

SF
Interviewer: Susan Resnik
Interviewee: D.K.

Session 1
September 19, 1991
Telephone Interview

Q: Today is September 19, 1991. This is Susan Resnik, doing a telephone interview with D.K., a person with hemophilia from Virginia. This is the first telephone interview that I am recording. Good evening, sir!

D.K.: Good evening.

Q: I'd like you to tell me a little bit about yourself in terms of where you live, how old you are, and share with me what it was like growing up with hemophilia for you.

D.K.: I am thirty-eight years old, and I live in the South, and hemophilia in the South is kind of different. We'll probably get into talking about that, I guess as time goes on. I think it would be interesting for you to know that I was born on Long Island and never did we have any kind of great incident about my hemophilia. There was no problem with circumcision or anything such as that so it basically went undetected, and we did not have to deal with it for the most part until there were teeth problems and teeth needed to be pulled. Also little head injuries in which hematomas formed and they would clot, and the clots would break open and the next morning you'd find your pillow and bed soaked with blood. Things such as that.

Q: How old were you when things like that happened?

D.K.: I would say about eight -- seven and eight.

Q: May I ask, are you severe?

D.K.: Mild. That's basically how come it went undetected.

Q: I see. O.K.

D.K.: Also, probably at this time I'm mild. There was once a time in which I was probably considered moderate. I'm now considered mild. I have had a fluctuating factor VIII level that has ranged from 4.5 percent all the way up to 48 percent.

Q: Is that unusual?

D.K.: That is very unusual.

Q: That's what I thought. I hadn't heard of that.

D.K.: Very unusual, and in the past year I have been tested -- excuse me, two years -- and we've taken the factor level, and it has gone from 24 percent to 45 percent. So it can fluctuate, and there is no reason that anybody knows of why it fluctuates. Someone needs to probably do some testing about that. I don't think anybody, with all the other issues, has --

Q: No, I really must say that I was not aware of that. I haven't heard that before.

D.K.: It's not normal. There still needs to be someone who would like to explore that.

Q: Interesting. So that's a little bit of a different experience. The other people I've spoken to up to this point have all been severe, so it's a slightly different experience, as you say, I guess, even though it is fluctuating. When you were in school, what was it like? Were you able to go to school most of the time?

D.K.: Oh, yes. I never had any problem going to school except when I would injure myself, and most of my bleeds came from trauma, which was because I was outside playing; playing football or basketball and twisted an ankle and tore ligaments and tendons and then would acquire quite a bleed doing that. But then again we still did not know that I was a hemophiliac. We just knew that there was something wrong.

Q: So at what age did you learn you were a hemophiliac?

D.K.: I learned that I was a hemophiliac when I was about seventeen.

Q: I see.

D.K.: We had gone to I think it was Long Island Jewish Medical Center on the recommendation of our physician, who finally said to my parents, "You need to take him someplace. Something's not normal. They took me and they did the testings there, and that's where they found out that I was a hemophiliac. I think what got my family really thinking prior to that is when I was at age thirteen. I had had a little accident with a BB-gun. It had been jammed, and while trying to unjam the trigger -- I had it laying down on a bench -- I had passed my hand in front of the barrel, and just as I had done that it had gone off and penetrated the hand. They had to operate to get it out, and due to that there was a trauma and in order to take care of the pain I was given aspirin, and just to complicate the matter the aspirin ate holes in the stomach, which caused a bleeding ulcer, which I almost died from, the bleeding ulcer, because they could not stop it. The only way they stopped it was with whole blood - - whole blood transfusion. And they still didn't know why it had stopped and still hadn't figured it out, that this was hemophilia.

Q: So in other words you did not have the identity as a person with hemophilia until you were seventeen years of age. That must have been quite a surprise to everyone.

D.K.: It was a very big surprise.

Q: Do you have siblings?

D.K.: Yes.

Q: Is there anyone else in the family with hemophilia? Any history?

D.K.: Yes, my older brother.

Q: I see.

D.K.: There are four boys in the family, and the two older have hemophilia. The two younger do not.

Q: Are they mild?

D.K.: The elder?

Q: Yes.

D.K.: The elder brother is mild, too. So two have hemophilia, two don't.

Q: So when did you move down South?

D.K.: When I started going to school, to college. I moved to South Carolina and went to school there and got married in North Carolina, lived there and eventually moved to Tennessee.

Q: During those years were you at all involved with people with hemophilia? Or because you were mild were you pretty much to yourself?

D.K.: No, I basically stayed in contact with people with hemophilia, especially through my parents, who were at that time pretty much associated with and wanted to continue to get information from the NHF.

Q: Were they involved in a chapter?

D.K.: At that time I think they were members of the Metropolitan chapter.

Q: I see. So you actually started out as a Yankee that didn't know it! Not only a Yankee, but a Long Island Yankee! That's where I'm from originally! Where were you from?

D.K.: Oh, I was out where the potato fields and corn fields were.

Q: That's further. O.K.

D.K.: Out in Suffolk County. That's where I was born. I didn't know what the city was like. For us to go to the city was

like going to a foreign country.

Q: It actually must have been quite a trip to Long Island Jewish.

D.K.: It was.

Q: Because I have interviewed Dr. Lipton, who talks about how difficult it was for many people to make that trip.

D.K.: And he has been there probably many years, right?

Q: Yes.

D.K.: He was the one who diagnosed me as having hemophilia. I still have the paperwork.

Q: My goodness. Yes, he started the program there. Right. Isn't that interesting. Wow. So -- did you feel any kind of school problems or any social problems because of this?

D.K.: The problem that I encountered -- once they discovered I had hemophilia -- once again there was I guess not a whole lot of knowledge about what kind of treatment to take except that you used fresh frozen plasma or whole blood to treat it. I was told that I had to be careful then of the activities that I would be doing, but by that time, when you're seventeen and eighteen going on to college, you've already developed a pattern. I continued to play basketball. I continued to play soccer, and especially continued to play soccer throughout college -- and continued to get injured.

Q: But you never experienced limping or crippling, did you?

D.K.: Oh, yes.

Q: You did.

D.K.: Oh, yes.

Q: I see.

D.K.: When I would be injured -- I think it was always frustrating to me, because I could get injured and my ankle would swell up very, very much. Other people I'd see their ankle, it would swell up and about two days later they were on the field playing. For me, a swollen ankle that would swell up tremendously, get black and blue and just hurt to even touch, would take me sometimes four to six weeks to get over.

Q: So you did perceive that. Was there a great deal of pain, do you recall?

D.K.: Lots of pain. I have been -- probably it's been very

interesting, because my dentist has said to me many times -- he said, "Have you gone through a lot of pain in your life?" And I said, "Well, why would you ask that question?" And he said, "Well, because you have these little pebbles or deposits in the canals of your teeth, which is evidence that you have really bitten down hard on your teeth, especially your back teeth.

Q: Oh, isn't that interesting.

D.K.: I told him about the many times I had gone through so much pain, weeks of pain and weeks of sleepless nights.

Q: As you recall your initial interaction with health care providers in hemophilia, what kind of an experience was it for you?

D.K.: I think upon finding out that I had hemophilia the primary physician that I had really took care of us from that point. Then going away to school -- I probably didn't get any kind of comprehensive care until I was married and was going to graduate school. I have a Masters of Divinity from Memphis Theological Seminary, and I guess that's where -- in Memphis was where I first began to get comprehensive care. They did an excellent job taking care of me there, giving me full evaluations and putting me in contact with the medication that I would need, or the factor -- going from whole blood, the fresh frozen plasma, to cryoprecipitate and then to factor. That was where I first experienced what comprehensive care was, and it was excellent. Then when I was in Chattanooga the Erlanger Hospital there gave great comprehensive care, and that's where I started to get involved a whole lot with hemophilia and the NHF chapter there.

Q: About when was that?

D.K.: I guess it would be in 1978. Really got involved, and even helped them with their counseling program, counseling hemophiliacs there.

