of be a member of your organization and whatnot. You had to submit an application to, I guess it was AGW at the time, Health and Human Service, Health Education and Welfare. And so you had to submit an application. And so the VA in Salem took a leadership role for this. And they started hosting meetings for us. And West Virginia had a similar group to our group in Virginia. So we just started talking to one another. And we had, I think, our first meeting. I can't even remember. I was still with the health department at the VA hospital in Salem. And we invited all these people. And we had a pretty good turnout. And it was, I was trying to think, Mary Lou Lewis was the nephrologist in West Virginia who was an extremely interesting woman. She had been a psychiatric nurse and went down to Atlanta and met Albert Tuttle down there. And Albert apparently asked her, why was she a nurse and not a physician? And she said, well, because apparently women in West Virginia and her family didn't become doctors. They were always nurses, she told me. And so he said, well, no, you need to go back to medical school. And so she did. And I think she trained out in California, but she became a nephrologist and went back to

West Virginia and found that she was having trouble seeing all her patients because they were so far flung. So she got her pilot's license and got a plane so she could fly around and see her patients and truck up mountains to see home patients and stuff. So she was really an incredible individual. And so she was one of the leaders up there. I was trying to think, there were some physicians out of West, she was in Charleston, and there were some physicians out of Morgantown at the university. And I can't remember who they were because shortly after we sort of pulled the organization together, Rick Latos from Wheeling became involved. And Rick has been involved, you know, to this day. But we had this meeting at the VA and we sort of put together this organization and applied to be the Network Coordinating Council.

DWM:
So what year would this have been?

NA:
That was early in 76.

DWM:
And you had to have 75% of your providers sort of get on board. Did that happen?

NA:
Oh, yeah.

DWM:
No problem.

NA:
No problem. They were all, you know, very willing to be a part of this. I think they were afraid that if they weren't part of it, then things would happen to them. And so they wanted to be at the table. And yeah, they were all pretty excited about it because they saw that it was really, the program was really going to go places and stuff. And that they wanted to have a say in where it was going and what was going on. And so the health department was really wonderful to us because I stayed there and worked there while I was doing all of this. And they knew that as soon as this got funded and going, you know, that I would be, I would leave. But they were very accommodating. They didn't, I mean, they, I think they, I hope they felt like I was giving them some value. And so it wasn't that they weren't getting anything for their money. So, because I was still doing Certificate of Need work and for them. And so by October of 76, we, I guess we're funded to actually, or we received designation as a network. And so I actually left the health department and I set up a little office in the 700 building in downtown Richmond. And I thought we needed to be in downtown so we could be close to MCV. I don't know why we thought that, but we did. And so I worked out of the office there and it was kind of interesting because originally the government didn't know how to fund these organizations, fund the networks. And so they wanted to have a pass-through. They could, they had a mechanism for funding a provider like a hospital, but not funding a separate organization. They didn't know what to do with us. And so we had to find somebody who would agree to accept the money and give it to us.

And so Richmond Memorial Hospital agreed to do that for us. And everybody was all uptight about that because they thought, well, one, are they going to take some of the money? And two, are they going to then control it? And so the guys decided we had to scurry around and become a 501c3 organization so we could remain independent. But we didn't have any money to hire a lawyer or do anything. And so I filled out the 501c3 application and after about a year, we finally, we got it. And it wasn't easy, but I remember talking to the IRS and I think the guy just took pity on because he said the application was just, you know, it was obvious that a lawyer hadn't filled it out and that somebody didn't, who was filling it out didn't know what they were doing. And so he sort of walked me through eventually just so he could get me off the phone, I think. And so we got the 501c3. But we, for about six months, we would give our invoices to Richmond Memorial and Richmond Memorial would send them up to the government. The government would pay Richmond Memorial and then they would pay me. And so it was really a convoluted process. But they were really great to work with. They never requested anything for doing that. It was just sort of a service that they were providing. And eventually the government thought, well, that's a little cumbersome. And so they figured out how to fund networks and they put us on cooperative agreements. And it was sort of a funding mechanism. They still have cooperative agreements, but I don't know how often they use them. But it sort of gave us the ability to bill directly. And I think that, you know, we just had, it was so little money. When I look back on it, I think my first budget for the whole year was like $150,000, you know.

DWM:
So what were you going to do with $150,000?

NA:
Hire staff, you know. We had an administrative assistant and then eventually we hired a nurse to staff the medical review board. And we had some functions that we were supposed to do. We were supposed to have a medical review board and we're supposed to review cases and we're supposed to design studies, medical care evaluation studies. We're supposed to develop criteria and standards for the dialysis centers, clinical criteria and standards. We did a lot of administrative stuff. And I tell you, the two functions that we really focused in on for the first five years, one was the certificate of need process. We continued to collect data and provide data to the provider community so that when they went to get a certificate of need, they could go armed with the correct information. And we helped providers sort of sort through was there a need in the area that they were looking for, you know, and how would they determine that? And how would they determine the size of the dialysis unit that they might want to open and, you know, put them in touch with other people who could do things. So that was one function that we did. The other thing, the certificate of need, I was trying to think what else, I had another thing that I had on my mind for this. I'm just drawing a blank there. Right.

DWM:
Yeah, no problem. So, yeah, you mentioned that, I mean, these are lots of big tasks, like reviewing actual cases, designing studies, clinical criteria and standards. That's a broad swath of activity.

NA: (38:33 - 38:34)
Oh, yeah, it was.

DWM: (38:34 - 39:51)
So were you able to accomplish that?

NA:
On a small scale, we were. The other thing that we did do in the early years is we subscribed to the Federal Register because regulations were being promulgated all the time. They were pushing out all sorts of regulations about minimum utilization rates and home training and staffing requirements and billing procedures. And we would get the Federal Register and clip all that stuff, copy it and mail it out to everybody. So I think that we really served as a clearinghouse for information and it was coming very rapidly. And it was being changed very rapidly. They would promulgate some regulations and then get a lot of pushback on it or they would put it out in notice of proposed rulemaking. So it was draft regulations and everybody would comment. And so we would get, we would sort of put all the comments together that everybody had and push that up, and actually have some influence over the regulations. And then when they came out in final form, we'd say, okay, here it is in final and stuff.

DWM: (39:51 - 39:57)
So who, so rapid fire, new things coming down the pike. Where do you think these regulations were being generated? Were folks in Washington just thinking them up? Did they have influence from people in the industry? Where were they coming from? And who was it, Health and Human Services sending them out? Who was sending them out?

NA: (40:14 - 42:57)
It was the Bureau of Health Insurance was the original organization, I think that had this. And there were a bunch of staff people up there that really were developing some expertise, but there were people that were very influential in this process. When I look back, when I think about someone like John Sadler, John Sadler was there all the time, I'm sure. And so there were committees and people that they were turning to. John Bower was another one. Nate Levin, I think, was involved in some of this. So they clearly had people of that caliber who were giving them some direction and who were thinking about some of these things and providing information. And so I don't think that it was probably evident to those of us in the field at that time, you know, who was sort of pulling the strings. But there were, you know, these nephrologists were actually very instrumental in some of this.

DWM:
Why do you think was coming so fast and furiously down the pike?

NA:
I think the program had been implemented in 72. And so they didn't really get it off the ground until about 76. And so I think there was probably some pressure of saying, okay, what's happening here? And then once you start providing these services to people, there's lots of patients. I mean, just lots of patients were coming forward. And I think these

nephrologists were seeing more and more patients and recognizing they needed these dialysis centers. And so it was just, you know, it was really sort of a frenzied time. I wonder if other people feel that. It would be interesting. I should go back and ask other people how they feel about that because I felt very overwhelmed with it. I mean, it was, it seemed to me that it was, you know, it was a lot coming down in one or two years.

DWM:
And you think that all of a sudden, these new patients really, there's just lots of patients. And so the business is trying to keep up with the influx of patients as well.

NA:
Yeah, I think that's right. And I had one of the docs say to me one time that dialysis was like, if you put a hamburger stand up, you're going to sell hamburgers. And if you put a dialysis center, you're going to find patients because there's just so many of them. And whereas patients from their primary care physicians would have been sent home to die. All of a sudden there was a technology available to save these people's lives. And it became apparent to everybody that, you know, they could do something for these patients.

DWM:
So your perception and your recollection is that there were patients who needed services and there were not enough services to deliver them. So they were just not being offered treatment.

NA: (42:57 - 42:58)
I think, yeah.

DWM: (42:58 - 46:17)
And the scramble was to create enough services to meet. Yeah, that overwhelming need.

NA:
Yeah, that was really out there and stuff. So, and I think early on too, that you had a very different kind of patient. I don't ever remember the role of diabetes in our early surveys. I mean, that we were looking more at hypertension patients.

DWM:
And why do you think that was?

NA:
I think that it didn't occur to people that diabetics could do well on dialysis. I think they thought that it was a comorbidity that didn't lend itself to, you know, treatment. And then that just shifted. And they obviously started treating more diabetics. And of course today, you know, it's probably the leading cause of renal failure. So, but I think they were just focusing more on the hypertensive patient because that's what the nephrologists were seeing. Perhaps they weren't seeing the diabetic patient as much. Maybe endocrinologists were taking care of diabetics. But, so yeah, it was a different, you know, focus in the early days and stuff. So, yeah, but it was, like I said, it did seem to me very frenzied and very, a lot

of information that people just needed in a very rapid time. And of course, you know, we didn't have computers and we didn't have email and we were mailing everything out. I mean, we were burning up the copier machine and just making copies of all this stuff and sending it out to people and making sure that they knew what was the newest information. And also trying to figure out what other networks were doing. There were 32 of us and so, or 31 of us, and so the feds would get us together. And I don't remember when our first meeting was. I think the last executive director may have been hired probably in the middle or late 1977. And probably around 78 we may have had our first actual meeting of everybody. So we all got together and got to meet each other. And it was interesting. A number of the executive directors had come from regional medical programs. A number came from national kidney foundations. Some of the executive directors came from state kidney programs. Some of them were individuals who had worked in dialysis centers. Jenny Kitsen, for example, had been a social worker. There were some nurses who had been nurses in dialysis centers and stuff. There was a guy in Oklahoma who used the network to sell oil wells. He and his brother, who was a nephrologist, had oil wells and they thought this was a good opportunity to have access to other docs who might be interested in investing in Oklahoma. And I don't know how long he held that job. But I remember coming to meetings and all of us talking about our real business stuff. And he didn't have any interest in the business of renal. He was interested in making contacts. And, you know, sort of...

DWM: (46:18 - 46:30)
So fascinating. It does sound like a big portion of the work in the late 1970s was literally networking. I mean, connecting people together. Would you say that's true?

NA:
Yeah, it was. And I think that there was, you know, natural groups of people that sort of coalesced around their mutual interests and stuff. I know I had a group of executive directors that I really enjoyed working with that I really felt safe in sharing information with that I could rely on if I had a question or something came up in our network area that I could call somebody. So yeah, I think these sort of natural alliances just sort of happened. Mostly women in the program, Dugan. It seemed like there were very few male executive directors.

DWM:
Why do you think that was?

NA:
I think that the positions didn't pay very much. And so I think a lot of our male counterparts weren't interested in the lower-paying positions. I think they, you know... I think at that time, males were going into hospital administration if they were doing that kind of work.

DWM:
How many of the executive directors were non-clinical, like you, versus clinical?

NA:
I'd say the vast majority of us were non-clinical.

DWM:
More administrative.

NA: (47:44 - 47:45)
Administrative people, yeah. Because it was a business that we were trying to run. And we were hiring people to staff, nurses to staff, the medical review board, and that type of thing. And over time, we hired social workers. I think we were the first network to actually hire a social worker. And then it became a requirement. I think we were one of the first networks to have a patient advisory committee. And after we got a patient advisory committee, we decided we needed a social worker to staff it. And we were also tasked, after a few years, to process patient grievances. So that's how we formed our patient advisory committee, because we were supposed to look at grievances that the patients had. And we thought, you know, we need patients to tell us about this stuff. And so we did that. But yeah, most of the executive directors, like I said, were administrative people that had come from regional medical programs or state health departments. And there were clearly some RNs and whatnot. But I don't recall that there were not a whole lot that had dialysis experience, because they just hadn't had that opportunity and stuff.

DWM:
You mentioned that you found a group where you felt safe in sharing information. What would make you feel unsafe? What was the environment?

