VoiceExpeditions

VOICE EXPEDITION INTERVIEW TRANSCRIPT
The Oral History of Nephrology
JOHN SADLER, MD
Interviewed by Dugan W. Maddux, MD
November 9, 2007

DWM: It is Friday, November 9, 2007, and today I am talking to Dr. John Sadler. We are conducting this interview in Dr. Sadler's office in Baltimore, Maryland. Dr. Sadler was born in December of 1935, in Greenville, South Carolina and he grew up on Donalds, South Carolina. He attended college at Duke University and stayed there to attend medical school as well. Dr. Sadler has been involved in the very heart of patient care in nephrology for his entire career. He was a founding member and the first president of the Renal Physicians' Association. He has won many awards including the AAKP Medal of Excellence in 2005. He has been a contributing author on numerous reports about patient care and survival on hemodialysis and peritoneal dialysis. He is a champion of quality patient care in nephrology with a career commitment to nonprofit dialysis care. He is the retired head of the nephrology division at the University of Maryland School of Medicine and is the current president and CEO of the independent dialysis foundation in Baltimore.

Dr. Sadler, thank you for letting me come to Baltimore to talk to you about the history of nephrology.

JS: I think it is a great idea.

DWM: Wonderful! I'd like to start with your finishing up medical school at Duke University and then tell me about your residency, where you went for your residency training.

JS: Well when I graduated from medical school, I went to Atlanta and did my residency and fellowship at Grady Hospital, which of course was the major teaching hospital of Emory in those days. They are changing some now, and I did that in part because I wanted to go to a place where it was clinically more active because Duke did not have a major population center to serve and although we got a lot of education and a lot of experience, it was qualitatively excellent but not in great quantity, and I knew that Dr. Stead, who was the chair of medicine, had been the chairman of medicine and the dean at Emory before he came to Duke, and so I thought it would be interesting to go there. And when I got there, I found that there was a man, Elbert Tuttle, who had spent several years with Alex Leaf in Boston and who really had a good grasp of how kidneys worked and how kidney disease affected people, and in those days there was no such thing as a nephrology division in most departments of medicine and there really wasn't anybody at Duke who focused on the kidney. There was a young faculty member in endocrinology and a couple more in cardiology who occasionally ran an old Travenol tank when somebody had to be dialyzed but I had never seen that operate, and I really didn't think I

understood kidneys and kidney function. So when I met Dr. Tuttle and I had moved around there, I very much wanted to come and was fortunate enough to go there.

DWM: What year would that have been?

JS: That was 1960.

DWM: 1960.

JS: And you know as a Grady intern, you did a little bit of everything except sleep. You worked really hard, but you saw everything that there was to see. And as someone said to me before I went there, that people who trained at Grady don't flinch at anything, they've seen it all, and I wanted to see it all. So I did that and then I had a fairly unusual training course because I had spent a lot of time in medical school and before medical school working summers in research labs and I had taken off 6 months during medical school to do research and I had gotten to be a pretty good vascular mechanic. I could make polyethylene tubing into catheters to put into blood vessels and I had gotten pretty good at getting needles into arteries and such...

DWM: Where did you learn how to do that?

JS: At Duke.

DWM: At Duke.

JS: Uh hm.

DWM: And these were polyethylene catheters that were being put into blood vessels for what purpose?

JS: I spent several months doing research, animal research into hypertension and we were trying to produce Goldblatt dogs and study them, and we had to measure blood pressure, and the best way to measure blood pressure in a dog was to put a needle in an artery and so I did a lot of that. And then when we wanted to leave lines in, I learned to draw out polyethylene tubing and turn it into a vascular, short vascular catheter, so all of that was something that I brought with me but I'm not sure anybody knew I had it. But when I finished my internship, I had a chance to do a renal fellowship directly out of that and so I did, and I was continuing with some research I had just started at Duke on thermodilution measurements of tissue blood flow and doing them in the kidney, so I started out getting some estimates made and getting set up and getting a protocol approved and while we were doing that, they discovered that I could slip lines into vessels easily, so when they needed to dialyze somebody, they would say "John, would you come over and put a line in," becuase ordinarily you would cut down on an artery and a vein, do the dialysis and ligate the vessels when you finished, and those vessels were no

longer useful and there weren't very many arteries you could sacrifice so that limited the number of times you could dialyze someone, so I would make the tubing and I would put it in percutaneously and when we finished the treatment, if we had to do it again the next day, we would just anchor it and leave it until the next day and if it was going to be a wait-and-see, I would take it out and the vessel would not be compromised. So that worked very well except that it took me out of the research lab and I laughed, I told them they took advantage of me because they had never done more than 12 dialysis treatments in a year before and we did over 50 the first year I was a fellow.

DWM: And that would have been what year?

JS: That would have been 1961-62. But that got me involved because we couldn't afford a Travanol tank. Dr. Tuttle had converted an old dishwasher, had put a canister in it and, because he discovered that they used the same pump in the Travanol tanks that came in a dishwasher. So we had mounted some pegboard up above it and hung some monitors on that so that we could keep track of things and you had to keep hands on the whole thing because it was a makeshift dialysis machine. And of course you had to weigh out the chemicals and make up the dialysate before you could go and this was something that we didn't delegate to anybody. The doctors had to do it. So having done that a few times I got reasonably competent and I got interested in it because I was excited by the fact that we could take off excess fluid and make people comfortable. We could correct uremia and wake them up, and you know, for a young doctor that is thrilling. And so I really enjoyed it but I did manage to get some work done in the research lab. Then after I finished my fellowship, I went back and did my residency and in those days doctors got drafted, and ah...

DWM: Right. Before we talk about your drafting, I want to go back to those days of your fellowship and talk a little bit specifically about, let's first talk about the access and the catheters. So if you went to a bedside and a patient was there who needed an access, did you have a kit that you used to create that access, or...

JS: No we would bring the patient down to the renal lab and ah, you know, when I knew I had to do it, the day before I would make the catheters the night before, and...

DWM: And what was that like, making the catheters?

JS: Well you just take some polyethylene tubing and a gas flame and you would hold it up there and get it warm enough that it would get soft and you would draw it out, which would produce a taper, and then you would cut a clean end on it, and put a hub on it, and then you would put it in a solution to sterilize it, and then it was ready to go. And we were, you know, we were doing everything ah, sort of on a shoestring because we didn't have any budget for this, and we couldn't afford Seldinger wires, which were stainless steel and fairly expensive, but we

discovered that you could buy guitar strings and coat them with silicone and sterilize them and do the same thing, and so we did. And so...

DWM: So you used an insertion that included a wire and then a catheter after a wire...

JS: Yeh, we'd use a Kovan needle to get into the vessel and then slip the wire in, and of course, just standard Seldinger technique, you'd pull the needle out and slide the catheter over the wire.

DWM: Now did it matter which guitar string you used? Did it have to be a...

JS: Yeh, it had to be one that would go through the needle. I don't remember which one it was now.

DWM: And the patient would come to you.

JS: Yeh, we brought the patients down to the lab and I guess that was mostly because our makeshift dialysis machine wasn't really very good at moving around and if we needed other resources we could get them there.

DWM: Um hm.

JS: You know, if something went wrong with the dialysate, I could go over and weigh out the chemicals and make up another batch, and so that was where we did it.

DWM: So if a patient came down, had their catheter put in, did you, tell me about weighing out the, how long did it take you to set up a dialysis machine, and tell me about the procedure, what were you doing first? Were you weighing chemicals and...

JS: Well after a little while, when I saw this was going to happen repeatedly, I got some glyceine envelops and weighed out the small quantities of chemicals and some larger ones, and made out the big ones so that I had them made up and ready to go, so that they were ready. And then, you know, we used just tap water and put the chemicals in, and in those days because we were afraid that the bicarbonate would cause the calcium to come out of solution, even diluted, we'd bubble CO_2 into the solution to keep the pH down and then we ran out of CO_2 one time and I discovered it didn't matter, so I quit doing that. But that's how you learned most things in those days, was by accident. Ah, but you know, the patient would come down and we would usually use a radial artery. We could generally do that, and use a radial artery and a forearm vein, put the lines in and we would dialyze the patient usually for 6 hours, sometimes for 8, using an old Travanol twin coil. Ah...

DWM: Tell me what the Travanol twin coil looked like.

JS: Well it looked like a coil. It was about 8 inches or 9 inches in diameter. It was fiberglass screening with 2 cellophane tubes wound with the fiberglass screening around a core, and ah, the you had a connection coming out of the center of the core for the venous connection and one coming out of the outside for the arterial, and you would - we had made the dialysis tubing by gluing pieces of PVC tubing together and that, we'd made those up and had them sterilized, so we had maybe 8 or 10 of those in the closet, and you would make the connections, and we used an old Sarns finger pump to drive the blood through the system and it gave you an approximate blood flow but it was not very accurate. And ah, you know, you, you ah had a heater in the dishwasher that you could turn off and on to keep the temperature of the dialysate where you wanted it and we used just ordinary manometers off a blood pressure cuff to read pressures, and that was what we did.

DWM: Now the patients who you were dialyzing during this residency time, were they acute renal failure patients?

JS: These were acute renal failure. If somebody had chronic renal failure, we didn't attempt it because we knew that they weren't going to get more kidney function recovered and we weren't going to be able to do anything other than prolong their dying.

DWM: And what condition were these patients in? Were they fairly stable at the time they would come to you for dialysis?

JS: Quite a mixture. Some of them would be barely controlled from hypertensive and uremic seizures. Most of them had depressed consciousness. Some of them were vomiting repeatedly. Some were in terrific volume overload and very short of breath - they would come down receiving oxygen by mask. You know, we didn't use a lot of endotracheal tubes in those days but they would come down receiving oxygen and propped up in bed and struggling to breathe. It was kind of hard to get those people on because they didn't like to sit still while I put the lines in.

DWM: Right.

JS: But you know, it was, we were trying to take care of people who probably were going to be dead tomorrow or the next day if you didn't.

DWM: And did you do treatments on a regular basis? Like once someone started, did you schedule a dialysis every day, every other day, or how did you decide when to dialyze them?

JS: Well if we had somebody who was really tremendously azotemic, and you would see patients with BUNs of 275 and creatinines of 22, but most of them would have a creatinine of 6 and a BUN of 200, because they had just started going up and they were very catabolic, and if

they were very high we would do them and plan to do them again the next day. Most of them didn't do that. We would do them and wait to see if they were going to get better. If they didn't get better, we might do them again in 3, or 4, or 5 days. I don't think we did anybody more than 3 times and most of them either recovered or died fairly shortly, so that it was not at all like what we do today. It was makeshift. It was hurry up. It was hope it works, and the patients were in terrible condition.

DWM: So you finished your residency, that one year internship - um, fellowship. One year internship...

JS: Yeh, and then I did 2 years of fellowship and then I went back and finished my residency.

DWM: Residency.

JS: And, you know, it was a very good place to be a medical resident because you saw a lot, you learned a lot and everybody from an intern up, felt that they had a duty to teach. Everybody was teaching everybody else, and we learned a great deal from each other, and we took care of each other. But it was, you know, those were the days when you were on every other night and you never expected to get any sleep the nights you were on, and you usually didn't get away before 8 or 9 o'clock the nights you were off, and so it wasn't much of a life for my family but they bore with it knowing that someday we would finish that and go on to something else. They didn't know how hard the something else was going to be either, and neither did I. But anyway, after I finished my residency, I had to at that point complete my deferment and go into the service and that was when the government decided that they had been doing chronic dialysis in Seattle and it was sort of a strange therapy, and they weren't sure it could be done without the kind of people they had in Seattle who were more or less obsessed with making it work. And so the Public Health Service gave out grants for 13 demonstration project facilities around the country, and so when I was about to go in the Air Force, we wanted to apply for one in Atlanta and they asked if I could get my service transferred to the Public Health Service and be assigned to do this, and the Public Health Service thought it was a good idea, and the Air Force said no. They didn't discuss it, they just said no. So I had to go spend 2 years in the Air Force. And Jim Shanaberger, who was several years, 4 years, ahead of me I believe, in the program and had made a commitment to the Army, was in the Army and he was at Walter Reed at the Army Institute of Research. And while he was there, he decided he didn't want to make a career of the Army, so he and I got out the same year and when that was clear, the folks at Emory said "Well with the two of you we know we ought to be able to talk them into allowing us to do this," so with a little bit of help from Jim and me, they applied for the grant and got it, and we came back and set up the facility and got it going.

DWM: Now this was a grant for Emory, this was not a...

JS: This was a grant for Emory.

DWM: And where did the grant come from?

JS: From the, I think they called it the chronic disease service in the Public Health Service.

DWM: And what year was this?

JS: That was '66.

DWM: Okay.

JS: And so we came back and they built the dialysis unit in the basement of the old Grady Hospital, which had been abandoned for several years. We had some of the world's largest rats and cockroaches but it had a tunnel that went under the street and into the administrative building across the street from Grady, so we could escape occasionally but it was sort of interesting when they asked me if I wanted to be involved in this dialysis program, I said well where is the dialysis center going to be and they told me, and I said well that's not far from my lab. That will be fine. I can do that. And once dialysis got started, my lab began growing cobwebs and I never made it back.

DWM: And so when you, in 1966, when you came back to Emory after your time in the Air Force, there had been a change because you were really talking about acute dialysis in 1961-62.

JS: '61.

DWM: So what happened in those 4 years do you think?

