

Interview with Francis Story for the Boston Hemophilia Center Oral History Project, A Gift of Experience, by Laura Gray, August 5, 2004.

GRAY: Laura Gray. It is Thursday, August 5th, 2004. I'm sitting in Beverly, with Mr. Francis Story, and this is for the "Gift of Experience," the oral history project. So thank you, Mr. Story. Thank you, Fran, for agreeing to be in this, and just let me ask you a couple of questions. First of all, when were you born and how old are you?

STORY: I was born in Beverly. As a matter of fact, where we're sitting today is just about a half a mile from where I was born on Lothrop Street in Beverly, on a kitchen table.

LG: And how old are you?

FS: I'll be seventy-six on the 18th of this month.

LG: Well, almost Happy Birthday. And what kind of factor deficiency do you have?

FS: I'm—mine is factor VIII.

LG: Factor VIII?

FS: Yes.

LG: And do you know what severity: mild, severe or moderate?

FS: I would say it's mild.

LG: Mild?

FS: Yes.

LG: Okay, so you're factor VIII and mild. And the only other thing that I want to comment on is that you chose the full disclosure of this oral history.

FS: Right.

LG: So you were starting to tell me that you were born on a kitchen table. Tell me who you lived with and what you remember about growing up in Beverly. Just tell me a little bit of who was in your family, how many brothers, sisters, your parents.

FS: My mother had—my mother and father. I had two older sisters. I was the third and then a few years after I was born, I had another sister and then about a year and a half after that, a brother.

LG: So you were one of five?

FS: Yes.

LG: And two boys, three girls?

FS: Yes. Right, right.

LG: And what did your dad and mom do?

FS: My father was a cabinet maker and my mother was at home. Originally, before they were married, she had been a nurse, but her—early on. She spent all of years just raising the family and later on in life, in the late '30s towards the end of the Depression, then she started working as a buyer and went on to do very well as a buyer in women's high fashion.

LG: Are you the only one in your family with hemophilia?

FS: No, my brother. My brother had hemophilia, but it was kind of a strange upbringing. My brother and I really got separated at a young age, and so for many years I was always told I was the only one that had hemophilia, and my brother did not have it. But then it showed up on him. It showed up at about the age of fourteen.

LG: Help me understand why you were separated?

FS: Okay, it was back—this is always the children as we sit around, they say, "Well, tell us Depression Story three," or four, or five. I

have a group of Depression stories. This is one of the Depression stories, actually. When we were growing up, as I mentioned, my older sisters and myself and my younger sister, but shortly after my mother had given birth to my brother, she was taken very ill and the family had to be split up. So my two older sisters went with my grandmother and my younger sister and myself and my younger brother went with a family in Salem until my mother could get herself back on her feet. Well, when she got herself back on her feet, it wasn't like, "Well, I'm all better now. I can bring the family all back together." It was a period, "Well, I could take two children." She took my sister and I back and my oldest two sisters stayed with my grandmother for a period of time, and my younger brother stayed with the family in Salem that had taken care of the three of us.

Well, with the Depression and everything, we reached the point where finally everybody was together, except my younger brother, who was the baby and at that point my father—and I don't mean to put blame like on my father, but my father was having difficulty feeding the whole family, so it came down to, "Let's"—the people that had my brother had said, "Gee, why don't we keep him a little bit longer?" and it was agreed that that was the best way to handle the whole situation. So he stayed with the other family for a period of years, and as the years went on. Then as things started to improve in the economy and they decided that we—there was enough money to feed everybody and to bring him back. At this point, he was old enough so he was sitting and saying and "Gee, I don't know if I want to go and live with my

brothers and sisters.” He enjoyed the life that he had, and rightfully so. It was a wonderful family that had brought him up. So he chose to stay and then as time went on, eventually as he got older, probably when he was out of high school at that point, he decided that he would like to come home, but at that time my mother and father had split up and the only one living at home was my father. But it was—

LG: The only one living at home was your father? Your mother was?

