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Interviewer: Susan Resnik
Interviewee: Dr. Robert K. Massie, Jr.

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Q: Today is July 24, 1991; this is Susan Resnik. I am here in lovely Haines Falls, New York, in the beautiful house of Dr. Robert Massie. Dr. Massie is an Episcopal Minister. He is currently the Henry Luce Fellow at Harvard Divinity School and Director of the Project on Business, Values, and the Economy.

I am really very excited to be here, Bob. As you know, I was first introduced to you via the book *Journey*, before I ever took the job that I took at the National Hemophilia Foundation, and it is a pleasure to be here face to face and to meet you and speak with you now with your perspective as an adult.

DR. MASSIE: I am glad to meet you, too, and I also think that your project is very important and I'm delighted to help you.

Q: I'd like to start out since we are talking about your perspectives regarding your personal life and your earliest recollections as a child growing up with hemophilia, as you well know; it was alternating chapters between your parents which described what it was like for them. I've read a little bit you've written in little snatches and quotes, but not really heard it as you saw it, from the beginning.

DR. MASSIE: Well, I think that the most important thing is that it took me a long time to become aware that there was something really problematic about my condition. I knew I had some difficulties from quite early on, but I think my family provided such a supportive structure that it really wasn't until I went to school, started going to nursery school and kindergarten, that I began to realize there were larger problems that I would have to cope with.

Also, it was when I was about five years old that I began having a really serious hemorrhaging in my knees which eventually put me into leg braces. So before that, until I was four or five, I'd had some bleeding, mainly bruising, but that didn't really bother me that much that I can remember. And it also did not have much effect on my joints. So when I think back on my childhood, a lot of it is coping with -- obviously there were the physical problems, but that was in a certain sense more cut and dried. I mean you would have a bleeding and you would wait for it to get better or you would have a problem with your leg and you would have to work to start walking again or whatever. I think more difficult and more what required more time to learn to work with were the social pressures. Learning to find a place in school society or the society of my peers was a lot of what I remember about back in my childhood. I also think that I've blocked out a certain amount. There were some very difficult times when I was a child, physically, a lot of occasions of very great pain and long convalescence. I really don't remember those very well. When I try to think back on them

I can picture little things, but I really feel like most of it has been erased or at least buried.

Q: Yes.

DR. MASSIE: But anyway, of course, we can talk about my earlier childhood but for me I think the biggest transition took place when I was about twelve because two or three things happened at once. That was in 1968. Nicholas and Alexandra came out the previous year and had done quite well. Factor VIII concentrate was invented, so that I was able to begin using concentrate and moved to France, where I was in a very different social setting and also where I was able to get large amounts of French concentrate for free and was covered under the French health system.

Q: Right.

DR. MASSIE: So that my life between the time I was, let's say, eleven and the time I was twelve changed pretty dramatically.

Actually, I think 1968 was an important time for a lot of reasons, not only because of the things that were happening in my life but also because it was about that time that I became aware of what was really going on in the world. I began to read the newspaper, follow politics; 1968 was certainly a pretty volatile time in the United States. So it was, I would say, to my mind, I sort of really began thinking and became aware in a whole new way in that period from 1967-68 because of these very different factors, moving and new medical technology and just getting to be a certain age.

Q: You moved to France, and compared to what it was like socially for you in the United States what was it like there?

DR. MASSIE: The trip, in a sense, solved the problem of hemophilia, because I had gone to a place where I was different for a lot of other reasons, too. In other words, I went over -- my first year that I was in France, I was in a school called the Ecole Bilengue, which was supposed to be a bilingual school where French kids and American kids spent a lot of time talking to each other, but the French kids pretty much hung out with the French kids and the American kids pretty much hung out with the American kids. We were all in a new setting, and we were all from very different backgrounds. We had diplomats' children and we had business peoples' children and we had people from French and American mixed marriages. Also, I was much better that year, because of the fraction. I still had some difficulties but on the whole I was better, so it was much less of a problem, and then the following year I went to a French school. I went to a school which turned co-ed, had been a girls' school and turned co-ed the year I was there, so there were twenty-six French girls in my class and a French boy and me. So I was very unusual, and the hemophilia was not the main characteristic that made unusual.

Q: What about relating to the doctors and nurses in France? Compared to experiences -- even though you say you've blocked out a lot, I guess my frame of reference is from reading Journey, things that I've heard from different people that have seen similarly the long waiting times and the whole struggle with residents and all the kinds of difficulties.

DR. MASSIE: It is hard to say exactly why I have this perception. I don't mean it to be critical of the physicians that I had in the United States, because I had wonderful doctors. I had Dr. Engel and Margaret Hilgartner and so forth. But there is no question in my mind that my experience in the French medical system was that it was -- at the time -- a far more humane system. It wasn't as technically fancy; some of their buildings were more run down and so forth. But there was a basic sense that care was the most important thing, that providing what was best medically for me was the most important thing -- and that the other problems, financial and so forth, were really secondary. Now in the United States there was always a battle between those two things, in other words the physicians were always nice and wanted to help you and then the insurance people, or the finance people at the hospital or somebody was always pounding on you. Of course they didn't pound on me as a child, they pounded on my parents. But there was always that -- I don't think I'm reading back on this -- I mean, there was just a higher level of anxiety about what the long-term nature of one's care would be in the United States. When I went to France there was really much more of a sense of "We're going to help you and take care of you. We're going to work with you." Here in the U.S. there was a crazy kind of patchwork quilt. A lot of the kind of care that we got depended on who we knew and how much noise your parents could make. It was and still is very, very unfair. This experience has definitely molded my strong belief now that the health system in the United States has been a disaster for a long time and needs to be reformed.

Q: Can you talk a little bit about some of your feelings about that now, even though we started out talking about your earlier times? What do you feel? I know right now that we are at a time where people are beginning to grasp --

DR. MASSIE: I should say that whereas my interest in these issues obviously has a personal origin, I now have acquired, since then, a lot of other takes on this, one of which is my doctoral training in business and economics; another comes from my convictions as a clergyman, another is my experience in Washington, D.C., where I worked for several years. So -- looking at it -- my feeling about the health insurance system in the United States is that if you consider it, absolutely at its most basic, what it does is that it provides the best care, at the lowest cost, for the people who least need it. And provides the worst care or no care at all at the highest cost for people who most need it.

The basic concept of insurance is the notion of distributing risk across populations. The way you make a profit in insurance is to eliminate people who have a predisposition to certain risks. So while this is potentially a good system in which to distribute risk (as long as you are not aware of the risks) and it is also a good way to make money, it is a very, very bad way to distribute health care. Because what you do is you get a gross over coverage of the people who don't need coverage; and a gross under coverage of the people who do. This is going to become a much more serious problem as we gain the ability, through genetic and other diagnostic techniques, to identify more and more people who have predispositions to certain kinds of conditions. These people will then systematically be eliminated from health insurance. You will get a smaller and smaller pool of people who are in essence "good investment risks" for the insurance company, and a larger and larger pool of people who simply have a wide range of medical needs, and I think that is one of the things that is going to force change.

The upshot is that American medicine -- while I've seen some improvements in the last ten or twenty years -- has never primarily been concerned with care for patients, or providing for their medical needs on an equitable basis. It has been driven by commercial interest and for a long time by the professional needs and professional insecurities of different blocks of people, including physicians. Now I think we're seeking a lot of change in that. And so I'm not particularly eager to dump on doctors, but there's still a problem there.

Finally one other piece, which I think is the only thing I saw that I really noticed was missing from your presentation, is an analysis of the role of pharmaceutical companies in all of this. The pharmaceutical companies have, in essence, been able if you look at it from an economic standpoint, to identify a population which has no alternative but to use their product. It is not a normal market where people can pick and choose. They have no alternative but to use this product, in order to maintain their lives or livelihoods. Yet the companies have no public accountability or scrutiny of their cost structure or anything. So one of the things that -- I'm now digressing a bit -- but one of the things that you identified in here which has always irritated me is the way in which pharmaceutical companies have spent tremendous amounts of money providing all sorts of little goodies for hemophilia chapters. I recognize the hemophilia chapters need this funding so I'm not really objecting to the hemophilia community -- but for magazines and tourniquets, free trips and this, that and the other.

Q: Yes.

DR. MASSIE: When, in fact, I think if you did -- I once did a kind of simple analysis. If you will look at what the probable profit generated from ten or twenty thousand hemophiliacs using product over a period of a year, it is immense. It is in the ten, twenty, thirty or maybe hundreds of millions of dollars if you look at it aggregated over time. And so it is not surprising to me that you can throw a million here and a million there, to

print some nice glossy stuff. To me it has always had an overtone of exploitation, and that bothers me. Yes -- that's one thing that has bothered me all along.

Q: I am interested in looking at that more closely. I think, as you know, because of the slant of what I've undertaken, which is the social history and the focus on this as a community (which we will get to), I really can't go into a great deal of depth about the economics and how this --

DR. MASSIE: It would be hard to. This material is hidden. It is extremely difficult to collect. I've made some attempts at different times.

Q: I am interested in it, and I think it is important to do, and when I do suggest things that I think should be done for the future, that I can't do in my study, I am very interested in this.

DR. MASSIE: I think the basic question that I would like you at least to raise as a question if not -- is whether this is a symbiotic or parasitic relationship between the hemophilia care community and the pharmaceuticals.

Q: Okay.

DR. MASSIE: By which I mean hemophilia patients and pharmaceutical companies is the best form of delivery. In other words, I can certainly imagine someone saying, well, we provide good products and we get the stuff out there and you know as long as you getting the care what do you care if we make a lot of money? If that is the best one, or whether it has in fact produced terrible distortions and inequities in the system, that is because of the way the system is structured. The product may be much more expensive than it needs to be; that in turn means that some people don't get it, or that it ends up being paid for by the taxpayer, or that it ends up or may even be that it is in a certain sense -- hinders research because, from, again, a purely business standpoint, once you have a product which is selling well and generating a good margin that is called a "Cash Cow." The last thing you ever want to do is kill a "Cash Cow." I mean, mainly these are questions. I am not faulting any particular company or any particular executive.

Q: No, I understand. I understand.