JS: Well I think that, you know, the first reports out of Seattle came in 1960. They had started doing dialysis on a chronic basis in '59. And, so when that was first reported at ASAIO, everybody was tremendously excited about it. But there was great skepticism as to whether it could be successfully carried out on a broad scale, and there was also great concern about the cost of it. What were we going to do? Were we going to raise hopes and then dash them because we can't do it? So these projects, these demonstration projects were the first to demonstrate that it could be done as a practical matter, away from Seattle, and we started out with the same kind of things they had in Seattle. We had a committee of laymen and professionals to consider all proposed candidates for dialysis. We had a couple of ministers. We had a social worker, a nurse. We had a businessman and a woman who had been a school teacher and was now retired from that and was a housewife, and we had 3 doctors and a nurse who basically collected all the papers and everybody's application and got it ready and presented it. So we, it took us, I guess about 4 months after Jim and I got back, to finish the construction and get things ready, and we got it set up and started taking in patients, and we started just one patient at a time so that by the end of the year we had about a dozen patients

and it became obvious to us at that point that there were just so many more patients than we could possibly take care of with 8 stations, because in those days you did an 8-hour dialysis twice a week, and so with 8 stations, we could only take care of one group a day at first, and then we decided we would do 2 groups a day but that, you know, that's not ever going to be very many people. That is going to be 48 patients and you are saturated. About the same time, word came out of Seattle that they were training patients to do their dialysis at home and we thought that that might be the way that we could expand our capacity, so we began working on that and it seemed to us that the patients, highly selected people that were going onto dialysis could certainly do this at home and for many of them who lived 20 or more miles away, it would be a great convenience. So about the time we decided to start doing that, Shanaberger moved to California and I was left by myself for a while and then Ed Macon, who had been really in a terrible situation because he proclaimed himself a conscientious objector and so since he wasn't drafted, they took him into some sort of involuntary servitude for 2 years, and they didn't pay him, and so he had a wife who was pregnant with twins and no income, and he was doing some work for a medical group that was largely just donkey work. He was running through records and moving things around and it turned out that Converse Peirce, who was a wonderful man, a surgical investigator and an artificial organs expert who worked mostly with oxygenators, knew Ed and so he made contact to see if we could get him to come and work with us, because if he came to work with us, we could take care of him, pay him and use his talents because he had had nephrology training, and we were able to get him. So then I had a companion and a partner after that. But while we were trying to get home dialysis going, I went to the State Division of Vocational Rehabilitation and I said, "This is how we rehabilitate people, and I have to have some money to pay for it, or I can't do it. If we don't do it, these people are going to die. If we do it, they are going to be restored to a level of health that will allow them to go back to their previous activities." And they decided they would, they said you know, we can only pay you for 6 months of care. That's our limit. So if you can train them and get them home, we can buy the machine. We can provide them with 6 months' worth of supplies and we can get them going. But after that, it is up to them. So we did it and they only gave us 12 so we could prove that it worked, and by the end of 1967, we had 12 people dialyzing at home and they had given us another authorization and this time I think it was for 20 patients. So we had that going. In between, I had had to file the first progress report for our demonstration project and it was obvious from my background I had never done that before. I didn't really know what I was doing but they had all these forms and each one was clearly labeled and told you what you had to put into it, so I filled out the forms and wrote the narratives, and when I got to it, the last page said how do you propose to support this operation in the future, and I said I'll apply for grant renewal and sent this thing in. Three days later it came back and said that the answer to question number whatever it was, is not responsive and unless there is a valid answer to this question, the grant cannot be continued. Well, you know this was May of '67, and if I didn't get the grant in July, I was dead. So I scrambled around and thought about it, and talked with some friends and I said I have funds from through the state for home dialysis. I have spoken to 3 insurance companies who say that if any of their clients develop chronic renal failure, they will pay for it and they didn't mind doing that because they thought it was going to

be maybe one person a year and would be good publicity for them and wouldn't cost much, and I said I have spoken to civic groups and I believe that I can raise enough money to carry us forward with this other support. I will make a fundraising effort, and they said okay that is valid, you can try this. And they continued the grant. Well then of course, I was obligated to go and raise money, and I didn't really know anything about raising money. So I called the development office at Emory and I said, "I'm going to have to have a program to raise funds to continue the operations of the dialysis center and I suspect I should talk to you all about it." They said that's right, come out this afternoon. So I went out there and sat down and the man reached over and pulled out a legal-sized sheet of paper that was printed all down one side and half down the other. He said this is a list of the organizations you are forbidden to contact. I gasped and I said, "What's the matter?" He said these are the benefactors of the university overall and we do not want our relationship confused or disturbed. You may not contact them. I said "Now what do I do?" He said well if you go to the library there is a book on philanthropic sources and you can go in there and look. Well sure enough they had left me a few small foundations and a list of companies that had been known to give some money that they hadn't worked on very hard, so I started. I had a friend who was a Newsweek writer, who headed their Atlanta bureau, who also wrote for Atlanta Magazine and he had done a feature on us a few months before, and he was very helpful, and he came and helped me put together things and told me what I would have to do. So we made a nice little notebook full of information about what we had done and what we were doing and what we needed and I began to go out and talk to organizations and companies and foundations, and we thought, well the best thing for us to do is ask them for a contribution each year for 3 years, so that we would be asking for so much money and they will get a chance to see what we do with it and decide whether this is worthwhile. And I guess three-quarters of them did give us a grant.

DWM: Can you remember who were some of the companies that helped you out?

JS: Ah, not very well. Ah, there was a printing company. There was a construction company, oh, and Calloway Mills gave us some money. I got to meet Mr. Calloway who was I guess at that time he was probably as old as I am now, and he spent half a day lecturing me about his Hereford cattle enterprise, but he gave me some money. He gave me $30,000 a year for 3 years, which was the largest grant I got.

DWM: $30,000 for 3 years.

JS: Most of them were $10,000 or $15,000 a year for 3 years, but in the end it wound up being about a half a million dollars, which was a lot of money in 1968.

DWM: Right.

JS: So we felt that we had some security with that, and the public health service was satisfied with us, so we continued our operations, and we grew the program. But you have to realize

they had by then started having contract home dialysis centers to see how they would do, and I think there were 16 of them around the country. I got to know Bill Anderson in Miami, who had the one that was closest to us and he was working away at it and we would share experiences and learn from that, and so we grew our program. Because we had a dialysis center in Atlanta, Walker Brown had another demonstration project in Birmingham. There was one in Louisville. I don't remember anymore where the others were. I think there was one in Chicago, one in Cincinnati. They were scattered around. Ah, and ah, and then Earl Ginn had a dialysis program at the VA in Nashville, and that was about it, but all of us talked to each other frequently, and every day you were learning. I mean there was no FDA oversight or devices in those days. There were no IRBs. If you thought something was a good idea, you did it, and saw if it worked or not. Our patients were very tolerant of that because they knew we were trying to help them and we were learning. But I can recall a number of days when you'd call and say, I want to tell you what I did this morning - don't ever do that.

DWM: It was a bad idea!

JS: Oh, and I ran across one of my old fraternity brothers who was running the film lab at Dupont, you know, making membranes, and I had complained that we had to import cuprophane from Germany and at the time there was a heavy tariff on it because American manufacturers of cellophane didn't want any competition. Well cuprophane wasn't very good cellophane for wrapping packages of cigarettes and stuff like that, but it was very good dialysis membrane compared to any other we had. He said, oh I can make you a membrane that is better than that. So he sent me a sample of membrane and it wasn't better than cuprophane. Matter of fact, it wasn't very good at all. So I sent it back and he sent us another one and it was a little better but it didn't work very well, and the third one he sent to us, he said, I think this one will really do it and we put a patient on it and her blood pressure just immediately dropped and she felt pretty bad, and we tried to get it back up, and finally we took her off and put her on a dialyzer made with cuprophane and she was fine. We thought well maybe that's just her. We tried it on another patient with exactly the same results, so I packaged it up and called Bill and said, "I don't think this is right. It's not working." He said what does the label on the package say, and I told him. He said, oh God - you got the wrong shipment. Send it back. I sent it back and when it got back apparently his supervisor saw what had happened and said you will not produce anything for dialysis. You stay away from that. That's too much liability. So we never had any help there. I did go up and work with a congressman to get the tariff off cuprophane, which we were able to do, and that also got me familiar with going up and lobbying Congress.

DWM: Right.

JS: And there were a lot of us doing that in those days because we didn't know what we were talking about. We just knew we needed money to pay for patients' care.

DWM: Absolutely. Before we get too far from talking about this dialysis demonstration project that, you know, began in 1966, tell me at that point when you are beginning to dialyze patients who are chronic dialysis patients, what access were you using then?

JS: We were using the standard Scribner shunts and we had, you know, Scribner started out with a shunt that was all Teflon. By the time that we started, he was using Teflon tips and silicone rubber tubing and they were still double-S curved. They started out putting a double-S curve in them because they thought if it was straight, there would be too much blood flow and they'd get high-output cardiac failure. But we looked at it and tried it on a couple of animals and decided it was easier to do it straight and it would work straight, so we did that. And I was working, Pierre Galletti was professor of physiology at Emory, and Pierre was one of the real pioneers in artificial organs. And Pierre had designed a device he called a Klung. It was a kidney-lung. He put, you could run dialysate in it and it was a dialyzer. You run oxygen through it and it was an oxygenator. And sure enough, it worked for both but it was a fairly complex device. You know the Kiil had 2 layers and you would build it with sheets of cuprophane. The Klung had 16 layers and you'd have to put an air bladder in the middle to compress the sheets to keep the blood path thin, but we learned to build them and they worked much better than a Kiil, so we kept going with them because most people were using Kiils for 12 hours and we were using Klungs for 8 hours and getting more dialysis than they could with a Kiil. So we thought that was a good thing. Most people looked at it and said, my God, how am I going to assemble all those layers but the smaller layers were easier to work with than the keel and they worked very well. But anyway, Pierre was always doing things that were innovative and creative, and many of them had no clinical relevance by the time he got through but our first chief technician was a guy who got his Masters' in Pierre's lab, and his assistant was one of the first graduates of Duke's PA program, so we had overqualified technicians in those days. But because we were doing this and working with it, we were developing techniques all the time, and we learned that you know, everybody's dialysate concentrate was made with acetate in those days because we didn't think it was possible to have 2 proportioning systems in a dialysis machine, and we discovered that no bacteria grew in that stuff. That concentrate, we didn't have to be worried about. We had a microbiology student who worked part-time with us who was convinced that there was something that would grow in there. He spent 9 months trying and nothing would grow in it, but you know, you learned all sorts of stuff like that. I remember that I think it was in 1969 or '70, I went to the ASAIO and a woman who was working with Stanley Sheldon, whose name shouldn't be left off, but I can't remember it right now, came and said you Americans are doing terrible things to your patients. You are giving them blood transfusions and they are all going to have hepatitis and hemosiderosis, and it is just because you don't know any better. And they said, you know, if you give them iron and you don't transfuse them, they will make enough blood to do well. Well I came back and I thought, this is Stanley. He's crazy of course. But if he is right, we have to try it. So I came back and I told my team that we were not going to transfuse the patients, we were going to allow their hematocrits to fall and see if they would recover on their own. Then the patients began wailing and moaning after about 10 days or 2 weeks and we used to write everybody's hematocrit down on the board because we used to do

it every day. We would spin it every dialysis. And so I quit putting them on the board. We just put them on a sheet of paper where they couldn't see them and sure enough, after about 3 weeks, they began to come up and they kept coming back up. Now you know, we were transfusing people up to hematocrits of 22 or 24 and letting them slide down to 15 or 16 and then transfusing them back up. Well these people went down to 15 and 14, and then they started back, and by the time 6 or 7 weeks had gone by, they were back where they were, but the patients were still whining and moaning, so I went back to the board and I put everybody's hematocrit on the board and I turned to the patients and I said, "Now I know I can't believe anything you tell me." We all had a good laugh and we didn't routinely transfuse anybody after that. But that's how you learn things.

DWM: Uh hm.

JS: I mean it was stressful on the patients. It was particularly stressful on us because we knew that if it didn't work, we were the ones who would hurt the people we were taking care of, and so it was really scary, but we felt that it offered a benefit so great we couldn't not try. But you know in those days, every shift you went in and you measured the osmolality of the dialysate before you started treatment because, you know, we had an old osmometer - it wasn't an old then, it was a new osmometer, but we ran the osmolality so we could be sure it was right because we only had the one gauge on this central system that made the dialysate and then distributed it, and we weren't too sure it was going to be accurate. We had to double check it with something, and so that's what we did. But there were a lot of things we did then that we learned we didn't have to do. You know the first 3 or 4 months we did dialysis, we were measuring chemistries on the patients before and after each treatment because we didn't know what we were doing. We had to see what we were accomplishing.

DWM: Right.

JS: After a while it got to the point where it wasn't necessary. I've always thought that if there is a clinical sin, it is measuring something you can predict, and that's what we were doing so we quit doing it. But we went on that way and actually our patients by and large did quite well. Now part of that was because they had been selected. We had one man who had coronary disease and if we had known he had coronary disease, he would never have gotten on dialysis.

DWM: Well let's talk about that selection. How were, were they pre-selected before they even got sent to you? Were you all seeing people and saying, no you're not a good...who... what patients actually made it to dialysis in your unit?