NA:
Well, at some point, we started to, you know, I think there was a shift. And I don't remember exactly when this happened, but I felt like there was a shift where the government had decided that they had learned enough from these people, you know. And so now they were running the show. And so they started to, at least it was my perception, they started to then not reach out and be as transparent as they had been. And so there was this tension that sort of came up between the provider community and the government. And I think that you sort of see that even today. And I always felt like the networks were sort of the go between with the federal government who was paying for the program and the providers who were actually providing the services. But I always felt that I really worked for the providers. And I didn't feel like, you know, I worked for the government. And so I think it was, you had to be careful with that because you do, and in reality, you work for the government. They're paying your, you know, your bills and they're paying for things. And so I felt that I had to be careful sometimes with some of the things that I said so that if we were arguing about a position and stuff, because I never had a whole lot of respect for the government people because I didn't think they ever really got out in the field. I don't think they ever really knew the issues that providers were having to deal with on a day-to-day issue or day-to-day matter. And it, I think you just have to sort of be careful about explaining that and how you did that because you had to be very politically correct. Because these people could, you know, defund you or they could reduce your funding and they could cause problems. And, you know.

DWM:

So let's talk about this issue. When do you think this happened, this government shift where in the beginning they had people like John Sander and Nathan Levin and all helping to sort of develop ideas and policy. When did that shift happen and why do you think it happened?

NA:
Um, I think it started to happen probably in the 80s. And I think because there was a lot of conflict of interest that started to come in. And I think that around the country now, I hate to sort of think that any of, you know, the guys I worked with, you know, were sort of self-serving. But I think around the country people were starting to see this as a business opportunity. And I think that it started to shift at that point. You know, I have often wondered what the program would look like today if the government had said they would only fund non-profit organizations. And I believe that was a debate at one time about whether or not they should make this a non-profit. And that was not a business model that they were willing to go with. And so when you start to have a for-profit sort of consideration, things change a little bit. And so I think the government was taking a step back and saying, you know, are these people doing this because they want to make money or are they doing it because they want to, you know, provide the service that needs to be provided. And I think they became a little skeptical and they became a little bit more guarded with what they were, the way they were approaching the program. And we saw that through the 80s that, you know, they decided, I guess when Ronald Reagan came in, they decided that they would get rid of networks, that they didn't really need them. And so we didn't know whether we were going to, you know, have jobs. And that was one of the things from early on. I can remember I had a group that I played bridge with every other week or so. And I think that my mantra was, oh, gosh, I hope I get funding next year, you know, because I never knew whether I was going to be funded from one year to the next because they were just, it was just, you know, one year funding. And I remember one of the women that I played bridge with said, you know, I'm really tired of you talking about this. And she said, you know, you're going to be working for that organization until you collect social security. And I thought, well, then that's not going to happen. But you know, it really has because, you know, I'm going to be collecting social security and I'm still here. But I mean, I really, it was difficult not knowing whether you were, you know, going to get funded and what was going on with this. And so I think that it just became different in the 80s with that. So Ronald Reagan came in and decided that, or his administration decided that we really didn't need the network program. And so he had it on the books to get rid of. And it was sort of a stressful time. Don Gentile was a doc out in California who was really, I guess he was president of the forum at the time. And the forum was all, the forum was the membership organization for all the ESRD networks.

DWM:
So the forum sort of collected the networks all together.

NA:
Every chairman of each network was a member of the forum. And you had to be a doc to be a member of the forum. They wouldn't let the executive directors be members of the organization. Well, because I think that's the way the male physicians wanted it. They only wanted the chairman of the group. They didn't want any administrative people. We could

come and sit in on the meetings and stuff, but we couldn't be members at that time. And we could take minutes and bring coffee. You know, so, but yeah. So anyway, but the forum under Don Gentile's leadership started lobbying Congress. They went up on Capitol Hill and worked with some of the staffers, I guess, who had done some of the original legislation. And I was trying to think the other night about who those people were. And I see faces, but I can't remember names at all. And so they were, they worked, and it was Alan Hull worked with Dom and Sid Baskin from Michigan, and Jenny Kitsen were going up and doing a lot of lobbying. And, you know, trying to make the case for the fact that these organizations were kind of essential, that they really did have a purpose and a role and whatnot. And so somebody in Congress, and I don't even remember what committee it was, probably a health oversights committee or something, said, well, if you guys want these networks, then you should fund them. And that's when the 50 cents per treatment came out. And so they said, let's have fewer networks and let's fund them with the money for the dialysis program. And so they came out again. It was, you know, some draft regulations and some boundaries were drawn. They originally said they were going to have 14 networks and then everybody screamed and hollered because you couldn't put North Carolina together with Virginia. And so they said, no, that's not going to work. And so they eventually came out with 18 of the network organizations. And so that was the original 18 that we have now. And in our area, there were three networks. There were only a couple of areas around the country that merged three networks. And we were one of those. And that was in 19, between about 1986 to 1988, because we were actually got the contract in 1988. So what we had to do as a network was scurry around and figure out who was who in the other two network areas so that we could see if we could build a coalition at the time. And could we put in for one contract or were they going to, were we going to have to compete against each other? Because we knew we were going to go in to have contracts. So we got, well, anyway, they were very successful and we got the 50 cents and they started to do that. And then they put it out for proposals. And we worked, that was the first time I met Lou Diamond. And so it was Lou Diamond. And then in the, he was, and Barry Strauch were the two individuals from the DC network that we met. And then we met. So they were already involved in the network.

DWM: (58:08 - 58:09)
They were involved in the network.

NA: (58:10 - 1:01:55)
Yes, in the DC network. And then in the Maryland network, there was Paul Light and John Sadler were the two probably dominant players there. And then we had Fred Westerfeld and Rick Latos. So each of the three networks had like two representatives that came together with this group. And so we started having these meetings up in Crystal City and talking about, did we think we could put together an organization? Did we want to do this separately? What would it look like? There was not staff in the DC area because about six or seven months before this all happened, the individual who was staffing that network was Judith Carey. And she went back to the government. She had worked for the government before this and she went back to the government. So the government had asked us to take over Network 23, which was the DC area. So we said, so we were staffing that at that time.

So there was no staff there, but there was staff in Maryland. And so then we all agreed that we would have this new organization called Mid-Atlantic Renal Coalition. And I think John Sadler was the one that came up with the name. And so we thought that would be good. And so we put in an application and then we decided, well, who was going to be the executive director? We put in the application and there was a group out of DC called System Sciences and they were sort of beltway bandits before the day when we all knew what beltway bandits were.

DWM: (1:01:55 - 1:01:56)
Yeah, what does that mean? What do you mean?

NA: (1:01:57 - 1:06:13)
Yeah, they were beltway bandits, you know, or just, you know, and it was just, it was fun, but they applied for all 18. So everybody had some competition and, but they weren't serious competition and stuff. And I can remember, oh, this is so funny, and we, we had gotten a computer. We inherited a computer from an IBM computer from Network 23. And we had it sitting in the office and everybody kept telling us about word processing. And we thought, okay, and we thought we had this, but we didn't have time to learn anything about it. So we did our original application on a typewriter and, you know, and we were just using, you know, write out and, you know, and copying it and stuff. And, and so our whole application was done that way. And we took it up. We had to have like five or six copies of this thing. And they still do that today. But we actually met a bunch of people. I mean, I don't know.

DWM:
So your application, you were doing it in, on a typewriter?

NA:
On a typewriter. Yeah, it was really kind of fun and making copies of it and stuff. And we had to, we were real nervous because at the time we'd heard all these horror stories about submitting a contract to the government because we'd never been on a contract. We'd been working under these cooperative agreements and it was a new set of rules. And so everybody was, you know, really nervous about it because we thought, oh, if you get, you know, one thing wrong, if you don't answer every single question, they're going to throw your contract out. You know, we'd heard all these horror stories. And, you know, if you don't get it in on time, which is true, if you don't get it in on time, you're, you know, you're toast. But so we were worried about that. And so we actually drove our contract up and we met some people up in the Washington area. And I think we picked up about three other executive directors and we all drove our contracts up to Social Security at the time. And it was so funny because I remember you didn't have, I mean, there was easy access to all the buildings. You just walked in and, you know, you ask somebody, I'm here to deliver this network contract. Oh, go down the hall. It's going to be the third door of the left and just drop it off. And so we went down this hall and in this room, there were all these applications. I mean, they were just stacked up. So we just left our application there. I think I did get somebody to sign that they had received it and stuff. But I'm thinking this is this is just really, you know, loosey goosey here. But that's the way it was. I mean, today you

wouldn't do any. I can't even get into the building today, of course. But, you know, back then it just nobody was there sitting there. There was just these, you know, suitcases full of and boxes full of proposals. And so but it was it was a tense time because there were networks that did compete against each other. For example, in Pennsylvania, there had been two networks, one for the Philadelphia area and then one for the Pittsburgh area that included Ohio. And those two networks could not combine. They just couldn't do it. So they competed against each other. And, you know, so that it it was a new dynamic when it came into play about who you were working with and stuff. And it really significantly increased the size of the areas that we were working with. And it was really it was a great thing as far as I was concerned, because we now had a much larger population to do our studies. We could, you know, we had some new, interesting people to work with that had new ideas. And so it just it was it was a real boost to the program. I really do think it did. It was a good thing. And it just made it easier to work with 17 colleagues than it was to work with that many other people and find out what was going on. And it was interesting that the provider community really rallied to the network program.

DWM:
Yeah, so let's talk about it. I mean, all of a sudden the financial burden is on the provider community. It's 50 cents a treatment. So why were they willing to take that on? Why? How well received was that?

NA:
You know, I think it was probably there was there's probably been some resentment of it. You know, people would probably like to have their 50 cents back. But, you know, it's been 50 cents since 1988. So, I mean, you know, if we were to inflate it, it'd probably be six dollars or something today. So I don't know that it's significant today as it was back then. I think the provider community liked the buffer that they got with the networks that we served as as the middle person so that they had a voice that they didn't have to go individually to the government. They could go through the network and say, this is an issue for us. You know, this is what, you know, we're thinking and stuff. And so they had a mechanism for getting, you know, their their issues heard through the networks. I think they felt like it was better that they had the networks than it would be to have somebody else from the government. The networks, at least they were part of the networks. And I think most of them did feel some loyalty to the organization. Now, I'm sure that there were providers, you know, and there are today and there always will be providers that didn't really want to have anything to do with the network. They don't have anything to do with the government. They're willing to accept the money and do the work, but they don't really want to, you know, be told anything. And so I think we had our share of those sort of people. But, you know, you're always going to have bottom feeders. You know, when we look at the the quality of care that's provided, you know, and we profile it, there's always somebody at the bottom and there's always somebody at the top. And, you know, and what we've learned over the years, and this is when we design our studies, for example, is we we want to do quality assurance and make sure that people are safe. But quality improvement is different. And we want to, we don't necessarily want to work with the bottom. We want

to work with the people who want to improve and can improve. So, you know, we were, I think that people did seem to have some appreciation for that, that we were not coming in trying to tell them how to do their business. We were coming in trying to help them do their business and improve their processes and look at things in a fresh way and stuff. So, but yeah, that was, it was an interesting time for us. Like I say, there was a lot of shake up and, but it gave us some stability, which we didn't have before, because we didn't have to worry about congressional appropriations. We didn't have to worry about being a line item in the HCFA at that time budget or CMS's budget. You know, we knew our money was pretty safe and they were supposed to, the first year, we were supposed to actually get 50 cents per treatment. And then they decided that there were some networks that were just too small, they couldn't support. And so they said, no, we're going to throw it all in a pot and everybody's going to vye for this money. And so that's what we've had to do. We don't get 50 cents for, you know, in my area.

DWM:
And so how do they figure out how to divide that up?

NA:
Well, we put in budgets. They give us a statement of work now and we put in budgets. And for a long time, you know, the rule of thumb is you want the first year that you ever do this, you want to get as much money as you can for everything for that point on is incremental. And, you know, they're going to give you a percentage increase, usually from what you have the next year. And so those people that did well the first couple of years continued to do well. There were some networks that really, I mean, I know in Texas, for example, for many, many years, they ended up with something like 24 cents per treatment. And, you know, they really, and the North Carolina network that was so big, they probably ended up with around 25 or 26 cents per treatment. And so it made it really difficult for those areas. And the forum was pretty good about trying to get the feds to change, but they wouldn't. They've never looked at that very seriously.

DWM:
So as you mentioned, you're still 50 cents a treatment. That's what the providers pay. So part of the reason, obviously that has an increase per treatment, but there are many more treatments than they used to be.

NA: (1:10:47 - 1:10:48)
So, yeah.