DR. MASSIE: But what you have here is, I think, a very problematic mix, all the way through the American health system, of very, very different motivations. And the motivations and the sort of structure can lead to abuse. Whether it has in this situation or not would take a lot more research and access to a lot more information than anyone can usually get. But I think that any physician, any director of a health, hemophilia comprehensive care center, would acknowledge that this is an uneasy and potentially conflicted relationship with these large

companies.

Q: Well, I am aware, in speaking with some of the people from the pharmaceutical industry, that they will say that their relationship with the hemophilia community is different than it has been with any other disease entity or illness.

DR. MASSIE: What do they mean by that?

Q: What they mean by that is that it is very special to them. They are personally involved. It is all the humanness of it.

DR. MASSIE: Well, I wouldn't want to doubt that too much, but on the other hand, my sense of, let's say -- if you take the people in charge of managing the product, sort of product managers, there is a fairly high turnover there. We never see one person getting in there and developing a lot of personal relationships over twenty years. It's more like a person doing it three or four or five years, then rotating into different branches of the business. When you have that high turnover, it can mitigate some of those loyalties.

Q: Yes.

DR. MASSIE: The real question is whether loyalty to the hemophilia community is what is best for the financial improvement of the firm and in some sense it may be and in other places it may not. From the firm's standpoint, you want to discourage acts of charity that may be prompted in the hearts of managers who are too emotionally involved.

Q: Also, recently you have a lot -- not a lot, but several sales reps who in fact are persons with hemophilia.

DR. MASSIE: Well, that's even -- that's a very sensitive area, and I certainly don't want to challenge either their need for employment or their motivation personally. However, it seems to me I've never had a chance to discuss this in any depth -- it seems to me that there are a whole host of questions of conflict of interest which I am sure they've had to work through and if they had not, they certainly ought to. It is yet another example of an intertwining --

Q: Absolutely.

DR. MASSIE: -- which to me is really problematic.

Q: Well, let's put it this way. I am certainly aware and will describe the intertwining. It is also to the point now where there are positions; there is one right now who is the director of one of the centers, who has now become a high executive of one of the pharmaceutical companies.

DR. MASSIE: Well --

Q: -- and he is leaving his post at the center, but there has been a lot of -- well, there is -- there is no question --

DR. MASSIE: The interests are not completely aligned.

Q: Yeah.

DR. MASSIE: If they were, this wouldn't be a problem, but the interests are not aligned. When they are not aligned, that is where the conflicts come. That is, whose interests are you really serving?

Q: Yes.

DR. MASSIE: This is a theme that is in Journey with my father in dealing with the American Red Cross and other institutions. It is a theme that I think is continued and is a theme that runs all the way through American medicine. That is to say, that's one reason we have spiraling health costs, and it is one reason why we have grossly inequitable health care. Why we have some people who have access to the best health care on the planet and we have thirty-seven million people who don't have any health insurance at all.

Q: That's right.

DR. MASSIE: And, to my mind, that is absolutely not the way you would design and health care system in any society that has any pretention of being just.

Q: Because people are now yet again looking at this, every twenty years or so there is this sense of "Let's look at our health care system and straighten it out." But one of the models that they are looking at is the hemophilia health care delivery model in terms of -- I think primarily -- the interdisciplinary team approach. Do you have any feelings on that?

DR. MASSIE: We're talking mainly now about health care delivery as opposed to health care financing?

Q: Yes, right now.

DR. MASSIE: For health care delivery, I think the team approach was an enormous boon to me personally and to others. My experience before teams was that you were really dependent on an individual doctor and that your time was worth nothing. You came in to waiting room after waiting room, sat around forever, and even though this may not always have been true, that is the mental image and the social relationship is that you come in and are crammed into this doctor's busy schedule. There is the delicate problem for parents or eventually the patient of managing multiple medical egos and sorting conflicting medical advice, so that you're having to be the arbiter between persons

who didn't want to talk to each other. It was a mess.

Q: Yes.

DR. MASSIE: And one of the things that the team approach did was, on a very simple level, it meant that everyone was in the same place. You could come in and find one-stop shopping.

Q: Right.

DR. MASSIE: And the one-stop shopping approach was not only convenient, it was also psychologically important, because it made you feel like these people were pulling together to help you as a whole person, rather than allowing you to have an audience with them in their special area. You see?

Q: Yes.

DR. MASSIE: So there was much more of a sense of being monitored completely. I still go in to my check-ups to my hemophilia clinic once a year, down at New York Hospital.

Q: I was going to ask you whether you are still going to New York, or --

DR. MASSIE: I am still going to New York Hospital.

Q: Or -- Margaret Hilgartner's?

DR. MASSIE: Still go to Margaret Hilgartner at least once a year. The whole battery of tests and interviews is done and we get everything straight, and now, of course, with all the federal tests, they take about 50 tubes of blood and we are done with it.

Q: Yes.

DR. MASSIE: So that's very good. I first experienced the team approach in 1973, when I went out to Shelby Dietrich's organization at Los Angeles Orthopedic Hospital. I had a very bad knee, that came up in the summer of 1973, and when -- we were in France at the time, and when we got back to -- we had actually returned to the United States for good, but we had gone back to France for the summer and when we returned to the United States in the fall of '73 I went out to Los Angeles Orthopedic for two weeks for rehabilitation. I just remember being overwhelmed by the sense of "we want to help you as a whole person." I mean, "we understand that the problems are interconnected in you and we want to give you a whole approach." I also had fairly intensive physical therapy at the time, and it made a big difference.

Q: I think that those two points really are such exciting innovations. I did read in Journey about Dr. Jordan. I have also heard about Dr. Jordan from various people and the difference in the rehabilitation philosophy that was expressed in

California -- that must have been quite an exciting thing for you.

DR. MASSIE: Well, it was. I had certainly heard about it, but I hadn't really been part of it. This was one of the things that was remarkable about my parents. They were very aggressive in pursuing what was going on and pursuing the latest and the best kind of thing. But this made me aware of what happens when you don't have parents who are well educated and articulate and in a position to put pressure on people because of their vocations as journalists. I mean, you know, they were willing to move around, and they had a certain amount of flexible time, and not necessarily that much money, but at least a lot of initiative. And I became very, very aware of what would have happened to me if that had not been the case.

Q: Was this something that you and your parents discussed as you got older and you were, as you say -- starting in '68, when you became aware of things; you were reading newspapers. Would you discuss this health system with them at that point?

DR. MASSIE: Oh, yes. Well, I've always had very strong opinions and that is, I think, part of my character. We talked about this stuff constantly, and of course my father and mother, but especially my father, felt very strongly. My father was very quick -- well, he bridles quickly at injustice and stupidity. And there is a lot of stupidity and injustice around. So I heard about it from him and that in a sense gave me permission to both think about it and express what I felt.

One of the things that my parents did best was manage the transition that took place there for about five years from the time I was twelve and began giving myself shots, and my father started giving them and then I began giving them, too, when I was seventeen, when I basically left home; went down to Washington to work for a year, and then went to college. So there was a critical five-year period during most of which we were in France where my parents had to let me do more and more stuff on my own, and at the time I thought very little of what that involved. Now that I am a parent, I realize there was more to it.

For example, when I was fifteen I went over to England and spent several weeks working over there. I was staying in the home of the head of the Hemophilia Foundation over there, one of their chapters, and I was working in a hospital so it wasn't as though I was really far away from medical care or from the hemophilia network. At the same time I was in London and they were in Paris. Gradually I did more and more stuff like that. To the point where I was in college, I was loading up fraction into a cooler and going to Europe by myself for six weeks.

Q: Which, of course, is the exciting thing about being able to do that. I read in Journey how your parents had that incident on the crossing where they didn't freeze what they were supposed to, so that was the first cryo -- it was the first time

that they actually gave you factor.

DR. MASSIE: That's not actually true. I actually received factor the first time, the concentrate, in the summer just before we left because I have a very clear memory of seeing this little bottle where we used to use bags; seeing this little bottle and looking at it when we were in Maine that summer. But the incident on the boat was certainly one of the very first, and it was definitely the first time they had given it to me.

Q: Which is what I think they said, that they had given it, and not that they had received it. They had given it.

DR. MASSIE: Okay. All right. Well, I had received it already, but it was the first time they had administered it.

Q: Right. The freedom of being able to do that and to travel apparently has meant so much to people with hemophilia.

DR. MASSIE: Oh, yes. I've had shots in just about every conceivable place that you can imagine, including several times in airplane bathrooms and things like that. Actually I have one quite funny story. I was traveling by myself on a train from Austria to Germany. It was at night and we had left, and I had gone to sleep in my compartment. Then I had woken up, and decided that I had some bleeding in my ankle. So I decided to give myself a shot and mixed up the stuff. I was by myself in the compartment, and I got the needle into my arm without problems. Just as I got it into my arm, the train stopped. We had reached the German border, and the German border guards were coming through to check the passports of everybody in the train. They were walking through the train, opening the compartments, waking up whoever was there, getting their passports, stamping them and moving on. This was not a big deal, except that I had a large syringe with a needle running straight into my vein in my right elbow. I thought, how are they going to react when they pull open the door and they see all this stuff? I just held my breath and they got to the compartment next to me, and thank goodness the persons next to me had a lot of trouble finding their passport. The police were in there for about eight or nine minutes, whereas they had been coming through every ten or twenty seconds. I probably gave that shot too fast, but by the time they got to me I had pulled the needle out and wrapped everything up and it away, and I just handed them my passport and they kept going. But that kind of thing has happened to me a lot.

Q: Yes. Have you had problems where people questioned you thinking that maybe they didn't understand it, that you were infusing drugs or something?

DR. MASSIE: Yes. Well, a couple of times people have noticed marks on my arms and have acted suspicious or downright badly, but this has been infrequent. Most of the time it has been really amazing. I went to the Soviet Union five years ago and took a large amount of factor and I had a letter that had

been translated into Russian, but I didn't have any trouble getting through. I suppose that they just couldn't believe that someone might actually walk through with large quantities of cocaine visible in small bottles.

Q: Yes. Well, as you say, the differences over time, and I guess seeing a different health care system and living with it for yourself, have given you an even greater sense of how different it is here and now, with all this. How did you -- as you went on in your education -- okay, after high school, where did you go?