JS: Well I suspect there was a great deal of preselection, that referring physicians just presumed that this person is too sick and never referred them, but we got about 3 times to 4 times as many people as we could take care of, and that's the number that got formally considered by our committee. It was interesting that after 2 years the committee came to me and said, you

don't need us. This has all become very predictable and you can do this without us. We shouldn't waste time having the committee. And I said well, I'm not sure I want this burden entirely on me and they said, well why don't we meet every 6 months and review what you've done because we don't think it is necessary and we'd just like to turn it over to you. So I accepted their decision, it wasn't just me, it was Ed, and a couple of our nurses, and our social worker, and sometimes out dietitian because the dietitians were remarkably good at learning how patients learn. They would teach them the diet and if the patient wouldn't pay attention, or didn't know enough to understand, they'd come back and tell us and that was another piece of information that went into the assessment. And so the whole team would look through these things and we would decide, with considerable unease, I must say, but the second time after 6 months we had the committee come back, they said you don't need us. You're doing a good job. We don't think there is any reason to review these anymore like this, and I guess it was becoming fairly routine. We knew that if somebody had had a myocardial infarction, we didn't put them on. If somebody had COPD, we didn't put them on. If they were diabetic, or if they had had a cancer within 2 years, we wouldn't put them on. If they had had a cancer 3, or 4, or 5 years before and had recovered, then we would put them on but, and we had one man who just had terrible allergies. He was allergic to all sorts of things and he had skin breaking down about something half the time and we just felt we couldn't keep him from getting infected. And when we started doing home dialysis, we had to have people who had a partner and I remember we had one woman who was living with a policeman, and they had never been married and so we said to him, you know, we need evidence of your commitment. If you get married, we can do this, but if you don't get married, we can't believe you're going to stand by her. He said I've been standing by her for 12 years, I am not going to let her go now, but I'm not going to get married. And that was one time we called the members of the committee and they agreed unanimously that he was not a reliable partner and so she didn't get on. But we had people who went on, we had one lady who had been basically a domestic. She had done housework for assorted ladies around Atlanta and she had had 2 years of grammar school and that was it but she had 5 children and she was so obviously committed to her children and so determined to take care of them that we decided we would try it and, you know, this was a woman who was totally unsophisticated, who had never been given any real freedom. She had children so she worked. She got paid. She took care of the children. She went back to work. She didn't have much of a life and we treated her like we treated everybody else, so she asked if there was somewhere she could go to school and I knew of an adult education program and I referred her over there and they said you know, she's bright and she is interested, she is going to be all right. She got a GED in just a few months and then she got a job as a clerk somewhere and then she got a better job, and a better job, and it was just amazing that because she was in an environment where she was treated like somebody, she decided she probably was somebody and did it. You know, so we had wonderful experiences like that with people who benefited so much from the team taking care of them, as well as from the treatment itself, and you know, I learned so much from those people, you know, because I learned what it is like to stare death in the eye and say not if I don't have to. And you know, these are courageous people because it is easy when you feel lousy and everybody says you are going to die, to just

curl up and die, and it is hard to say no, I don't want to feel like this, I don't want to be like this but I've got to live, I've got things I need to do. And they would get up and go do it. And you know, we had people who were farmers, who were truck drivers, who were school teachers and a few women who had families to look after. We had one doctor. We had one businessman who was a very successful man. We had one lawyer and I had an old GP from Southern Alabama who wanted to train to go home and he was 68, and I said most people your age don't go on dialysis because this is a fairly demanding therapy. You have to be very disciplined and you have a lot to do and at 68, with renal failure, you've probably got cardiovascular disease. He said, yeah, and I've got enough money to pay for it. Are you willing to let me try? Well, if it's your money, I guess I can't say no and he came over and he and his wife learned to do it. They came in a pickup truck so they could take their machine home and they took it home and I sent a technician to help them set it up and get things going. They put him up in their house and kept him there for 3 days, and everything went well. I don't know how long he lived because I guess it was 1970 when he went on and I left there in '71. I know he was still alive in '75, but I never checked on him after that.

DWM: That was pretty good at age 68.

JS: Oh yeh. That was, you know, you learned a lot about humanity. You learned a lot about people and so you learned a lot about yourself in the course of that.

DWM: Right. The dialysis machines that you were using, both in the center and that you sent home with patients, what were you using then?

JS: Well when we started in the center, we had a big central Milton-Roy proportioning machine and Milton-Roy made the individual patient stations, which didn't do anything but display the temperature and the pressures, and it was just a venous pressure and a dialysate pressure. And, that was the nature of the equipment. When we started talking about home dialysis, I had talked to Scrib and he said there are a couple of guys out here who have made a new machine that we think is the best we've ever seen. Their names are Drake and Willock, and that's the name of the machine, so I called and I talked to Charlie Willock and he said yeh, we're making them and if you'd like one, I think we can ship it to you. So he made it and he sent it to us and I remember Shanaberger said, we paid him $2900 for it and he's probably got $2800 worth of parts in it. He didn't make any money but we used the Drake-Willocks for people at home and they were about the size of a small desk, but Charlie Willock was really a genius. He devised a proportioning system that was driven by water pressure that was absolutely reliable. There was just no question about it. He devised a degassing system using a heat exchanger so that you didn't have to have a big heater and that made the proportioning, you didn't have a dissolved gas in the water so that you could depend on your proportioning. He devised very simple means of creating negative pressure in the dialysate. He always said you ought to dialyze people on the second floor. You can put the outlet out the window and let it hang down, if you need more pressure than we can get from the normal drain, and actually I did that once, but

Charlie was a creative genius and an energetic man. In later years, I'd go out there, I remember he designed a machine. It was a very nice machine but it was only about 30 inches high and I called him up and I said Charlie what's the matter with you. My nurses are not going to work with a machine that's that short. That's just wrong. You can't do it. He said just hush and come out here and show me what you want. So I went to Portland and we made some sketches and we talked about things and he said okay, I understand. The next afternoon he called and says you want to come back and look at your machine. I said Charlie, I just got back. He said okay, I'll send it to you. So he sent me a machine and sure enough it was taller, had a work space on it, was very good. We used them for years and that was how you got things done. Now he didn't have to get anybody to approve his machine. He made it. He only made one bad mistake in his machines. You know, he made one once that folded over and could be carried, if you were strong enough to carry something that weighed about 80 pounds, and unfortunately in that one he used, because he wanted it to be study for travel, he used copper tubing and that's when we learned that copper tubing releases the copper into the hungry water that you make dialysate out of and the high copper levels cause hemolysis. So, he got all those back the next week. But you know, when we learned, unfortunately the patient suffered, but that was just the way we learned and the people in Seattle were very good. Every time they had a mishap, they published it. They let everybody know so that we wouldn't do the same thing, and so everybody got in the habit of doing that. We'd share the information. And we'd go to ASAIO and do the same thing. We'd talk about everything that we'd done that was wrong and then because ASAIO only came once a year in the spring, we formed the Southeastern Dialysis Conference, which became the Southeastern Dialysis and Transplant Association because we needed to get together more often. We needed to talk about these things, and ah, so that was the first sort of rump organization we had that would sit down and talk about practical clinical matters, and I remember the first meeting we had was in Birmingham, and we drove over from Atlanta in 2 Porsches with Jim Shanaberger and me, and our head nurse, and our chief technician, and the next year we went to Nashville, and the third year I hosted it in Atlanta, and it just kept growing because there were a lot of people who wanted to know. What's really going on? What are you learning? What do I need to know? Can you answer this question? These were very practical sessions.

DWM: And we are going to talk more about meetings and organizations here in a minute. Back to still dialysis in this outpatient unit and home dialysis using the Drake-Willock machine and the Scribner shunts, what dialyzers were you using?

JS: We were still using Klungs that the patients were taught to assemble because...

DWM: Wow.

JS: ...you know, somewhere I guess about 1970, the Cordis hollow fiber dialyzers began to be available, but they cost $30. I mean $30 dollars was the consumables for 6 treatments. We

couldn't do that and so we kept doing it with the Klungs because you know, once we got the tariff off, it took about a dollar and a quarter worth of membranes...

DWM: Uh hm.

JS: ...and you cleaned all of the other fittings and reused them, and everything went well, and after a little while we learned that you could clean the blood tubing and reuse it, which was wonderful because the patients would get 6 months' supply of blood tubing and use it for 3 or 4 years. It was funny. I had a home dialysis patient who was the student health physician at Clemson and we had just tested cleaning out the tubing with bleach and found that it worked and that the only problem was that after you'd done it several times the ends of the tubing got inelastic and you had to cut them off so that you could put another piece on the fitting. When it got too short you couldn't do it. So he had called about something different and I said when you come down, we will teach you how to reuse your blood tubing so you won't have to get so many of them and won't have to spend money on them. He said, oh, is it complicated and I said no basically you just rinse it out, fill it with bleach and let it sit and when you are through you drain the bleach out and then rinse it again and it is ready to go. He said oh, that sounds good. Well he came in for a checkup about a month later and I said now I want you to go back here with Ron, he's going to teach you how to reuse your blood lines. He said, oh I've been doing it ever since you called me. He said, I just reached into the trash can, pulled out the set from the night before and he said sure enough, you rinse it with bleach and everything clears up, so I left the bleach in it until the next treatment, hooked it up, ran saline through it, so I'm still using the same set. I was floored, but you know, it was that simple and that spontaneous and that's how we did things until today. There is almost nothing published about the reuse of blood tubing because there is nothing to it. You know, there is nothing to write. It is so simple. You run bleach through it, you rinse the bleach out and continue to use it. Almost nobody reuses blood tubing because in those days a blood set cost about $7 and today it costs about $2, so it's not really worth the trouble. That's another story. You know were, we had started out doing acute dialysis, making out own tubing sets. That was a struggle because we weren't very good at it. And then we got a guy who would make sets for us and send them to us and he was charging us about nine dollars and a half, and they weren't very good but they were usable. And then I met a guy named Bob Collins at ASAIO, and Bob and Rand Bellows had just formed a company they called COBE, and they had some blood tubing, and they sent a guy named Dennis Valentine down to see me and show me the tubing, and I said man, this is better than anything we've ever had. He said well we have to charge you $7.30 a set for them. I said done. That was it, and we used COBE's tubing for a long, long time.

DWM: Well that is amazing. I mean you went from 1966-1967 having a handful of patients on, until 1971. How many patients do you suspect you were dialyzing by then?

JS: Well we had the full capacity in the center, which was, we were still doing, we were doing at that time, I think we cut back to 6 hours per treatment because we had seen that the Klung was

a good dialyzer and it had 2 square meters and it was a good dialyzer and getting the job done, so we could get 2 shifts in every day, and I think we were pretty well full. I think we had 48 patients in-center, and I don't remember the exact number, but it was about 28 or 30 patients at home, and some of them were in North Carolina and some of them were in South Georgia. We had a few in the northern part of Florida and a couple in Alabama and 1 or 2 in Tennessee. They were all over the place, because you know, there wasn't any dialysis in those places and so people would come in, get trained and go home, and we tried to get them to come back once a month and it turned out that was an obvious hardship, so we'd get them to come back every 3 months (excuse me) if we could, and I remember we had one woman who came down from North Carolina and she was so very lethargic, and I asked her sister, who was her partner in dialysis, how she had been doing and she said she does pretty good but she gets this way before every dialysis and I said well maybe she is not getting enough dialysis but I'll examine her later. Let's just go in here and give her her dialysis. And I drew some blood beforehand and her potassium was 8.6, and so we dialyzed her and she was fine in about an hour and so we finished the treatment after a while and it turned out that she had decided that the diet we had given her was too much trouble and she really loved fruit, so she was having a lot of oranges and bananas. We had a talk about that and sent her home with considerable trepidation but it never happened again.

DWM: And these patients were probably doing pretty well. I mean a very preselected group of patients and...

JS: Oh yeh. We didn't take anybody who was over 50. We didn't treat children. Our lower limit was 15, and we had very few adolescents. We had a couple of high school students who one of them I will always remember because the principal of his school said you know this boy was a good student in the 8th and 9th grade and he just can't do the work anymore. And he got on dialysis and got straightened out and he graduated 3rd in his class, so I was really very proud of that. But we had, you know, just a lot of little triumphs like that.

DWM: Absolutely.

JS: But everybody, you know, it sort of, you preselect people so that they can't fail.

DWM: Right.

JS: Everybody we put on was somebody who had a job or else had an important obligation that they wanted to go back to. They had motivation. You know, today one of the big problems is motivating people to do something other than sit there and survive and those people came with motivation sticking out all over them. They wanted to be helped because they had something they needed to do.

DWM: Right.

JS: And it was really exciting. You had all kinds of things and of course, we were learning all the time about how to control things, you know, while I'm telling about patients, I remember I had 1 guy who had been a professional football player, you know a huge man. He told us to call him Moose because that's what his friends called him, and Moose had weighed, when he was playing football, about 300 pounds, and now he was 44 years old, he had chronic renal failure. He still weighed about 300 pounds, but about 80 pounds of it was water and so he came in and we dialyzed him in the hospital very aggressively for a while and got most of the water off him and when he was getting ready to leave the hospital, he said doctor, you just don't understand. He said I'm a big man and you made me a little man. I don't like being little. I said well Moose, you were already little, we just revealed that and he said well we've got to do something about that. Well he came in for his first dialysis and he had about 12 liters of fluid on him. I said Moose you can't do this, you're going to drown in it. He said doctor, I'm a big man, you can't make me little. I said you already made yourself little. We're just showing you what you are. Well we couldn't get it all off. We took off as much as we can and he came back the next time with 8 more, then after about 4 or 5 more times of this, I said Moose you just are asking too much of us. If you come in with more than 2 kilos on you, we are going to take 2 off and let you deal with the rest. He said you wouldn't do that. I said I'm doing it right now and we did that for about 3 or 4 times and he came in just about in bubbling pulmonary edema. And he said please, please don't leave me like this, so we took off, I don't know 6-7 kilos of fluid, and he got a lot better and I said now if you come in with 2 on, we'll take off as much as we can. If you come in with more than 2, we're just going to take off 2. He came in the next time with 1.6 and he kept it under control after that he got in pretty good balance and got better nourished and felt well, but I remember that about 3 or 4 months later we had somebody who had started with the same kind of habits, though not quite as egregious, and she was telling me that I didn't understand and I told her, I said now the only thing I know to do is if you are going to keep putting on all this, we'll just take off 2 kilos each time and let you deal with the rest of it and this voice booms from the other side of the room, and don't you believe he won't do it, too! So it worked again, but you had to do things like that. You know, we knew that if we didn't teach our patients discipline, they weren't going to survive. I still know that but very few nephrologists know that anymore. They don't try to make their patients discipline themselves. They ask the dietician to have them do it. They ask the social worker to have them do it, but the doctor doesn't do it. It just has a lot more impact coming from the doctor and that was one of the wonderful experiences of being there in the early days, was that we were all a team. Everybody on the team focused on that patient and we were all consistent in what we told them and if the patient needed to get their diet straightened out, I told them to get their diet straightened out and then the dietician came and told them how to do it. It wasn't a matter of sending the dietician off to take care of it and I go do something else. You know, it was close teamwork. It was rewarding teamwork, and I think the patients sensed it and they really appreciated it and enjoyed it. In our first center we even had a kitchen where we were supposed to prepare foods for the patients according to their diet. I mean you may never have used wheat starch but that was what we used because it was a gluten-free form of flour and we

learned to make cakes and cookies and bread out of wheat starch that didn't have any protein in them, so that the patients could eat it and we would send them home with a can of wheat starch and most of them never made anything with it because it was pretty hard to do. But we did things like that to try to help them do it because we thought they really had to restrict their protein because we couldn't get that much urea out of them and these days we are always worried about giving them enough protein, but in those days we tried the other way around, and it, you know, I had to learn how to give people simple instructions in a low-sodium diet because complex instructions didn't work. My dieticians still fuss at me and say that it is an oversimplification. Well if it is an oversimplification and they understand it and follow it, that's better than giving them the straight answer that they don't understand and can't do, and so all of those things were important parts of it. And you know, as this was going on, we were beginning to get some medications we could use for blood pressure, which was important. I mean Scrib always said if you get them to dry weight, the blood pressure would come down and be normal and that was true for probably 60% or 70% of the patients but there were some people you just couldn't get down and we didn't have very good drugs. You know, they were, I think in '69 was when they got Aldomet. Before that it was bad news. I mean we didn't have any good stuff, and so we really had to struggle to get peoples' blood pressure down and I can recall giving people Nitroprusside on dialysis...