DWM: (1:10:48 - 1:16:47)
So I'm assuming the money has increased over time that's allocated.

NA:
The money has increased and we've also, we're much more efficient, just like the dialysis centers are more efficient. The networks are more efficient. I mean, I don't have a typewriter anymore. I can do, you know, emails and we can just do things so much more

efficiently. We don't, I mean, our copying expenses and our postage expenses, have basically gone away. You know, when I look at the budgets and stuff, we don't have the telephone bills that we used to have. We don't have the meeting expenses that we used to have. We do webinars. And so we, you know, there's a bigger patient population, but we're much more efficient.

DWM:
So if you think back to the 1980s, what would have been the bulk of your budget then? And what is the bulk of your budget spend now?

NA:
You know, we had, there were a lot of meetings back then and we were doing a lot of training back in the 80s too. You know, that's when we started looking at continuous quality improvement. And so a lot of our staff were getting trained. We were going places and getting trained. But the biggest bulk of our stuff was the copying and postage. It really was. We were still sending out paper newsletters, you know, and expanding those. We were sending out medical review board meeting books. We had medical review board meetings four times a year. We have board of directors meetings four times a year. We have patient advisory committees four times a year. And every time we met, they got a three ring binder full of, you know, paper that told them everything they need to know and probably went in the trash as soon as they went home. But we would try to, especially with the continuous quality improvement sort of coming into its own, we were trying to give guys a lot of information about CQI and how to design studies and what the science was, you know, the Deming science and [?]. So we were getting articles and sort of saying here, read these while you're looking at your meeting materials and stuff. So we were really trying to push the envelope on some of that and try to get them to think about process science and process thinking and, you know, how they do things and stuff. So, yeah, that was probably the bulk of our budgets back then.

DWM:
And what's the bulk of it today?

NA:
Well, we can't say this, but the bulk of today is my indirect costs that I have to pay corporate. And that's really high. But the bulk of it today would probably be running our computer systems, you know, the staff that we have. We have more staff than we had back in the day because it depends on our statement of work. But for example, our statement of work for this year has us conducting eight quality improvement projects. And so we've got as little, as few as nine facilities with as many as 70 facilities enrolled in all those quality improvement projects and trying to provide technical assistance on Crown Web to the facilities. So we're still doing a lot of that. But the biggest bulk of my stuff is just the manpower that we're paying for.

DWM:
And do networks still think in terms of cents per treatment? And when, like, if you get your money allocated to you, do you look around and look at the treatments that are in your network and think of your...

NA:
I do. I don't think other people do. You know, I'm the last original executive director and everybody else has sort of retired from the program. And I will be retiring in October. But I think that, no, I don't think that people think that way anymore. And it's hard to find out sometimes. I mean, if you calculate, if you can go on Fedbiz and find out what everybody's contract awards are. And so you can certainly calculate it out. But, you know, now all of the networks are a part of, except for one, are part of QIOs or QINs. And so that function that we had at one time as executive directors of doing all the bookkeeping, I mean, before we joined the QIO, I was the bookkeeper. I was the HR person. I was the CEO. You know, I was the bottle washer. I was stapling, you know, newsletters if somebody needed to do that. We were, you know, running the council meetings and stuff. And so we did all of that. I mean, we did everything. I, you know, I can't tell you how many times I felt like pulling out my hair for QuickBooks trying to do payroll and stuff. Because we didn't have people that did all of that. We had an accountant that came in once a month and reconciled ledgers and stuff. But, you know, as executive directors, we did it all. And then when we joined the QIOs, those functions, those back office functions were sort of taken away from us. And it was a good thing for most of us. I mean, I've enjoyed it because it allowed us to go out and seek some grant funding and get some additional funding brought into the organization. I never had time to do that too much until we did join the QIO. So all of that is being done now. So no, I don't think the executive directors today think of too much about how much of the 50 cents they're actually getting. That's somebody else's job. I think they're thinking about how to run their contract. They're project managers as opposed to executive directors. And I don't mean that in a derogatory manner. I just think the job has changed.

DWM:
So let's go back to the 1980s where you're just getting these 18 networks together. And how around that time you had been really involved in just like you said, new regulations coming out, communicating that, beginning to set up certificate of need, some case review. So what changed?

NA: (1:16:49 - 1:28:02)
Yeah, there was a shift to looking more at the design of the projects, what they should look like, making them more evidence-based, actually looking at the literature. And like I said, the whole CQI movement was really big in the network program. I think that there are people like Bill McClellan who sort of drove some of this. Jay Wish worked with Bill McClellan doing medical case review and switching that over to these kinds of different kinds of study designs. The other thing that changed in the 80s is that networks were always collected the 2728, the medical evidence form and the death, or they not always, but after a few years, we started receiving those from the dialysis facility. So it was the medical

evidence form, the death notification form, there were transplant and transplant follow-up forms that we got. So it was a lot of paper that came into our office and we would look at it for completeness and timeliness. You know, there was no way for us to know whether the diagnosis was correct or whether the cause of death was correct, but we wanted to make sure all the boxes were checked and that somebody had signed the form and that type of thing. And then we would package them up and send that into the government and we'd keep a copy. And we just recently have gotten rid of all the last of them that we had because we don't do that anymore. So in the 80s, the government decided that they wanted to have some computerization of that. So they developed a software called EDDES, which was E-D-D-E-S and it was like End Stage Renal Disease Data System or something. I don't remember what it stood for. But we each were given the software package and when these forms came in, we were supposed to key all of the information and then we would send a disk every month to CMS because we didn't have any way of, you know, sending it electronically. So we would send them a disk every month and we would keep a copy of the hard copy in our files and we were supposed to keep those for three to five years or whatnot. So this was the first time that we really had electronic data. And so what most networks did is they said, OK, well, let's develop an interface so that we can have the electronic data downloaded into a database for us. And we had, we hired people and we had a system that we named Marcus. So Marcus was our relational database. And so for the first time, we were able to actually get some comparative data for all of our facilities without having to do it manually. And it was pretty nice. Now, what we didn't have is good clinical data, you know. So, but we could look at it and say, we knew how many diabetics we had. We knew how many African-Americans we had. So we could look at the demographic data and we could start to think about, well, if we're going to design a study, do we need to do some case mix with this? Because, you know, this is what our population looks like. So it was, and most networks, I think, were sort of doing that. And it became really clear to us that, well, we didn't have the capability of comparing Network 5 with Network 1, because, you know, they just, we weren't talking to each other and stuff. And so that's when SIMS came in. It was the Standardized Information Management System. And so I guess, I can't remember what year SIMS was, but it was probably in the 90s, by mid-90s. Network 6, Jenna Krisher, was given a contract to pull together a system that would combine all the legacy systems that the network had. And this was the forerunner for the Crown Web. And it was really a nice system. And so we, since we were so close to North Carolina, Jenna asked us if we would be her alpha tester for this. And so we alpha tested it and we beta tested it. And we, you know, we had a really fun time with it. And, oh, there was a lot of fights about it, because some people just didn't want to give up, you know, the systems that they had. And there were definitional problems. You know, when do you define a first start? And, you know, how, you know, different things that just really had to be resolved. And it was a very elegant system that was finally put into place. And so for the first time, we could actually compare network, I mean, compare our data with other people, because we couldn't manipulate anybody else's data, but we could download the data and we could, you know, use it, you know, to look at and stuff.

DWM:
What year would this have been?

NA:
Oh, I have to, let me see if I have some notes on that, because I was thinking about that. It was in the 90s. I mean, 1999, the contract was awarded to Southeastern Kidney Council. So it took a while, you know, between, it took about 10 years, I guess, for us, because we were developing our systems and doing this before the idea really came about. For Jenna to do that. And the piece that we missed in that was the clinical data. And so Diane Carlson in Network 11 got the idea that we could do this thing called eLab. And so she started working with the laboratories and asking them, the national laboratories, and said, okay, if we give you a database of our patients, can you match it with the clinical data that you have? And it always sounds so easy, but it's not. And so there were about five of us that worked with Diane for a couple of years, sort of doing that and sort of seeing, you know, what were the problems with that and how could it work and stuff. And it worked very well. I mean, it was really a very nice system. It was not real time data. And we only did it once a year. But we had clinical data and we could, you know, sort of look at that. Now, the other player in all of this was USRDS. And they were getting a lot of claims data. Now, none of us ever had the capability to use claims data. I mean, we just didn't have data systems that were that large that could accommodate that. And we didn't have the expertise in the offices. I mean, we didn't have PhDs and we didn't have people who, I mean, claims data is a really tricky thing. And you have to know coding. You have to know all this stuff. And we just didn't have any of that capability. But USRDS was, of course, printing a lot of data and using a lot of stuff. And we didn't know how to work for USRDS. I mean, we-

DWM:
What kind of work?

NA:
Oh, gosh. We did a renal biopsy study. We did a data validation study. We did a case mix study. I mean, this is one of the things that CMS has allowed other groups and contractors to use the networks a lot. USRDS used us for a lot of years. And we would actually send people out in the field and do data validation. Or I guess we would get charts too. And I mean, I had a medical records person who would actually go through the charts and validate data and whatnot. And the CDC is another group that we've done a lot of work for.
We used to do their annual surveillance, national surveillance survey that they did at the end of each year. And so we'd get all that. There was a two page. It was a bear of a survey because then we'd always have to call people up and explain the difference between antigen antibodies. And I'm not a clinical person, but I can just remember the nurses just going crazy, trying to say, no, you can't, you got to fill this out correctly and stuff. So it was really, it was kind of challenging for them. But today we even do the NHSN. We had to train all of our facilities and get them all registered for NHSN for the CDC. So I mean, we're here

to do the work for whatever CMS tells us to do, but people go to CMS and say they need the networks. And so we've done this work for them over the years.

DWM:
So I want to get back to this, that the providers are now paying for the networks and yet your statement of work still comes out of CMS. So do the providers get any say so for how their money is being spent in the networks? And how does that work?

NA:
You know, and I think that's one of the things that has really been sad to me, because when we had medical review boards, well, we still have medical review boards, but our medical review boards used to come to us and based on their expertise would tell us what a problem was in their area. And we might design a study around what their problems were. So they were local studies. And over time, the work has become so prescriptive from CMS that we don't have the same function for our medical review board anymore. And it's harder, I think, to recruit people to serve on medical review boards, because we're told now what to do. It's so prescriptive in our statement of work that they even tell us the number of facilities or the percent of patients that have to be represented in each of the studies. And these are not well-designed studies. They're, a lot of times, they're ill-conceived and they don't have good measures. And so it's really, it's very frustrating for the staff to sort of roll these out. And I'm sure it's frustrating for the providers, because these are not necessarily, there's no alignment between what, for example, the LDOs are doing and what their focus might be and what the networks are doing. And so it's become very frustrating. And so more and more, the networks are, I think, sort of perceiving themselves as working for CMS as opposed to working for the providers. And, you know, that shift just started probably in probably as early as 2007 or 8 when they started to really come up with studies that they designed for us to implement. And then, of course, there was Crown Web. And I think everything's gone haywire since Crown Web.

DWM:
I want to talk about Crown Web and just, I mean, but this is a, just listening to this conversation where, you know, when this first began in the 1970s, you're very much local provider driven, servicing the provider. And so the common good that you can see in your local area till today, I mean, CMS driven, which may or may not be pertinent, really in your mind for what is needed to be done. And yet we've gone from totally being government funded to now being provider funded. So it's like, looks like it's totally backwards. So why do you think that transition, why do you think now CMS does not give more autonomy to the provider medical review board, the network leadership and having some say-so in the project, more say-so in the projects and the approach to the study?

NA:
You know, they've done this with the QIO program too. And I don't know to tell you the truth why that is. You know, I don't know whether it's, was personality driven and the people that were coming in to lead the program just had a strong vision about the way things should be done. And the idea that these are contracts and the government has to get their value for contracts. And the only way to assure that you do that is if you control what's

being done. I think there's some of that. I think that there's probably when you look at the network program, I think that there's been better networks than others. And I think that some networks probably didn't do the kind of job that they should have done. And so the government felt that they needed more scrutiny. And so it came down on all of us and that there needed to be more uniformity. And so it all came down. You know, it was easier to control a program if you know that everybody's on the same page and everybody's doing the same thing rather than evaluating what 18 networks are doing if they're all doing different things. So it's probably expediency for one thing. And it's probably a sense of control. This is our program. It's not the provider's program. Providers are providing service, but they don't necessarily know how to design it and stuff. And I think there's been a lot of, again, you know, sort of going back to the profit that's been made. I think there's a lot of mistrust in the government. I mean, you see stuff every day about, I don't know if you saw the, what was it, John Oslo, is that his name? Who does HBO?