Q: I see. You know, in terms of the way I've been trying to conceptualize this and get different perspectives -- and as you know from my little abstract that I wrote -- I've been thinking that there sort of was this dismal age that went on for hundreds and hundreds of years and then they began to use blood, to infuse blood, and then when Judith Graham Poole discovered cryoprecipitate that perhaps was the beginning of a new time. But for you, your personal perspective, do you remember when you felt that things really got much better or different?

D.K.: I think for me it was when factor came out.

Q: I hope I wasn't pushing that, but I've been hearing that from so many people who said, "No, no, you have it wrong, Susan. It's not the Golden Era when cryo came out, it's when factor came out!"

D.K.: Yes. Cryo was good, but factor was really like, "Wow. We have reached it." It's like hemophiliacs now looking at probably gene therapy, looking forward to that and then probably experiencing that. For me to experience factor was like "This is like the miracle drug. We can now be normal, and all we need to do is -- you when we get hurt or I play soccer and get injured, injure my ankle, that all I have to do is come in and get some factor infused?" (Or at that time go to an emergency room, or something like that.) "Have factor infused and you mean then I could probably be up and about in two days? You're telling me this is a miracle!"

Q: Yes. So that was the time. Well, being mild -- about how often would you have to infuse? How would that work?

D.K.: Just being mild, it was only due to trauma. Injury.

Q: I see.

D.K.: But an injury was very painful. After talking with friends I have who are severe and had spontaneous bleeds in the joints and they would say that they were very painful -- and many times them telling me, "Well, you really didn't know what it was like," I said, "Well, I did know what it was like because I would be out there running around and I'd be the one who would tear ligaments and tendons, and I'd be the one put in a cast and walking around on crutches for weeks and weeks and weeks, and the pain was just excruciating." So I said, "I can identify in many ways."

Q: It's interesting to me that you did choose to interact with others with hemophilia, etc. Did you see this as a community? What --

D.K.: Definitely. I would definitely say it's a community. Every time I found out that there was someone who had hemophilia, whether it was in a clinic that you passed by and you met someone -- it was real exciting to find someone else, and you just felt drawn to them immediately, like you had a bond and something in common with them.

Q: I'm trying to understand this. I hear it a lot, yet I also hear this great sense of wanting privacy, you know? It seems like there's a sense of some people not wanting others to know they have hemophilia and yet I guess wanting to reach out to others who do?

D.K.: I would say that's, I think, a very real paradox. It's very real. I think there is a desire to want to reach out, I think especially in the older population, but then there is the desire to want to be self sufficient, especially when factor came out. I can do this myself. I can take care of me. I really don't need the doctor except for looking over my joints and mak-

ing sure that everything is fine, giving me my prescription and so on and so forth. But now I can do this at home. I think in that sense there is a sense of wanting to be private. You know, you can take care of yourself. But on the other hand, I think there's time when you really want to talk to someone and ask them, "Do you really have the same problems I have? And how do you cope with them?" I think that is where the desire to meet someone else is. How do they really cope with it?

Q: Was there that kind of sharing before AIDS became an issue? Did you have any of that?

D.K.: I don't believe so. I think most of it came when AIDS became an issue in the hemophilia community.

Q: Going back a little bit to your choices -- going to school, and I heard you mention your Masters of Divinity -- did you feel -- in any particular way were you drawn to the theological? Do you feel your hemophilia entered into any of this thinking, or was that just coincidental?

D.K.: No, I don't really think the hemophilia entered into it. For the most part I felt like once I understood what hemophilia was about it's just o.k., let's try to make life as normal as possible, even though they say that hemophiliacs only lived to be -- what? -- they would live to be fifty years old at the max at that time. I thought, well, we live in the twentieth century. Something's going to happen. They'll find something that will prolong life. Plenty of time to think about it. So I would say for the most part everything was normal.

Q: With your brother -- was there kind of mutual support? Or differences?

D.K.: I would say because my brother had the same problems -- he would have injuries and he would be laid up. He could be hospitalized due to an injury the same way I was. I think that's where we had a good support group with each other. We would talk to each other about it and we would understand how each other hurt when those things happened. I think there's a real closeness between him and me due to our childhood experiences with hemophilia, pre-knowing it and post-knowing it.

Q: That's interesting. The very earliest years were here in the North, but then when you went down South -- you mentioned some good care, but did you see any other situations or attitudes or anything else you'd like to talk about, being in the South?

D.K.: I think some of the problems that I encountered were getting injured and going to an emergency room and telling them that you were hemophiliac and having them look at you cross-eyed and think well, what is a hemophiliac? And then you'd have to explain to them what a hemophiliac is, and that you needed factor VIII, and they look and eventually after hours of being in an

emergency room and watching the joint or injury swell and being in pain and them not knowing whether they wanted to give you pain medication or not because they didn't know if it would affect your hemophilia or not -- you'd be sitting there in an emergency room, waiting. They'd finally figure it out and then they had to figure how to mix the factor, and then they tried to figure out how they're going to put it in you. Do they drip it in you? Or should they I.V. push it? Or what? Then they would think this is such a large volume -- that's back when they were using a large volume, the heat-treated factor. They said, "I don't think he can take this large amount of volume just in a push, so we'll have to drip it in." And then they'd lay you there and they'd drip it in over hours, and you know it's really not that good. It's not effective. So that was a frustration that I really had.

Q: It must have been terrible. What about -- was there any kind of folk remedies or anything when you were growing up that touched on your life?

D.K.: I think I remembered hearing my parents and family, extended family, talk about "Why don't you bolster the kids with a bunch of Vitamin K? That should stop the bleeding." There were just little things like that along the way.

Q: You missed out on the peanut butter, apparently.

D.K.: Yes, I missed out.

Q: I've been hearing all kinds of sagas about people having to drink peanut butter milkshakes and all sorts of things like that.

D.K.: Although growing up as kids that was probably a staple for us.

Q: Yes, that's true. That's kind of universal. That's true. Then I guess -- what about going on to working? Any discrimination problems? Did you choose in your different settings to reveal that you had hemophilia? Or not?

D.K.: Yes, I didn't have any problem doing that, because at that time there was no -- not too many people knew a whole lot about hemophilia, and you would just tell them that it was a bleeding disorder and they would say, "If you get cut are you going to bleed to death on us?" And I'd say no. Most of the places I worked they would have insurance that covered it because they would be part of group insurance, and again I was not using factor in a great quantity. It was -- again, there would be things due to falling down and bumping a shin real hard -- just trauma incidents for me -- but when they happened, you know, you would have to go to a hospital and things such as that. I remember there were times that I could be out of work and again, not like a severe hemophiliac who would have a joint bleed and then be out of work because of the joint bleed. My bleeds were

due to injury, or wanting to play sports. I remember being out of work sometimes two or three weeks because I chose to slide into second base and tear up my ankles.

Q: When you were a teenager -- now I'm sure you've become familiar with them talking about teenagers with hemophilia doing all kinds of things, like riding motorcycles -- did you act out in those ways? Or just try to part of what everybody did?

D.K.: I tried to be part of what everybody did. As I told you, when you learn you're a hemophiliac at seventeen basically your patterns have been set and you're not going to be changing them so much. I do remember people -- especially when I was in college playing soccer on the soccer team I remember the coach sometimes giving me a hard time about having hemophilia.

Q: Oh, really?

D.K.: Saying that I shouldn't even be playing. You know, there were times that they would see -- sometimes when you had an injury they'd just kind of -- they didn't use the word at that time, but thought you were kind of wimp? I didn't want to have the image of being a wimp. You know, I wanted to still hold my identity as being someone who played sports, or if you want to -- and I say this in a nice way, not the way it has turned out, as society's made it -- you want to keep that male machoness. I can play a sport, and then people look up to you and stuff like that. That was something that was important to me then, and I wasn't about to give that up just because I found out that I had hemophilia.

Q: I see. So clearly it seems that you were able to forge ahead with education and the finances for this? I guess, as you say, it wasn't an ongoing thing. The costs per year -- do you have any sense? In other words, it wasn't like having to infuse on a regular basis.

D.K.: Right.

Q: Do you have any sense of average, of how much per year? Or you wouldn't know?