DWM: Wow.

JS: ...and I haven't done that in 30 years, but you know, it was what you had to do. Of course, I also remember I had a patient who came in who obviously was hypokalemic and so I just sat there and squeezed potassium in out of a syringe. Everybody said you can't do that. I said I have to do it. If I don't do it he is going to get in trouble, and no harm came of it, but you know, you could give people so much because it was being diluted in so much blood, if you put it into the tubing...

DWM: Right.

JS: ...that you didn't have to give it in a dilute solution. But as I think back on all the things we did and all the things we got away with, and we got away with almost all of it, it was wonderful, but I'm so glad we don't have to improvise and learn so much every day. You know, I told you that I went to a Kidney Foundation meeting and went to the Scientific Advisory Board meeting. They used to run the Kidney Foundation, and these were a bunch of high-powered laboratory scientists who were nephrologists and one of them told me one day that what's wrong with you people is that you just embarked on treatment without understanding the treatments. You didn't know what you were doing, you didn't understand the science behind it and that was just quite unsatisfactory and I said yes, but we knew the one critical factor, which was that if we did it the patients lived and if we didn't, they died. How could we not do it.

DWM: And that's a perfect place for us to talk about Belding Scribner because I certainly think that the scientific community was not very kind to Dr. Scribner in that he did a lot of the things that you are talking about now, which is that he took care of patients and he worked to see what innovations and changes he could make to directly help patients, so did you meet Dr. Scribner, and if so, where did you meet him? How did you meet him?

JS: Well I think the first time I met him was at an ASAIO meeting and I met him lots of times after that and we got to know each other fairly well and I must say I'm just an absolute fan of Scrib. He was such a marvelous human being. He was, you know, he could be - I was told - very harsh and get very angry but I never saw him that way. He was always a soft-spoken thoughtful person, but he understood what he was doing and what we were doing to a degree that you know, he would just immediately give you insights at times into what might be and what might help. He was, and he was so caring, and he did take a lot of, I guess it wasn't so much abuse as it was just shameful disregard of his accomplishments by the renal community of scientists. They really put him down. You know until the American Society of Nephrology was almost 20 years old before they managed to recognize him and I guess I didn't have his equanimity. He never indicated that it mattered. He knew that he was doing what he thought was right and it was working, and if they didn't understand or appreciate it, that was their problem, not his problem but you know, Scrib had terrible problems with his eyes. He had multiple corneal transplants and for a long time he rejected them and he was having a hard time with it and his vision was just a terrible struggle. He was using a lot of drops and he couldn't tolerate bright lights and he couldn't see in dim light and he was going to Europe to have procedures done and then he finally got it right and he was fine. Of course I'd laugh. We'd go to dinner at meetings and Ethel, his wife, would sit next to me and she would say, now John you have to take care of the tab and I'd say what do you mean and she say well Scrib won't be here when we finish and he would, a few minutes before 9, get up and leave, and he had gone upstairs to bed. The rest of us were still sitting there talking about him and I remember once his daughter came and she was a physician, too, and I told her what a wonderful man I thought that her father was. I said he is a genuinely great physician and there are not very many of them, and I said you don't have to be him, you just have to be proud of him, and she said I don't have any choice. Everybody in the world tells me to be proud of him.

DWM: The same thing. Now did you go to Seattle to look at procedures and learn things, or did you learn them by just communication and going to the meetings?

JS: No Scrib used to tease me that that I was the only person involved in dialysis in America that never came to Seattle, and the reason I didn't was because I was working with Pierre Galletti, and Pierre really thought that he was Scrib's equal and it would have really hurt his feelings if I had gone. And Pierre was a tremendous resource for me. Every time you asked him, he either had a thoughtful answer or he said give me a day or two in the lab and I'll let you know. And he would go and test something and try it and come back. He was really a marvelous man. You know, he came from Belgium and he was the first person who demonstrated to me when I met

his wife, that women learn languages better than men. She spoke English with a charming accent. He spoke English that was so heavily accented it was hard to understand and they'd both been here the same time and it was along time. But he was really good. When I was a fellow, he made all of us come out to the campus, you know we were all downtown at Grady, he had us come out to the Emory campus and made us take calculus becuase we had never taken it in college and he said all the graduate students think you are ignoramuses because you don't know calculus. You've got to learn and we had a hard time with it until I found a book entitled *Calculus Made Simple* and I understood enough then that I could fake my way through it.

DWM: Well in, when you were finishing up then in 1971, where did you go? What did you do?

JS: Well, you know, it became obvious that Albert Tuttle was still a young man and there wasn't much growing room under him, and he didn't get involved much in the dialysis but he was always the chief when he was there, and so I decided to look around and I discovered very quickly that for a young nephrologist, there were lots of opportunities because there weren't very many of us. You know, we were part of a fortunate generation. We came along, we got interested in dialysis, we got started and moved ahead and we were successful, and there was no establishment to move over and let us in. We became the establishment very rapidly. So I went out and looked at jobs from Florida to California and I went to Richmond to MCV because they needed somebody else to work in dialysis. John Setter, who had been leading their dialysis unit was moving to Norfolk and I knew several people there. I had been involved with Dave Richardson and some hypertension studies, and so I thought I'd try that. And, I went there and helped them set up a free-standing outpatient unit and redo the unit in the hospital. I worked very hard but I wasn't very happy with the man I was working with. They called me the co-director o the division but he didn't yield an ounce of authority and we differed on a lot of things, but I really felt I got accomplished a good bit there, because I had really upgraded the technology. When I got there they had old Sweden-Freezer tanks in which they made batches of cold dialysate and then warmed it up and nobody in America had done that since 1968, I think but that is what they did, so I went in and changed the equipment around and changed the procedures and the practices and started a home dialysis program and then we built a dialysis unit out across town and my chief owned that unit and after a while became obsessed with making it earn money and I was so distressed with that that I really didn't want to be part of it, and then Dr. Woodward, the chairman of medicine at Maryland called me and said that he needed a head of nephrology and he'd like me to come look at the job and I said well I don't know, I hadn't been here but 6 months and I'm not looking for a job and he said well that's okay, you may have found one. Come on up and have a look and I said Dr. Woodward, I don't think I want to live in Baltimore. He said what do you know about Baltimore. I said well I've been through it several times. He said in other words nothing. Come on up, it's my money. Waste it. Come on up. So my wife and I came up and there weren't very many hotels in Baltimore in those days. They put us up at the Holiday Inn down the street and so we got in one evening and the next morning I told her, well you take the car and drive around and I'd walk

over to the hospital. So I came over, met Dr. Woodward and a lot of other people and walked around, looked at the place and I thought my God, this is a clean sheet of paper. There is nothing here. I can do anything I want to do, I just have to round up the resources yet.

DWM: Was there a dialysis program here?

JS: There was a little dialysis unit that was run by a urologist who had never bothered to get a license in the United States and he was under the supervision of somebody in surgery and they were building a dialysis unit in a nursing home about 10 blocks away and nobody knew what they were doing. And I came in and talked to them and they were really very open and very forthcoming and it was clear that they really needed somebody like me and so I walked back to the hotel that night and thought, gee, it's too bad this is in Baltimore. This is a good opportunity. I got back to the hotel and asked my wife how as her day, and she said, oh I had a good time. This is a nice town. That almost sealed it right there. Then they took us out the Engineer's Club and fed us crab cakes and I was never going to leave, so I finished out the year in Richmond and we moved to Baltimore and you know, it's been very, very gratifying. It is like everything else, you know, there are struggles and problems but it has been a very good thing. You know I have to say when I went to Richmond, one of the things that happened was that they were using hollow fiber dialyzers and reprocessing for reuse, and I had not done that, but I realized that we didn't have to have all the paraphernalia to assemble dialyzers, we didn't have to have as many technicians and that as long as you did reuse well and it worked okay, that it was another good way to get the job done and probably simpler than what I had been doing in Atlanta, and I found that you had to stay after people to get them to do reuse right because that was in the days when it was all manual and it was a boring process. It wasn't very exciting and it also wasn't very safe because we didn't use gloves and we handled a lot of blood but I had learned about that and had learned about other equipment and other peoples' ideas, so moving was good for me. It expanded my horizons and I had to do more teaching on a formal basis at MCV than I had done at Grady and that was good for me because I needed to get back to that, and so when I came here, we put in Drake-Willock machines over in the new facility and ultimately got them into the hospital unit and I ran off everybody in the hospital unit and hired new staff. I didn't make a lot of friends there but I couldn't bear the way they were doing things and you know, it was, I was younger and I was brash and I knew I was right and I was impatient and not as sensitive as I should have been. But within 7 or 8 months we had a good dialysis program that was doing the job and was meeting the needs of the community. I had to laugh that the people at Hopkins had come to see me in Atlanta 4 years before and I went over to visit and they were still doing things exactly the way I had done them...

DWM: Along time ago. Well let's talk about 1971 and Richmond, and then transitioning into Baltimore. Who was paying for dialysis?

JS: Well in 1971, we were still cobbling together bits and pieces. In Georgia when I left, the Medicaid program was practically nonexistent, so they didn't pay for anything. In Virginia they

had a Medicaid program that paid a little bit to the doctors - well not to the doctors but to the institutions, and so that helped some. But we still were seeking private health insurance and I got a similar home dialysis support out of the state that I had had in Georgia and just struggling to make do. But being closer to Washington, I started going more often to lobby them and it was interesting because there were a number of us doing it and the folks from the kidney foundation kept telling everybody else, you go away. We'll take care of it. This is our enterprise. You don't need to be involved, and we didn't think they had our best interest at heart and we knew that they wanted to control us and so we didn't go anywhere. We just kept coming back and we would come when they were coming because they always announced they were coming and we would come at other times and we wouldn't announce anything. And I had a lot of contacts from my previous work with the demonstration project because I knew a lot of people at HHS, or it was HEW then, and so I used those contacts to help get through things and we tried a lot of different twists and turns. I couldn't make much headway with the delegations in Georgia and I didn't know the ones from Virginia because I wasn't there long, but they were very conservative people who didn't want the government to get into this sort of thing. And, so we just struggled and struggled and struggled. And when I came here in 1972, we were still trying to work it out and in August of that year, Stuart Kleit got together with Vance Hartke who was, you know, Vance was a fairly pedestrian senator. I don't think he had any particular interest in healthcare but he was into constituent service and Stu was in Indianapolis and he told him this was important and gave him a really good pitch about how these people were dying because the richest country in the world wasn't providing support for life-sustaining treatment and he was moved and he put a line into the Omnibus budget act that was sufficiently insignificant that nobody bothered to remove it and that is really the classic way it got done but you know, and so that put Medicare to work making it go and we've been struggling with it ever since, but it goes. But in Richmond, we were just struggling to do it and my chief, he was trying to keep me from putting anybody on dialysis that didn't have private health insurance and I was trying to take care of the people that I thought could do well. We were still selecting patients. We didn't take people with diabetes. We didn't take people who were over 60. We didn't take children. We didn't take people who had heart disease or lung disease because we didn't think we could cope with that so that we were still taking people who had fairly pure kidney disease and who had a history of employment and motivation to go back to it, so it was still a pretty selective population.

DWM: In 1972, when the public law was passed, did that make a big difference for you?

JS: Yeh. It didn't make it immediately but it, you know, because the law was passed in November and the folks at Medicare discovered in December that they had 7 months to put into play a completely new program about something they knew nothing about. Well they were justifiably angry and very concerned, and so they set up a group they called the CRD, the Chronic Renal Disease group, Philip Joos headed that group and I think Phil is still around, and I want you to see him, and they started trying to learn, so the first thing they did was go to Seattle and they spent time out there learning from Chris and Scrib, and seeing what was going

on and then they came back and they told them I was here in Baltimore, and so that being convenient, they spent a lot of time in our units and the thing that we didn't understand, you know, I don't think there was a nephrologist in America who understood what the phrase Health Policy meant and so we had no idea about policy making or how regulations were written, how laws were implemented. They would come and ask us how do you do this, what do you need to do that, and we'd just tell them what we did and then those things wound up in regulation, which was not the way it should have been done and you know, I still feel guilty about that because it was our naivete and and our ignorance that allowed us to mislead those people who were well meaning. I must say after years of working with folks at HEW in Rockville, when I first came out to meet the people at Medicare and Social Security, I thought my God, these people are different. They know they have a purpose. They want to take care of their beneficiaries. They are focused. I had never met bureaucrats like that in my life. They really had a purpose and they wanted to achieve it. And these were good people. In those days, you know today, the bureau program policy out there is probably 400 people. In those days it was Irv Wolkstein and about 6 assistants. And Irv was a very wise man and Phil, Philip Joos was just a very good guy. He immediately saw that this was a worthy thing to do, that this was something they had to do and they had to learn how to do it and he really had, I think, the best intent of serving the patients. He wasn't trying to fulfill the minimum requirements of the law and get out of the way. He was trying to make it work. Well, of course, there was not supposed to be any funding until July of '73 and in June the draft regulations came out and we had a fit. They didn't know how to handle machinery because their durable medical equipment rules were just inappropriate to what we were doing and they hadn't changed them. They didn't know what to do with consumables because they had never had a service that used so much consumables. They didn't know how to pay doctors and Chris had said, well I don't charge the patients for anything. They pay for dialysis and then the facility pays me and I was not interested in money and fees, so I didn't tell them that, but I must have reinforced it, so then they said that they weren't going to pay doctors, they were just going to pay the facility and the facilities were universally owned by hospitals and hospitals weren't going to share the money with us, so nephrologists all over the country said these rules won't do and it was that outrage that really was the nucleus of what became the Renal Physicians Association. You know, we had telephone calls flying all around the country and then Stu Kleit suggested that we get together at O'Hare and so we were there on Friday the 13th of July.