DWM:
Oliver.

NA: (1:31:04 - 1:31:04)
Oliver.

DWM: (1:31:04 - 1:45:32)
John Oliver. John Oliver. Yep.

NA:
Yep. And you know, that's the kind, and ProPublica has had a lot of things and stuff. And so that just makes the government think that they have to control this program because it will, if it hasn't already, it might get out of control. And then the way to do that is to sort of tell networks what they need to do and not have the trust in the provider community that they used to have. And there's a lot of, you know, trying to move away from the physician dominance. We're now told that we can't have, but X percent of our board members can be physicians. You know, they're that prescriptive in terms of what our board should look like even, even though we're non-profit organizations. And they want to assure that we have patients. And I love having patients involved in our work. We've always had patients, but they want to, you know, they have to mandate that now. And they even tell us on our patient advisory committees, we can't have, we have to have a certain percentage of people who are waiting for transplant. And we've tried to explain, you know, that's a very dynamic and flowing thing. You could, you know, so when somebody gets a transplant, do we have to drop them off the committee now? I mean, it's sort of ridiculous stuff. They, they put down some of these rules without really thinking about it. But, you know, they've, they've, they're the rule makers. They're the gold, they hold the gold. So they make the rules. And, and I don't know why that really came about, but I think it was that there were some networks that weren't performing the way they should. And rather than deal with some of that, they just went to all of us.

DWM:

Does CMS have the expertise to do the work that needs to be done, to oversee the work that needs to be done?

NA:
I've always had a lot of misgivings about that. I used, I think that when I look at some of the other programs that CMS runs, I'm really impressed with the caliber of people that work in CMS. There's a lot of really gifted people. I don't know that we've had that many gifted people in the renal program that are running it. Had some awfully nice people. And I like that about the program. But I'm always amazed when I go to meetings and I ask the CMS staff if they've ever been to a dialysis center. And the majority of them have not. And over the years, I've pushed it and they've taken me up on it frequently. And so we arrange tours since they're in our area. And that's one of the requirements I always have. Everybody who works here has to go see a dialysis unit. They have to know what this is all about. They'll never know what it's all about, but they have to know what it looks like, what it feels like in a dialysis center. And I think that the CMS people don't have that. So they're running a program that is a little distant from the real world. And so it's easy for them to say, well, we're going to talk about hypercalcemia. That's going to be one of our topics. Whereas, you know, that's really not the most important issue in our dialysis facilities. And so we're going to spend a lot of money designing a hypercalcemia project and making sure the providers collect data and do stuff. Whereas maybe what we should be looking at is depression. Maybe we should be looking at some of the things that we have local issues about. But that doesn't happen too much anymore. So it's been an interesting shift. And that's one of the reasons as a network here that I think we've really sort of gone outside of the ESRD network work. We've done a lot of work with patient safety. We've done a lot of work with end of life. Back in the early days, we worked with Harvard on a transplant project, the CONSORT project. It was really a great project. Found out a lot of information about disparities in transplant referral and transplant. So we've been fortunate that we've had a very supportive board that has allowed us to sort of, you know, go outside the box. And I think that's what's made the work interesting for us. When we get frustrated with some of the statement of work stuff, and we know we have to do that, it's not very gratifying sometimes. And so we can turn to these other projects and say, OK, let's put some energy here too. So we've been a leader in some of those areas. And not many networks have done that. I agree.

DWM:
So let's begin to talk about some of that. Let's actually let's start with Crown Web. So how did Crown Web ever get started? And what's sort of the evolution of that? What's the role of the networks in Crown Web?

NA:
Yeah, it was really very political, I think. We all thought that SIMS was rolling along very well. And, you know, what was happening is that you had, you know, at the time, probably 4,000 dialysis centers that were sending these forms into 18 networks. And probably the networks had maybe one, two, at the most three people who were keying in all this information. So, you know, it was not I mean, the data was pretty clean. I mean, we were putting if the facilities were filling out the forms, then at least what we were putting in and we did, you know, validation checks and ran the data and did comparisons to make sure that the people

who were keying it in, you know, didn't have an inappropriate error rate. And it was, boy, it was it was really, I mean, I was always amazed that somebody could sit on a computer all day and enter all this data and get it, you know, 98% accurate and sometimes 100% when we would look at it. It was like, well, you know, I couldn't do that. But networks did a really nice job with this. And I don't know exactly why the government decided that they wanted to do this crown web thing. And I remember Dugan, Frank, who has always been a visionary in this area, you know, Frank had the idea that we could do this on a web-based platform. And I remember Frank and I went up to talk to CMS about this and they would have none of it. They would have none of it. And I think at the time, as a network, we were probably willing to put some money into this to see if we could, you know, do this and get it to work. And they adamantly refused to do anything that was going to be on the Internet. That wasn't a secure system and that would never be secure. And as it turned out, I think that the individuals that we talked to had this in mind and subsequently left the government and went out to contractors. So the conflict of interest or the potential conflict of interest runs both ways. But at any rate, so at some point, somebody decided that crown web would be the way to go and that they would take the system away from Network 6 and the networks. And they would develop this system where the facilities could put all the data in to the electronic software. And then they would have, they would collect all this clinical data. And I think they originally thought that all of that would be entered manually because they really are not very far thinking about some of this. And so, I mean, networks were just appalled at this because the idea that you were going to go from, you know, 18 people entering data to 4,000 people entering data. What was going to happen to the quality of our data? And I mean, we worked so hard to get the data in. I mean, calling facilities and, you know, getting the forms in and making sure that they got in on time. You know, we just didn't think this was going to happen. And we knew from the SIMS experience how hard it was to actually develop software and to actually track patients. That's not an easy thing. And I can remember talking to Lou. And my thing about Lou has always been that, you know, Lou's mantra should be nothing's impossible for the man who doesn't have to do it himself. Because Lou is perfectly willing to say, here, go do this, you know, and it doesn't matter to him, you know, that it's really hard. You know, you can do it. And so Lou kept saying, you know, well, this is, you know, these are the systems that we need. And you just, you know, it just, you just make it happen. And so, I mean, we had all made it happen. You know, in terms of putting the SIMS data in, and really a lot of blood, sweat and tears went into that system. And all of a sudden, we were going to have this crown web. And oh, the other beauty about SIMS is that Jenna had set up user groups. And so for every aspect of this, there was a work group that was, had network representatives that were talking to one another and figuring out what the problems were and what the best practices were and stuff. So she designed, the system was, really had input from everybody. And it was really nice. And then when crown web came along, we were totally, we weren't at the table at all. It was, you know, the contractors. And there were a lot of contractors over the years that have made a lot of money off of crown web. And they would design it, and it would be done without any inputs from anybody. And it would be wrong. And it took them probably 10 years to actually get it launched. Because they, and then they never saw networks as being end users of this system. It was all for the government or for the providers. And we kept telling them, you know, and I guess when it first started, the, I don't think the dialysis

facilities had electronic medical records. And so it was a perfect time to sort of sit down at the table and think about, how do you integrate an electronic medical record with a national data system? And if they had brought the right people to the table, that could have been done. And people could have agreed to the standards, and people could have agreed to the data elements and the definitions. I mean, we knew it was possible because we've done SIMS. So it could have worked. But they didn't do any of that. They developed it totally in a vacuum. And we kept telling them, and by the time it was launched anyway, we kept telling them, the providers are not going to use this system. They have their own medical record system. They're not going to have extra people sit down and enter all this clinical data. This is just not going to happen. And so then they came up with the batch, and NRAA came up with the batch, and they are continuously tweaking this system. And it is laborious. We can't get data anymore. I cannot. When I had SIMS, I could get our data people to go in. If I had a request, I could say, how many people live in Frederick County? And what do these people in Frederick County look like? And where are they going for treatment? Now, I couldn't necessarily look at all their clinical data, but I knew something about these people. And if I wanted to look at, for example, since we were doing a lot of end of life work, I could look at our population and say, how many patients who have died in the last year have used hospice? And I could say to other networks, could you pull this report for me? And we could give them an access report for your data system. So I would know nationally how many people had used hospice. What did these people look like that used hospice? You know, I could do things like that. And the medical review board could say, you know, well, we want to look at certain things. How many patients start with an AV fistula in our network area? You know, we could go into the system and mine the data. We cannot do any of that anymore. We get canned reports. Here's your data report.
And here's what it says. If it looks funny, come back to us and talk to us some more. And if, you know, we have money, then we'll, you know, maybe rerun it and stuff. But we can't do any of the data mining, any of the investigative work. We can't do any of that anymore because we're stuck with this crown web system. And we're required to help the facilities get into the system. We're required to make sure that they put the forms in on a timely basis. But, you know, we don't know who's in there and who's not in there. And it's just, you know, from my perspective, it's just, it's very difficult and it's a real step backwards. And like I say, I don't think it integrates with anybody's medical record. And, you know, which is a real lost opportunity. So, and CMS, like I say, they rolled it out in July of 2012 with great fanfare. And, you know, they were hoping with fingers crossed that the system wouldn't crash. As people across the country, you know, registered for it and stuff. And it's been one, one difficult thing after another.

DWM:
I don't think it's still like smooth sailing.

NA:
No, it's really not. And I really feel for the facilities because I think that it's, it's a real burden, you know, and we become a burden to the facilities because we're sending them reports and saying, you know, you didn't fill out this death notification form on this patient. Well, you know, the patient transferred somewhere. Well, you didn't put that in Crown Web. So,

you know, it's just, it's really, it's really, I mean, I really feel bad because the dialysis centers are really bare bones staffing these days. And we're, we're taking staff away from, you know, patient care. And I don't, I don't think the government much considers that or really cares about it too much. They have a system that they're, they're operating. They rely on it for a quality incentive program. And for some of the aspects of the quality incentive program, but they also know that it's got so many flaws that they still use claims data for some of it too. So it's not the system that anybody wanted, but it's the system that everybody has. So

DWM:
It's taken a long time to get it too.

NA:
It has.

DWM: (1:45:37 - 2:14:50)
Yeah. So I want to talk about some things that the Mid-Atlantic Renal Coalition Network 5 has really been well known for. So why don't you talk about Fistula First?

NA:
We, when we started the Fistula First project, gosh, and that was, that was sort of an outgrowth of the continuous quality improvement work.

DWM:
Yeah, so talk about how it even came about.

NA:
Yeah, well, I think that, you know, we were starting to look at studies and using data, you know, CQI is data driven. So we started to look at the fistula rate and we were always very low. We have very low fistula rate. In fact, we were the bottom of the country for, you know, a lot of times. And I got in trouble because there was a reporter from the Baltimore Sun who called me up and wanted to know why we're at the bottom, you know, national in the country. And I said, well, you know, somebody's got to be at the bottom. You know, I really shouldn't have been so flip. But I mean, it's true. You got to start somewhere. And I said, you know, that's, that gives us a bigger opportunity for improvement. And, you know, I was always, um, it always bothered me that the federal government can say they want things, but when you present barriers to them that they can do something about, they won't. And there were lots of things with the fistula first project. There were barriers that they could have improved. They could have changed the reimbursement rate. They could have made some changes so that patients could get fistulas while they were in the hospital and didn't have to come back for a second admission. They could have looked at graphs differently. You know, I think there's some patients, I mean, a graft and a fistula, a graft is better than a catheter. You know, so they were not, you know, willing to sort of make some of the big system changes that really could have had an impact on this. But it was a very successful program. And we started looking at it and stuff. And again, we use the CQI model to sort of show the data to people. And we worked with surgeons and we worked with

dialysis centers and stuff. And the fistula first project was driven by initially IHI. They had the Breakthrough Collaborative. And so then we all got trained in the Breakthrough Collaboratives and how to run these programs and stuff. So it was a real learning experience for all of us. And it was the right thing to do. I mean, patients do need to have fistulas. And we had a really low rate. I mean, I think when we started, our rate of fistulas was something like 23, 24%, which is really disgraceful. And we're up in the 60s now. We're not as high as some of the other network areas. And we're still at the bottom. We're not the bottom. But again, I don't see a lot of comparative data anymore. So we don't have that basis for comparison. But I know that we did a lot of work with that. And then the contractor for the fistula first project was out in California. And I'm not sure exactly why CMS decided to compete that contract. And it could have been that the person who was staffing that resigned. And so they lost some of the staffing. I think that's right. They did. That network got into some trouble. And so they pulled the contract. And so then they put a competitive contract out to serve as the fistula first contractor. So we did that for a couple of years. And that was interesting work because we developed some more change concepts. And we actually did a strategic plan. And that was really sort of toward the end of CMS's involvement with fistula first. I think they decided that they'd had enough of it. And they were moving on to other things. And so after two years, they took the contract from us and just gave it to the network coordinating center, which was at that time run by IPRO out of New York. And they just rolled it into a bunch of other things. And they haven't had the emphasis like our last statement of work. We don't even work on fistulas. They have us working on catheters, catheter reduction. And so we've moved away from some of that.