DR. MASSIE: After high school -- I graduated from high school when I was sixteen and I took a year off, and I worked in the United States Senate for a year. One of the things that worked on actually was on the international flow and distribution of blood products. I was working for Senator Scoop Jackson of Washington, Henry M. Jackson; for the Investigations Subcommittee of the Committee on Government Operations in the U.S. Senate. I was just an intern but I was there for a year, and they were working on the Jackson-Vanik Amendment, Jewish Emigration from the Soviet Union, oil companies, and lots of other things. I expressed an interest in this blood question and they said "Great, why don't you go do some research." I did some and they got quite interested, and it actually developed into some things, which I would be happy to tell you about, actually. I hadn't really intended to tell you. Let me tell you what happened.

Q: I think that would be very interesting.

DR. MASSIE: I interviewed a lot of people, and I was actually interested in this question of where blood was coming from. I heard that there was a shortage of blood and of fraction and concentrate products in the United States. About the same time I heard that American products were being shipped in large numbers to Europe, and so I wondered what was going on here. As I looked into it I came across various sorts of minor issues, like the New York Blood Center's Euro Blood program where they were swapping American equipment for excess German blood from the German Red Cross and so forth. Then I became interested in the collection of blood from other sources, for example one of the places where -- I can't remember which drug company was getting it, but they had these large plasma collection facilities in places like Nicaragua. The plasma center was one of the places that was burned down within the first few days of the Sandinista uprising against Somoza. It was a particularly unpleasant symbol of capitalist exploitation, the literal draining of a people's blood. I became very interested in the economics of this, sort of what we were talking about before. If you have 10,000 hemophiliacs a year using 100 bottles a year, which cost \$100 a year, that's 10,000 hemophiliacs using in essence \$10,000 worth of stuff. That makes for gross revenues of \$100 million, so you know right away that it is a \$100 million industry. I wanted to know where this \$100 million was going. That is grossly

underestimated now. I mean, in other words, if you look at what I get now -- it is \$600 a bottle. I use probably \$200,000 worth of stuff a year. So if you take \$200,000 times 10,000 hemophiliacs, that would be a \$2 billion industry. It is a huge, huge -- if you just look at it in terms of dollars flowing somewhere, it is a lot of dollars. Then suppose they're making 20% return on investment. On a \$100 million, that means they're making -- somebody is making twenty million bucks, which is a lot of money. I wanted to know where that money is going and why it isn't going more into research or whatever. My questions were fairly direct, but my understanding of how business worked was a little simple. I tried to overcome that by talking to a lot of people. What then happened was I wrote a long report -- I was only seventeen.

Q: This is fantastic.

DR. MASSIE: Well, I might even be able to find it for you. I really don't know where it is now, but I wrote up a long report. Senator Jackson read it and he was very sweet, really. You know, it was a seventeen-year-old's effort and so it had a lot of flaws, but he was sort of impressed. I wrote a sixty-five page report, and I was full of fervor. He said, "Well, let's take a look at this." I went to college in fall of '74, and I came back in the spring of '75 in Washington. Jackson hired me back again for the summer, and he told me that I was going to be working again for the Investigations Subcommittee with a young lawyer who had just gotten out of Harvard Law School and had been hired by Scoop to work for him. Jackson wanted him, among other things, to look into this blood stuff. So I went down and found myself in a tiny little green room with this young lawyer. I would be his research assistant and flunky. I was then a college freshman, and he was a recent Harvard Law School graduate. His name was Elliot Abrams.

Q: Oh, my.

DR. MASSIE: So I spent the summer with Elliot; and Elliot and I got quite interested in this stuff. He was working on several other projects, but we got quite interested in this. We wrote a questionnaire, a detailed questionnaire which we were going to send out to all of the pharmaceutical companies in which we asked where do you get your blood? How much are you making? What are your costs? and so forth. We then -- I've got to get the chronology right here -- we either sent it out that summer -- I think we sent it out that summer or fall, and we basically got very little reaction. A few companies sent us a big stack of stuff, a lot just sent a one-page letter. Some of the others were intermediate. I think there were about ten or twelve companies we sent it to.

Then I went off to college again in the fall of '75 and the spring of '76; came back again, and I actually -- during my sophomore year, fall of '75/spring of '76, I was actually on the payroll of the U.S. Senate as a consultant and went down to

Washington every other week for two days to help with this ongoing project. So that is how the questionnaire developed. I kept it up, and we got it out in the fall and it came back and then I went back in the summer to take it to the next step. This is where the story got quite interesting. First of all, Elliott got more and more involved in Scoop Jackson's presidential campaign. Jackson ran for President in the spring of '76, and so Elliot was out of it. The guy who was the Majority Counsel for the Investigation Subcommittee, his name was Howard. I can't remember his last name, it's Howard something -- decided he wanted to go forward with the probe. He felt that the companies had not really been forthcoming. There were serious discussions of issuing a subpoena to get all the information and bring all the people in and hold hearings. This looked like good stuff for them to work on.

But it was being muddled a bit by the presidential campaign. So it all came down to one day -- I'm now eighteen or nineteen, and I had been working on this on and off for a year or two and found out a lot of interesting stuff. I then get a phone call from the Minority Counsel, whose name again I forgot. "Would you come down to my office, please?" he said. You know, the Majority Counsel's is a big staff. Minority Counsel's is a little bitty staff to keep the minority side, in this case the Republican side (although it switched a few years later). So I went down and I talked to this guy and I remember his face really clearly. He basically said this to me: "Senator Percy, Charles Percy, has been receiving some information or complaints that the Investigation Subcommittee is pursuing this line of investigation." Of course I instantly realized that Baxter Travenol was based in Illinois at the time, and they called Percy. The Counsel continued, "We understand from Senator Jackson that there is serious consideration being given to issuing a subpoena on this. What I would like you to realize is that your role in this" -- speaking to me, and he didn't put it quite this bluntly. He was more diplomatic, but what it boiled down to is this: "Your role is unacceptable because you have personal involvement in this and a personal bias, which means that this investigation cannot go forward without being influenced by you. So this is the deal."

Q: He said, "So this is the deal"?

DR. MASSIE: Not quite that bluntly, but it was pretty blunt.

Q: Wow.

DR. MASSIE: He said, "There is a choice here. Either you can withdraw personally from this investigation or Senator Percy will not find it possible to approve a subpoena. So I went back and I was absolutely furious. I knew when I'd been hit with a baseball bat. But you see the problem was -- it was a very effective thing, because Jackson was distracted, Abrams was off, I was working with an attorney who a nice guy, but of infinitely

less ability than Elliott. And also -- so I knew that either way I was dead. That investigation was dead. If I went off of it, then the interest, which was flagging, would drop. If I stayed on it, they would freeze the subpoena. I went back and told the Majority Counsel and he was irritated, you know. He said, "They didn't have any right to talk to you. This is outrageous." And so forth. But you know I think then what happened was it just put everything on hold. The question was, I think, now that I look back on it, well, we'll be in a lot better position if Jackson is elected president of the United States. Then we'll be able to do a bit more about this, and if he is not then we can work on it when he is back. But in essence neither one of those things happened. He wasn't elected President, and when he came back there wasn't any great interest. They were on to other thing. You know, that's how things happen.

Q: Right.

DR. MASSIE: So that great investigation into the pricing structure and distribution system sort of collection and distribution system of plasma products -- and it wasn't just Factor VIII, it was albumen and all the different -- was clobbered right then and there by a sort of fairly classic --

Q: That's a fantastic story.

DR. MASSIE: It's a fairly classic political hardball.

Q: At the stage that you were, I mean -- it was really quite incredible doing that at that age.

DR. MASSIE: I was a kid, but I was also a pretty determined kind, and in strict terms what they were saying was true. I did have a personal interest. But you see a lot of people have personal interests in a lot of things and that doesn't mean investigations don't go forward. The other thing about it is that if you eliminated everyone who had a personal interest in it you would only have people who weren't interesting in things doing it. In other words, being interested in a topic, as I argued to the Senator, should not disqualify you from being involved in it. That seems like it is sort of the opposite of what should be.

Q: Yes.

DR. MASSIE: What it boils down to, the truth was that somebody from one of these big companies, probably Baxter Travenol, talked to Percy and said, "What is this crap? And who is this Massie?" I don't know exactly how they figured out I was there, but anyway --

Q: Was National Hemophilia at all involved in this?

DR. MASSIE: I don't really remember. I think we were pursuing this fairly independently and I can't remember why. I

may have been that we were just ignorant, or it may have been that we felt like we didn't want to tip our hand. In other words, my sense of the National Hemophilia Foundation was -- at least prior to the time that I got to know Alan Brownstein and got to know the Foundation better, my sense of it, growing up and probably because of the stuff described in Journey, was that it was often ineffective, clumsy, shot itself in the foot every now and then, not to be trusted completely.

It had not taken an aggressive enough position earlier with the creation of fraction, and it was in bed with a lot of these companies, to put it bluntly -- because of the dependence on money and so forth. So you didn't want to -- now, looking on, I am much more sophisticated now. Now, you know, if I were running this thing, there are a lot of stones that I would have overturned in pursuing it; but at the time I think there was just a basic unwillingness to involve a lot of other people, since I had, I mean, at least a piece of the Senate Investigation Subcommittee churning along rather nicely on this.

Q: Have you ever found any of the papers and material that you feel would be worth sharing?

DR. MASSIE: Gosh, where is all that stuff? Some of it has got to be back in my father's house, in Irvington. I did come across it a few years ago.

Q: It would be very interesting, and I know that -- you know NHF --

(END SIDE A/BEGINNING SIDE B)

Q: This is Susan Resnik with Bob Massie.

DR. MASSIE: What's a key thing?

Q: Okay, the idea of -- you were saying there were moments when you were more aware of your hemophilia than others?

DR. MASSIE: This is, I think, one of the dilemmas any person with a chronic illness faces. And probably, especially with hemophilia, you spend a good part of your life trying to detach yourself from hemophilia's dominance and to gain some independence of it. So that often means that you -- well, in my case I get involved in a lot of other things and I care about a lot of other things besides hemophilia. On the other hand, that sometimes drives you away from what you were calling the "hemophilia community." While I do acknowledge that it is a community, I also acknowledge that I haven't always done my bit in it, that I have at different times wanted to be more involved and at other times felt real ambivalence.