DWM: What year?

JS: That was '73. And I guess there must have been 30 or 40 of us and after we got through expressing our outrage, we started trying to figure out what to do and we decided we would need an organization but we really didn't know what to do about that.

DWM: Now would you consider this the first meeting of the RPA?

JS: No it was sort of a preamble to the first meeting.

DWM: And who all can you remember that was there in O'Hare, in the airport that day?

JS: Well Stu Kleit and Dick Hamburger from Indianapolis were there because they had organized it. Elbert Tuttle was there, uh, and I think Bill Anderson was there, Fred Westervelt from Virginia, I think Jack Maher from Georgetown might have been there. Um, I just don't remember anymore.

DWM: That's a good group. So how many people do you think were there probably?

JS: I think at least 30.

DWM: 30? And so you all discussed your outrage.

JS: Yes.

DWM: And then...

JS: And so we decided we had to talk to them. John Bower was there. And, ah, and so since I was closest to Baltimore, I took all the notes that everybody had and I went and talked to Irv about it, and he first tried to slough me off, but then when he saw I wasn't going anywhere he listened and we began to make some changes and they made some changes in the rules and then he said now look, if you want to change this physician payment thing, and we had said you know, what we are doing is taking care of the patients. It is not just being there for dialysis. We don't want to get a fee for dialysis, we want to get a fee for the care of the patient. He said, well if you want to do that, you are going to have to get the AMA to approve it because they don't like global fees. They don't want capitation. So I started trying to talk to the AMA. Well by this time it was late October and the ASN was in Washington and at the request of the group, I got the ASN to give us a meeting room and we held a meeting that evening and we had probably 250 people there. And so I talked about what we had done and what we might do and we listened to a lot of peoples' ideas and recommendations, and so we agreed to form an organization called the Renal Physicians' Association. I suggested that name because I didn't want to exclude transplant surgeons and urologists. I wanted to include as many people as we could. As it turned out, it never worked out very well and we never really got very many of them to come with us but we did that. The meeting went on for about 2 hours and at the end of the meeting, I said well we need an organization, we need leadership, we need a board. How do you want to go about this? And, somebody in the audience said John you're doing fine. You just take care of it and everybody left. So that was how I got to be the first President of the RPA. And so I called people I knew around the country that I thought were involved and level-headed and created a board, and then I sent out notices to all the people who had attended and asked them to pay $15 in dues and most of them did and the board understood that they were to have meetings whenever we needed them and that there was no reimbursement. It was out of

their pocket. And a few of them like Chris, who had very big expenses, coming from the West Coast, had an organization that said we think this is important. You do it and we'll pay for it. And, the rest of us I think pretty well had to bite the bullet but we went forward with it and I met with the AMA Council on Medical Services, and I'm trying to remember the guy's name. He was an older physician who was the leader of a medical group in Neenah, Wisconsin, very fine man, and several others that I got to know fairly well, and it took them a while to accept that what I was asking was not capitation but was a global fee and I said, you know, gynecologists charge a global fee for an uneventful pregnancy, delivery and post-partum followup. I said that is a global fee. That's not capitation. That's what we want to do. And after about 3 meetings with them, they gave me a letter concurring and I took that back to Irv and he said okay, and that's how they came out with what was first called the alternate method of payment, which was to carve out the $12 per treatment out of the fee and allow that to be paid to the nephrologist responsible for the patient. And I guess that was the first major change they made in the regulations, though they had made several minor changes to allow durable medical equipment to be purchased, to allow the consumables to be sort of listed in a comprehensive fee for dialysis and they made some changes for transplant that were important because with this 3-month delay in entitlement, if you had somebody who was going to get an early transplant or if you wanted to list them for transplant, they had to have tissue typing done. They had to have an evaluation to be sure that they were a suitable candidate. If they had a live donor, you had to work up the donor and so they contrived the rule that pretransplant services could be included in the organ procurement fee, which would be paid at the time of transplant but which would include everything that went into the preparation so that the transplanting institutions could accumulate all their costs, divide it by the number of transplants they did, and that was their organ procurement fee, and they had one for live donors and one for cadaver donors and that was the way it was done until recent years. And it was purely a contrivance that Irv came up with because he wanted to help. He wasn't trying to save money. He wasn't trying to protect his budget. He was trying to help. And it did.

DWM: So did you think, once you got through this initial outrage in the summer of 1973, did you think you all in those early years ended up with support from Medicare that was a good thing? Did it improve what you had to work with in providing dialysis?

JS: Oh, it was a tremendous improvement. There is no question about it. We had, you know, I've always said that as soon as it was done, we went to Medicare and said, we're here about dialysis. We know how to do dialysis, you provide us the money and they said no, we know how to pay for healthcare, you tell us about dialysis. And, ever since then it has been about money and that's been sad because both parties care about the provision of care, but when we talk to Medicare and Medicare talks to us, it has always been about money. But they did get it going and we did get paid for the treatment. The dialysis unit got paid. The doctors didn't get paid for over a year, until we finally got that alternate method of payment, which I think was in September or October of 1974. And when we got that, they paid us for the preceding year. You know, so we got lump sums that helped out a lot. You know, one of the reasons I think that we

successful was that John Capelli in New Jersey, and his New Jersey Renal Physicians' Association, were angry, noisy, litigious and they filed suit against Medicare and they don't have to get sued now but they are a little bit more used to it. In those days, they really didn't want to get sued, and so they were trying to make that suit moot by solving the problem and that helped a great deal, though I must say most of us on the RPA board, of which John was a member, were a little leary of John. We thought he was the wild man among us but he was very effective and he did a good job. Now he was also at that July 13th meeting and he was outspoken because John was in private practice and trying to make a living, and most people doing dialysis were working in academic programs. So, we at least had a salary and our institutions complained when we didn't get paid for what we were doing, but we did have a salary.

DWM: Well speaking of money, let's talk a minute about at about that time, the late 1960s, early 1970s, there was this emergence of the for-profit dialysis centers, outpatient dialysis centers, versus the nonprofits. Tell me what you remember about that time where that was beginning to happen.

JS: I guess the simplest way to express it is when we heard what they were doing in Boston, we were horrified.

DWM: What did you hear about what they were doing in Boston?

JS: We heard that these guys had gotten some money and set up a for-profit dialysis unit and we thought for-profit healthcare, that can't be good. And then as soon as Medicare came out, I think before the end of 1973, they had switched from twice a week dialysis to 3 times a week dialysis. They were very clever. They figured out the regulations didn't say how many times a week you could get paid for dialysis and if they did 3 times a week, they could do shorter dialysis. It would cost them a little less to provide each one and they would get the same fee for each one, and sure enough they did.

DWM: Was that money-driven? What did you think about 3 times a week dialysis versus, as far as patient care goes?

JS: At first we thought it was just a ploy to get more money. And I think it was. But then we began to realize that it really was better for the patients and everybody started doing it because it solved that problem of having a long 3-day hiatus between treatments and having to struggle every Monday with the guy who got dialyzed on Thursday, and so it really was better for patients, it was better for scheduling. It made us a more efficient thing. So they did a good thing but we didn't trust them when they did it at first and I think that they were willing to talk in public about money and none of the rest of us ever wanted to do that. It was sort of one of those things you didn't do. It was, you know, it was unprofessional to talk about money. And so I think that we were really very leary of them, but they had money to build dialysis units when

nobody else did. Because Medicare wasn't coming along and saying we'll give you an advance so you can go to another dialysis unit, they were just paying for the care you provided and I know my friend, Bill Anderson, who had the home dialysis program in Miami, opened one of the first BMA dialysis facilities remote from Boston and he told me, he said there is no other place to get the money and we need it badly and I'm going to do it. And he said, you know, I'm going to make some money out of this, too. So he did and it worked but by the time his contract was up, he was so unhappy with the BMA folks that he wouldn't renew his contract and he went across the street and opened a competing facility and took all the patients. I think that is when BMA began to learn that they had to do something about competition and they started putting restrictive covenants in their medical director contracts.

DWM: Well when did you become involved in DCI, and what was the thinking behind DCI?

JS: Well you know, I guess I have to go back a ways. When I was running the program creating home dialysis in Atlanta, Keith Johnson was in the Army at Fort Gordon in Augusta and I had a retired colonel who was a home dialysis patient and in those days using the Scribner shunts, everybody was supposed to dialyze without a blood pump because we thought that was a big safety factor at home, that if your blood pressure dropped, the flow would slow down and the worse thing that could happen was the system would clot but you'd be all right and so we were very strongly opposed to using blood pumps and he had a good bit of trouble with his shunt not working. He wouldn't get good blood flow and once in a while he would get an infection and he would get sick from other things and he'd show up int he emergency room at Fort Gordon and Keith had had 1 year of nephrology training I think at that point and so he was the only one around who knew anything about kidney disease and dialysis, so he always saw the colonel, and he and I spent hours on the phone. And he was a great help to me because he kept the colonel in Augusta when he otherwise would have had to come back to Atlanta. And he was a huge help to the colonel. So, when he was ready to get out of the Army, I tried very hard to get him to come to Emory and he went to Vanderbilt instead, and he worked with Earl Ginn and came to compete heard with him because they had differing approaches to things and of course, Earl, like most people running dialysis programs and nephrology divisions, was fairly autocratic, and Keith struggled under that, and the dialysis at Vanderbilt Hospital was just one machine and not much to go with it and Earl had created a program at the VA. And actually, Earl had taught us how to do dialysis for less than 8 hours because the VA required that his staff work an 8-hour day - period. And so he had to do dialysis that was only 6-1/2 hours so they could get them on, treat them, get them off, be prepared for the next day. And so he used Klungs up there because they were the most powerful dialyzer he could get and he wanted to be able to give them a decent dialysis in that period of time and he convinced us it was reasonable to do that short dialysis but he was doing that, but they had patients and nowhere to go. And Keith was just bitterly frustrated because he didn't have anywhere for patients to go and this was, I suspect somewhere around 1969 or '70, and Keith's father was an internist in New York who had started the Life Extension Institute and all these things and had become, I think, fairly wealthy but he was really a very devoted physician and Keith called him and said I don't know what I'm

going to do. I've just got all these patients and I have nowhere to treat them and it is just breaking my heart, and his father said well how much would it cost to set up a dialysis unit? And Keith said I don't know, probably $100,000 and his father said well I'll lend you $100,000 and you set up a dialysis unit. So he did and he created a nonprofit organization to own it and they were enormously successful, because you know, the patients just flooded in. There was nowhere else to go, they had lots of patients. We had, and a number of them had health insurance that would pay for it and he was working everything just like I was, at the same time, and I guess by 1971, our friend Arthur Williams down in Charleston said, Keith do you think you could help me set up a unit in Charleston. And Keith talked to his father who said sure, help him. You don't have to pay me back. That money is doing good things, I don't need it, you just keep it and help him out. So they built a unit in Charleston and then they built a couple of other units in other places in Tennessee and I thought it was really a great model and I was about to do the same thing in Atlanta before I left, and I didn't get any support from anybody. Nobody wanted me to do it, but I already had an option on a space to lease and plans for a dialysis center, and a bank that would lend me the money. And, then I left so I never got that followed through on and nothing ever came until DCI came and opened a unit for them in Atlanta. But I had known all this, and Keith was a friend, and we were involved in SEOPF, the transplant registry, and so we would see each other regularly there, and he would occasionally come to the South Eastern meetings and I don't know, I guess it was probably 1980 when at one of the SEOPF meetings he asked me to go to breakfast with him and I did, and he said I need somebody who thinks like I do that I can talk to and bounce ideas off, somebody that the rest of us can depend on if I'm not around. He said I really want you to just come and advise me and listen and help. And so I've been doing it ever since. I'm not a member of their board, but I attend their board meetings and comment on what is going on. I go to their medical director meetings every year and participate in the programs for that. I chair the committee that reviews their grant process and we dispense about a half a million dollars a year in funds contributed by DCI facilities and the corporation, so I've been involved with them for a long time in this fairly formal way but I've known them since they started and I really approve of them and what they do and we've tried to do with IDF, about the same thing on a much smaller scale. Keith got there early and knew a lot of people and they had needs, and he helped them. And I think that's how DCI got to be so big. I mean they have 200 facilities now in 26 different states. I don't think I would want to do that. But, you know, I understand how it happens because when we formed IDF, we were going to have 1 facility and it has grown because people needed help and we gave it to them.

DWM: What do you think now your perspective in 2007, what is your perspective just in general about for-profit versus nonprofit, that including the large dialysis organizations?