DWM:
So do you think there is still active work on fistula first at all? Or is it just sort of dwindled?

NA:
I think it's sort of dwindled. I think it's, well, it's really become institutionalized. I mean, people do recognize and know what needs to be done. They know the change concepts are out there. And I think there's a different attitude than there was. I think that in our area in the South, they were putting a lot of graphs in. I think people think twice about that now. And they put fistulas in. So I don't think there is the same emphasis, just like with adequacy of dialysis. I mean, you know, that was back in the 80s when we did this. We had a big adequacy project. We had big anemia projects. And those things have sort of come full circle. So I think that when you look at that, there are measures that may have topped out to some extent. You know, practically everybody has a good KT over V these days. I mean, there's some people who don't, obviously. But it's not the issue that it was. And so you move on to other things. And I think that's happened with fistula first. We really need to focus in on catheters because we still have a high incident rate with catheters. And that's, you know, we'd like to change that. But there's a different emphasis.

DWM:
Yeah, so we sort of have the theme themes for a couple of years that come and go. And so, so patient safety, when do you think that became sort of a theme? And how did you all get interested in that?

NA:
That was driven to a large extent by Lou Diamond, who was, you know, the Institute of Medicine Studies came out, you know, to err is human. And, you know, people were reading those books and saying, you know, we do have a lot of medical errors and whatnot. And so the medical review board was sort of charged with looking at that. And we spent about six months, you know, sort of looking at the literature and sort of reading stuff and thinking, you know, what kind of problems do we have? And we, we talked about issuing a white paper. And I remember one night thinking about this and thinking, you know, we don't need another white paper. Nobody's going to, that's not going to make any change. And I started thinking about what would really make a change in our patient safety? What, what could we do? You know, we're educators is, is, you know, that's one of the things we do. We, you know, we put on programs, we have council meetings, we send out literature, we tell people things, you know, we show them how to do things. So what could we do that would help the dialysis centers? What's a pain point for them? For, you know, what was, why aren't they doing something with patient safety? And I thought, well, maybe one of the reasons and we'd had some experience, we'd got a contract from CMS and we worked with a group at the time called American Educ, Academy, or was it Academy for Educational Development? And we had done some talk quality programs and we had done some modules, some educational modules about talking around quality. And I thought those were pretty good, you know, and they were sort of off the shelf type things. And so I thought maybe we could do something with, with that kind of model where we could have programs that the dialysis center could actually run to talk about patient safety, different aspects of patient safety. So I came back and talked to the staff about this and I said, you know, what kind of modules could we have? You know, we could have a patient safety principal module. We can have, you know, a module on falls, slips and trips, you know, the safety issues that we were reading about. So we called the New England Network with Jenny Kitson and I said, you know, you want to work with us on this and, you know, can we develop a program? And we said, okay. So we came up with a design that we would have one required module and a facility would get, you know, points or a bonus or a star or a diamond or something for it. And if they did all, if they did five modules, so they would be, you know, it turned out five diamond facility. I remember going to the board and originally I was thinking it would be five stars is what I was thinking. I went to the board and I presented this and I said, we need some money for this. Would you do this? And they went back and forth and they didn't like the stars because they thought, well, you know, DaVita at the time, I don't know if they're still, but their logo is this big star. And they said, you know, and it wasn't that, you know, I mean, we had DaVita people on the board and Fresenius, we had everybody on the board and they said, you know, is it going to be sort of associated with DaVita if it's a star? And I said, okay, well, so we'll make a diamond and, you know, Lou Diamonds on our board, we'll just make a diamond. So they went along with that. And, you know, it took us a while to sort of get it launched. And we did it in network one and five originally. And people seem to like the program. They liked that they could, you know, have these modules and they could do these educational things. And so we designed it. It's all the same. So we, each module has,

you know, objectives and they have, it has a PowerPoint presentation. It has tools and resources. And it has required things, activities that you have to do for each module. But then there are optional things. And there's usually something for patients if you want to engage your patients. And we didn't want to make it like a state survey thing where we were going to monitor it. You know, it was sort of an honor system that if a facility said they completed it, you know, and they finished the attestation form and they gave us some information, then we were going to say, yes, okay, you did that. And only if, in the most egregious situation, if we really felt that they hadn't done anything, could we always retain the option of sort of auditing or getting the materials and stuff. And we really haven't done too much of that. And so it worked pretty well for the first couple of years. So then we started offering it up to other networks. And a lot of the networks really took us up on it because it was an opportunity for them to then celebrate their facilities at the end of the program. And they could, you know, we gave free passes to our council meeting, to our five diamond awardees. I had one unit one time asked if they could make a banner promoting themselves as a five diamond facility. I said, yeah, go for it. So they hung it out their window of their dialysis center. And this is a hospital based unit. And they were sort of like on the third floor or something. And a unit down the street called us up and said, we want a banner. And we said, well, you got to earn it until you got to make it because we're not providing banners and stuff. So, I mean, we got some competition in some of the facilities and stuff. And at one time, we had probably 14 of the 18 networks that were participating. And we kept every year, it was our goal to sort of refine it a little bit to improve it, update the modules, add more modules. And we've continued to do that. About three years ago, we automated the system so that people can actually go online, fill in the information. It gets approved at whatever network or here. And then they get a certificate for that diamond and stuff. So, I mean, we're doing that. And we've contracted with Darlene Rogers, who used to be the executive director of Network 15. And they lost their contract. And she has gone into business for herself. And so Darlene has been a very nice partner because she's coming up with some good ideas about new modules. She's putting at this point, she's putting some speaker points on all of the PowerPoints. So, I mean, we're just making things a little bit better. And then, of course, last year, what really helped us was that Fresenius decided to embrace the program. And of course, our numbers shot way up. And they really did a nice job with it because I think they had about 90% of their facilities become five diamond. And I mean, we really, really appreciate that. And then we have DCI, who's been in the program. And U.S. Renal Care is in the program. And it's been endorsed by all the associations and stuff. So it's been a fun program to work on. And like I say, it's just the idea that each year we can make it a little bit better and make it a little bit more meaningful. There's probably some modules. We did retire a couple of modules. And we've added some new ones on and stuff. And it's more, it's not just all about safety now. I'm working with, I'm serving on a PCORI group for University of Michigan. And they're looking at cardiovascular safety. You know, what constitutes a bad dialysis, you know, cramping, hypotensive episodes and stuff. And the reason they wanted to come to us is because they want us to do a five diamond. They want them to do a five diamond module for their program. And so, you know, we'll be adding that in. So it's gotten a lot of national recognition. People know about it. And it's just been a fun program to work with. Now, you know, I don't know whether it's

changed safety, you know, patient safety. But for the first time this year on the patient safety module, we have a pre and post survey. And so after this year, we may be able to analyze some of that data and look at it a little bit more closely and stuff. But our goal with the project was just to change the culture and have people start thinking about safety. You know, and one of the ways of thinking about it is to do some modules and to do some work. I don't know, you know. So it's been, it's been fun.

DWM:
Interesting. So, and fistula first is a little bit about just getting people to think about it and learn more about it.

NA:
And what was fistula first, it was actually, you know, we actually did a lot of tools and resources for the facilities, you know, to show them how to collect their data, to show them how to have the conversation with patients about switching to a fistula, to work with their surgeons, to start the communication so that their surgeons, you know, were accountable. You know, when they came back to the unit and stuff, if the fistula didn't work, you know, call the surgeon up and talk to them. You know, this is pretty simple stuff sometimes. But these are not things that I think the dialysis centers were looking at. So trying to pull together best practices and making sure that they got pushed out and that there's, there's a champion, for example, that's one of the change packages that you have one person in the dialysis center who's responsible for this. So that it's not just a nurse on a shift who's looking at his or her patients, but one person in the unit who may be looking at all the data and looking at everybody who's coming in and saying we have, you know, 20 new admits and 15 of them have catheters. What are we going to do to convert those catheters? So it's, I think having people look at things differently. And they don't get this in their clinical training. They don't get information on how to look at data. You know, you all are trained to look at the patient. You're not trained to look at the population. And I think networks bring that. To the, to the program and say, let's look at everybody, you know, let's not look at Mr. Jones. And I can remember when we would do this stuff, I'd have a lot of docs who would call me up and want to go through each and every one of their patients. You know, why Mr. Jones couldn't have a fistula. Or why, you know, Mrs. Smith, you know, is, is a double amputee and, you know, she can't have, you know. And it's, I want to hear this. You know, I don't want to hear about every single patient. I'm, that's not what we're trying to do. We're trying to let, have you look at your population and say, you have this kind of population and so does the person down the street. And the person down the street has a fistula rate of, you know, 70%. You have a fistula rate of 30%. Why do you think you're different from the guy down the street? You know, he has sick patients. And this is what the data started allowing us to do is to sort of show people, you know, because everybody has the sickest, oldest patients. And we can actually pull the data and we, through the whole fistula first report, we were giving, project, we were giving feedback reports to everybody. You don't have the sickest patient population. Your patient population is just like everybody else's, you know. And so, I mean, data speaks to people and it, you know, it is real. And so you can't get away from that when you start to look at your population. And that's when, you know, and the next step in all of that is, okay, what systems can you change, you know, in your unit? You know, so that

it's not relying on just one person. It's, you know, you're changing the system so that, you know, do you have a system so that when people come in, you look at what their graph is, you know, is that part of your protocol? Or you just start dialysis on them, you know. And so, I mean, just working with people like that. Now, you know, I think the LDOs probably do that. You know, they've put in a lot of systems and they've done a lot of work and stuff. But it's, and the independents don't really have the, or they didn't, you know, too much of the advantage of some of that. So I think that, you know, there was a role for us with the independents. There's a role for us with the LDOs too. But, you know.

DWM:
That makes total sense. So that sort of dovetails into how, what happened several years ago that ended up with you merging with the QIO. What is the background of the QIO and how did that end up coming together?

NA:
You know, QIOs are charged with doing for Medicare, population as a total, what we do more or less for renal. Looking at the quality of care, using data to look at the quality of care, looking at outliers. They now also are given very directive studies that they have to do from CMS and stuff. Diabetes studies or, you know, probably in the next, they're getting ready to go into a, what they call the 12th statement of work. And probably we'll be looking in that statement of work on CKD in another year or two. And opioid abuse. So, you know, these are the topics that they'll be working on. And they're very large, well-funded organizations. And there used to be one QIO per state. And then they also got consolidated and merged. So now they're down to, I think, 14 actual contractors for each of these state organizations. So they still have, it's still state level, but they don't have as many contractors working. So for example, Quality Insights, which is the company that holds the network contract, they have five states. But I think that there were just some signals out of CMS that they liked this model. That they didn't want to have as many contractors. Running a lot of contracts takes a lot of manpower at CMS. I mean, just reviewing, reading contracts and reviewing contracts. And their reimbursement systems are different. Networks have always been on a fixed price contract. So I get one twelfth of the money and I can spend it any way I want as long as I submit my deliverables. And as long as I'm doing the work to their satisfaction, they don't care about my line items and whatnot. And it's a very nice contract mechanism because it does allow you to shift money around and do the QIMs because they're such large contracts work on cost reimbursed contracts. And so there's a lot of accounting that goes on in the federal level. And you have to submit invoices for the work that you're doing and it's different. You can't make line item switches and that type of thing. So it's a different contract model, but it results in a lot of manpower and work that needs to be done at the federal level. So it's a lot easier for them if they have fewer contractors. And so probably about 10 years ago, we just started seeing signals that they probably wanted to have fewer contractors and that this was going to be the way of the future. Networks 7, which was in Florida at the time, lost their contract. Some of these networks have, I mean, over the years, networks and QIOs have lost contracts for performance issues. And they did