D.K.: That it cost me?

Q: Yes.

D.K.: I wouldn't know. No. It wasn't a burden upon my family.

Q: I hear that.

D.K.: It wasn't a burden.

Q: So it was different.

D.K.: I think it became a burden on my family when my older brother and I would continue to injure ourselves. That's when it became a burden, because my mother would say "I can't believe that we have visited the emergency room eight times this year, and that we have had eight casts this year." Sometimes she would just tally up how much we were in, saying that we could have saved, or gone on how many vacations, had these incidents not taken place. So there was -- I would have to say it is a burden. The hemophilia caused the burden, because most of the injuries that you would have that other people would have, like a sprained ankle, did not bleed like a hemophiliac's sprained ankle.

Q: Right. So next I guess chronologically, you -- as you say, you're married, and you have kids, yes?

D.K.: Right.

Q: Tell us about that.

D.K.: I met a girl from North Carolina while I was going to college, and we got married and lived in North Carolina, and I had graduated with a degree in biblical education. I was then looking for some kind of an opportunity to get into some kind of ministry work. The Cumberland Presbyterian Church in Chattanooga, Tennessee asked me to come and to work with their -- they had a Cumberland Youth Foundation, which was a great recreational facility, plus to do youth ministry work in their church. So that's where I went, and that's where I really got put into a hemophilia clinic.

Q: I see.

D.K.: And that's what I did for a number of years, and then that church after serving them for a number of years felt like I had some good potential and they asked me if I would like to go to seminary. I said I would, but I didn't have the finances to go, so they said, "Well, we'll pay for the finances if you'll go." So they paid for my Masters of Divinity degree. While I was going to school I worked in a small country church, and that's the year we had a little boy born into our family. That was 1980. I continued to go to school and graduated in 1983, and we had a planned graduation gift, which was a little girl.

Q: Yes. How nice.

D.K.: She was born in 1983, the day after graduation.

Q: That's a lovely gift. That's a lovely gift. So you have two children.

D.K.: Right.

Q: And up until that time it sounds like things were really going along pretty well. What did your wife do?

D.K.: She was a physical therapist.

Q: I see. O.K. Then when did you first hear about HIV?

D.K.: What happened is when I had gone to Memphis -- that's when I got back in contact with another hemophilia treatment center, which happened to be the Memphis Treatment Center, through the University of Tennessee Medical School. A Dr. Dugdale was looking after me there. I remember going there for comprehensive care, and she basically told me like all the doctors told me "You need to be careful of what you do but you're mild, so just be real cautious about things." Sometime in 1983 during the year that I was getting ready to get out of seminary, graduate, I had been playing basketball for a charity, to raise money for a charity, and I went up for a shot, came down, landed on someone's foot, and completely twisted and broke my foot. A bleed occurred due to that and the foot swelled tremendously, and we called Dr. Dugdale and she said to go to the hospital and infuse, so they had factor waiting for me. Specifically at that time I had known through NHF updates and through things that the CDC was saying in 1982 that HIV could possibly be blood borne. I told them to please give me cryoprecipitate, because I knew cryoprecipitate had few donors. It could be screened better. Factor, I knew, could be hundreds of donors, which would be very difficult to screen. Even NHF said that if at all possible try to go with cryo.

Q: And they said that as early as that time.

D.K.: And they said that as early as that time. I remember the updates that came out in January, February and March of 1983. So I asked for cryoprecipitate, and the hospital did not give me that. They gave me factor, and they gave me -- at that time I had never received cryo (or plasma), so I never knew what it would look like, the differences.

Q: So they just went ahead and did that.

D.K.: Yes. If I had known that they had given me -- or if I had known the color of the liquid I probably could have said something, but I had no idea that it wasn't the same color as factor or fresh frozen plasma or something like that. So they infused me and it happened to be the only time that I received factor, and it was contaminated with HIV. I was infused on the 28th of March of 1983, and on the 4th of April -- I think it was either the 3rd or the 4th of April -- I was hospitalized with a severe case of hepatitis. They were trying to decide what kind of hepatitis it was -- was it A? Was it B? They did testings for it. And I told them -- matter of fact, I was the one who diagnosed that I had hepatitis by getting my wife's medical book out, and I could see all the symptoms. They were telling me "No, it can't be hepatitis, it hasn't been that long to incubate into hepatitis." I said "Yes, it is," and after doing all the test-

ings they finally said it was called non-A, non-B hepatitis.

Well, they kept me in the hospital for about a week until the fever came down. The liver was swollen, and my belly was just so swollen to even touch it -- red as a beet. When that went down they sent me home. When I went home I started breaking out in all kinds of weird rashes, had constant diarrhea and constant throwing up, and nothing could be done to really stop it. They took me back to the doctor again and the doctors just didn't know what was wrong, and they said they could only treat the symptoms. They just treated the symptoms the best they could, and there was a couple days there that I thought I would be leaving this world because there was just no more energy in me.

Q: Must have been awful.

D.K.: I remember -- I guess at that time there were I imagine a lot of people that said little prayers for me, because I remember just going to bed that night -- I never got out of bed, but going to sleep that night and realizing and saying to my wife that I think that this is going to end. She was at that time nine months pregnant with our little girl on the way, and it just seemed like the next morning I finally -- I woke and I felt better. I was hungry for the first time, and the diarrhea and vomiting had gone away. It was interesting, because I had started to lose my hair a little bit. It was just coming out in clumps. After -- now, after talking to people from the CDC who were really good with hemophilia and AIDS epidemiology, they said that more than likely in that factor there was a large dosage of the AIDS virus and that's probably what I had.

Q: Oh, my goodness.

D.K.: Had a bout with it.

Q: And of course nobody recognized what was going on.

D.K.: Right.

Q: And they weren't testing for it yet, were they?

D.K.: Oh, no, no. There was no testing then.

Q: So you had no thought that that was it at that time.

D.K.: Right. There was no thought of that, because, again, I thought it was the hepatitis. There was not a lot publicized about symptoms that AIDS people had. So after that it took me approximately six months to recover.

Q: Must have been a terrible time from the way you're describing it.

D.K.: Meanwhile my daughter was born, and so -- we didn't know really what had transpired and what had happened to me.

Like you said, there was no testing. But after I graduated we stayed there and I worked in another church for a while which was part of the same denomination, this time worked as an associate minister, and then we got a call back to come to Chattanooga. We went back to Chattanooga, and when I got back there I got back with the original hemophilia comprehensive care clinic I had gone to and that's when they were really talking a lot about HIV, and that was about 1985.

Q: That's right.

D.K.: They were really talking about it, and they were testing people at least if they knew that they'd had a lot of factor. Well, I remember going to the clinic because I had received a lot of information and I was reading about it.

Q: Did you get most of this information from NHF directly?

D.K.: I got it from NHF that would give it to the treatment centers, and then they would -- and I would ask for things to read about it. And my parents would send me a lot that they got from the Metropolitan chapter. Let's see.

Q: So this was 1985 now.

D.K.: '85, right. In '85 I went to my clinic, and I remember the nurse and I were real good friends, and the doctor, and I said to the nurse, I said, "You know, everybody's getting tested for HIV. Do you think I should be?" And she said, "Oh, no, no. You've only received factor once in your life. You don't need it. There's no reason to." I'm the type of person that doesn't like to leave any stone unturned, so I said "Go ahead and take it. Just go ahead and take it and send it off." Well, they sent it off -- at that time they had to send it off to Vanderbilt -- and they called me to come into clinic. So I came into clinic, and they told me that I was HIV positive. They said they couldn't believe it, and they said "Can we take another test?" I said, "Sure." They just couldn't believe it. They said, "One time?" So they took the second test and it was confirmed the first time with an ELISA and confirmed the second time with a Western blot. From that point on I had a real emotional problem with that, an emotional time with it. At that time the clinic did the best they could to help, but I was pretty psychologically torn up about the whole thing.

Q: Also because you were educated enough to understand the implications, etc.