JS: Well I still have reservations about for-profit healthcare whether it is a hospital or a dialysis company or anything else because they have to respond to their shareholders more than to their patients and I think that that's something that I'm distressed about. It doesn't mean they don't do a good job. I think they do. By and large, I think the big dialysis companies do a good

job. They do exercise more control over their facilities than we try to do over ours, at least over the budgets and that sort of thing. We try very hard to set up procedures and policies that are good for patients and enforce them but out budget process is a little lax compared to theirs. But I cannot say that they are a bad thing because a lot of dialysis wouldn't have happened without them, but I have real reservations about what they do and why they do it. And you know, I have even more reservations about for-profit hospitals. That disturbs me. But that is just because I'm an old man and an old-fashioned man and I think that healthcare ought to be basically a fairly altruistic prospect that we do for the welfare of our patients. But the large dialysis organizations, as they are now called, are not bad things. I see them as a threat to small organizations like my own, and I see them as more of a threat because I'm afraid that the people at CMS think it might be simpler if the rest of us disappeared and were subsumed into these big organizations and then they wouldn't have to both with us, they could just deal with them. I think they are sadly mistaken because if they had to just deal with them, their life would be a lot harder than it is now because they'd be in a much stronger position and they are in a strong position as it is, so it's, you know, it changes the environment. We are currently working on some of the Maryland regulations that relate to dialysis, and Maryland is a highly regulated state. We've got more regulations than anybody with the possible exception of New York, but when we start trying to redo this, I have to keep reminding the people from the state that you are not talking about a bunch of freestanding independent facilities, there are only about a dozen facilities in Maryland that don't belong to hospitals or to one of the larger organizations. So you're trying to write regulations that apply to those few of us and most of the regulations need to apply to everybody. You've got to understand these are chains of dialysis units. They don't operate the way you think they do. They have different administrative policies and mechanisms and if you don't address that, your regulations will never work, and they really don't want to confront that. They don't want to think about the fact that the way they originally designed them is not the way they ought to be and they want to do a little modification, but you know, they try to tell us how the administrator ought to be in every facility and we don't have administrators in every facility, we have nurse managers who do the administrative function and we have administrators who go and oversee the business affairs and help them with things periodically and provide the guidance, and certainly that is what Fresenius and DaVita do. They have regional administrators, not individual ones. Well it's just really giving the state a hard time trying to figure out how to regulate us when they don't understand what we are doing. And so I see the big companies as, I don't think they are any longer trying to take over my organization but they'd be just a happy if they could.

DWM: Well let's talk a minute about organizations. Let's talk about, we've talked about the RPA, but I want to know what you remember about the American Society of Artificial Internal Organs, how that began, and what impact that had in the early days.

JS: Oh that was a tremendous resource. You know, ASAIO, I've always said, is the society of medical tinkerers and the first time I went to one of their meetings, I heard people talking about oxygenators. I heard people talk about pumps to replace cardiac function. I heard them

talk about devices that might control an incontinent bladder and I heard them talk about dialyzers. And, this was the only national meeting where you could go and talk about dialyzers without having to blush because as I had said before, the serious scientific nephrologists looked at me as an artificial nephrologist because I worked with artificial kidneys and I insulted them by telling them that in spite of that, people like me paid the salaries of a lot of people like you, and I think you ought to give us some respect. But you know, you could go to ASAIO and dialysis was an important element in the range of devices that were being discussed and so you got a little respect there and that was great, and you could talk to the innovators. You could talk to people. You know, you could talk to Converse Peirce. You could talk to Ed Leonard. You could talk to Scribner. You could talk to all sorts of people that you didn't get to see at other meetings and so it was a tremendous place to learn and every year you tried to get on the program there and you tried to have something to do with it because you wanted to go and see what other people had been doing and you wanted to talk to people about what you were doing. So it was an exciting meeting and I must say it really kind of broke my heart when I gave up my membership about, I guess 6 or 7 years ago. Actually I gave up my membership when Chris Blagg was president and I wrote him first and told him I was going to do it because I had been to a couple of meetings and it was almost nothing about dialysis anymore. It's all about other devices because dialysis has moved on. ASN had to give up and let us in, so you can talk about dialysis at ASN, and we have the other meetings that go on where we can do it, so we didn't need ASAIO and ASAIO didn't need us, and at the same time they had raised the dues from $50 to $300 and it just wasn't a value for me, so I wrote him and letter and told him so and dropped out, and I think it is sad because I felt that it was part of the foundation I stood on to grow but it's changed and I've changed and so it is no longer appropriate.

DWM: Those early days at the ASAIO, were they actually bringing devices there and you were holding new innovative devices?

JS: Some people would bring their latest toy and show it off, and you know that was where Scrib showed up with his, well not his first patient, but with a graduate student who was I think his 3rd patient who came up and gave the presentation and then uncovered his arm and showed his shunt and the crowd went wild. So yes, it was a place for a little showmanship, and you know, you'd go in wondering what was going on and you'd come out with plans for 3 clinical trials that you were going to do with your friends from other places in the country. It was lively, it was creative, it was not at all organized or high bound, it was the place you went to learn and to share, and it was wonderful. We tried for a while to get them to hold 2 meetings a year, and when they didn't was why we started other organizations.

DWM: You mentioned Leonard. Are you talking about Leonard of the Leonard-Skeggs?

JS: Skeggs-Leonard, yes.

DWM: Skeggs-Leonard? Tell me about him and about that dialyzer, if you remember anything.

JS: Well I never used that dialyzer. I saw it at ASAIO and I thought it was a lot smaller than a Kiil, and it was reported to be more effective but it really wasn't practical. We didn't think we could build it, you couldn't buy it and Ed was not a particularly warm and outgoing person, so I never really got to know him very well, but I had to admire him because he was really bright and he really had a great grasp of how these things worked, but there were a lot of people like that. You know, there were just all kinds of people there that were fairly serious scientists who just got off into the device end of it and so there were a lot of people who would come up and make presentations with mathematical formulas and physical formulas and chemistries that were far above me, but you know, then they'd bring it back and make it useful and it was really a very good meeting and there were a lot of exciting people there.

DWM: Well you just mentioned the Kiil dialyzer. Tell me what it was like to build a Kiil dialyzer when you were getting ready to start a treatment.

JS: Well you had these big plates. You know, they were about 20 inches wide and about 48 inches long and you had this big clamp, and so you would, the plates would have been scrubbed and cleaned and you would lay the plate out and you would have these rolls of cuprophane, and you would put the cuprophane down and then you would put the blood port in and you'd put the other layer of cuprophane on, then you'd put the next plate on top of it, and you'd do that again. You had 2 layers. Then you'd put the clamp on and you'd use a torque wrench to tighten the clamp evenly all around, and you would wet it and then you'd test it to see if it held air, and then you'd fill it with a disinfectant and clean it, and after it had been, usually they were left overnight in formaldehyde in the early days, and then you'd drain it, rinse it and use it.

DWM: The cuprophane that you were making the sheets out of, what did it look like when it arrived? I mean, what did you have?

JS: You would get it in rolls and it was a clear cellophane that had sort of a metallic glaze to it. Ah, but it was just clear cellophane. You could order it in different sizes. When we were building Klungs, we got it in rolls because a Klung was about 9 inches wide and about 22 or 24 inches long. We used a smaller sheet and we used lots more of them. And we would get it in rolls that were folded double and we would lay it out and we had templates that we would put down on top of it and then we would cut it with a press. And, so because ours had to have holes in it, what you used for a Kiil, they just slid a blood port in it and closed it down over it, so it didn't have to have holes in it. But it was made in Bamberg, Germany, and it was good membrane for dialysis compared to anything else we had in those days. Of course, you know, it's not very good for middle molecules and larger. It is very good for things up to molecular weights of 150 or 200 and the cut off is not abrupt but it is very steady after that.

DWM: Well other societies then, lets talk about the ASN. Do you remember when the ASN sort of emerged and what role it filled early on?

JS: Well to start with the International Congress of Nephrology, which was put on by the International Society of Nephrology, came to the United States for the first time, I think in '66 - may have been '67. It met in Los Angeles at the old Biltmore Hotel, and Jim and I went out there. We were present at the first meeting and I've only missed one since. Ah, but we were just tremendously excited because it meant that nephrologist was what we were. Nobody used that term before that. It was new. There may have been a few people who did, but it was not the usual thing that people did. And so, we were just tremendously excited. I guess that first meeting must have drawn 700 or 800 people, and there were a number of presentations, and it was just very exciting to be a subspecialty now named and identified by itself and at that meeting, we agreed to form, you know, at the International Congress, we agreed to try to form the ASN and the ASN, I think that a few people like George Schreiner, and John Merrill, and maybe Don Seldon, were really the key people who made it happen and so when we, it got formalized at that meeting in Los Angeles, and it has since then been the scientific society in nephrology and its function is to put on the best nephrology meeting in the world, and they do.

DWM: Were they talking about dialysis in those early meetings in 1966? What would have been the thought about dialysis as part of ah,...

JS: Ah, I think it was still that dialysis was something that some nephrologists threw the careers at and that we were doomed, you know, that it was not a respectable way to practice medicine or to study science.

DWM: Well some people have certainly said that in the early days of dialysis, there were certainly, there was the thought that this was experimental.

JS: Yes. There was no question that a lot of people thought it was experimental. A lot of people thought that we were supposed to be studying it like an experiment, when we were just treating patients and actually, I think that everybody who was doing dialysis in the '60s and then the early '70s, was really doing it and monitoring it and reporting what they learned, almost as if it were an experiment, because every day you saw something you hadn't seen before. It is impossible to convey what kind of a learning experience it was, because you would, you knew that the treatment was suboptimal and you kept trying to improve it, and sometimes what you would try would be awful, and you know, and you'd come away saying God I'm so glad I didn't kill anybody. And the next time something else would work and you'd say, man this is great. It's going to be better. It's going to be easier. We can do this, you know, but it was all trial and error. And so, yeh, we were not respected for what we were doing. It was very much as I told you, you know, you people have done this without a scientific basis. You don't understand what you are doing, and that was the way they saw us. They really felt that it was not a proper expenditure of a highly trained physician's efforts and that we were much to be questioned and put down for that because they felt that we were basically wasting the potential of our careers, and I think that without exception, every one of us who was doing it

weren't concerned about our careers. We were concerned about our patients. And, you know, so it was a long struggle, and ASAIO really allowed us to develop much of our legitimacy because that's where a lot of the stuff was published that finally said this is the scientific basis for dialysis, and I think enough of it was published that they really could no longer say this is experimental, this is not nephrology. And I have said for a generation now, that nephrology training programs should be ashamed of themselves, because many of them still tell their fellows ah, get into the lab and do something worthwhile. Don't waste your energy on dialysis, it's just not worth your effort. And then they finish their training and go into practice and discover that dialysis is how they make their living, and they don't know how. And I think that is shameful. And I think that it is improving. I think that nephrology program directors recognize that their fellows have to learn clinical nephrology and they have to learn dialysis, and they have to get some education and transplantation, and if they don't do that, it isn't adequate training. And I think that is one reason that a lot of programs are going to 3 years of training instead of 2, is because they still want to get all of the laboratory investigation, and all the experimentation done, but they acknowledge that this also needs to be done, and as transplant has become a larger component of what people do, they realize it is going to take some time to learn how to do transplants because you know, I learned to do transplants by being there. You know, transplantation was, when I was at Emory, we did maybe 3 or 4 transplants a year when somebody came up with a donor, and then you know, SEOPF started off as another public health service thing. They had set up a few programs to do organ procurement and see if it was possible to get cadaver kidneys for transplant and to see if there was any way to do tissue typing because in those days, tissue typing wasn't standardized. There were all these multivalent antibodies that could not identify single antigens and so we were searching, and searching, and searching, and hoping that we could find the secret of compatibility so that transplantation would be successful. And so we had one of these organ procurement grants in Atlanta, and David Hume in Richmond, thought that we were in Atlanta, we had a big city hospital, we had lots of potential for harvesting cadaver kidneys. He was in Richmond, he had one of the world's first and most successful transplant programs, and he didn't have enough kidneys and so he hooked up with us and with the folks at the University of Virginia, at Georgetown, at Duke and the University of North Carolina at Wake Forest, and I guess that was everybody, and we formed what was known as the South Eastern Regional Organ Procurement organization and that was SEROP, and then it became SEOPF when we lost our grant and we became a private entity. But, you know, we were learning how to do tissue typing. We were learning how to obtain organs and so while I was running dialysis, I was also going out at night helping people obtain organs and preparing them for transplant and when our pathologist who had been running the tissue typing lab left, I wound up being responsible for the tissue typing lab, and all I knew about tissue typing was what you do with the results, but you know, you had to do it because it had to be done, so that was the way it went. And when I went to Richmond, Dave kept saying that he and I were going to go out and teach people about organ retrieval but he was always so busy, we never did much of that. Ah, but I did a good bit with the transplant program while I was there, and you know, when SEOPF became SEOPF, Keith was the first president and Fred Westervelt was second, and I was the third president, and we just kept it

going. It was during my tenure that we created UNOS as a voluntary organization that people outside SEOPF could come in, because SEOPF had taken in a lot of people who were contiguous, but we didn't take anybody from elsewhere, and we allowed people from other places in the country to be part of UNOS, which was a free service. All they had to do was pay for the time they used on the time-sharing computer, and so that was that, and it really, you know it worked out, and as we were going along, we were finding more monovalent antibodies and were able to improve tissue typing, and we were, first we were competing with Terasaki and then we were collaborating with Terasaki. We were competing with the Europeans and then we were collaborating with the Europeans and we all learned, and everything got better because of it. And when I came here, I ran the organ procurement organization for the first 3 years I was here, and so it was you know, it was very exciting. I guess Hopkins was part of the original, I don't know if they were part of the original SEROP or not, but they were certainly part of SEOPF, or a very strong part.

DWM: Early on, right.

JS: And the University of Maryland was for a good while, but we haven't been active in the organization now for more than 10 years, well 15 years, which is a disappointment to me but the organization has sort of ceased to have any meetings because we gave our function to UNOS...

DWM: Right.

JS: ...and you know,...

DWM: UNOS has really become the...

JS: ...right, and it became the registry. Of course, we won't get into all the details.

DWM: Well speaking of groups coming together, let's talk about, back to dialysis, let's talk about the networks, and they, I think they originated about 1976. And, what do you think they brought to the dialysis community?

JS: Well you have to remember this is also some of the blame that goes to those of us who were telling Medicare how to write the regulations, because what we talked about - Chris talked about it, I talked about it, so did other people. A network was going to be the network of dialysis centers that supplied patients to transplant units. So the transplant center would have a network of dialysis centers around it and that was what it was. Well then Al Goodman came down from Connecticut to spend a sabbatical year at Medicare and he was considered to be the authority, because he had been running a dialysis unit up there, and ah, Al, you know, Connecticut, New York, that was a fairly competitive medical community up there, and Al looked at the concept of a network and he realized that if that is the way the network is, the

transplant center is going to control the dialysis units, because it is one transplant center. So he wrote a rule that said that a network had to contain at least 2 transplant centers, which now means the dialysis centers can control the transplant centers and make them compete, and that's the way it was, and then it grew. Because once it got to be that, they decided that it should be larger areas and it should be an information exchange, and a data collection, and a collaboration. So that's how we wound up with the first 31 networks. And then they decided we were more trouble than we were worth and they couldn't get rid of us, but they could shrink us down and turn us into 18, and make us larger so that we wouldn't be quite so cohesive and antagonistic.