lose their contract for a performance issue. And so CMS put out a bid, RFP for that network area. And we're always looking for new business. So we bid on it. And the QIO in Florida bid on it. And I don't remember what year that was, but the QIO was awarded the contract. And it was, I mean, some of us looked at that and said, this is a big red flag. This was the first time that they have given network contracts to anybody that wasn't a network. First time that it wasn't going to be a network board running the network. Things are changing. And we started going to meetings and the feds were really sort of touting this as a really nice model. That, you know, all this stuff was being done in the back room and, you know, freeing up the network to do all this other stuff. And man, we were pretty resentful and pretty resistant to that. And then it just became clearer and clearer that this was the way of the future. This was what was going to happen. And so we started to look around and think, you know, it, do we want to, you know, stick with the old ways? We've always been pretty, you know, forward thinking. We've always been, you know, on the cutting edge of stuff. And if that's where we want to be, maybe this is what we need to do. And it turned out that Rick Latos at the time had been asked to serve on the West Virginia board. So he was on the West Virginia board. He later became president of the West Virginia board. So he was on the board and he started to talk to us about West Virginia Medical Institute. He was still on our board and just said, you know, maybe you ought to think about this and, you know, come to meetings and stuff. And so they started inviting me to meetings and I sort of, you know, went and I liked the people and we just sort of got to know one another and stuff. And so we had a board meeting and we were debating about all of this and we put, you know, did we want to join another organization? Did we want to join a QIO at the time? Or did we want to try to remain independent? And we spent about a year and a half, you know, going through the pros and cons of all of that. And we laughed about it later and said we had a long engagement with West Virginia before we actually married 'em. And, you know, and we talked to other QIOs about maybe merging with them and stuff. But I think that WVMI, and they have since changed their name, they're now Quality Insights, but WVMI really valued us as a network. They really valued what we brought to the table. They valued the work that we were doing. And a lot of the QIOs sort of were dismissive of networks because we're small. And, you know, David Shulke one time who was head of the AHQA, which is the American Healthcare Quality Association, which was the big lobbying organizations for QIOs. He probably had 15 or 16 staff members. And, I mean, they had big bucks from the QIOs. And I remember Jenny Kitson and I were meeting with him for something. And he said that we never had to worry as networks because we were budget dust. And budget dust. Yeah, that our program was so small that we were just budget dust. And we were not going to be, you know, and I think that's the way a lot of the QIOs felt about us. I mean, we were just a tiny little program and they were doing big, important things, you know, because they, and they had the big bucks to prove it. And so, you know, when you were talking to the QIOs, some of them just didn't want to mess with us at all and stuff. But I never got that sense from WVMI. Like I say, they, I think probably because of the relationships with Rick Latos. And we, as time went on, we got to know them and stuff. And so I felt like they were a really respectful organization. They valued, and we started thinking

about what benefit would we get if we belonged to a QIO? And one of the big benefits was protection. You know, if CMS decided to compete our contracts, it was better to have sort of a big brother with us that helped us with some of this. And I think that was right. I think that it has helped us. So we joined them about seven years ago and 2010, I guess, and maybe 2009. I don't remember exactly. And part of what we asked is that they would put one of our board members on their board, their parent board. And they did that. So we've had Lou Diamond and Rick Latos on their board, which has really been nice because they keep the renal activities at the forefront. About the same time we were doing this Network 3, which is New Jersey and Puerto Rico and Virgin Islands was shopping around for a QIO. And they knew what we were doing, I think. And they just joined. They just, the executive director wanted to retire and she wanted to have somebody, someplace to park her organization. And so they joined WVMI and about the same time that we did. So, and then a few years later, they took half of the networks and they said they were going to do, CMS said they were going to do a random draw and half of the networks would be competed that year. And then they said in the next process that the other half would be competed. So we were all sort of chomping at the bit and wondering what was going on and sort of was like the lottery, I guess. And we were not competed that first year. I can't remember exactly who was competed, but it was very stressful and the networks who were associated with QIOs did a lot better in that. And then the next time, it was I think three years later in 2016, they decided, no, they wouldn't. It wasn't the other half's time. It was everybody's time. And so everybody was going to have a competitive contract. And it's become quite clear the networks that had QIOs, QIOs took a lot of the network contracts that weren't associated with any QIO. Network 1 was taken by a QIO. Network 13 was taken by a QIO. We had three QIOs. So basically today, everybody is either a part of a QIO except Network 11, either by choice or because they've lost their contract.

DWM:
So how has Network 11 survived? Where is Network 11?

NA:
It's Minnesota. So it's Michigan, Minnesota, South Dakota, North Dakota. I think they're a decent network. I think they're a good network. So that helps them. I don't think they've ever had any competition.

DWM:
There's nobody there who wants the business.

NA: (2:14:51 - 2:14:51)
Yes. So I don't know. But like I said, they're the only ones now that are not associated with the QIO. So everybody else is folded into a QIO. And the nature of the work has changed.

DWM:
In what way?

NA:
QIOs have always been followers of CMS. They've done what CMS wanted without question. They always, I always got the impression that they felt like CMS was paying. They were the primary customer. We've had debates about this. And, you know, your primary customer is the one that you work for. And so they viewed them as the primary customer. So there's not been the challenge of CMS that networks have historically pushed for. I mean, I never felt uncomfortable pushing CMS and asking questions and arguing. You know, I'm a fairly confrontational type person anyway. So it doesn't, you know, that's sort of in my nature. But I feel like, you know, you really do need to, you know, have a healthy debate about things. It doesn't mean you're being disagreeable. It's just, you know, things need to be talked out. And you need to make sure that you have all views represented. And so I've always, you know, felt like that was one thing that we should do when we have meetings with CMS is we should present, you know, another side or just sort of say, well, where are you thinking? You know, why are you coming up with this? I never found that the QIOs did that. They sort of rolled over and did what CMS told them to do. And so that's when you have a mentality like that, and now, you know, you're working for somebody like that, then that's going to become the culture in the network too. And so that's, I think, what's happened with some of this. And, you know, it's a, it's not, it's not a business anymore with a lot of the networks there. It's a product line. It's a, you know, it's a contract. It's a project that you're working on. So you lose some of it. You lose some of your autonomy. We are no longer Mid-Atlantic Renal Coalition. We, we're not an independent 501c3 now. We are a part of, we're not even part of, we are Quality Insights. And I think when I retire, that they'll probably change the name and drop MARC, we'll become Quality Insights Network 5. And, you know, it makes me a little sad, you know, that we've been MARC so long. And I think MARC has a brand, but it's not the brand the company wants anymore. We want to be all one as Quality Insights. And so that's, that's what we'll do. And I think that's what, you know, some of the other networks will, you know, sort of just not be the same program. But it will be fine. I think it will be, you know, still be networks.

DWM:
So I'll put you in a little bit of a spot here asking you this question, you don't have to answer it. So listening to this thought that for the QIO, CMS is the primary customer. Yeah, I'm thinking when we talked about how you originally started and you were very tightly sort of tied to patient, patient care, patient outcomes. And CMS has a conflict of interest. I mean, they don't necessarily advocate totally for the patient. And they have a, they have a cost. They want to control cost. And so they have a conflict of interest in that they want to control cost. So that's not that as if the CMS is a direct representative or advocate for the patients. So if CMS is the primary customer, how removed do you feel from providing support, best care, overseeing the quality of care for patients?

NA:

You know, I don't think it's quite as drastic as you sort of outlined, because I think that CMS has spent a lot of time over the last 10 years thinking about patient engagement, you know, and thinking about patient advocacy. You know, I think I would, I have to give them credit for sort of making sure that the patient's voice is being heard. I mean, they do that with, when they have their quality conferences, they bring in patient and family members. They do a lot of work in that area, you know, making sure, I think they do see themselves as being beneficiary focused. So I think it's not too hard for us to think of the, although CMS may be our primary customer, the beneficiary is, and the patient is the benefit of all of that. Now, we do more work as networks with patients than the QIOs ever did, because they don't really do, they don't have patient advisory committees. They don't, for example, when they process patient grievances, they don't have a social worker on staff. It's a chart review. They're looking at the quality of care, whereas we're really looking at psychosocial issues. You know, most of our grievances are due to poor communication, you know, that somebody was disrespectful to somebody, or that they didn't, you know, explain something properly, or, you know, or they didn't tell the patient that, you know, they're going to be put on late today. And I mean, that just causes all sorts of problems and stuff. The QIOs have never gotten down to patient grievances like that. They just, you know, didn't do that. And so I think that, you know, CMS is aware that the networks have that expertise. In fact, they drag out our patients all the time at their national meetings and pull them on stage and, you know, say how wonderful these patients are and stuff. And they are wonderful. But I mean, it's just, it's been interesting to me that they don't have that in the QIO program as such.

DWM:
So you're, you still feel like you're very connected to work that directly benefits patients?

NA: (2:21:11 - 2:21:11)
Yes. We, yes, I do. And, you know, we have a really dynamic patient advisory committee. And they do a lot of really interesting things. They, they did something last year. We wanted, and they designed their own projects. That's the other thing that we haven't lost that capability. And we wanted to do something in emergency preparedness. And so, you know, we were presenting ideas to them and stuff. And they just blew every idea we had off the table, you know. So they came up with this campaign that has been picked up by the national case or emergency preparedness people. But it was a what, what if campaign. So they had a series of posters that we gave to all the dialysis centers that they could talk to their patients about. What if you had no water at home? You know, what if you had no electricity? And it was just, you know, the patients coming up with, you know, what would you do if you had these things? And so that was really an ingenious campaign. And it's, you know, it was really, really spoke to their issues. What would they do in some of these things? And so it was nice to see that. So yeah, the patient advisory committee is great. We still do that. We still do newsletters for the patient advisory committee. That's probably the only postage we have anymore. So, I mean, I think we're very much in touch with patients. And we also, over the last couple of years, we have work groups from the medical review board that work with us in implementing and designing the QIAs, the quality improvement activities that we have to do. And about four years ago, we started putting patients on each

of those work groups. And so we always have two patients on each of the work groups now. And they bring a very different perspective to the work. And we have really worked hard to try to demonstrate to the dialysis centers that patients need to be at the table. Now, I don't know that we need to go so far as to require patients on governing boards. I mean, that's always been something CMS has talked about. But I think it really does improve and benefit everybody when you have a patient at the table. And, you know, somebody who can give you their perspective. And so we really do push that. And CMS has been pretty good about pushing that also. I can't fault them for any of their beneficiary work.

DWM:
Great. So you want to talk about end-of-life care just a minute?

NA:
Oh, gosh.

DWM:
That's your latest one?

NA:
Yeah, we're very passionate about end-of-life care. We started, well, Woody Moss, who has been a leader in all of this across the country, has been in our network, you know, for all these years. He was one of our early Medical Review Board chairs and stuff. And so I think that, you know, just sort of picking up on people's interests and stuff has been one of the things that we've been very good at. Because, you know, we can tap into that expertise and knowledge. And we've worked with Woody for a long time. And back in 2003, we actually had a Caring Through the Continuum was the name of the symposium that we had in Florida. And CMS was very supportive of that. They gave us a chunk of money to do some work and stuff. And we had Ira Biok come and speak. And it was a really good two-day conference. And so we've put together a coalition. And over the years, you know, we've just, we've supported it, but we've not done a whole lot with it. Because it was, you know, we just, you know, we talked to Woody and he'd go off and do something. And we'd go off and do something. We'd come back together again and we'd do some things. So finally, about, I guess it was about five years ago, I told the board of directors, you know, we had some reserve funds. And I said, you know, we really need to get serious with this. If we're going to do something, we need to throw some money at it. And we need to spend some time trying to find some grant money. And so they said, okay. And they put a dollar amount. They said, you have X amount of dollars for two years and see what you can do with it. And because we didn't have, we weren't doing all the HR stuff. We weren't doing all the business stuff. I mean, the QIO had taken all this over. I, for the first time, had time to actually do some things with this. And so we hired a consultant, Dale Lupu, a PhD out of DC who had worked for the National Hospice. I don't even know what the group was, but it was hospice physicians for the most part. And she's really great. And she's really a lot of fun to work with and stuff. And so we said, you know, we said, we need a strategic plan. We need to, you know, build this coalition. We need to, you know, start marketing some of this. And we really started to become very aggressive about the work we were doing and trying to get