I just think that is a theme in most peoples' lives. Most people with hemophilia don't want to be completely defined by this condition. There are some people I know who make hemophilia their whole life. They are deeply devoted to the

Foundation or they perhaps become physicians or they go and work for pharmaceutical companies or whatever. That has never been something that I wanted to do.

And so this question came up in the context of -- are there certain moments when I think more about hemophilia than other, and I think the answer to that is when it is affecting me. Like right now I have a bad left knee, and one that is much worse than I've had in more than a year, and I think yes, right now I am much more aware of it, and certainly it causes me to have all kinds of sort of wispy recollections of my childhood, not all of which are pleasant. When I am basically fine, except for a little arthritis, then I am really on to a million other projects -- to being a minister or to being a professor or being interested in the various things that I am committed to. So it is a strange thing, because on the one hand there is no question that the experience of hemophilia has enriched me in some ways and made it possible for me to understand or to feel a much deeper commitment to a lot of other social problems and forms of human suffering. On the other hand, it feels like an intrusion when it interrupts those other things, so anyway --

Q: Yes. Well, in reading things that you've written and other things about experiencing a chronic illness as a child, imaginative play, developing the mind, doing a lot of things like that I would think carries through as you become an adult doing many things -- and listening to some of the things that you do -- I mean, you're a minister, you have a Doctorate in business -- a minister and many things. It is like you're juggling many, many things. Did that start early?

DR. MASSIE: I think so. As I said in Journey, really it is hard for me to identify those aspects of my character and personality which would have existed independent of hemophilia. There are certain traits like stubbornness that I see in lots of other people in my family, and which have perhaps been amplified or reduced. I was thinking about this this morning, before you came. I really do believe, and I think it is partly a function of my childhood, that ideas are as important as physical things. The physical world is wonderful and I love it, but I also think so much of what we live physically as human beings is determined by ideas. I don't mean this in a spiritual sense. I can talk about spiritual issues, but what I mean more is that -- take racism, for example, which I'm writing about in relation to South Africa. If you have a fear of a person who is different that isn't just an idea, it is something that has enormous physical impact on your life and on their life. If you have an idea that nature is something to be conquered or something to be preserved, it has an enormously different, physical impact on that nature. So that the ideas, the way we conceive of our social relationships, has immense impact on the physical world we live in.

Q: Absolutely.

DR. MASSIE: I think that kind of way of thinking is partly

influenced by my experience as a child, where my own life is dramatically improved if people take one sort of attitude toward chronic illness and dramatically worsened if people take another sort of attitude, and that similarly, I've learned that about myself. That if I approach certain settings with one set of assumptions it is going to lead to a very different set of actions on my part than with a different set of assumptions.

Q: Yes, yes, I think so. I think that they do so much research on that knowledge/attitude behavior, and the mind set when you come into a situation, I think it is very interesting and I certainly am interested in hearing, as we talk about the hemophilia community, the experience of people who have spent different years as persons growing up with hemophilia and then becoming adults with hemophilia because of the different contexts of what existed at the time.

DR. MASSIE: Right. Well, there is kind of -- there are two things going on. One is the history of hemophilia in the periods that you have described.

Q: Right.

DR. MASSIE: And the other is a kind of life cycle of the person.

Q: Of the person. Exactly.

DR. MASSIE: And where you peak or where you hit which segment of your life in which period, that's an interesting problem and interesting issue.

Q: That's why I'm speaking with people of different ages -

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DR. MASSIE: And different generations.

Q: Yes, different generations, and different geographical locations. When you spoke about the aggressiveness of your parents and the successful -- not in a negative sense, in a positive sense, how much that accomplished. You know, what if people didn't have parents who were educated and could do that?

DR. MASSIE: And not intimidated. That's an important thing. One of the aspects of education is not just the information you receive, but the idea that you have the right to go into some elite group and say, "Now, why aren't you doing this differently?"

Q: Right.

DR. MASSIE: If you don't have that kind of education in the broad sense, then you can be very easily intimidated by the powers that be.

Q: That's right.

DR. MASSIE: But -- well, I don't know what aspect of this community idea you'd like to pursue.

Q: Well, starting back, do you -- I know as I said from Journey, that I recall when your mother looked in the phone book and found The National Hemophilia Foundation, that was some kind of linking with this. But from your recollection prior to your doing the work in the Senate or maybe, like you said you spent a summer in England with someone -- from that. Do you remember early on having some connection with others?

DR. MASSIE: Yes, but I think I need to be very candid here, because I think it is important to your research.

Q: Okay.

DR. MASSIE: I had no real desire to be part of the hemophilia community.

Q: No?

DR. MASSIE: I'm not describing this as a praise-worthy attitude.

Q: No, it's okay.

DR. MASSIE: I'm trying to sort this through now. It's just that I was interested. I occasionally met other kids with hemophilia, and that was interesting. I certainly cared a lot about the politics of hemophilia, I mean making sure that people got care, so I was involved in an abstract sense, but I really didn't feel like hanging out with people with hemophilia. Now I've thought about this a bit; the positive explanation that I can think of is just simply that I didn't want to be drowning in it. I mean hemophilia was a part of my life, and I wanted it to be a secondary or tertiary part of my life. I had a lot of other things I wanted to do.

Q: Right.

DR. MASSIE: There was in certain communities -- when you gather in hemophilic conferences and so forth, you get the feeling that people are obsessed by this. I mean this is their life, and so -- and that often -- this is unfair, but there is occasionally not only obsessive but even a depressed or defeatist element to it. Like not only is this all of my life, but I can't do much about it. Now of course that is unfair to the many, many people who do lots of active and aggressive and forward looking things, but there is a resistance. You spent a lot of your time, in your personal life, trying to disentangle yourself from this. So the desire to go and spend a lot of time back in that setting is pretty small unless there is a medical reason or unless you're

facing some tremendous personal crisis, where you really need a support group or understanding group, which has happened to me and happens to others. But in general the goal is to get away from this, not to go into it. Now that is the positive interpretation.

The more negative interpretation is that you develop as a child with hemophilia a certain mode of being which is somehow dependent on your being the only one around with this. It gets tied in with your ego. When you are with a lot of other hemophiliacs, this effect is neutralized a bit. While I have tried throughout my life, really with every fiber of my being, to avoid ever using hemophilia as an excuse or as a sort of mechanism in human relations, I am sure that it creeps in anyway. I sometimes find myself a little irritated when I am with a bunch of other hemophiliacs who then make all these pronouncements about various things that I do not agree with. It grates a bit.

This happened actually once, with a person I don't think I need to name who it is, but -- with a person who actually had gone from being a hemophiliac to being a caregiver. I don't know exactly what it was, whether it was just his personal style, or what. But I just didn't like taking advice from him at all. I don't know what it is. It is actually related to this. It's a very interesting dynamic, which I am sure you've noticed, which is that many, many of the physicians in hemophilia are women, and many of the -- most of the hemophiliacs are males.

Q: That's correct.

DR. MASSIE: Boys and men. So that there is a certain pattern that you get used to, which I don't think is necessarily unhealthy.

Q: That has come up.

DR. MASSIE: But the pattern of female caregivers -- it is quite interesting. I mean there is Shelby Dietrich, Margaret Hilgartner, there is --

Q: There is Jean Lusner now --

DR. MASSIE: Jean Lusner. There is Diane Komp in Connecticut, head of the hemophilia group in Connecticut.

Q: Margaret Ragni --

DR. MASSIE: Right. There are many. And I don't know whether it is something about hematology that attracts women, I mean its --

Q: I'm trying to sort this through now. I'm not sure. In Philadelphia, Children's Hospital -- there have been women physicians, and of course the nurse coordinators. You mentioned the nurse, and a lot of what I've gotten to listen to and so related to -- because in my former life as a health educator

working with self care teaching I worked with so many of the nurses and know so many of them, and this role of the nurse in hemophilia care is quite a special one.

DR. MASSIE: Well -- I'll talk about it a little bit. I came at it fairly late. In other words, the first nurse that I worked with was Elaine Sergis at New York Hospital.

Q: I know that.

DR. MASSIE: -- now out in California, and I had enormous respect for Elaine. She taught me to give myself shots, and it was more than respect. I really had deep affection for her. When she gave me advice, I really listened to it. I think it was, you know, there were a lot of things involved in that, partly her style, partly my age and so forth. Since then I haven't really ever identified a particular nurse practitioner or nurse coordinator who has played that role, but I've had good relationships with almost all of them. Particularly now, thinking about the ones at New York Hospital -- and one thing that again I think I really need to sort of bring up here, even though it is not always easy to talk about. It is difficult to be dependent on a clinic, and it is hard for me to do certain things that the clinic expects. Now I am an extremely organized person in most of my life, do a lot of different things, but I have certain difficulties doing very, very basic things with the hemophilia family. For example, it is still hard for me to call up and order fraction. I feel like somebody on the other end is going to be thinking, God, didn't he just call here a month ago? -- or something like that. You know -- isn't he using too much? -- or something along those lines. It feels like an imposition to call. Now there has never been even the slightest peep consciously from anyone. I mean people have never been anything but friendly, receptive, helpful and so forth. But I still find it hard to call. The other thing that I have absolutely failed to do with any systematic success is keep my logs. And I have tried a million different ways. It is such a major failure on my part, over a long period of time, which is in such contrast to everything else. I keep records of everything that I do. You know, the older I get the more I'm like my Swiss grandfather. I write everything down. But I have tremendous trouble keeping shot records. Not just filling out those long logs, but -- I can give you some theories about it, but it is almost beyond my control. I'll do it for a week or ten days or a month, and then there is this -- there will be a long --

Q: Do you have any idea why? This is something that interests me a lot in terms of people who don't do things like this having been labeled as noncompliers. I have a problem with the concept of calling them noncompliers.

Q: I don't know what -- yes --

Q: There has to be something underlying this.