D.K.: Sure. And I not only had the education of knowing about it, but also had the education of being trained in counseling, and many a time I would have to apply my counseling principles to myself. But they were very supportive, the nurse and the doctor at that treatment center. They were very supportive, and I worked through it well enough that they asked me to help some of the other patients who weren't dealing with it as well.

Q: Did you experience -- as you said, they were supportive, etc. It doesn't sound like you were enraged at them in any respect.

D.K.: No, I wasn't enraged at them. Who I was enraged at at that time was -- it went from -- I think at that time before I really learned a lot I was outraged first at the gay population.

Q: I see.

D.K.: Because this is where I thought it came from. Again, this is Southern mentality, that gayness is not accepted in the South. This is a lifestyle that is not accepted, because this is basically the Bible Belt, and it is very biblically oriented down deep to its roots, so most of the people who understood AIDS and HIV related it to the gay community.

Q: I see.

D.K.: So I was outraged at that first, and then I became outraged at the pharmaceutical companies because how could they do this? How could they hear about warnings -- when I began to look into this -- and not do anything about it? It was like -- now that I look back on it I would relate it to the Tylenol scandal that we had. Tylenol was -- three people died I think, or four people died from Tylenol and they pulled everything off the shelf.

Q: Right.

D.K.: But when they had people that they were suspecting were dying from a blood borne disease, AIDS, and it was being transmitted they think through the blood, did they pull it all off the shelf? No.

Q: That's an interesting way to look at it.

D.K.: And it was to me, now that I look in retrospect, that was an inconsistency and all I could think -- you know, at that time it wasn't very sound. I can look at it now and probably my personal perspective now is that I really believe the issue over shortage of blood was a fear as well as I know that there's big money in it.

Q: Have you pursued thinking about things like that? Or you just sort of --

D.K.: Oh, I still pursue thinking about those things -- or pursue getting information about it, as well as reading what the Committee of Oversight and Investigation had to say about it on the trials that they had in 1989. I think most of them were 1989.

Q: Can you tell me a little about that? Because nobody's discussed that to date.

D.K.: A lot of the reading that I had obtained from the Committee of Oversight and Investigation was that there was evidence that it was blood borne even as early as '82, and in 1982 there were many physicians who felt like -- they can test for other viral infections and come up with the results, and they felt like these same tests which could show that there were viral infections, and they were very similar -- the viruses were very similar to that which they would call HTLV-3 at that time. They were warning the FDA all along that they knew that this was blood borne. I think one of the people, one of the doctors from Stanford University was one of the people who was a pioneer in the HIV testing --

Q: I see.

D.K.: And he was saying it all along, and no one wanted to listen to him until he could come up with more circumstantial proof. So this all took place in the hearings. There were a whole lot of markers, viral markers, which were very similar, and they warned -- I know this doctor and a couple of other doctors warned and said "You need to give warnings about blood and blood products, and you need to use even these limited markers and heed the warnings from these limited markers." Because these guys were scientists, they knew exactly that this was associated with it, but they just didn't have all the technology at that time. They had the best they could go with.

Q: You mean in other words nobody would listen to them?

D.K.: Right.

Q: Who wouldn't? Who wouldn't listen?

D.K.: The FDA wanted more proof, but as I read the proof was there. It was just that no one wanted to really listen to them, and the more I read the more I saw where good scientific epidemiology or lab work would have said "It's in the blood. We really need to get on this and we need to screen it out in some way or we need to stop the blood supply until we can figure this out." On the other hand, there were those I could see in the hearings saying, "But if we stop the blood supply we're going to have a shortage of it and we're still probably going to have it transmitted some way, so we really can't do it until we come up with a definite way of testing."

Q: And that seemed to have prevailed.

D.K.: That prevailed. This is all documented. Anybody can --

[END OF SIDE 1, TAPE 1; BEGINNING OF SIDE 2, TAPE 1]

Q: Please continue and say what you were saying.

D.K.: I said that you can obtain this information -- it's all public -- from the Committee of Oversight and Investigation that took place regarding AIDS and the blood safety, blood safety in the country.

Q: How did you feel about what NHF was doing or not doing during this time?

D.K.: I feel that NHF was doing the best it possibly could. Again, NHF is a service organization, and it still has to take the information that it gets from the Centers for Disease Control and information that it gets from the Maternal and Child Health Bureau, and it's got to process it and give it to the community. NHF cannot say that -- or probably could not say at that time to the FDA "Pull all the factor off the shelf," because they're not proficient in epidemiology and not proficient in the studies that the CDC was doing. So all they could say is that they knew from what they were gleaning from all the information that was going around that it could possibly be blood borne. I even remember reading an old 1982 -- I think it was the Hemophilia News Notes or whatever, in which the CDC was discussing that it possibly could be blood borne.

Q: Yes. That's right. It was 1982.

D.K.: I think in that case NHF was doing what it could possibly do.

Q: You mean the role of the disseminator of information.

D.K.: Right.

Q: Which of course has been underscored as their role. So -- let's go back to you personally. This has had quite an impact on your life.

D.K.: It has.

Q: I don't know how much you want to share, but it's up to you.

D.K.: I guess after I found out that I was HIV positive the concern that I had was I needed to be educated on how this was transmitted, and they educated me on how it was transmitted from that point on. And I say this, and I say this with all conviction and no reservations, that I practiced safe sex a hundred percent of the time. I've gone to many conferences since I've learned about that, and they say when somebody says a hundred percent of the time you know they're probably not telling the truth, but I did. I was very serious about this. Being in a ministerial position, I knew that I had an obligation not only

ethical and moral but I felt like a spiritual obligation not to transmit this. So from that point on, when I learned about it we bought condoms, we used condoms, we did not participate in anything that would be considered unsafe. However, it was too late. When I found out in '85, remember, from 1983 when I was first exposed to the poor factor to 1985 we had not known that there was anything about transmission through --

Q: I don't think there was any communication because I think they didn't even know that it could be.

D.K.: Right. It wasn't until NHF came out with I think it's -- question and answers?

Q: Right. Q & A's. Right.

D.K.: Q & A. I think it was red, written in red.

Q: That's right.

D.K.: That was the first -- I think that came out if I'm not mistaken -- I'm not sure. Maybe '85? '86?

Q: Somehow I think it's '86, but --

D.K.: '86. But I remember reading that thoroughly. But again, I was learning how to use condoms in 1985, '86, right there, with all that information that was again right on the horizon, just being published. But it had already been too late. Little did we know that it had been too late.

Q: So in other words you never even thought about it, that it could have happened.

D.K.: Right. So I was under the assumption that there was no problem when we were using condoms. We had no idea that my wife was exposed and infected.

Q: And nobody suggested she be tested.

D.K.: Oh, no. No one had suggested that. So what we ended up doing was just practicing safe sex, and what had happened is that eventually -- she always had bronchial infections ever since she was a child, but they started to become more numerous. She had a bout of pneumonia, and then she got over that. Then she had a bronchial infection, and then she had another little bout of pneumonia and she got over those things. During that time we had a lot of I guess difficulties in adjusting as a new family and her being sick and having I guess HIV hanging over your head, even though that did not hinder her intimacy with me at all. She was very good about it. She was not worried about it, again, because of the information we received that if you practice safe sex you're going to be o.k., and we felt very confident about that. But what had happened, and I'm not sure to this day whether it was due to dementia or just due to all this stress,

but out of the blue one day -- and this was just totally a shock to me -- she had asked for a divorce.

Q: Oh, my.

D.K.: And it was just out of the blue. She even considered going for counseling and we went for counseling, and even the psychologist and psychiatrist said that they didn't understand why she was doing this. It just didn't make any sense. During that time she was having large yeast infections. Candida. Vaginal yeast infections. They were very numerous all during this time of counseling and all during this time of "irrational thinking" as they put it.

Q: So that's probably -- yes.

D.K.: And what happened was she finally succeeded in getting the divorce, gaining custody of the children, leaving me in Chattanooga and her living in Jackson, Tennessee.

Q: Oh, boy. Oh, I didn't know any of this. Oh, my.

D.K.: And the Court at that time because of the situation -- here I was a minister with a good reputation. I was only allowed to see the children once every five weeks.