the word out. You know, working with ASN, we got Anne O'Hare involved and Dan Lamb involved and trying to figure out who was doing what. Jane Schell, you know, up in Pittsburgh. So we were starting to identify some of the players, a lot of young people, you know, coming into the field or sort of getting involved in this. And it's, I just feel really passionate about it. I feel passionate about it for myself. You know, I'd like to have the appropriate end of life care. And we see so many things that happen that are just so sad. You know, people aren't given a choice about conservative management. And you can go into a dialysis unit so many times and see, you know, the van from the nursing home roll up and patients are just, you know, have such poor quality of life. And I, you know, I wouldn't want that for myself. I don't know, you know, and if people want that, you know, we're all in favor of that or I am, but it's just, I think we need to think about it differently. And when we tried a couple of times to get CMS to talk with us and I had one of the CMS administrative people tell me they wouldn't touch it with a 10 foot pole. It was too political. And, you know, this was, I guess, during this Obama's re-election for a second term. And they said, no, you know, Sarah Palin had talked about death committees and they didn't want to go there with this. So we, it became clear like that, you know, government was going to do anything. And that's when I was very pleased that the board decided to support this. So we started working and then we found out about the Betty and Gordon Moore Foundation. And we thought, well, this is going to be a, you know, potentially be a match. And it turned out that Lou knew Janet Corrigan who had been hired. Well, but we had a guy there that we were working with and we worked with him for about eight months trying to, you know, getting, bring him in and tell him about our ideas and stuff. And we thought we were making some progress. And then all of a sudden he left. And so we thought, oh my God, you know, we're back to the drawing board. I was so frustrated because I thought we wasted all this time and we thought we were going to, you know, have some interest and stuff. And then it turned out that Janet Corrigan was named to be his successor. And I called Lou up and I said, do you know this woman? And he said, of course I know her. She was with, she was with NQF. And I said, well, maybe, maybe we're in good shape again. So I said, you know, asked Lou, I said, well, can you do some introductions for us? And so we can start talking to her about, you know, this program that we were thinking about. And he did. And she was interested. And it turned out at the same time that January, I guess, Harvey Feinstein, Feinberg, he used to be at Institute of Medicine, was named as the CEO. And they had changed their priorities. And one of their priorities was end of life care. So it was like all the stars just sort of aligned. And we put in a grant proposal with them, which they have awarded, as you know. And we're, we've called it the Pathways Project. And what we're trying to do is to think about the pathways for conservative management, a pathway for withdrawal from dialysis, and a pathway for providing supportive and palliative care for patients throughout the continuum. And as you know, because you serve on our technical expert panel, you know, it has turned out, we were sort of thinking about this in terms of an official first model of a breakthrough initiative. And so we're designing change packages. And you can't just have a change package for one, you know, for conservative management, blah, blah, blah, because they're so intermeshed. And so we are sort of developing those change concepts, and we'll be testing those. And I think they're, we're pretty close, you know, to looking at that. And then phase two of the project, we'll go back to Moore, and they will entertain another proposal from us because we decided to break it up in two

phases to actually pilot test these. And I think that we'll be pilot testing them in the sort of independent ESCOs. I don't, after talking to, you know, Frank, I don't know that that's going to work well in a Fresenius ESCO, but Doug Johnson is pretty supportive. And it's just they have a different situation. And so we're going to be asking maybe Rogasin and Northwest. I don't know who we're going to be using yet, but we'll test that. And then what I'm hoping is that once we get the change concepts tested and they seem to work and stuff, that maybe CMS will talk to us and think about incorporating this in the network statement of work. So that down the road, networks can then roll this out across the country. Now, I don't know whether we'll be able to achieve that, but at least we have a plan. And, and I think it's very important work because people don't know how to have the conversations and people don't have time. And, you know, just doing some work so that people feel more comfortable with this topic. So you can actually talk to people. I think it's very important. So the quality of, of our end of life care needs to be improved, you know, whether it's dialysis or in any other aspect. So, you know, so that's, that's been really, it's been fun work and it's been fun to sort of see it all come together. And it's, it's sort of reminds me, Dugan, of the early days when we were working with the nephrologist, because you get a bunch of people together in a room and they have that same passion and that same energy that I remember from our early days in the program, because this is real sort of groundbreaking work and people are just sort of at the cutting edge of some of this. Now, lots of people have been doing it, but not in a real organized way. And so it's, it's like they're excited and passionate and that's, it's really nice to be involved in that. So I like it. And I really, I really appreciate that the board has been very generous, you know, with the funds and allowing us to have the time. In fact, it was Frank, who the board said after two years said, well, you know, have you gotten a grant? And Frank was the one who says, wait a minute guys, this takes some time, you know, let's, let's give it some more time here and stuff. So, yeah, he was, he's been very supportive. So, you know.

DWM:
A lot of these projects, this one included for you, just they unfold very, very slowly. They really do.

NA:
Yes.

DWM:
So when you look back, I mean, now we're talking about mid 1970s to 2017.

NA: (2:32:48 - 2:32:48)
Yeah.

DWM: (2:32:49 - 2:36:30)
What do you see has been the really, some of the really big changes in dialysis delivery and patients receiving dialysis? What are some of the big, big changes that you see?

NA:

Well, I think the patient population has aged so much. And it's, I think it's a much more dependent population than it was. You know, when the program started, there really was a lot of discussion about voc rehab, about returning people to work, about, you know, I don't think it was supposed to be a small program. It wasn't supposed to be, you know, nobody anticipated it would be a large program. And I think that, you know, so that's been a shift that patients, and maybe it's shifting back again, because I think there is a lot with patient engagement. So maybe there's going to be another shift where patients are going to be more involved in their care. And I hope, I hope we see that over the next few years, because I think we went through a period where patients were not very engaged in their care. And they didn't, you know, dialysis was something that they had to do every day. And, but I think it, I'm seeing more and more patients who think of it as a secondary part of their life. It's not a primary part of their life. It's something they have to do, but they have other interests and other, you know, things going on. And, and so that's, I think we're taking a swing back. So that, that was a change. You know, the other thing I think that I'm really sorry that we don't see, and this is, I blame the government for not funding this, but we really need nocturnal dialysis. I mean, I think that people need longer dialysis than just 12 hours a week. And I think it's unfortunate that, you know, we don't find mechanisms and ways to do home dialysis and nocturnal dialysis and a longer dialysis, because I think people would feel healthier or they would feel better. You know, I was interested in the article that was in Health Affairs just recently about the number of African-Americans and Hispanics that are being transplanted now because of the allocation of organs, you know, and the change in that. And I think that's really wonderful. And I think that, you know, we should, you know, see more with transplant. That would be nice. The other changes that I see is that, you know, I don't think that people enjoy the work in dialysis the way they used to. And that's been a long time coming. I would not want to be a nurse in a dialysis center today. I think there's a lot of pressure on nurses and technicians. There's a lot of staff turnover. And I really, that was always one of the areas that I wanted to get into to see if we could design a project that would reduce staff turnover and give people more satisfaction with their job. Because I'm convinced people don't necessarily work for money. I mean, it's nice, but that's not the driving motivator for most people. They work because they enjoy the work and they get some personal satisfaction. And I think there's really something missing in the dialysis centers.

DWM:
What is it?

NA: (2:36:30 - 2:36:31)
I don't know. I think that the profit margin is part of it, I think. It is, you know, I think that the dialysis centers go for the bottom line a lot of times. And I think they lose something in all of that by doing that. I think that they don't invest enough in their dialysis staff. And, you know, I don't think there's not much emphasis on staff development from our perspective. You know, I know it's a challenge for the dialysis unit staff, for example, to come to council meetings. You know, their companies don't a lot of times pay for them to do that. They don't pay for them to go to ANNA meetings, go to NKF meetings and stuff. And this is where they, you know, this is something that I think they get, they would get satisfaction from

dealing with their peers and getting outside their organization and stuff. So I think there's some things like that, that I always sort of wanted to take that on as a little project, like I said, to sort of look at staff retention and from a perspective that we have that's not in the unit and stuff. So that makes me sad because I can remember, you know, going into a dialysis center and seeing a lot of nurses that were really happy with their care and, I mean, their work and the care they were providing and stuff. I see an awful lot of burnout. And, you know, I occasionally will call a dialysis unit up and ask them if I can come to, you know, one of their quality meetings and stuff, their patient care meetings and stuff. And, you know, maybe I just don't know people like I used to, but I always think there's some fear now of the government coming in, which I didn't sense before. I think that people are really nervous about all the regulations and everything. And that's sort of changed a little bit.

DWM:
Yeah, I mean, so over this period of time, certainly regulations have grown pretty significantly. I mean, I definitely think, you know, having a surveyor come in is a frightening event, a high pressure event. Also, you know, you talked a little bit, and this sort of dovetails into your end of life work that you're doing today. I mean, patients that were dialyzing 30 years ago were much more independent. Nurses have, nurses in patient care techs have a lot broader group of patients to care for today.

NA: (2:39:11 - 2:39:11)
Yes, they do.

DWM: (2:39:11 - 2:40:37)
Do you feel that as well as part of this?

NA:
Yes, they do. And they have sicker patients and they don't have the, I don't think they have the nephrology support that they used to have too. I mean, there's just, there's too few nephrologists to go around. And so they don't have the time to really devote to, you know.

DWM:
But what about extenders? I mean, we're certainly seeing a lot more use of extenders. How do you feel about that, the use of extenders?

NA:
I think that's great. And, you know, we don't work with PAs and NPs very much. You know, they're just, we don't have them on our boards. I don't have to think about that because we don't, we don't have any of them on our boards. And you're right. They are definitely playing a big role.

DWM:
Yeah.

NA:

And, I mean, we've talked about them with the supportive care work because we think that's probably, those are probably going to be the individuals that actually do most of this. But we don't, I don't think we have a single nurse practitioner on our medical review board.

DWM:
And I certainly think from rounding in the dialysis unit, a lot of the staff really benefit from the more attention they get from a nurse practitioner or a PA that happens to be really involved in the dialysis facility. Just thinking of nephrology support, clinician support that they need.

NA:
Yeah.

DWM:
You mentioned earlier that in the 1970s, when everybody was starting to work and the networks were being set up, everybody thought the program would be relatively small.Why do you think they thought it would be small?

NA: (2:40:40 - 2:41:49)
Oh, I think that's what everybody was told at the congressional level that, you know, that there wouldn't be that many. I think they thought it would cap out at about 60,000 patients. I mean, there's. They just didn't think there were that many. They didn't think there were that many people that would have renal failure. And of course, at that time, they weren't dialyzing diabetics. They, you know, diabetics were not even, you know, offered dialysis in the early days. And so I think they thought that this was going to be a very limited number of people who were going to need these services. And they were going to, you know, rehabilitate these people and send them off to work. And they were going to contribute to Social Security. And so, I mean, I just think it was a miscalculation. And I think there's all sorts of miscalculations in health care. Look at, you know, the ACA and now what we're having, you know, with Trump care and stuff. And I think it's just very difficult to predict all of this. I don't know, you know, so.

DWM:
Yeah. And technology has changed. I mean, we certainly today have a lot more people surviving their cardiovascular disease to get renal disease. Or surviving their diabetes. Exactly. Living much longer with diabetes. So, yeah. The technology of other diseases has changed a lot.

NA:
Yeah, because I think there's probably 600,000 patients now.

DWM:
Yeah. Do you want to talk for a minute about friends and people that you think have been really important to you or to the care that really have impacted sort of the way that dialysis is being delivered today?