DR. MASSIE: There are very few areas where I feel like I can't impose some order if -- or at least if there is some problem that I have I at least understand what -- sort of basically where it comes from. This I really don't understand, and it really feels like it is beyond my control, and there are very few things that I say that about. I have tried putting it on my computer, I have tried putting it in my diary book, I've tried keeping separate sheets right on top of the fractions so that I can't get to the fraction without writing it down. I've tried enlisting other support sort of mechanisms. I mean -- what always happens is that I do it for a couple of weeks, and then I stop. I think what it basically has to do with is something like this -- when I decide to give myself a shot, even though it is a rational decision, it has an element of trauma in it.

Q: Okay.

DR. MASSIE: I am now so used to it, but it is still a basic pattern of being upset that I have to do this. And upset that I either have to do it because I'm having some kind of hemorrhage or upset that I'm dependent on it or upset that it is interrupting my schedule or whatever. Even though I can do a shot from start to finish, in, you know -- fifteen or twenty minutes, a very short amount of time, mixing and fusing it now that the volumes are low, it takes almost no time at all, it still is something that I want to forget as quickly as possible -- dispose of the stuff, get rid of it, and get back to what I was doing.

And making a record is -- I mean it is almost like I can't do it. It's like I have to -- it's like forcing myself at a completely different level to admit or to acknowledge -- I mean that's just one theory. I don't really know what goes on, but I do know that for one thing I have never been able to deal with it with any success. I can do my exercises, I can take my medications, I can go to my clinics, I can do all the other things that are expected of me, but keep my logs -- forget it. And if you looked in my files at New York Hospital you would laugh, because I think every other year I wrote a letter to Elaine saying: "Dear Elaine, I promise to keep my logs from now on." And I deliberately used my affection for her, saying okay, now you've written her and now you've got to do it, and then I'd do it and forget or stop or -- I don't know how many other people --

Q: It seems to happen to a lot of people.

DR. MASSIE: Yes.

Q: That's why it certainly is interesting and important --

DR. MASSIE: You know, what I suggested once to somebody as a system to deal with this is to make up the logs for you. That

is to say where all you would have -- you know, just computerize it, so that when the shipment arrived it would have your name, your hospital number, every bit of information on there, all the lot numbers laid out, and all you would have to do it -- because part of the problem -- I mean this is a mechanical problem -- is that it is a pain in the butt to write all those lot numbers down. Then all you would have to do is just put the date and what it was for. You know --

Q: I'm surprised they don't have that by now.

DR. MASSIE: Well, they don't. They don't.

Q: When you were going in --

DR. MASSIE: You have to fill out all those stupid lot numbers for each thing, and you have to write down a lot of extraneous information like, you know, what was your mood that day, or at least that is with the New York Hospital log. I mean that's part of the thing that is complicated, but I even computerized that.

You see, I even did what I said to you myself. I put the lot -- but I still have to go get the lots and figure it out and do it, and you know -- or another possibility would be for the pharmaceutical companies to put a sticker on their boxes, which you would just peel off and pop onto a form.

Q: A menu is done -- not for the transcriber, but because of the --

DR. MASSIE: I think that would help solve the problem. If you -- to open the box had to peel a sticker off, like just a little removable label, you'd have the stupid thing in your hand. Now it would really be hard just to throw it away. That would make no sense at all. So if you had to peel a sticker off to open the box, and then all you had to do is glue it on top of some other form and then check off something or write down one thing, then the lot numbers -- you wouldn't be -- I mean, in other words --

Q: I understand.

DR. MASSIE: I don't think this has been dealt with adequately as a problem in medical education.

Q: That's interesting, and --

DR. MASSIE: And in patient management -- because --

Q: -- in management.

DR. MASSIE: The couple of times I've raised this, the response of people -- you know, I understand this, but I've talked about this with Margaret and her response was, "Well, just

keep them." Nine times out of ten when Margaret says something like that I appreciate it, because it is very down to earth and true. Her attitude is, "Let's not coddle you, let's just do it." And that is right. But in this case, you know, it is one of these situations.

Anyway, I want to go back to the healthcare providers, the nurse practitioners for a second, the nurse coordinators. The most important thing they do for me now is when I have a problem that I don't know quite how to handle I call them up, and almost invariably they encourage me to give more fraction than I would have. For example, with this bleeding in my knee I was frightened by how much fraction I was using. I was using an enormous amount. And I call up, first of all to find if -- am I doing the right thing. What they almost always say is, "You're not giving enough." -- or, "You're giving almost enough, but why don't you give a bit more?" And that is an extremely valuable thing, because you see one of the dynamics of home care is that you're having to make complicated, emotionally laden decisions, day after day after day after day after day. Most of the time you have both the experience and the decision rules to make them competently. But when you get in a situation where you don't know anymore exactly how to -- and where you feel guilty about using too much fraction, or where the pattern is uncertain, you need advice. I normally do two bottles -- about 2,000 units -- every other day or every third day. On Sunday I had three bottles in the morning just prophylactically, because I'd had a very big day. Actually it was around lunchtime, not very long -- later that evening my left knee began to bleed like crazy. I mean, just out of the blue. I gave myself four more bottles and then three more bottles the next morning. So I'd had 10,000 units in less than twenty-four hours, and it was still bleeding. That was a third of all the supply I had bought for the month that I was here. I called up and said, "What should I do?" She said, "Give more." That was extremely reassuring, because it made me feel like, you know, I should be -- that I had the support to do what I needed to do. So, you know, that's a very important thing. Sort of -- permission.

Q: Giving permission.

DR. MASSIE: And to put it in spiritual terms, there is a certain element of forgiveness which emanates from them, which is important. You didn't screw up. This was unavoidable, and you did the right thing. It still got bad and now you can do this to fix it.

Q: There is a model. Who created the problem? Who is responsible for solving the problem? You didn't create this problem, and we're here to help you solve this problem.

DR. MASSIE: But, you see, in the broad sense of the word I didn't create it, but you always wonder whether some error in judgement -- so, but see, the important thing is that sort -- at both levels, both you didn't create it in the first place, which

is one thing that Dana is very helpful with reminding me, this isn't your fault. And the other thing is that well, even if you did make a mistake -- but that's okay -- in this case you didn't, so that's doubly okay. That's a very important role because anyone with hemophilia gets used to making extremely complicated threshold judgments all the time. You know, should I do this or should I do that? Will I be able to manage this, can I do that, or should I do a shot now or should I wait? I mean it is a constant, constant thing. There is a certain amount of fatigue and stress that comes from that, even if people are handling it very, very well. It is very important to have someone say, you know, you've done okay.

Q: So in other words -- you know, it is interesting, because when I first started to -- before I did the dissertation proposal I was doing summer field work in an anthropology colloquium. I was doing field work in a hemophilia clinic in the summer of 1983, looking at the dynamics of the team, and then came back and replicated that, in the summer of '88 actually -- but one of the questions that came up among the group that I presented what I had done to was the whole concept about the medical model and the health care delivery model in hemophilia and self care, and wouldn't it be great if people with hemophilia didn't have to go to a hospital at all or to relate to providers at all, and could just get this product and just do it. And as I'm listening to you, it seems like, as independent and educated and everything that you are, it seems, if I'm understanding, that it is helpful to have some structure there.

DR. MASSIE: There is some fear built into it, as I was talking about it earlier, having hemophilia, and it is irrational. But it also is very helpful to have -- you know I would say definitely, because you don't know everything. Another thing I really need the hemophilia center for is information, because I separate myself from the hemophilia flow of information a bit. I mean, I read what comes through but I'm not sitting there waiting for every new bit of information about coagulation and technologies or about HIV or about -- you know, I mean because I think that too is a bit obsessive. I read it when it comes and I am glad to have it, but you need somebody who is really following it that you can say -- when you go in for your clinic or when you feel a certain need for information you can call up and say, "Now, what is going on? What is it about, this?" And it must be someone you trust, whose judgement you trust. That's another important thing, that you really need to feel that this person is not likely to over react in some direction that is unacceptable -- too cautious or too aggressive. So that's a very important piece, too. But I would say that when I go to the hemophilia clinic I feel probably more vulnerable than any time in my normal sort of adult life. I mean you go in and you feel very exposed, and so on the one hand you understand that it is necessary and on the other hand you really need people to understand that is a part of what is going through people's minds when they come there is that they are feeling very wild and

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Q: Okay. Tell me more about the other part of your life, because we were just getting up to college and I would like to just fill in a little bit in your history.

DR. MASSIE: All right. I went to -- I finished in the Senate in fall of '74 and started at Princeton and went to Princeton for four years and majored in history, European history. I was very involved in student politics, but not electoral politics, but in railing against the establishment about various different things, including investment in South Africa. Between my junior/senior year I went to France for a summer to do some research for what I thought was going to be my senior thesis, which it turned out not to be. During that period I had a very unexpected reawakening of my faith, which really I think qualified as a conversion. I had grown up in the Episcopal Church, and always had a residual admiration and respect for it, but it was quite distant. And I thought, "Isn't it wonderful what those people do?" And so it came back with a -- the nature of the experience was simply that I had felt -- I described it a bit in the epilogue to Journey, the new version of Journey which came out in '84 -- but in essence I felt -- I came to a point where I really wondered whether God existed, and really wondered if there was any reality to the idea of Jesus Christ. So what I did was -- I encountered a group of very active sort of fundamentalist Christians in Paris, who asked me very bluntly about my faith. I was deeply disturbed that I didn't have anything I could say to them with any coherence, so I sort of prayed a prayer which was, in essence, "I know I am not perfect, but if you're out there I would really like to know if you're there, and I would like to experience your presence." I had a very deep feeling after that of the forgiveness of God and the presence of God in Christ from then on. It was a completely unexpected thing. It wasn't like there were lights and bells and sounds and so forth, but was just a very deep sense of peace which came from nowhere. Anyway, I went back to the college and so religion was the one thing we couldn't really talk about among ourselves, because people didn't know what they thought. It was a taboo topic. So I sat with this thing, and in the middle of the year I decided that instead of going to law school I really wanted to go to divinity school. I wanted to be in a setting where it was okay to talk about this kind of stuff, to ask, "Is this real? What is going on?" I didn't know really anything about religion in general, or Christianity in particular.

Q: Had you gone to a formal Sunday School?