DWM: What trouble were the networks for CMS?

JS: Oh, it was a place for us to come together and complain. I mean, that's the only trouble it was. We weren't really causing any great trouble, but we were making noise and using up their time and energy. And so when they made us bigger, our professional staff became more important and the institutional members became less important.

DWM: Over the years, what function do you think the networks have provided? What has been sort of the main thing they've given to the dialysis community?

JS: That's kind of hard because I am very ambivalent about networks. You know, I was a founding member of the one we had originally, which was just Maryland, and I was a founding member of the one we have now. And I have tried to create them because I thought that having an organization composed of the clinical entities that took care of patients was important. Ah, but they are also a nuisance. And because they are sometimes led by people who are more concerned with their importance than their function, I get aggravated with them. Not necessarily our network because I think it really has worked pretty well, and I think we have done well with some experienced people leading it. But it ah, but the networks, if you come right down to it, all they do now is collect information, validate it and forward it on to CMS and then come back with more requirements to the dialysis and transplant programs that could have come directly if we wanted to do it. So I think that they are one way to get the job done, but I think there are more efficient ways to do it. I think I'd rather have my 50 cents a treatment back and respond directly to CMS than to do it through a network. But the networks are resources for education, for communication and collaboration, and they continue to do that to some degree, but there are still now, they say that their principal duty now is quality improvement but its basically data collection and validation.

DWM: I can see that. Um, we haven't talked much at all about peritoneal dialysis.

JS: Well I think that ah, you know, peritoneal dialysis came along after hemodialysis. And, most of us who were heavily involved in hemodialysis said uh huh, and went on with what we were doing. And that wasn't quite fair, but that's what we did. Ah, but we learned to do peritoneal

dialysis acutely because it was a way to take care of somebody who came in with dangerous levels of uremia and we didn't have the capacity to do an acute hemodialysis right then. So you know, I've probably done more than 1000 abdominal punctures to set up peritoneal dialysis and make it go, and we've done lots of acute dialysis. But ah, you know, then when Henry Tenckhoff devised the catheter, that looked promising and you know, what happened in Seattle, happened all over the country. When Henry suggested doing this, they said yeh Henry, go ahead, you do that. And nobody paid him much attention. And he worked it out and demonstrated that it worked, and then he was left to take care of those patients that couldn't be accepted onto hemodialysis, so he got the leavings. And at first, it was uncommon for him to have one of those patients who lived more than a year, because they were pretty sick people. And then as time went on, he learned and they learned, and they began to do better, and the rest of us began to learn as well. We didn't do much of it because Medicare hadn't adapted a way to pay for it, and they weren't sure what to do. Well I guess it was about, maybe 1977 or '78, that Baxter decided to get into it. It was after the guys in Texas developed CAPD, which made a lot of difference because then you didn't need any kind of a machine. You know Charlie Willock had made a machine that made dialysate, making water, making infusible water and very clever. It was good, and some other people made one, too, but Charlie's was better. It was little bigger, but it was better. And it didn't go very far because if you are going to have to have a machine, you might as well do hemodialysis. And, but we all started after Medicare said they'd pay for it, to do it with patients that we weren't confident could succeed on hemodialysis, and I've always been a little bit resentful because Baxter went to Medicare and said, look at this, dialysis with no machine, dialysis with no staff. Look at this, simple, effective. They went (clap) damn! Cheap! And so they approved it. It turned out it wasn't cheap at all. It cost the same thing as hemodialysis, and as a matter of fact, it cost more than home hemodialysis. And ah, so Medicare got fooled again, and Travanol made vast profits. You know, they still make vast profits because they sell dialysate for 30 times what it costs to produce it, and I can't help resenting that a little bit, but it was good business for them. It's made them a lot of money and I wish they had done more good with their money and they haven't. You know, if Baxter were really an effective company, nobody else would be in the dialysis business. They had a decade to do this before anybody else got started and they just didn't do it. They just dropped the ball. And they've dropped the ball on a lot of things since, but that is, you know, and they are not the only company. Lots of companies do that, but Baxter talked the government into it, who believed that simple meant cheap, and turned out it wasn't. However, as time has passed, we have gone from having the poorest patients, the sickest patients going on PD, to some of the most motivated, healthiest patients going on PD because it is the easiest way to dialyze at home. And that has been very effective and very good, but I think that when Lee Henderson went to work for Baxter, he came around and said why aren't you guys interested in peritoneal dialysis? And he got a group of us together and said I don't understand why. And I said well it is very simple, Lee. In the first place we started out doing hemodialysis and this came along, and it was sort of an aside. I said the second thing is, there is some technology in hemodialysis. You can twiddle it, you can tweak it, you can play with it, you can improve it. Peritoneal dialysis just is. There is not much you can do. The catheter either works

or it doesn't. You either add another exchange or make the exchanges bigger or you don't. And that's it. Where is anything to get interested in. He laughed but I think he understood because Lee is a, you know, Lee is a real scientist. He understands a lot about all the technology and all the tweaks you could do with hemodialysis, and so I'm sure he was being a good company man when he asked the question, but I suspect he already knew the answer. But peritoneal dialysis has for all of those reasons, never been as popular as they thought it ought to be. I think another thing that makes a big difference now, when you start a new patient and you suggest to them that there are 2 ways they could do their dialysis, these days a lot of people have seen hemodialysis, they've seen it on television, they've seen it in real life, they have a friend or a family member who has been on, and so when you say dialysis, that's what they think, and the mind is closed. There is no consideration. And that has, I guess it's only been the last 10 or 15 years that I've been aware of that, but there is no question. They expect dialysis to mean hemodialysis so they don't think about it, and it is very hard to change somebody's mind when they come at something from that kind of perspective.

DWM: I think that's true. Um, when do you think you started doing some peritoneal dialysis of any substance?

JS: Ah, I think we were still doing just acute peritoneal dialysis when I left Atlanta. We did maybe a couple of patients when I was in Richmond. When we got here, I know we didn't do any the first 2 or 3 years I was here because I was just busy working with what I was familiar with, but then we had some patients who had terrible vascular disease and we didn't have any access, so we put them on peritoneal dialysis. And they did okay, and we used it more and more, and we've continued to use it, but it's always been...

DWM: Secondary?

JS: ...secondary. And I couldn't tell you all the reasons, but I've told you the ones that I think are most important.

DWM: How in the world did you find time to, early on, you know take care of patients, put in catheters, set up dialysis, treat patients and go out into the community in Atlanta and raise money, and then later on run a division of nephrology, oversee dialysis, take care of patients and go, you know, deal with the folks in Washington? How did you find time to do all of these things?

JS: It never crossed my mind that I didn't have to. You know, it needed doing, and so I did it. I guess because I had associates and colleagues who were willing to support me in the effort is one of the important things. I mean, they were willing to back me up and to do the things I wasn't able to do because I wasn't here, and I think because I was having so much fun. I was excited. And, you know I worked an awful lot of hours, and you know, I laugh now that I'm largely retired and that means that I probably work 30 or 40 hours a week and that seems like

nothing. And, so it's, that's the difference. You know, I remember I had a young man I tried to recruit to join our division and after he had his visit, he said you all are a good group of people, I really enjoy being around you. I think this is a nice opportunity, but I'm not looking for an opportunity to work 80 hours a week. I've been doing that all through my training and I don't want to continue. And, I'm afraid that's pretty much what we were doing. And you worked a lot, but it was very gratifying. It's like my wife says. She likes painting because you can look back and see what you've done. And I could always look back and see what I'd done. You know, I think, people talk a lot in sort of pontifical terms about making a difference. But I know that my life and my career have made a difference. I don't have to be told. I know that, and that's not boastful. That's just the truth. I know it happened. And, was it because I'm a wonderful person. No, it's because I was at the right place at the right time and I guess because I had the right values and I wanted to see things done.

DWM: Well certainly physicians today I think have a lot of trouble being politically influential, politically active. And that's something you certainly found time to do in the midst of this busy clinical practice.

JS: Well it started because if we didn't do it, we were never going to get the money to pay for dialysis. So we had to do that. And so I started doing it, working with the state government in Georgia and I continued doing it with other organizations, and with the federal government, and of course, I had to work with the bureaucracy that provided the grant for our first dialysis facility and that's politics. The bureaucracy lives on it. You know, they are the immortals in politics. Everybody else has to get elected and reelected. They get in there and they stay for a lifetime and they are succeeded by somebody they trained who is just like them, so it's the immortal government and you have to be aware of that. And, you have to learn what their priorities are. You know, they have to get the job done, but the have to not be seen as making a decision that might be controversial. And they have to maintain what they are doing in order to maintain a budget, and so if you help them serve their purposes, they'll help you serve yours. And, the same thing applies to congressmen. When I went up to try to get the 100% tariff off cuprophane, I was working with a congressman from our district that I thought was an incompetent, and I really didn't hold him in very high regard. But ah, he was in the congress and I was not. He could get something done. And he knew that this was not going to be of enough interest for anybody to object to, and he was willing to do it, if I would help him get a little publicity for it, and so I did, and so he did, and that was nice. Then when he came for re-election, he came back and he said now, I know you didn't support me last time and I can't ask for your vote unless you want to give it, but would you please not sign a petition for my opponent, because I had signed a petition for his opponent that was published in the paper the 2 years before, and I promised him I wouldn't and I never told him how I voted, and he was re-elected once and then he was defeated, but you know, you work with people and you sometimes hold your nose and work with them because you have to get things done. But after a while you learn. But I guess part of it too, is that my father never was able to get the education he wanted. He was a rural letter carrier, and because he couldn't do much in that

job, he became the president of the State Rural Letter Carriers' Association and an officer of the National Letter Carriers' Association, and this sort of stuff. So he believed in working in organizations because it allowed you to accomplish something and it gave him a little stature. I've always said I do the things I do not because I want be important, but because I want to do something important and I think that's the motivation. You know, it boils down to recognizing that I can take care of a patient but I need a structure to take care of many patients and I want those patients to be able to get care, and in order to do that, I've got to get help from lots of different resources and you just have to be willing to work with them to get there. So you know, it's, I think I developed a political sensibility out of necessity, but it has been very helpful.

DWM: You said earlier in the interview, that during this time you have been taking care of patients and dialysis patients in particular, that you've learned a lot about humanity, and you've learned a lot about yourself.

JS: Uh hm.

DWM: What do you mean?

JS: Well, I think when you deal with people who are staring death in the eye, you deal with people who are having to change their life in order to keep their life. You deal with people who have to make sacrifices on a continuing basis. You see something of the emotional cost. The cost in relationships. The cost in time and the changes in belief systems they have to have to be able to do this. And so you have to think about how that would apply to you, and you have to develop sensitivity to those people or you can't help them. Ah, and so you recognize that there are some things that you are not very good at. There are some things you are better at. But you can always get help. You recognize that you have to develop the skills to lead a team because it takes a whole team to do this and that you have to bite your tongue sometimes to lead a team, and that you have to make compromises in everything you do. And you learn that there are some diseases you devoutly hope you never develop, and some that you think you could probably cope with, and you have to recognize after a while that someday you won't be the doctor, you'll be the patient. You can't live with patients as closely as this, without an awareness of that. You can't keep it at arms' length. It comes in. It's an environment and you are part of the environment, and you don't step out of it. You have to be aware that what you're learning about their mortality applies to you, and you know, I once read that Walt Whitman wrote that no young man ever believes that he will die, and we all talk about the sense of immortality that young people have. What we don't talk about is the fact that once you realize that, yes I will someday die, I am mortal and my life is limited, that there is an element of youth that you will never have again. So that that's part of not growing up, but maturing and getting a little wiser, and you get a little bit wiser from every contact you have with every human being because they are all different. That's why I always say that we talk about the quality of healthcare, but the highest quality care is individualized care and hardly anybody will ever have that again because you can't afford to do it and nobody will pay for it.

That's sad. It makes me sad. I still do it because I don't care whether they pay me or not, but that's at this point in my career. You know, and it's very gratifying to do it, but you can't always do it, but you can always, you know, you reap so much joy from people doing well. It is impossible to put into words.

DWM: Is there anything else you can think of that we have not talked about, that we need to talk about today?