NA:
I think that, you know, some of the pioneers in the program, you know, like John Sadler and John Bauer were people that I worked with because I was working with the forum for a while. And John Bauer was chairman of the forum. I think Fred Westerfeld, Lou Diamond. Lou was very instrumental in policy issues, was the RPA president. You know, Rick was the RPA president. You know, all of these guys had had an impact on the program and were willing to come to, you know, meetings and stand up and present views to CMS, you know, for them to think about or go lobby. And we can't lobby, but go to Congress and do some things. So I think it's just, you know, and I really have had an opportunity to work with a lot of really great people. Woody Moss has been great over the years. I really enjoyed working with Bill McClellan. And I really miss him. Janet Lynch and I were talking about him the other day because he was really great with our official first project when we were the contractor for that. He was very helpful. Jay Wish was very helpful to us. So there's just been a lot of people over the years, you know, who have from other networks. I think about Allen Kliger was a lot of fun to work with and Clemon Myers. We had a peer up project that did peer to peer mentoring and Clemons worked with us on that project. You know, we had, you know, all of the board members that I've had have been very supportive and just really good at sort of keeping us grounded and keeping us, you know, on track and saying, you know, don't get so discouraged by the government stuff. Just go forth, do good work. So it's been nice. Our first medical review board chairman was Jack Hall, which you knew from Danville. And Jack was so much fun because he was, he didn't believe in this federal program at all. But if we were going to have it, he was going to be part of it. And so he was our first medical review board chairman. He would actually fly himself up from Danville. And I never knew how to reimburse Jack. And so he would submit a voucher and say, just pay me, you know, what the travel, the mileage would be. And so he was, you know, really good. And so there was, you know, and then when Frank came on, Frank was very involved with us with Gamewood and got us sort of up and running with websites and some emails and stuff like that. So everybody has just sort of contributed a piece to all of this. And it's been really nice. I've had some really nice colleagues, network colleagues. I've mentioned Jenny Kitsen, but I was Jenna Krisher, who did the SIMS, was wonderful to work with. And Glenda Harbert, who has been in Texas and who is also retiring in October, has been, you know, Glenda was a dialysis nurse. And so she was somebody that we could sort of turn to for that expertise when we were looking for, you know, questions. If we didn't want to turn to our own nurses, you know, Diane Carlson has been fun. Susie Stark has been a lot of fun to work with. And so these were, this was sort of a close group. And these are women that I probably will, you know, keep in touch with for many years to come because we've just had this shared experience of working in this program. Susie lost her contract and now has a great position with ASN, doing work with CDC and doing ASN. Jenny has pretty much retired and is doing some really interesting things in Connecticut with the land trust that she works with. She's also on the AAKP board. Jenna's working for the QIO in her area. So everybody's sort of landed on their feet which I think is nice. But I think we're all sort of driven, you know, to do something and, you know, work and keep plugging away.

DWM:

In the time that you've been doing this work, I would guess in the 1970s, we were talking about a lot of small independent dialysis facilities even through the 1980s. How has it happened that we've gone from all these little independents to rolling up to small, middle-sized, large dialysis organizations? Why has that happened so much and what are the good things and the bad things about that?

NA:
Well, I think it's happened because you need efficiencies. I mean, you have to run a program that allows, I mean, if you're going to be a for-profit, you have to be able to make a profit. And the only way to do that is to be efficient. And you can be efficient with size and, you know, just sort of having mass and stuff. And I think that providers, I mean, early on, the docs sort of owned all these dialysis centers and that became, you know, unacceptable. And so it became...

DWM:
How was it unacceptable?

NA:
Well, I guess the government decided that, you know, with the Stark rules and stuff that you couldn't, it was a conflict of interest, you know, just like, you know, pulmonologists couldn't, you know, own their own companies that provided oxygen machines and whatnot. So, I mean, I think there was some of that. And so it became increasingly more difficult for people to be independent. And so it was easier just to, you know, join an LDO. And I think the LDOs have been pretty good at marketing and pretty good at the sell, you know, and convincing, you know, people to buy, to sell out to them. And, you know, thinking... I think it's unfortunate sometimes I think I have heard conversations from physicians saying they got X amount of dollars for all, you know, per patient. And it sort of makes me kind of cringe because they think of patients as sort of a commodity to be bought and sold. And that's unfortunate. And I'm sure at the end of the day, that's probably not the way they feel. But that's sort of the message that they give out that, you know, here's, I've got a large unit and I'm going to make a lot of money selling this to an LDO. And they have in a lot of cases and stuff. So I think there are good things and bad things with that. I think the good things are that it really is more efficient. I think the bad things over time is that it really... I think some of the quality of care has suffered in some of the dialysis organizations because they do have difficulty retaining staff and they do have difficulty getting down to the patient level for some of this. I don't know, Dugan.

DWM:
Are you nostalgic for the days? I mean, if we could take cost out of it and we still had a lot of little independent dialysis facilities, do you think that would be better?

NA:
No, I don't think it would necessarily be better. I really do think that... I mean, I've worked in a non-profit environment my whole life. And this is, I mean, that's what I believe in a non-profit. I would like to have seen more non-profit organizations like DCI and Independent Dialysis, John Sadler's Group. I think that would have been better for the program. I think

that, you know, shoveling whatever profits one can make back into the program. And non-profit doesn't mean that people don't get paid well because they can get paid well. They can get paid very well. But it's just different, I think, when you're not accountable to stockholders and you're not accountable or you're not constantly thinking about the bottom line. It bothers me that there's a lot of MBAs in the program, you know, and a lot of people that, when I talk to some of the dialysis nurses, they are given tasks that directly relate to the bottom line. And not necessarily relate to patient care. And that they have a lot of stuff hanging over them. And they don't know sometimes about the quality tools that are available to them because they don't get it from corporate. They only know what comes from corporate. And that's, I mean, that's on them too. Because they could certainly, you know, step out and learn things too. But they get very insulated into a corporate mindset. And I think that's not necessarily a good thing. So, you know, so it does. Yeah, I think, I think it does make me a little sad that I don't think that, you know, having 6,000 independent dialysis centers is the way to go. But I think having some less emphasis on profit would have been the way to go.

DWM:
One of the things that I know from my experience in the LDO that is of real interest to the LDO is to have a standard of care delivery. And so in that sense, I do wonder whether when you, you know, first were experiencing things in the 70s and 80s, there must have been a lot of variability. I mean, some clinics that were very well run, totally excellent, centers of excellence.

NA:
Yes, absolutely.

DWM:
And some centers where they just had, so would you say there's some value to at least having an expected standard of care, whether that's a not-for-profit or a for-profit organization? Does that help?

NA:
You know, I think it probably does. But I've also seen with even, I've seen some really bad dialysis units in large organizations too. And I think that it's sometimes hard for the large organizations to really figure out how to make that better, you know, because you've got maybe a medical director that, you know, in a small area, you don't have any choice. You got to use this guy or gal. And, you know, there's a limit to what you can do. And so you do what you have to do, you know, to provide those patients with something. And so I think that, you know, it's, there's going to be bottom feeders everywhere. There's going to be, you know, there's, it's just a natural order of things. So you're going to see them in LDOs, you're going to see them in independents and stuff. So I think that, yeah, we should have a standard, but sometimes those standards don't get applied equally. You know.

DWM:
Speaking of which, what happened to the Certificate of Need in Virginia?

NA:
I think it went away. Most states, I don't think there are very many states that have Certificate of Need anymore. And I think that the ones that do have it have assigned a dollar value to it. So if it's a big ticket item, you need a Certificate of Need. I think there's a Certificate of Need in DC and West Virginia, but I don't think it's, it's not as rigorously reviewed as it was at one time. And I think they've found that it didn't really, it wasn't really a cost savings. So why put all this money into this when they're, you know, because what was happening is they were approving everything that was coming along anyway. And they were saying, let the market, you know, deal with it. And so we don't even have Certificate of Need anymore. We used to, when we had access to data, we used to put zip code reports out. And so we had the number of patients by zip code and stuff. And people use those for, you know, deciding where they were going to do. And we don't even do that anymore. We get requests for them and stuff. But I don't know where people are getting their marketing information and stuff. I guess, you know, they're doing their own thing now. But so that was, like I said, that was another service we used to provide. And we don't, we have no access to that data anymore.

DWM:
So it's just all market driven.

NA:
Yeah, it is market driven.

DWM:
So what do you see as the future for dialysis? You have to look 10 or 20 years. What do you think will be sort of some of the big changes that we'll see in dialysis in particular, renal care in general?

NA:
I don't know. Somebody sent me an article the other day where they're thinking about they're doing some research on an implantable kidney. And so maybe, wouldn't it be nice if everybody was just out of business? I mean, I don't, I mean, it really would be, you know, nephrologists could go back to taking care of CKD patients and, you know, being internists and, you know, doing that kind of thing. And I mean, I don't know what that's going to do to the whole industry and stuff, but that would, I thought about that. I thought, you know, that would be kind of nice if we didn't have to worry about this anymore. I don't see that happening really. You know what I'd like to, I think will happen in the next 10 years is there's got to be greater emphasis on home dialysis. There's got to be greater emphasis on transplant. You know, we got to figure out how we're going to get people transplanted. That's the only way you can really rehabilitate people. The government's got to get serious about how they're going to, the payment models that's going to promote some of that. You know, so that, I'd really like to see some of that. I'd also like to see, with this whole end of life, I'd like to see that we don't dialyze people who don't have real quality of life. I'd like to see that, you know, maybe we, you know, you don't want to have arbitrary age limits and

stuff, but, you know, I'd like to be able to look at the data at some point down the road and not see patients who are 95 and 100 years old on dialysis. You know, that bothers me because I, I mean, I shouldn't be, I'm not trying to be judgmental, but I got to really question, you know, what kind of quality of life does a 100 year old person have going to dialysis three days a week? That makes me kind of sad. And I can say that's, that's probably not right because, you know, maybe they have a great quality of life. I don't know. But I would like to see that we're making sure that people who do receive dialysis have more than just coming in three days a week and just, you know, sitting in a chair and going home and not feeling well. So I don't know how that will come about. I don't know that networks will make it another five or 10 years. I really don't. I think that, you know, healthcare is changing fairly significantly. And what we're willing to pay for is changing significantly. And I think that, you know, at some point, I think people will start to look at this program because it is expensive. You know, they always say it's 1% of the Medicare population and they take 6% of the Medicare budget. And somebody's going to, you know, look at that and sort of say, you know, some politician at some point but I don't know. I don't know what it's going to be 10 years from now.

DWM:
It is a time of change. A big technology, science and technology change and healthcare system delivery change.

NA: (2:58:35 - 3:03:04)
It is changing. And I'm looking forward to getting out of it, to tell you the truth. So what is retirement?

DWM:
You say you're retiring in October of this year. What does that look like for you?

NA:
I have bought a house in Polson, Montana. And I'm moving there in October, 1st of October. I've sold my house here and I'm running it back. And, you know, so we're, it's a new phase of our life. I have a daughter who lives in Missoula, which is about an hour and 20 minutes. I'm leaving a son here, which makes me very sad. But I know that he and his family will come out and visit us and we'll come back here. And I am planning on just spending the first six months or so just reading and doing things that I haven't been able to do for a while. And sleeping late, that appeals to me. We'll probably get snowed in over the winter. but it's going to be fine. I have, I have three dogs and I have three grandkids out there and they'll come up in the summer and we'll go into town in Missoula if it gets bad and I'll stay with them. But yeah, so I don't, I haven't really made any real plans yet. So looking forward to learning new things out in, it's a different part of the country and I've never, I've always lived in Virginia, different parts of Virginia. So I think this will be a real change for me to go out there and see what it's like.

DWM:
Oh, that is a big change. Yes. Do you have hobbies that you're planning to take up?

NA:

Well, I really like to read and I really like to sort of get out and walk. And I'd like to learn something about the Indian culture out there. And, you know, so no, I don't know that I have specific hobbies. I'm probably going to spend some time. It'll probably, quite frankly, didn't take me probably six months to unpack everything. And, you know, that's sort of my plan. Maybe by, if we move in October, that by next spring, we'll be ready to, you know, have people come and visit that I'll have things unpacked and be able to find everything. Because you just, well, you know, you just accumulate stuff and it's just everywhere. And you have to get rid of a lot of stuff and you pack up stuff that you don't need. I'm sure we're going to, you know, pay to move stuff that I will probably never look at again. But, you know, it will be there for the kids to take care of at some point in our lives. So, but yeah, it should be, it should be fun. I'm looking forward to it.

DWM:
So. So we've been talking a while. Is there anything that we have not talked about that you can think of today that you want to mention?

NA:
Um, I don't think so. I think that, you know, we've covered this. I, you know, I hope it's been of interest to you that, you know, it's a little bit, it's a different perspective than I think you're, you've probably gotten from the physicians because they have real hands-on. Mine is a very bureaucratic, you know, kind of perspective of the program. But no, it's been a great program to work in. I've often wondered, you know, people don't stay in the same job every, you know, this many years anymore. And when I think about that, I don't think I've been in the same job 40 years. It's changed so much over time that it's felt like a different job with every statement of work that has come along and every phase. It has been, you know, learning new things and it's been a different job. And I think that's, you know, been nice. And I've really, I've really valued the autonomy that I've had working for the network. You know, I never had a board chairman or a board member who was micromanaging what we did. And that's been such a nice thing, you know, to be able to have the freedom to take some risk and do some things and have a safety net that you can go back to with the board and have somebody say, that wasn't a good idea, you know, let's start over. But yeah, so it's been, it's been a very nice career and I've enjoyed it, so.

DWM:
That's wonderful. Nancy, thank you so much for this time. Well, thank you too. For being a part of the Nephrology Oral History Project.

NA: (3:03:04 - 3:03:04)
Thank you. I appreciate you too. Thanks.