DR. MASSIE: I went about eight to ten times a year. We went a little more often than the major holidays but not much, maybe once a month or every six weeks. It was very sporadic. When I was in college as a freshman I had written a little essay, which is in one of my journals, where I had pondered whether I wanted to be a minister. I decided that I didn't because I

thought that to be a minister you had to be a very good person. I knew that even if I could put up the appearance of being a very good person, that inside there would be a lot of ambition or lust or all kinds of stuff that -- and I believed that the absolute worst thing was to be a hypocrite. I felt that was absolutely the worst thing, so it would be better for me not to be involved. That is why the notion of forgiveness was so important, that my relationship to God was not tied to my performance and that it had to do with just me being me and as an act of grace. If my relationship to God was not tied to my performance, in a sense that freed me then to serve and to make mistakes -- because I was no longer worried about climbing that ladder. Anyway, I decided to go to Yale Divinity School. That was a big shock to a lot of people around me. I went to Yale Divinity School and I knew that I wanted to take a year off from Yale, because I wanted to be sure that I wasn't going into the ministry just because I was in a kind of sluice with everybody else. So I took a year off, went back to Washington to work for Ralph Nader for a year.

Q: Did you? That must have been interesting!

DR. MASSIE: Yes, it was very interesting.

Q: What did you work on?

DR. MASSIE: I worked for a group called Congress Watch, which was the Congress monitoring group. Then I was the research director for an intergroup coalition called Big Business Day, which was really looking at corporate governance issues. It was before Reagan, kind of a last gasp of some kind of liberal effort. It was a coalition of labor unions and consumer groups and environmental groups and, you know, all these different groups coming together, and formed a large steering committee. The president of the steering committee was a guy named Mark Green. You may have run across him.

Q: He is now in New York City.

DR. MASSIE: Yes, I know Mark very well. Mark and I are good friends. I worked for Mark, and I was handling all this information coming in from everywhere about what corporations were doing that was good and bad, and so we pulled this thing off. It was designed partly to get Jimmy Carter to pay a little more attention to these economic issues, that we felt -- I mean it wasn't a really bad feeling about Carter, but it was just like we want to move him in our direction. Then Reagan was elected and everything changed. So, I now look back on it as a little bit of a -- it wasn't hopeless but it was sort of -- we were swimming in the wrong direction at that time, compared to the country.

Q: Well, --

Mr. MASSIE: So, --

Q: A different direction compared to -- the country --

Mr. MASSIE: Oh, yes a different direction. I mean, it was sort of like swimming upstream in a river that was going very fast, the other way, so. No, I'm glad I was doing it but it was -- one of the things that came out of that, I -- actually two things came out of it. One, was that I decided when I was there that I really did want to go into the ministry. I thought, -- this is great but my spiritual interests which had now been puttering along for several years, didn't die when I went back to Washington. So, I thought, okay, that's kind of a confirmation that I should keep going. The other thing, is that I realized that I was pretty glib doing the Naear stuff, but I really didn't know how to read a balance sheet or income statement. I didn't really understand companies very well, I didn't know or understand how the stock market worked very well. I mean, I had a good layperson's understanding but I thought at some point, I really what to go and do graduate work in business or in economics. So that sort of is where that germ -- well, it had already been planted in the senate experience really, but it was even more, like I don't want to keep doing this as an amateur.

Q: Yes.

DR. MASSIE: So, I went back, did two years at Yale Divinity School, met Dana, got engaged in my last year there.

Q: Was she at school?

DR. MASSIE: Dana was doing a doctorate in American Religious History at Yale, with Sidney Ahlstrom (ph) and she appeared at the Divinity School from time to time, like a wraith because she was there but not there, and she wasn't in any of my classes. Then eventually I found out she was a doctoral student and she was warned not to go out with third year divinity students because they were supposedly only interested in getting married and going out to congregations! But she, fortunately, ignored that warning and we were engaged, and I was ordained in the Episcopal Church, first a deacon and then a priest. I was ordained a deacon in June of '82 and started at Grace Church in September of '82, and was married in November of '82. So, it was a big year, boom-boom-boom. Then, I did two years at Grace Church; Dana finished her doctorate and was hired as a Professor at Boston University in the School of Theology.

So we moved to Boston, primarily because of her job, and I applied -- I thought well, I can go into a parish or I can do doctoral work in business. I applied to the doctoral program at Harvard Business School, and lo and behold, they admitted me and so that's what I did --

Q: That's great.

DR. MASSIE: I did the first year of the MBA Program, because I

didn't have an MBA, and I did my doctoral work. I can give you a CV.

Q: Yes, as a matter of fact, I'm going to be asking everybody who has one --

DR. MASSIE: -- I don't have one here. I have it on my computer but I --

Q: Okay, well I don't need it for today, but you can always, get --

DR. MASSIE: After a year at the business school, I really missed being in a church, so I ended up being also being the pastor of a little working class church in Sommerville which I loved. It was a wonderful, counter balance to my -- to our business school which is a kind of peculiar world. I mean, just a rather self-centered world. I think that's the best way to put it.

Q: There has been so much talk about the ethics of business and all the things that have been going on, Miliken and all this stuff, that must have --

DR. MASSIE: I sort of rode that wave a bit. I got there before -- I did the first year of the MBA program before Miliken and Boesky and all of that stuff.

Q: Yes.

DR. MASSIE: It was actually during the fall that Reagan was re-elected. This was a tough time to be essentially liberal at the Harvard Business School because it was during the apotheosis of the Reagan attitude that the market could solve everything. I would say 85% of my class believed that, absolutely. So, it would have been very nice if Boesky had come along right about then because then I could have had a little counter evidence at the time my idea that the government had a role to play in maintaining the equitable functioning of the markets, was just considered completely passe. I mean, -- but anyway, in a certain sense, now this is sort of funny, and you might find it interesting. My training as someone with hemophilia, that is being someone who was used to being different from that environment, gave me an ability to sit in the Harvard Business School, and be different.

Q: That's very interesting.

DR. MASSIE: There is an awful lot of pressure to conform in Harvard Business School. I know it influenced me in some ways, but in the end, I had a lot thicker skin. It also in a sense, maybe made me more stubborn. I looked at my class and thought "just because there are a lot of you, doesn't mean you're right."

Q: Yes.

DR. MASSIE: Harvard University in response to this ethics boom created a new program called the Program in Ethics and the Professions, where they brought in middle level faculty and researchers and I was one of the first fellows in that program in 1987. They've gotten it well off the ground now, for 4-5 years now, but I was in the first little group. Then I finished my dissertation and two years ago, was hired by the Divinity School, and so now I teach economics, sort of how churches and businesses interact or how theology and economics interact and so forth.

Q: How great for -- perfect.

DR. MASSIE: So my interests finally, finally came together. And, I am now the director of this project on Business, Values, and the Economy which is again a kind of fusing. But it has taken until my early mid-thirties to get it all into one box. So, you see with all of that going this is one reason why I don't -- why I always feel a certain desire to be helpful in the hemophilia community. And desire not to get reabsorbed by it. What I like to do and what I have done, is on occasion people have asked me to come speak. After Journey came out, I used to do a tremendous amount of speaking to local chapters. I don't do that much any more.

Q: Among your array of friends over the years, are there any who are persons with hemophilia, or no?

DR. MASSIE: Close friends? I mean, I certainly met a lot of people.

Q: Yes.

DR. MASSIE: I have to say no. Not that I can think of anyone. I've, as I said, been to a lot of chapters, and I've met a lot of hemophiliacs who I have --

Q: How about any of the providers, any relationships, -- well, I know Margaret and has been your physician, yes.,

DR. MASSIE: Margaret and Shelby and --

Q: Yes.

DR. MASSIE: Yes, there are long friendships. That's funny, you know, -- I mean I know there is a friendship and an affection but there is also a need to maintain certain professional quality there and I think that is probably the healthy thing to do.

Q: Yes.

DR. MASSIE: But, you know it is easier for me to talk to you about my affection for them, than for me to talk to them about my affection for them.

Q: Yes. Well, I have interviewed them both.

DR. MASSIE: Really? Shelby and Margaret?

Q: Yes. So, and I have worked with them both.

DR. MASSIE: Right.

Q: Again, it is that whole sense of kind of the network there is a whole other -- yet another way to look at this which I am just touching on which is network analysis. It's the way people interact over the years.

DR. MASSIE: Well, yes I mean, I've been -- I was born in NY Hospital, and I've been cared for -- my hemophilia care has been done there since I was probably 5 or 6.

Q: Yes.

DR. MASSIE: So, we're looking at 30 years almost.

Q: Right.

DR. MASSIE: Almost the entire time with Margaret, too. That's very important.

END SIDE TAPE 1/SIDE B

BEGIN TAPE 2/SIDE A

Q: This is Susan Resnik, continuing discussion with Robert Massie.

DR. MASSIE: Alright, what would you like to ask?

Q: Okay, well we're getting up to a point where we were talking about being in the mid-80's, early 80's and as we look at the history of hemophilia, it is beginning of the AIDS era, as I have called it in my outline. How has this impacted upon you?

DR. MASSIE: Well I suppose the first thing I need to say is that I am very glad that I got married before it hit. I don't know how I would have weathered all the issues that arise from HIV if I hadn't already been married. I suppose I first became aware of HIV -- I can't remember exactly, -- '82 sometime, maybe or '83. I mean --

Q: '82 is early. It is when the first cases were discussed -

DR. MASSIE: I got married in November of '82 and I am almost certain that I didn't give it any thought before I got married. And I think in '83 it first started becoming -- and in '84, is when I am pretty sure that I was tested and first told that I was

HIV positive. I remember sitting in Margaret's office and I'd been tested six months earlier or something and she said, "well, you know, would you like to know the results?" and I said, "sure," and she opened the book and said -- "Well, you're positive." And the interesting of that is that I now read about how people have a whole elaborate system for telling people and having a support system, but there really wasn't any system at the time.

Q: That's right. That was early.