Q: Oh, my goodness!

D.K.: And it was a very ---

Q: It must have been a very terrible time for you.

D.K.: Oh, it was a very difficult time. And knowing that I was HIV positive, knowing that my opportunities to probably ever be married again were very slim, it was a very trying time. It wasn't I guess until -- let's see -- I'm trying to think -- give me break here.

Q: Sure. Wait a minute.

[tape off]

D.K.: As I was saying, what happened was that while I was in Chattanooga and I was associate pastoring the church at that time there -- we had probably been divorced for I'd say nine months, and then one day I got a call. I had noticed that she had been losing weight every time I would come and pick up the kids or meet her half way in Nashville to pick up the kids. I noticed that she didn't look good, but I thought well, maybe that's just because this has been really hard on her also. But I knew she wasn't well. Didn't know what it was all about. Well, I got a call from her mother, who had come to spend some time with her, and her mother was all in tears saying, "Please come. The children need you. She's going into the hospital for some tests. We don't know what's wrong with her." So I packed my

stuff quick, got in the car and went, and the kids were just emotionally all torn up. They didn't know what was happening.

Q: Frightened, I'm sure.

D.K.: Yes. They put her in the hospital and they did tests and they couldn't figure out what was going on, and I went in there with the doctor and I finally said to him, "Will you please do an HIV test?" And he said, "Why?" I said, "Because I'm a hemophiliac, and I'm HIV positive." At that point they had done a test, and when I said I was HIV positive and that she possibly could be HIV positive the nurses and the doctor himself all backed out of the room.

Q: You know, that is just what I somehow knew you were going to say. God. Isn't that incredible.

D.K.: They left. And when they found out that she was HIV positive, they would just push the food in front of the door.

Q: I've heard those stories.

D.K.: And they would come in, and they would --

Q: This was Nashville?

D.K.: No, this was in Jackson, Tennessee.

Q: Oh, Jackson.

D.K.: And they would come in completely with goggles -- head gear. Facial gear. Garments and gloves. Everything. Even the little boots that go on your shoes.

Q: Oh, my goodness.

D.K.: That's the way they would deal with her. And I knew it wasn't transmitted that way, and I really got aggravated. She became progressively worse, because they wouldn't deal with her, and they didn't know -- and I told them -- I said, "She has probably pneumocystis," and they had no idea what that was and they were leaving her probably just to die. So I insisted that they get her transferred to a more advanced medical facility and that was Nashville, and they said they weren't going to do it, and I told them, "You do it or I will sue this hospital so it'll never see the light again." And I said "And I want it in one hour from now." I said "I don't give a rip. I will rant and rave up and down these halls. I will go to the hospital administrator. I will do anything I have to." I said, "I will sue you people for neglect." I said, "Get her into an ambulance and get her there now." Within the hour, less than an hour, they had her on the way. They almost lost her on the way because of the poor breathing that she had, and when they got her there they took very good care of her. I was so impressed with Vanderbilt. They took very good care of her. They did not treat her like a leper.

They worked very well with me. They allowed me to bring the children in to see her.

Q: Did she know what was going on?

D.F.: At that time -- she did not really know what was going on at that time, and the doctors and nurses said there was no one to do counseling, psychosocial counseling, who knew about this, especially with hemophilia. They said "The only people we have are the Friends of Nashville," which was a gay organization. They sent someone up to talk to her about it, but she really didn't understand anything. Well, it got real difficult because they said that it was a touch and go situation, and they asked me to explain HIV and AIDS to her and to give her counseling because they knew my background. So I had to counsel my own wife about what was going on.

Q: What a time.

D.K.: It was a real emotional time for me, and I knew that I had to do it because I knew she needed the help and there was no one to help her.

Q: And of course that kind of stress couldn't have been great for you, either.

D.K.: It was a very stressful time.

Q: Well, at least you got her moved to a better place. That was important.

D.K.: We got her moved there, and if you recall also in 1985 -- excuse me, 1987. The beginning of 1987. If you recall at that time that was when AZT was not yet approved by the FDA, and if you needed AZT you had to apply for it and it took anywhere from one to three months to apply for it. They were trying to get her AZT and I remember signing the papers and everything and they were trying to push it through and there was a lot of holdup on it and a lot of red tape and politicking at that time. I don't know -- at that time I look back and it was politicking in the FDA, politicking with the federal government and also with the gay groups. They were politicking for it, but it was all tied up in this neat little bundle of politics and meanwhile she needed it. They were almost positive it could help her and that she would live, you know, at least until they could get something else in her, and they only could treat her with Bactrum (ph) at that for the pneumocystis -- there was no Pentamidine or anything like that, either. Because of the delay -- she went in I think in the beginning of May, and twenty -- it was like the first or second of May, and then by the twenty-seventh of May she died.

Q: Oh, my. So were the kids with you by this time?

D.K.: By that time, yes. I had the kids while she was in the hospital.

Q: How -- was it her mother, you said, or her parents?

D.K.: Her mother.

Q: Were they willing to let you have the kids and everything? Was there any problem?

D.K.: No, no problem. Probably the story that makes it a good ending story I guess for a horrible situation is that during the times that she was in the hospital I would bring the children back from Chattanooga sometimes overnight and we'd come on the weekends, every weekend, and stay all weekend. During that time after they had started to give her some kind of antibiotics her mind seemed to clear up and she did seem to be a little bit better. She even was very remorseful that she had gotten a divorce and had asked me to please forgive her and to try to -- "Let's try to put this marriage back together again."

Q: So in a way, as you say, that added something positive but in a very negative context.

D.K.: Yes.

Q: Yes. What a hard time. So certainly -- from the initial shock of being a person with so-called mild hemophilia, just having that one-shot thing, this all snowballed.

D.K.: Yes. They asked me if -- they wanted me to report her death to the NHF for statistics, and I had chosen at that time not to because this was so -- this would be devastating that she knew that she died of AIDS and I was in pastoral ministry. How would people take it, especially people living in the South and associating it with what they associated with it and looking at this also being so leprous and so contagious? So I remained anonymous and allowed her name to remain anonymous and her statistic to remain anonymous, but I was told that she was the fourth wife of a transfused person in the United States to die from AIDS.

Q: I see. And this was in '87?

D.K.: Right. I look back and I wonder if that could be statistically true, and it's possible that that could have been statistically true. I'm not sure if they meant the fourth woman to die from AIDS in the United States or --

Q: Or in the hemophilia community, I think.

D.K.: Or the fourth woman in the hemophilia community, or the fourth person --

Q: Person in the hemophilia community. I have a feeling

that's what it was, but maybe not. I'm not sure.

D.K.: I still would like to find out that information.

Q: You could find out. Linda Augustiniak (ph) would know. Or they could trace it back from the CDC. They would have that, I'm sure. Wow. So that really was a rough time. When you were talking about the South again -- with all of this going on did you feel that -- did you -- from your initial stance about the gay impact on this did you have any sense -- anything different happening? What was going on in terms of your interaction with hemophilia rap groups or whatever? What was happening?

D.K.: Really there was not a lot happening. There were no support groups. There were no support groups at that time. The only support you got was going to your hemophilia treatment center, and that's when the treatment center in Chattanooga -- once they knew this story, and I had told them all about this and they followed me very closely with all this -- that's when they realized that I had at least emerged from this to the point where I could help other people and they asked me if I'd be willing to help them in their clinic.

Q: And so you did.

D.K.: So I did.

Q: Which made them very fortunate.

D.K.: And that's the point, I guess. Once my wife passed away I could no longer fulfill obligations as a minister, because that's a very rigorous schedule. You'd have evenings away and things such as that and I could no longer do that so I had to move to Virginia where my parents were for them to help me take care of the kids. The three of us lived by ourselves in a home, but we lived close enough to my parents where they could help us out when we needed them. At that point, after my wife died, with no one -- no support group and no one to support her except me and no one who understood about this because it was so new -- that's when I made my vow that I would never allow anybody to ever have to go through the situation I went through alone if I could ever help it, and that's how I ended up becoming a clinical counselor with the hemophilia HIV population.