JS: Well I guess the things that I would say is that underlying everything that I've done, there have always been institutions. Now everybody who works in an institution winds up complaining about it some of the time, because institutions are of necessity, ah, a mixed bag. I tell people that I've spent most of my career at the University of Maryland, and so I have considerable affection for it. But I have no illusions about it. You know, I know that it uses people, that it uses them up and throws them away, and that's the nature of it. That's how they have to do it. You know, I used to recruit people who would say, well what's the medical school going to give me and I'd say, don't be silly. Academic medical institutions don't give, they take. But in doing so, they provide a foundation under what we do. They provide support. They rarely provide understanding and insight because they are too busy looking at a whole broad range of things, but without academic medical centers, none of this would have ever happened. You know, if Scrib had been somewhere other than the University of Washington, he might have wanted to do it, but he would never have been able to do it. Out there he had the stature of being an important faculty member at the University of Washington. He could get in touch with Les Babb, he could get in touch with William Quinton. He could get in touch with people and share ideas and do something, and so I think that we have to give some respect to the academic institutions that enabled us. They didn't encourage us. They didn't allow us. They didn't promote us. They didn't appreciate us, but they enabled us, and you know, I guess I should also say a little bit about the pleasure of modern dialysis, because you know, I was really very skeptical about a lot of things that happened. I'm not one of those early adopters, I always want to see what's going on. When a new drug comes out, I watch, and usually within 6 months or a year, if it is good, I start using it. But I don't jump in at the beginning most of the time. And similarly, when people started talking about using higher concentrations of sodium in the dialysate and being able to dialyze faster, I was skeptical until I realized the way they got the higher concentration was using bicarbonate instead of acetate, and that allowed us to do it faster. Because I went along for many years wondering why are people complaining about acetate making their patients sick, and then I realized, oh - it's because their running higher blood flows than I am running on my patients and they can handle the amount of acetate they get when we do it, but they can't handle it when you try to do it fast. As one of my chief technicians said many years ago, when we still had a lot of visitors from places that wanted to set up programs or wanted to know how to do things, he said every time people come in here, they say the same two things. They'd say, why do you dialyze your patients so long. And then they'd say, my your patients sure do look good. And, he said I'd tell them, those things are connected and they were. But when we started using bicarbonate dialysis and we found that

there were machines that could reliably do that, because that was a great concern of mine, that allowed us to dialyze people a lot faster without making them symptomatic. And when we got machines that could control ultrafiltration, that made the dialysis staff work a lot easier. They weren't having to get people up and weigh them every 2 hours and have 1 out of 5 collapse when they did it. You know, and you didn't have to worry about whether you were going to hit the weight or not because you are going to hit it. It's there. It's just a matter of whether the doctor prescribed the correct weight. If he got it wrong, you are going to get it wrong, and so that's where we are, you know, we've got these machines that, one of the great advantages of a modern dialysis machine is it shows the time of treatment. So the patient who goes on at 8 o'clock and has the machine shut down for 10 minutes and has 5 minutes of struggle with his access, doesn't get off until 12:15 instead of 12 o'clock. But he knows it says 4 hours on there he can get off. That's acceptable. Before, if he didn't get off at 12 o'clock, he was complaining. So just that change in the clock made a lot of things better, and a lot of things are easier. You know, the machines are easier to move around. They are easier to disinfect. They are more reliable. We just got some new machines in 2 of our facilities and now I have too many equipment technicians because they haven't needed much effort. They really are very reliable, very easy to service. Their preventive maintenance is much wider than it used to be. You know, formerly when somebody came and said we have a new dialyzer, I'd say send me a case of them and we'll test them. Today if somebody comes and says they have a new dialyzer, it is either just like the ones we have, or it is a little bit better, or it has one particular characteristic, because they are all very good and they are all very similar. It's, you know, if we had started like this, I wouldn't have had nearly as much fun, but I wouldn't have had to work nearly as hard because you know, it's a mature field now. Everything that we use is really pretty good but the sad thing is that most of the companies we used to work with don't exist anymore. They are gone. They are merged. They are bought out, or they are gone, so now there are only, you know, there are only 3 manufacturers of dialysis machines, none of which is an American company. I just saw another one from Japan. Maybe there will be 4, but you know, that's sad. When you look at dialyzers, you know, there may be 6 companies making dialyzers but 2 of them don't ship to the United States and at least 2 of the others are minor players, so we have got very few people to deal with. And I get very uneasy buying products from Fresenius when I know that they would like to devour us, you know, so that's, those are different things. Then again, it is not because Fresenius is a bad company, it's because it does what it has to do. It has its priorities and I have mine, and so we keep on keeping on. But it's, everything is different in the world these days. I don't think there are very many doctors who would work as hard as I did. I don't think they will have as much fun as I did. I don't think they will feel as rewarded by success and I do and there is a sadness in that. They will have a better home life than I did. You know, when my son was 5 years old, somebody asked him if he wanted to be a doctor. He said no. They said well what do you want to do. He said I want to be a bread truck driver. They said why would you want to be a bread truck driver. He said Tommy's daddy is a bread truck driver and he comes home every day at 2:30. I heard that and I cringed but I couldn't do anything about it. You know, so yeh, I neglected my wife and my children a lot more than I would have wanted to, but I think that they understand that what I was doing mattered, and I think that

they forgave me for it. At least I hope so, but you know, you have a wonderful career, you meet a lot of great people, you have a sense of comradery. Somebody asked Chris Blagg at the ASN, how did you get to know John Sadler so well. He said we went through the fire together, and we did. We went through the fire together. Struggling without money, starting the RPA, dealing with the government, trying to get things done, it has been the fire, and yet we came through it and we got what we had to do done. So, yeh, I think that's great. I think that it's good that modern doctors and clinicians are going to have a better family life, but I think it is sad that they won't get back from the patients as much as I did.

DWM: I agree.

JS: And, I guess we're done. I think we've covered all you needed to hear from me.

DWM: Maybe so. One thing I realized we haven't talked about at all, I'd just see if you have any thoughts about it, is erythropoietin. Do you remember before and after erythropoietin? Do you have any thoughts about EPO.

JS: Oh yes. I don't know if you want to record all of them but you know, I remember when we heard that it was out there, because I had several years ago, I'm embarrassed to say I've forgotten the man's name, there was a professor at Jefferson who had learned how to measure it. He could measure it in the urine, and so I sent one of my fellows up there to learn and he was very gracious and he taught him the techniques. And my fellow came back and I tried to get him to stay on the faculty and he left and went into practice and we never did anything with it. But we had an interest, and so when ah, we had struggled and learned that you don't have to transfuse everybody, we had learned that anabolic steroids will help people to make blood and so we gave them to a lot of poeple. We learned they are not all good for people, but we used them when we could. We learned that if you really are good you can scavenge down to the last 2 cc of blood in the extracorporeal circuit and by not wasting blood you can do better, and we did everything we could to maintain them, and that meant maintaining most people with a hematocrit above 20. Rarely above 25. And the young people did okay. I remember one boy who was 18 years go, who used to go play pickup basketball with an hematocrit of 14, and he just was healthy enough to do it, but a lot of people really dragged, and when I think about erythropoietin, I think about Bob Myers. Bob was a patient that had, actually had a congenital pelvic kidney and he came to me after he had, when he was planning to get married. He never had a physical in his life and he thought he probably ought to have one before he got married and his doctor found out that his kidney function wasn't normal and his urinalysis wasn't normal and sent him to me. So I agreed that he had blood in his urine and his serum creatinine was 3.5 and I was very concerned, so I did an IVP and found that he had a single pelvic kidney. And then I discovered that the contrast had raised his creatinine to 6, and I told him don't get married, don't run off, I need to see you. He said my wedding is Saturday, I'll see you when I get back. And when he got back, his creatinine was back down to 3.5. You are right, I felt very much relieved and Bob was fine, and his brother wanted to give him a kidney, and we had a not very

good transplant surgeon in those days and he insisted that Bob have his kidney out before he got transplanted. And I said, it's never been infected, his blood pressure is easily controlled, why do you want to take it out? He said it is abnormal. It is pathological. I can't put a new kidney in somebody who's got one like that. So he took it out. He put his brother's kidney in him and I don't know what happened, but it never functioned. So Bob came back to dialysis without his transplant and with no kidneys and he had previously maintained his hemoglobin at a very healthy level. He kept an hematocrit above 30, and now he couldn't make blood. We gave him everything we knew how to give him and he couldn't make blood, so he was transfusion dependent, and when Amgen came out with EPO, I was a little too late to get into their clinical trials, so I couldn't get any for my patients when they were doing it, and Fujisawa had an erythropoietin, and so we got onto their clinical trials and Bob was one of the people we put into the trial and you would have thought we had fertilized a flower. It changed his life. And so, I thought when we got EPO generally available that it would be life-changing for 15% of patients. It would be a great improvement for another 25% and the rest of them probably wouldn't need it. Shows you what I know. But anyway, when it came out, before it came out, we had received a questionnaire that said how much do you think 1000 units of erythropoietin ought to sell for and I said between $1 and $2. Nobody listened to me. We were terrified when we learned the price. We were gratified when Medicare agreed to pay for it, and it has been a wonderful advance for patients. I has made an enormous difference. It has given them much better quality of life. It has given much more secure health, so I think it is really great, but I think that it has been profiteered on until the fact that I am ashamed of it. I think that Amgen artificially jacked up the price and congress caved in. And I think congress knows that it caved in and they are embarrassed by it and they've been trying to get around that ever since and that's sad. Ah, and I think these days, Amgen is being run by a new group of people. The original people there, I think, had a focus on their function and on their product and on its effects, and so although they made obscene profits, they sponsored a lot of good things with some of those obscene profits. Now they are turned over to the financial officers and the bean counters and they just focus on their profits and they don't do as much as they used to. And, you can't talk to them like you used to. I had a lot of friends at Amgen in the past. I think I have one left. You know, and that makes me sad but it's still critical for the patient's to get it. And I was hopeful that the competition was going to get into the market because I think competition would be very good. Ah, but they are blocked out for another 2 years and ah, we just have to live with it. And I think, you know, I don't blame Medicare and the congress for trying to correct how they pay for dialysis and erythropoietin, but I think they are going about it the wrong way and I think they are punishing us worse. And I think that it's ultimately going to hurt patients. And when the IOM committee did its work in the late '80s, I was privileged to serve on that committee. And the question was has the reduction in payments for dialysis decreased the quality of care. And the first time the committee met, we realized that we didn't know how to measure quality of care, and there were a lot of people, a lot of distinguished physicians who said measuring the quality of healthcare is not possible. And we met some of the people from the medical outcome study and they said yes it is possible, we think it makes a difference. We can do this in primary care. You can do this in nephrology. We commissioned a few papers. We tried to do it. When

we concluded we said that we cannot demonstrate objectively that the quality of care has gone down. We can demonstrate clearly that the quality of education of the people providing the care has gone down. The number of nurses per patient has diminished by more than half. The number of technicians has increased by almost half. The amount of physician contact has fallen by three quarters. We believe that these are dangerous trends but that was as much as we could say. And coming out of that, we decided that we needed to have another meeting, another subgroup about quality of care, and so we did. And then we got interested in the instruments to measure health-related quality of life and so we had yet another one to do that, and ah, and I think that we were successful in making those measures a standard part of dialysis assessment now, and I think that was very important and very good. But we didn't get any changes in Medicare payment and I think that the payment is always going to be a problem because you know, there were people at Medicare who, I guess in 1975, read the Annual Report For National Medical Care and they said these people are making a fortune off Medicare benefits and they have been determined to see to it that it ceased and that it's never done again. And some of those resentful people are still there. And a lot of people in congress disapprove because they keep coming back and saying you're less than 2% of the Medicare population and you're using up 10% of the budget, and I keep saying aren't you glad you're not one of that 2%. Nobody wants to use up a lot of the budget. Nobody wants to need it, but that doesn't change things. They don't want the money spent and I've told them very directly, if you don't want the money spent, cancel the program. Put your name on it and cancel the program. They'll never do it. We all know that but they still complain and they still try to find ways to make it cheaper and you can't make it cheaper because it is a labor-intense therapy and the cost to people has gone up about five-fold since we started. When we started the cost of dialysis was a third staff, a third consumables and a third everything else, and today it's about 60% staff, about 10% consumables and then everything else including a lot of insurance we didn't bother with in the old days, the rent of the space, which is much more than it was, and all these reporting requirements that we have, collecting data that we are required to send to the network costs us almost $2 a treatment. I mean that's, and nobody pays for it. Talk about unfunded mandates. That's unfunded mandates. But, that's part of the problem with EPO, is that they are so angry about what it has cost, because it costs as much as dialysis in some instances, and they can't, having already set the price at what I think of as an exorbitant level, they keep nibbling it down but they nibble it down by changing what they pay us, not changing what Amgen is allowed to charge, and so Amgen gives a break to the large organizations and they give a small break to us, which isn't enough to make it viable. So if we were committed to treating patients, we'd go into another business so we could make some money. and I think that's really troublesome. You know we had a meeting 6 weeks ago, I guess, about the potential bundling plan, because they are required now to bundle by 2009, I guess, and I said I don't care if they bundle. I think it is not illogical, but the real problem is that if you bundle at a rate that is still less than the cost of the care, you're not going to resolve the problem. We're still going to have to try to contrive some way to survive and if we can't survive, then we're all going to be subsumed into the large organizations and then they are going to hold a gun to your head.

DWM: This is true.

JS: And so, you know, this is what is so sad about having to argue about money. Whether you are arguing with Medicare, or the congress, or each other - that's not supposed to be the substance of what we do. I mean it's there, yes. It's part of the mix. But it shouldn't be central to what we do. We shouldn't spend so much time and effort on it. I shouldn't have to know the regulations, as well as the regulators know them, but I do, and I think that that's not good use of my energy but it's a necessity. So, yeh, EPO has brought down the wrath of congress on us still greater than it was, and it's not our fault, but we have to be punished for it. But it has been you know, after all, dialysis doesn't add anything, it takes things out. EPO adds something. That's makes their lives richer. That makes it better. That's good, we have to do it, they need it, and we'll have to continue doing it, and we'll have to find a way to afford it. You know, I am scared to death of the future because I'm afraid they are going to change things and make us financially nonviable.

DWM: Right.

JS: And you know, this is my life's work and I'd hate to see it crushed.

DWM: Anything else?

JS: Don't guess so except that it has been fun to train a lot of people to do this and you know, it's funny, my fellows always came out knowing how to be good clinicians and knowing how to do dialysis, and I'd have fellows coming from other prestigious programs who would say - would you teach me about dialysis? I didn't learn anything in my fellowship.

DWM: Right.

JS: There have been a half a dozen of those through the years, who at least were smart enough to know what they didn't know.

DWM: Right.

JS: And you have to learn it. You know, everybody learns dialysis in a dialysis center. You don't learn it in a medical school or a nursing school, or even in some of these technical schools. You learn it in a dialysis center.

DWM: That's true.

JS: And so you have to come here and do it, and I used to make my fellows come in with me on a weekend to do a dialysis in the hospital with their own hands, because I thought it was good experience. I've had so many of them years later come back and tell me they remember that

experience. And I think it was a good one. But you know, it's really good to have trained a lot of people and still see them and find that they still want to talk to you, you know, because you can imagine that some of them might've wanted to stay away from you. But, ah, no, it's been an interesting career so far, and as far as I can tell, it's not over.

END OF DICTATION

Dugan W. Maddux, MD
DWM/jhl
T: 11/26/07