DR. MASSIE: And, also I sort of expected that I would be and I don't remember really being that alarmed. In other words it was sort of like being positive for Hepatitis, or something which I - - it was more than that but I guess it was still so early in the whole thing that I didn't really understand it. I remember sitting there thinking okay and then walking out and never really thinking about it that much anymore. And, of course there may have been an element of denial in that. I think there was certainly an element of denial in it afterwards as it got more serious. There have been several difficult transitions that Dana and I have had to make, of course the first one is having to use condoms, because that had not been part of our relationship before. And, but -- I forget exactly when we did; it certainly wasn't right away, but it was fairly soon. I mean, after it really became clear that this was something that we were going to have to start thinking about. I think it was while we were still in NY or shortly afterwards, so lets say the middle of '84 or end of '84, which is when we went to Boston. So, then we knew that of course, there is the issue of having children. We had been married in '82; Dana finished her dissertation in '84 and it was pretty clear that she didn't -- that we didn't want to have children when I was in the MBA program and she was doing her first year of teaching. So, it got to about '85 and then there really was an issue because we were ready. We'd been married for 3 years. So what we did was -- well actually Dana really should be in on this -- Dana wanted to go to a counselor in the fall of '84 to start talking about this issue, and I absolutely resisted. And, my reasoning was not that I didn't want to go to a counselor, but that I didn't want to go to a counselor right then when I was in the middle of this difficult experience at harvard -- the Harvard MBA program is pretty grueling.

Q: I'm sure.

DR. MASSIE: And I thought, you know, I'm doing three cases a night and I am putting up with all right wing crap at the business school, and I don't want, on top of this, to go and disentangle my deepest fears about hemophilia and sexuality and all that flowed from that and you know death. It seemed like I could potentially unravel. So, we got through the Spring of '85 and I think it was in that -- yes, that was when it was, the Spring of '85 just as I was finishing up the year that I said okay. And so, either that summer or first thing that fall, we spent the whole fall going once a week to a counselor, at the

Fenway Community Health Plan -- Fenway Community health Center, which was primarily a gay health center dealing with HIV stuff.

But they also had counselling for other people. And so we went to a guy every other week after a while, and we talked out as many issues as we could. It was very, very helpful. It wasn't always easy, but it was very helpful. And then, I don't completely remember this, but I mean basically we decided to try to have children. I think we discussed how we felt about a lot of things, including dying. We both talked about how much we wanted to have children and I think part of it was that it was the risk assessment looked different to us than to the hemophilia care givers. You know when you're a person and you are told well, if you have children there is a 1 in 100 chance that or -- I in X chance that you can die. That's very different than if you're a health professional looking at 100 people and knowing that 1 of them or 10 of them are going to die. In other words, the probabilities look really different.

A: That's right, and that is why it is so important to hear the different perspective as people experience these things.

DR. MASSIE: if you had 10 people in a room and said, should these people engage in a behavior in which is going to kill one of them, the person who is responsible for the 10 would say no, but if you were one of the 10, you might say, I'll take the risk.

Q: Exactly.

Q: That's a very fundamental distinction, which is something that I tried to bring up later. Anyway, so we decided to try and have children. We found out that we were pregnant on the -- I may be getting the timing a little screwed up here because this process of counselling may have gone through '85 and the Spring of '86. se found out that Dana was pregnant, I remember on the first of Advent 1986, which was the 30th of November, Dana took one of these home tests and she was pregnant. Then, I had been invited to come out and talk about HIV and stuff at this big Las Vegas thing. I had also been invited to write an article for Ladies Home Journal on being HIV positive, which I discussed with the hemophilia foundation.

Q: Did you do it?

DR. MASSIE: Well, they were -- the Hemophilia Foundation was in favor of it. There was a question of did you want to reinforce the association of HIV and hemophilia --

Q: Oh yes. That is --

DR. MASSIE: That was a tricky thing. Or did you what to come out and explain it? Or did you what to just let it go? And the Hemophilia Foundation, Brownstein and people said, finally decided it would be a good idea, to write it. At least I

remember getting a basic go ahead. They may have had some reservations but I remember getting a basic go ahead from them, and I decided not to do it. So, but I did go out and give this talk, and I have the talk. I have a copy of the talk.

Q: Oh, great.

DR. MASSIE: You've got to make a list of stuff that I've promised to give you.

Q: Okay.

DR. MASSIE: I've promised to give you my CV and a copy of the Las Vegas talk

Q: Don't -- you know, if you --

DR. MASSIE: If I eve' go back to my father's house and get that senate stuff, I will get that.

Q: Okay.

DR. MASSIE: So I gave this talk in which I talked about some of these -- I forget exactly how I structured the talk, I have it on the computer but, -- well let me pull it up.

I say that I've talked about hemophilia for a long time, for 12 years since my parents came out with Journey and that I have some uncertainty about whether I as a single person really have that much to offer on this topic or AIDS. But, I then talk about some general reactions to AIDS. It was still called HTLV-3, then.

Q: That's right.

MR. MASSIE: AIDS is frightening; I talked about the fear that comes from that. The fear that comes from being forced to face possibility of a terminal illness. AIDS is depressing, because of it certainty, because it was contagious. And I will let you read this later. Then AIDS is unfair. I told the story of a friend of mine who I knew in college who was a very mild hemophiliac. In fact when he told me he had hemophilia initially I didn't believe him, because he rowed crew and I thought yeah, right. But he had to have two shots a year, and he got AIDS from one of them. He died on Christmas Day in 1985. I visited him when he was sick. And here I was I had gotten thousands of shots, and he'd gotten two and died.

Then, I talked about -- you'll like this because here is our personal reaction. I was confronted that -- there are three phases that Dana and I went through. Our first, 81-82; I first became aware of AIDS in '81, sometime after the center for disease control reported the first cases of kaposi sarcoma, but I had no idea that there would be a connection to hemophilia.

then we got married and so forth and got used to hemophilia but at that time, AIDS was like a small dark cloud on the horizon. I

suppose I was vaguely aware but it didn't seem to have much bearing on us. Then the traumatic learning period; the second phase, came during the time that we lived in NYC. Some time during that period I was tested and found to be antibody positive. We read informational material sent to us by the Foundation and specifically we decided to heed the recommendations to delay having children, since that was more or less what we had planned to do anyway, and that's when we started using condoms. I didn't like them, because they were a constant reminder, but we changed our habits.

Then, I think the hardest thing about this period were stories in the press when the trauma of this caused in us and in the persons around us. I can remember walking down the aisle of our supermarket in Boston, about 2 years ago, and from a good 15 yards away, I was suddenly confronted by the word AIDS screaming at me in red letters from the cover of Life magazine. When I approached and read the cover which said -- "AIDS: Now No One is Safe." I remember feeling a mixture of anger and panic. John Coffey, my friend who died had a wife who used to take his bedclothes down to the laundromat which had large enough machines to wash all of them, and she would sit and fantasize about what would happen if other customers who used the machines discovered her husband had AIDS. The articles put a tremendous burden on the hemophiliac's family. My sisters and my wife were constantly answering questions about my condition. Even my mother-in-law in Louisiana had to get used to modest acquaintances coming after her and asking her point blank if I had AIDS. Alright, so then we -- I heard the story the other day about a 17 year-old young man in Massachusetts who does not have AIDS but is antibody positive when the UPI and AP did a story on him the local press picked it up and produced strong protest and walk-out at his high school.

Q: I remember that.

DR. MASSIE: Okay, and then the current period, '85-'86; I talk about actually, how important Margaret was in helping us cope with the uncertainty. How the problem of being too focused on -- that the sort of general cultural focus was so much on homosexuality it was hard to know how to deal with this at that time.

Q: That was before all the drug and --

DR. MASSIE: we still have to cope with the remarks of outsiders but this is what I wanted to show you. We had to pay for Family Community Health out of our own pockets by the way. However we discussed the medical and genetic dimensions. As you see, and then I announced that we had decided to have children and were expecting our first child on the 7th. This produced a certain reaction in the conference. A lot of the people were very supportive. Almost everyone we talked to was very supportive, but know some people thought we were just absolutely

out of out of our minds. but you know, I figured, I ought to tell them the truth and they ought to deal with the fact that they were worried or they thought it was crazy didn't mean that everyone in the hemophilia population was going to think it was crazy and they might as well realize that right now. So this storm of protest like how could you, that we got a little backwash from was --

Q: Was Dana with you?

DR. MASSIE: Yes, she was pregnant.

Q: That must have been very hard.

DR. MASSIE: In Las Vegas with all that greasy food, throwing up in our room. Finally it just got so that we ordered room service because she didn't want to go out - because of the terrible smell of those endless free buffets.

Anyway, oh, and then I was talking, I'll let you read the rest of it later. -- I sort of make some recommendations that every hemophiliac should have somebody to talk to -- hemophiliacs need a steady stream of factual information. They established during the debate whether they should still get every detail.

Q: Yes. Not that is the whole thing. Do you feel that as the National Hemophilia Foundation became aware of information -- it was changing information over time, as you have said, it was called one thing and then it became AIDS. Things were changing, but there has been -- a lot of people have been talking about the years between 1982 and 1985 or '86, when some information came out to everyone and some information didn't come out to everyone.

DR. MASSIE: Well, is your question -- what's your question?

Q: Do you feel that the National Hemophilia Foundation as soon as they got information --

DR. MASSIE: Well, I don't really remember. First of all, should they have? Yes.

Q: Sure. Yes. That's the question.

DR. MASSIE: I'll just respond personally.

Q: Yes.

DR. MASSIE: There is a larger question here as to whether everybody would react the way I would. But my reaction was that I --

Q: No, I'm asking you.

DR. MASSIE: -- having my interest in medical stuff and the

kind of academic training I've had, I wanted everything. I mean I felt I was in certainly as good a position to evaluate it as an official of the Hemophilia Foundation. My closest friend, this is actually an interesting aside -- my closest friend was a physician at Boston Children's Hospital who specialized in pediatric AIDS, so, you know, anything that I didn't understand, I'd simply call him up. He was my college roommate for four years and so, you know, I wanted to get everything --

Q: Right.

DR. MASSIE: Because the last thing I wanted -- I mean it was much worse dealing with the crap that came through the press then. You know, if there was a medical bulletin and so forth, that was very helpful.