Q: Where are you based now? Tell us about your work a little bit.

D.K.: In Richmond, Virginia, in the medical college of Virginia Hospital. I do the hemophilia risk reduction counseling, probably a whole lot of other things such as seeing many of the hemophiliacs throughout the state of Virginia and knowing them pretty well know, being their support and being a person who they know understands hemophilia and HIV as well as helping patients get on different protocols that they need to get on or inquire about.

Q: When we were talking initially -- I guess I keep bringing this up because I'm trying to understand what are the differences in the Southern geography -- different kinds of prejudice, or what? What is it that's different about the South that you wanted to talk about? Because I had jotted some things down, but maybe it was more about the Deep South that I think you brought it.

D.K.: Oh, yes. I think if I remember correctly I was saying that in the Deep South there is more of -- like going back to the time of the Civil Rights time there is more prejudice that has to do with ethnic groups.

Q: O.K. I think that's what you were talking about. Right.

D.K.: Right. And then there is a prejudice that has to go along with the gay community, because -- as I said, in the Deep South for someone to be gay they probably would never say anything about it because it is so rejected and so not accepted because again it's such a Bible Belt, and you feel like -- the real Southern conservatism says that this is because of biblical implications that this is not an acceptable lifestyle. So this is not accepted, and when AIDS comes into the picture that is what the Deep South still thinks in many ways about what AIDS is all about -- it's the gay person's disease.

Q: They still do.

D.K.: In places, yes. I guess as you move further north in the South there is a mentality that -- again, it's a little more accepting that there are people of different cultures. There's more being accepted as ethnic cultures. But again, the gay population is not very well accepted. Then as you start moving north into Pennsylvania, further, especially in the metropolitan areas of New Jersey, New York, this is part of the lifestyle there. From what I understand the ethnic groups are pretty well accepted and life goes on.

Q: Well, as you know it's kind of volatile in the cities now on an ethnic basis, but that's a different issue though. I don't know. Certainly in the Northeast here there's just so much HIV positivity, and it's all around us. It's still something where you feel -- in terms of your counseling do you still have to do a lot of educating about safer sex? Or do most people seem to know what's going on by now?

D.K.: Most of my population knows what's going on right now. I feel pretty good right now that I've been able to talk with all the couples, encourage their spouses to be tested. I think there's only one spouse that I have not had tested -- or sexual partner -- but they've all received transmission education.

Q: Do you feel that -- it's hard to generalize, but that generally most people are acting pretty responsibly? Or do you feel there's a denial?

D.K.: I think they've pretty much gone past the denial stage. I think they're now down to choices, that they are going to make informed choices. I know that there are some people who choose to still practice sex without condoms, but they will use a sponge, and that's what they've chosen to do. And they have been informed very well about all this. I think the same thing holds true with having children. I've seen a number of people in our clinics who have been told this and warned that it is dangerous to have children and what the percentages are that children could become HIV positive as well as the spouse and yet they have gone on to have children.

Q: What do you think that's all about? Or do you think it varies? Or is there some underlying theme to that?

D.K.: I think as I've dealt with these patients and fellow hemophiliacs I have realized that -- I have been given the statements or the answers to those questions in kind of an interesting way. I've had a wife tell me that she does not want her husband to use a condom because she loves him and it doesn't matter what's wrong with him. She still wants to be part of his life. She feels like that's a barrier, and it's a barrier almost of his love towards her. She just does not want to use it. And husbands have felt the same way. They felt like it hindered the closeness that they would like to have. As far as having children, their statements have been to me, "But we want our own children. We want to leave our wives with a piece of us."

Q: That's what I was wondering about.

D.K.: A piece of us when we're gone, because we know that HIV eventually will get us, and we want to leave our wives with just not memories but with a family, so she won't have to go home to live with her family that she left many years ago to be married but that she'll have her own family.

Q: I've heard things like that too, and I guess that's the way it is. I've also heard people -- I don't know, I've just heard this in a few cases but maybe you've heard more, because I just happened to notice it -- of people buying houses and kind of like really forging ahead, which is very positive, I think. Saying, "I'm going to buy a new house. Fix it up."

D.K.: Well, it's interesting because speaking again from a personal point of view when I found out that I was HIV positive my life changed in the sense -- once I got past the stages of anger and denial and -- you know, the stages that Elisabeth K bler-Ross puts forth -- once I got through them and to the point of acceptance, at least acceptance the best possible

(because there are still times that it upsets me to know that I'm HIV positive, that I could not be here to see my kids graduate from high school) -- but I've lived life differently, and the way I've lived it differently is that I live it with real quality. Every day I wake up and it's like this is a new and exciting day. What can I learn from people and what can I leave people with and what can I help people with? And the other thing is, I take vacations.

Q: That's interesting.

D.K.: I don't worry about how some people are constantly saving and saving and saving and they'll save for their retirement to take a trip to the Bahamas. I go yearly and I enjoy myself, and I feel like I'm going to build good memories and good relationships with my kids and -- I am married again -- I guess you may want to ask me some questions about that, but I'm married again and I like to build good relationships and to have fun in life now, while I can -- not to the place where I become -- not using common sense, but I purchased a house and I've also done other things. I've made sure that my family in case of my demise would be well cared for.

Q: It's clear that the way you have approached this you must be such a help to so many people as a role model as well as a counselor, for them to see that one doesn't have to just completely fall apart. I did meet your lovely wife last year in September, when I was embarking on my first interviews, in Washington at the World Federation Meeting. Had you been just recently married? I don't know.

D.K.: April. 1990.

Q: And I met her in September 1990.

D.K.: That was interesting because she's a hemophilia nurse, came from that background, and we had met at a conference and she was very well educated about hemophilia and HIV. I knew that when I was dating her -- even though I had never told her I was HIV positive she knew I was, but before we even -- I can even say before we even got dating I made sure she knew my status because I wasn't going to carry on any relationship and not be honest with someone.

Q: It's clear that with her education and understanding I'm sure that it's been a real mutual support, and I'm sure it's good for the kids, too.

D.K.: It's been excellent for the kids. Excellent.

Q: How old are they now?

D.K.: They are now eleven and eight.

Q: I was thinking how long it's been for them since their first Mom died and since the trauma that they had gone through. It must have been a lot. Did they have to have counseling?

DK: Really there was no one that was going to be able to counsel them because -- well, I was usually the one who counseled them. I was the one who did it, and it was real interesting because I would have to be strong for them and counsel them and take care of their tears and their questions during the day and it was almost like I'd learned how to separate myself. Then when I would put them to bed at night that's when I would sit down and I would do my crying and I would do my getting angry and saying how things were so unfair and why does this have to happen to me, and really would work through it then myself.

Q: Wow. It's quite a saga. Quite a saga. I know you have made and are continuing to make a tremendous contribution on that level in terms of your counseling, but also you've become very involved -- and maybe you'd like to talk about other involvement more nationally and anything else that you'd like to discuss --

D.K.: Well, I guess I started out as an alternate Regional Director. I was asked to do that in Anaheim, at the annual meeting in Anaheim.

Q: Right.

D.K.: I accepted doing that and from that time I embarked onto NHF, I would say not only -- not on a -- I guess a volunteer basis full-time -- and through that became I guess known to NHF in all the various areas. I also had taken this job on with the Maternal and Child Bureau of Funding, and I just got involved with NHF -- with the Board meetings and learning about NHF and learning about -- getting to be I guess on the Government Relations Committee and the AIDS Task Force, and really serving in different capacities, including being an ad hoc panel member to the various CDC committees, so I had an opportunity to really let people know about hemophilia not only from a professional perspective but also wear that hat as a personal one.

Q: Right. Which is such a valuable contribution. Yes.

D.K.: I have felt that that has been I guess one of those paradoxes again, or as some people would put it, a mixed blessing.

Q: You know, in the hemophilia world it seems like quite a few people wear different hats. You have persons with hemophilia working as pharmaceutical reps. There are so many different kinds of combinations and permutations that you see. But you were mentioning something that's going on very currently that maybe you'd like to discuss.