Now whether every single person either wanted it or should get it, I don't know. I mean my general feeling is that it is patronizing and paternalistic to say they shouldn't get stuff. But I suppose there are some people who obsess about things so much that they would not benefit. One thing that my mother said to me though which was actually very good advice. We started talking about AIDS fairly early on, and she said, "Whatever you do, don't open a file on it." I don't know why she said that because, you know, I don't obsessively open files on -- I mean, I've got lots of files, but I hadn't really been planning to -- but as soon as she said that, I decided okay, I won't. And I figured that was a very good thing, because it would be, you know -- by now that file would be really fat, and it would be filled with lots of things that were wrong, and --

Q: I have such a file.

DR. MASSIE: It is okay for you to, but --

Q: I was going to say that you're right. There are things that have changed, and that's the whole thing. It is filled with many things that --

DR. MASSIE: What she was saying is to be concerned, but don't go overboard on this.

Q: Right. Right.

DR. MASSIE: Sort of let it come as it comes. I was starting to get a lot of stuff in the mail and thinking what do I do with this? Well, what I usually did was read it and throw it out. Or after I read it if I thought it was particularly valuable I would read it and put it aside, or I would read it and give it to Dana or something. But I didn't keep it, and I think that was actually good advice. Anyway, I feel like I'm rambling a bit.

Q: No. It's okay. So you and Dana have this lovely little boy.

DR. MASSIE: Yes, actually it is an interesting thing. We had Samuel and --

Q: Was she -- may I ask -- I mean it is up to you if you want to tell me. Was she tested prior to --

DR. MASSIE: She was tested before and she was HIV negative, and she was tested afterwards and she was HIV negative. We've had both our children and she has remained HIV negative, which is a miracle. But just so you know, this I probably wouldn't want to put in your dissertation, just this little bit.

Q: Shall I turn this off?

DR. MASSIE: No, I can put it in here, because I don't mind it being in the sort of long-term history.

Q: Okay, because that's -- okay, so we won't put it in --

DR. MASSIE: But in short-term history -- the long-term history is that when Dana and I were married she had a blood test and she actually had several blood tests performed at New York Hospital and elsewhere, which showed she was in the carrier range for hemophilia. Dana has no hemophilia in her family, but they did four separate blood tests on her and they showed there was a distinct possibility that Dana was a carrier. So when we had Samuel we were working with not only the HIV thing but the fact that he might actually have hemophilia. And this is one reason why he is not named Robert K. Massie, V -- because I thought if this little boy is born and has hemophilia, I'm not going to name this kid Bobby Massie. That would just be too weird for him to go through this and he would -- what kind of identity would he feel he had.

Q: Yes, I understand.

DR. MASSIE: To have the same problem and the same name and -- so that is one reason we began looking around for other things. But it turns out that both kids were born and neither has HIV and neither has hemophilia, and Dana is fine. And we're not having any more kids.

Q: That's wonderful, and so neat.

DR. MASSIE: It is neat, and of course we feel confirmed in our choice. But I recognize that not everyone has had such a good experience.

Q: I know.

DR. MASSIE: The other thing that is important to know is that Dana got pregnant very quickly. I think -- I can't remember, but it took just a few months, like two months, for Samuel and it took only try for John. There was not a lot of

unsafe sex here. So to that extent, that was good.

Q: Yes. Well, of course since the time you gave that speech there has been what the epidemiologists call the secondary epidemic in hemophilia, which is a lot of the women.

DR. MASSIE: Right, which I think is very scary. What do they attribute that to?

Q: What was interesting when the first speech was given by Dale Lawrence, I remember he spoke to a group of us at a conference -- he is an epidemiologist for the CDC -- was that it was most pronounced among older wives of men with hemophilia who perhaps couldn't deal with telling their husbands to wear condoms after how many years of marriage, and part of what I got involved in was starting a women's network. We started one and part of what he even had is kind of a role playing with a lot of women to explain the gravity of this, because at that time (we're talking about '86 or '87 up to '88) a lot of couples were not practicing "safer sex" or using condoms. There has been a big change since then.

DR. MASSIE: Yes. Well, I mean just reflecting on this from my own life -- I mean, I know that the Hemophilia Foundation and so forth did the best they could, but I also feel that -- I don't know. I feel like there could have been some -- maybe more direct intervention in the sense of the way it came across to me was: "This is what you have to do." Not from the Hemophilia Foundation so much, but it was -- there was no mechanism for me to express my fear or resentment or any of those things that came out of this. In other words, I think it almost would have been better to target each person in a center and say -- I mean not necessarily Margaret, but somebody to say, "Look. We want to come and actually talk about this, and here is what we are going to do." And then have a setting where first of all I had to deal with it, because there was enough denial. I mean Dana and I, I think, worked through this fairly quickly, but still -- and thirdly, where I had an opportunity to express a lot of things that made it very, very hard.

Q: Now they're dealing with things like this. It --

DR. MASSIE: -- took a long time.

Q: Took a long time. I was recently at Long Island Jewish Hospital, and they are really into all kinds of -- it is like rap groups, they have a psychiatrist who works just with the staff and all their feelings. There has been an incredible amount of staff --

DR. MASSIE: That's probably all to the good in the long run.

Q: Yes.

DR. MASSIE: Not just for hemophilia and AIDS, but for a lot of other things. But recognizing --

Q: But it took a long time. It took -- it is like everything else.

DR. MASSIE: Well, I suppose it took a failure to realize that a bulletin in an envelope isn't going to do it.

Q: Yes.

DR. MASSIE: Or isn't going to do enough of it. Dana and I ran into a little bit of this. This is complicated, but there did get to be a point where Dana sort of had to say, "Look. This is what I want you to do." And the problem that I had with that is that she went to talk to her counselor. She was feeling a lot of anxiety because I had been sick, and in fact my T-cells have been very high but she was worried, and I said, "Well, I'm not sure I can help you worry about that anxiety." We worked through that anxiety very well. So she went to a counselor and saw the counselor and came back and said, essentially, "Here is how you have to change your behavior." My reaction to that was that I did. But it was also very, very hard to have her go talk about something -- I had no inkling that this was the issue -- and then come back with a kind of -- not an ultimatum, but an edict from some counselor that I had never met.

Q: That is hard.

DR. MASSIE: I just thought, who is this person? First of all, even if I agreed with this, I'd like to have some say or at least some discussion. Anyway, so -- I know that -- the truth is I feel I have told you almost everything I planned to plus a lot of other stuff, so I'm not feeling --

Q: Well, why don't we stop for now. We've shared so much. You've sparked my thinking about many things, and I also would like to hear your feelings about the future of hemophilia a little bit. Have you thought about that? Are you "au courant" on some of the research and stuff that has been going on?

DR. MASSIE: Well, there are a couple of avenues in research that would be very helpful to me personally. I haven't really given it a lot of thought beyond how it would affect me, but one would be obviously an AIDS vaccine. Because that would be something that would help Dana and -- I mean, I would just feel more relaxed about all kinds of things. Not that we would necessarily change our behavior, but still -- so that would be good. Then, obviously, something that actually dealt with AIDS as a virus. I mean sort of a magic bullet that would remove the Sword of Damocles that hangs over people.

Then on the hemophilia side, I know that there is this sort of recombinant stuff that is coming out, although I'm

worried about the financial side of that.

Q: It's out. I mean they are using -- babies now are on it.

DR. MASSIE: Well, I'm just worried about --

Q: Finances. Yes.

DR. MASSIE: Yes. I mean because Factor VIII used to be ten cents an AHF unit -- then with the monoclonate it went up to sixty cents an AHF unit, and with the genetic stuff it is supposed to be a buck an AHF unit. If that were true, then I used \$10,000 worth of stuff in twenty-four hours and it didn't stop it, or it just barely stopped it. And I've used, you know -- so I have fears and -- both personal and broader concerns about how can you sustain and all the issues that we talked about earlier. Then, I also know of these genetic therapies and the genetic -- I mean obviously if something like that came along and actually worked, it would just --

Q: I spent -- do you know Dr. Fred Rickles?

DR. MASSIE: No.

Q: He's at Farmington, Connecticut and is now head of the Medical and Scientific Advisory Committee for NHF and he is involved a lot in the research, and some of the most marvelous things are they are looking into organoids now which are mini-organs. They now know that the Factor is manufactured in the liver and are looking into -- if I'm saying this correctly -- I'll listen to his tape again when I go home -- that they can in mice actually make mini livers. He feels that five to ten years from now --

DR. MASSIE: Well, you know, that's wonderful, but you see you have to realize that for -- since I was conscious I've been hearing that "in five to ten years," and one thing that has been a real disappointment is that when Factor came in concentrate in 1968 there was a sense that, well, this was just, you know, a brief step on the road to a cure.

Q: Oh, I see.

DR. MASSIE: And that we would have something dramatically different in ten years. And the fact is that we have been using Factor now for twenty-three years, and although the technology for creating it has changed, though obviously the monoclonate and the genetic are enormous advances in terms of how you actually make the stuff, it is essentially the same therapy.

Q: Right. Right.

DR. MASSIE: So, you know, that is not to say -- I guess my

sense of it is that I'm very happy about the future developments, but I am wondering what impact they will have on my life, whether they will come along in time. So, you know -- but if it does come along I may be one of those lucky few who lived in the span between when hemophilia was fatal and before it was cured.

Q: That's why when I decided to do this dissertation I felt that somebody had to just look at these forty years and look at what has happened.

DR. MASSIE: One thing I said to you over the phone, Susan, is that I really understand your motivation because it is the same way I feel about the South African divestment question. You look into a unique period in history with a lot of complex interactions, and if you don't actually talk to the people involved it will die and no one will ever really know exactly what happened.

Q: It is real important to me. I am so thrilled you agreed to have me come up here, and I must admit I was introduced to hemophilia by the book about you so it is kind of exciting to me to say that here I am. It is kind of coming full circle in terms of my interviews, also.

DR. MASSIE: I hope you're talking to some wives and I also -- I don't know if Dana would be willing to talk to you, but if you feel that at some point that would be appropriate --

Q: As a matter of fact I have spoken with some; if she was interested I would be very interested.

DR. MASSIE: I don't know if she would be. She's a more private person than I am, and less used to -- I mean she is a very, very -- a person of great candor and integrity, but I just don't know what her reaction would be to it. But if you find you would need it or if you feel in review of this that it would be valuable, you could certainly ask her and see what she says.

Q: Thank you again.