D.K.: Yes. Back I guess at the Pediatric AIDS Conference in Los Angeles -- I think that was 1989 -- I remember I had an idea, and my idea was let's -- at that time the Women's Outreach

Network of the National Hemophilia Foundation was established, and I just couldn't understand why they started with women if this was -- this great need with hemophilia and HIV was with men. I knew in myself that men wanted to talk about this and they wanted to deal with it in some way with other hemophiliacs, but everybody had told me "No, they don't want to do that. They want to just save themselves." And I said, "No, I know this community so well that I know there is this need for it, and there's need for someone to advocate for them." Someone encouraged me to talk to Alan Brownstein. Other people said, "No, you don't want to talk to him. He will never listen to you." Well, I ended up confronting him and asking for a time to talk, and we met at that conference and we had dinner one night and I told him of my plan for a men's group of some sort that would be national, similar to the Women's Outreach Network. I remember writing to him and giving him what could be the agenda for this kind of a workshop or a training session that these men could have, and what this whole network would look like, writing him a letter about it and stating the psychosocial issues that the men would want to talk about and be involved in. He really listened intently, and he also listened to much of the story that I have just told you tonight. I saw him really take an interest in this from that point on, and I think he shared my letter with the Board and he kept on looking into this, and finally I wrote some more letters and I remember when we came to the meeting, WHF meeting, World Hemophilia meeting in Washington, D.C. -- last year, right? Was that last year?

Q: Yes. 1990.

D.K.: There was a group of guys who had the same idea, or a similar idea, but they were -- some of the approaches I felt were not really good approaches. They were not protocol. They weren't doing it right, and they were taking some pot shots at NHF and blaming them for things that they should be blaming the CDC or Maternal and Child Health Bureau for. Anyway, whether it was done in the proper order or not and with the right direction or not it caught the attention of the National Hemophilia Foundation and I was kind of acting like liaison to try to smooth everything and not blow this thing sky high or have this other little subgroup blow this thing sky high, things that I'd been looking for to happen for quite some time. I remember having meetings about it, but out of that the AIDS Task Force was given an assignment to explore this. They explored it and they got with the Centers for Disease Control and they decided to take the information that came out of a focus group that took place in San Francisco that was sponsored by the National Hemophilia Foundation and the Centers for Disease Control, and through this focus group they found out that everything that I had said probably plus more was expressed by thirty guys throughout the country, and from that point on, the program began to develop and it developed into a working group of consumers or hemophiliacs which I chaired and then we brought on a co-chair from California, and it developed with goals and objectives and it became known as MANN --

Q: Correct.

D.K.: Men's Advocacy Network of the National Hemophilia Foundation.

Q: Right. So you have really moved your ideas onto that national level. You know, as you say there were thirty guys expressing -- not just you -- many of the concerns -- are they mostly centered on HIV or is it just other kinds of concerns as well that the men --

D.K.: I would think it falls into a couple of categories. I think it is HIV, and the concerns that are there, the psychosocial concerns which some guys don't want to deal with because they've gotten kind of burnt out with the idea of "Support Group." "Support Group." They like to look at it as advocacy now. I guess that's a better way of putting it. But they still like to know that there are other guys who are suffering as they are suffering and who are coping and can give them help in learning skills to cope. I think the Maternal and Child Health Bureau with their risk reduction has done a great job, probably -- it's like oh, no, am I going to get a condom talk again? They understand all this information, but sometimes they just like to talk about some of the sexual issues -- about can they date again? You know, some of the ethical issues -- should I tell her on the first date that I'm HIV positive? Things such as that. And I guess some other avenues that they are really concerned about are treatment, and getting on different protocols. And is the treatment good enough and can they push through other treatments that are in the FDA and lobby for them, that would help them to live longer and to at least have a quality of life?

Q: Yes. So quality of life is a big thing, yes?

D.K.: Yes. I know that I've even talked -- I've been asked to go and speak before the National AIDS Commission and to give my story, which I have, and I have told them -- I said, "You know -- I ask one thing for the hemophiliac who is HIV positive, and that is that you strive -- NHF, the Centers for Disease Control, the Maternal and Child Health Bureau, the FDA, the nation -- that they strive to give HIV hemophiliacs the best quality of life that they can give them for the longest possible time. Because, you know, no matter what anybody says I feel like being HIV positive you're doomed anyway until they can come up with a cure, and you're just biding time and you're doing the best you can to overcome it and to live the best you can, and to keep a positive mental frame.

Q: Have you found that the centers -- the hemophilia treatment centers -- have been supportive enough to the men who are HIV positive? Or do they feel that they're being drawn away from? What's the general feeling? Or does it vary from place to place from what you've heard?

D.K.: That the centers might be drawing away?

Q: Or that they're -- for instance, I've heard that there's a whole new population of kids coming up now.

D.K.: Yes, yes. I think there's a whole new population of kids coming up and I can even see where there's starting to be a tension between the hemophiliacs who are HIV positive and those who are negative.

Q: That's what I'm talking about.

D.K.: And how the negatives don't really want to be associated with the positives. I can start to see this take place.

Q: That's what I'm asking about, because I sort of see it a little and I was wondering if that's a real perception of mine. I've kind of been hearing that -- when you say -- the negatives don't want to be associated with the positives? Because I would think -- I've heard some of the others who are -- like the new parents of young babies -- just feel that they don't want to deal with HIV.

D.K.: Right. They don't want to deal with it because it's not their problem. It's the problem of the past. Unfortunately, I feel like -- and I can see some of the things that have taken place in our legislation that -- there is an underlying sentiment that they're not going to have this problem five years down the road.

Q: How do you think that's been reflected? Where do you see that?

D.K.: I see that reflected in some of the policies that have been legislated. Some of it is not so overt as it is covert -- underneath the scenes, different laws that are being passed and things such as this.

Q: Do you think -- this list that I gave you -- we've touched on quite a few of the items, but this hemophilia model -- one of the reasons I think I got funding to work on this dissertation is because people are interested in saying, "There's this health care delivery model or this community model. What can we learn from it for other populations?" What do you think are the positives of the hemophilia community that others can learn from?

[END OF SIDE 2, TAPE 1; BEGINNING OF SIDE 1, TAPE 2]

Q: This is Susan Resnik continuing talking with D.K. on September 19, 1991. I was just starting to ask you about this hemophilia model. I've heard people talk about the model. Some people talk about the comprehensive care team, others talk about the delivery model as it's represented on the national level.

Other people talk about other things. What do you think the hemophilia community has to offer to the population at large? Anything that you'd like to highlight or talk about?

D.K.: Well, I think the comprehensive care model is something that is far advanced. People are just discovering something similar to it now, especially with AIDS, and we have had the comprehensive care model I think since '76 or something like that.

Q: That's right. That's correct.

D.K.: This has been a life saver to the hemophiliacs, and it has helped improve their health, improve their work capabilities, their school capabilities. It has been not only getting the medical treatment and getting genetic counseling. Physical therapy, orthopedics work, dental work, counseling, social work, nutrition, all these different disciplines have helped the hemophilia community and makes up the model.

Q: Right.

D.K.: This has been something that different state programs have been initiating slowly but surely and finding out that they've been very effective, and as far as I know it's the hemophilia community that pioneered this and made it successful.

Q: Do you have any feelings about what is negative or what we need to overcome or problems that you still think should be worked on?

D.K.: I think probably the only glitch I think there is in this model is that hemophiliacs have been going to their clinics or seeing their physician -- probably have grown up with their physician -- since they were born, and a lot of times the physicians -- sometimes, especially when HIV came along, were hesitant to talk to them about HIV. I think the health care professionals went into denial themselves because here is a child that they helped bring up medically, and to help this child deal with the hemophilia and get this child on factor and to see the life expectancy of this child increase and then all of a sudden be hit in the face with this child is HIV positive --

Q: You got it.

D.K.: There was a denial of wanting to deal with it, because they just didn't want to give up these children. This was like the last blow for them, so I think many of them hesitated to talk to their patients about it, wanted to just pretend it would go away, and also I think sometimes it maybe even blemished some of their treatment of the patient. Not that they neglected the patient, but they were just so hurt about it that I guess their intensity of treatment wasn't what it used to be.

Q: That's very interesting. You think that something like MANN can be useful in kind of putting some things back into balance?

D.K.: Yes, I think they can be helpful. I think, again, because of this comprehensive care, physicians and patients have worked pretty closely together even though -- even to the extent that many a physician would consult with a patient themselves and say "What do you think we should do?" Because a lot of times the hemophiliacs really knew what was going on in their bodies, and I really think the best part of the model was that doctors would consult with the patient themselves and kind of come up to decisions together.

Q: Do you think that that kind of -- at the current time -- is happening more and more? Or not? In terms of the patient as partner, or whatever.

D.K.: I couldn't hear you on that, Susie.

Q: I'm sorry. I was wondering if you think that's happening more and more, that the patient is being seen as a partner in their care.

D.K.: I think so. In many clinics, yes, I think when there is -- again, you could run into a little problem with doctors who feel like they want to be the know-it-alls, and again I would never try to usurp their position and their education about knowing all about hemophilia but there's lots of times when you just want to be consulted as a patient about what you should do instead of someone making a decision for you what you need to do. You want to be included in that decision.

Q: Yes. Is there anything else you'd like to raise? We've covered a lot of issues, and you've certainly broadened my perspective. I'm so appreciative of your sharing your personal life experience as well as your perspectives and viewpoints and ideas. Anything else that you'd like to touch on that we haven't?

D.K.: I think as you and I talked about earlier it's just the concern that's going on in our government right now, and that is we're at the place in our history of HIV where there is -- the Centers for Disease Control has made recommendations that health care workers who are I guess what they call "the prone exposure invasive procedures," which simply means that they're in contact with a patient's blood through dangerous procedures of some sort which would expose them to the blood -- that they need to be tested for HIV, and this all comes on the time of or comes out of a dentist exposing patients of his to the HIV disease, and they have seroconverted and it just caused a great problem with the Centers for Disease Control and all the medical field. And then the Senate has gotten hold of the Jesse Helms portion of this, which says that there should be mandatory testing of these health

care workers and if they don't follow this procedure -- this was passed by the Senate and it's going to the House now -- if they don't follow these mandatory testings they'll probably lose their job, be imprisoned and be fined up to ten thousand dollars.

Then there is also the concern that I have for the Centers for Disease Control allowing politics to kind of push them around, which would be right now the American Medical Association and Act Up, which are trying to get them to change the definition of AIDS so that it would include any person who has a T4 count below 200. In this case it will have a big impact upon our hemophilia community as I was explaining before, that we have told our hemophiliacs that below 200 they really need to get on Pentamidine. They still don't have AIDS, and they really need to be on AZT. They need to be on AZT below 500, but even more specifically below 200. And they still don't have AIDS, but yet come January 1, 1992 if this goes through, as it sounds like it will, we're going to have to tell our patients that now they have AIDS if they're below 200. It's going to have psychological effects upon them. So these are real concerns, and right now I feel like the Centers for Disease Control is not doing good epidemiology. I think they're getting into the politics and not getting into what they're really set forth to do.

Q: Again, when I asked you the question -- because as I said I really wasn't that up on all of this -- why aren't they just focussing on adding on the conditions they haven't mentioned vis-a-vis the women rather than focussing on the numbers of T cells? Do they say why?

D.K.: The reason that we hear is that there are -- in the 1987 MNWR, which defined AIDS through twenty opportunistic infections -- they said a lot of those infections are not inclusive of opportunistic infections that are typical that women get, and some of those are pelvic inflammatory disease and yeast infections and things such as that. But I feel like it's pretty simple -- they could just add to the list of twenty.

Q: That's what I was saying. Why don't they just do that?

D.K.: I think there's a lot of political pressure not to do that but to do the redefinition. I think also the reason behind redoing the redefinition is they feel like there will be more treatments that people could qualify for plus more of the Social Security disability. But as I told you before, our country's in enough problems with giving out Social Security disability, qualifying people for that. The funds are limited, and if we add on as they predict another hundred and fifty to two hundred thousand persons with this new definition they in turn can apply for disability and I think that would be financially taxing upon our government. It just doesn't make sense. A lot of this just doesn't make sense.

Q: So how is NHF -- is NHF involved in taking a stance about any of this?

D.K.: NHF is right now in discussion with the Centers for Disease Control. I don't know how much they can really do to change this. It sounds like this is something that is very political and high up. However, my recommendation to NHF was that at least they explain in an AIDS update that although this law is going to take effect, or this redefinition is going to take effect, that they at least express the concerns that NHF has in this. I think the other reason the NHF does not want to really take a stand -- I think it doesn't have anything to do with funding from the Centers for Disease Control, but I think NHF is afraid that if they take a stand against it it would be basically taking a stand against ACT UP, and taking a stand against ACT UP would be like taking a stand against another AIDS organization.

Q: I see.

D.K.: So they feel like it could be politically unsound. I have told them I think the hemophiliacs are probably at the point where they want NHF to take a stand. If NHF doesn't take a stand they could be on the verge of losing a lot of the trust of the hemophiliacs.

Q: So it sounds like we're into a very serious -- yet another time where there's going to be a lot happening, which of course I will be trying to keep apprised of. I hope things work out positively -- in the good sense! That seems like it's the major concern of the moment, all of this. Well, I want to thank you for sharing again, and if there's anything else that you think of don't hesitate -- we can always add on. You're really contributing a lot by adding your perspectives and your experiences, and I think you.

D.K.: Well, you're welcome.

Q: O.K., I'm going to turn it off. Is there anything else you'd like to add?

D.K.: I think in retrospect, Susie, after talking to you about all that has taken place in my life with hemophilia it would be my hope that when people listen to this in future years that hopefully there'll be a time in which people would not let this happen again, and learn from the past history. I think we are wise people. As they say, you can always learn from history, and let's hope that history does not repeat itself in this sense. I think there need to be champions who champion the cause of AIDS, and I know I feel like I'm one of those people.

Q: You certainly are.

D.K.: To champion the cause to get the best possible treatment, quality of life for hemophiliacs. I think that's the way I'd always want to be remembered in this life that we have or until this epidemic is cured. I would just hope that people who listen to this would really catch a glimpse of it and not let it

repeat itself but do everything they can from the consumer all the way up to the top official in government -- that they will never let this happen again, and that they would shortcut things as quickly as possible, find tests as quickly as possible and find cures as quickly as possible.

Q: Well, it's important as I said that we hear voices that say these things, and that's why I appreciate having the opportunity to record them. It's a very important contribution. Thank you.

D.K.: You're welcome.

[tape is shut off and restarted]

D.K.: I wanted to pick up a couple of other thoughts I think I left unturned, and that was -- I think when you talked about how does this affect my theology or where I'm coming from. I feel like it has developed my faith, my faith in God, a whole lot more, in realizing that there is this strength that I can acquire with a relationship there, with God. I think even going further than that is that I remember coming to a point or telling you that I had this real blame against the gay population, and I really had a lot of changing I guess or let's say challenging of my theology, in that I realized that -- I think the main message that we get in a Judeo-Christian faith is that people are supposed to not judge other people, and that our main intent on this earth from what I read and from what I've learned in theology is that we are supposed to help people come into reconciliation with God, and that seems to be the intent that we're here for. How that takes place is really left up to God Himself. When I took that perspective then I realized I could not judge any gay person or any person whose lifestyle is different from mine. I could not judge them. That's not my place to do that. Coming from a theological background that's God's place, and my job is just to do my best to help them to be reconciled to God and to see God for who He is and what He can be to them. This has really given me a real exciting perspective on life and helped me to develop what I would call real God-felt love for people. It's really done a lot of changing my life.

Q: Well, you certainly have turned things into something positive, haven't you? That's really wonderful. The spirituality -- I'm glad you did choose to discuss it, because I think it's important to share that, too. Once again, I thank you very much.

END OF SESSION