FS: My mother had gone. She had left, and set out on a life for herself and my oldest sisters had gotten married and my youngest—when my mother left, she took my younger sister with her to live with her. It was like—you know, “You don’t need me here any more. Your two older sisters are married, and so they’ve gone off on their own, and you’re old enough to take care of yourself now.”

LG: And how old were you at that time?

FS: And I was like sixteen at that time. She says, “You’re old enough to take care of yourself.”

LG: So who did you live with at sixteen?

FS: I lived with my father for a few years.

LG: Now, tell me when—did you have any knowledge of people with hemophilia before you, in your parents, grandparents or cousins?

FS: Well, the only—I really didn’t have any real concrete knowledge. I had—hemophilia showed up in me when—I’m not sure just how old I was, but I would think I was like maybe three.

LG: Maybe three.

FS: Yeah.

LG: Okay.

FS: Maybe three, but I was circumcised and it was at that age and I can just—and I don't know whether this is just in my imagination, you know, but I have always felt that I can remember standing in my crib and my mother hollering, "He's bleeding. He's bleeding. He's going to bleed to death." Like I say, fact of fiction, but it's something that's always been in my mind. So I figure I don't think I could remember something like that if it was two, and I'm almost positive that that's the way it was, you know. But I mean, I was always told that that's when it showed up, so that's why I'm putting the age of, you know, three on it.

LG: But you remember hearing your mother say, "He's bleeding. He's bleeding. He's going to die."

FS: Yeah, right.

LG: Oh, my goodness.

FS: Yeah, yeah, and then with that—you know, I was—as we went along, I was told, you know, that I was a bleeder.

LG: That was the term used, that you were a bleeder?

FS: I was a bleeder and that I had this rare bleeding problem that came down through my mother's side of the family because it was classified as the disease or royalty and my mother, bless her soul, loved to think in terms of—she was like an Auntie Mame type, a wonderful person, but very flighty and just loved to think in terms of luxurious lifestyle prior to her getting married and her own family. Her mother and father had died at a young age, and so she—it was because of this royal connection that supposedly this bleeding disorder came down through.

LG: So she had a certain pride?

FS: Yes.

LG: In the fact that she was passing on this bleeding disorder because it had a royal connotation for her.

FS: Right. Yes. Yeah, and I would—we went from living just down the street where I say about a half a mile from here, to moving out in the country and we moved out in the country when I was about—there again, three, three and a half, four, and the country being about three miles from here, but still in Beverly. But the country was a small, close-knit community, farming community and so word gets around with the community, the local church that we attended and that. “They have a son that has a problem and is bleeding,” and so in this close-knit community, I was known as ‘the bleeder,’ you know, and bleeders don’t live very long, you know.

We could—this was supported by probably—you know, all I heard of was a cousin that was on my mother’s side who I never met, a cousin by the name of Billie, and it was like, “He’s just like Billie,” and then lo and behold, at twenty-six Billie died from bleeding to death from a hit on the head. He was a—what you call a debit man for John Hancock. Debit men would go around the houses and collect the weekly premium and he was going about his route when he encountered a drunk some place that hit him on the head with a bottle. So he went home and had severe headaches and was bleeding internally. By the time they got him to the hospital, he died.

LG: So this was the legacy given to you.

FS: Yes, right, and so with that, I guess, you know, I tied into like ‘bleeders don’t live long,’ and I had so much, “Well, you can’t do this and you can’t do that because you’ll bleed to death,” that I pretty much locked in, “Well, if I could live to be twenty-six, you know, I’m really lucky.” So I’m on the plus side of life. Anything beyond twenty-six, I was on the plus side, so right now I’m fifty years on the plus side, you know. But it was this type of thing. I don’t mean to be talking too much here, but—

LG: No, it’s wonderful.

FS: But I was just brought up with this whole thing, and I was called Sonny, Sonny Story, and it was like, “If you play with Sonny Story, you know, don’t do this. Don’t chase him because he might fall down and bruise his legs,” you know. At Halloween time it was, “Don’t let the tires out of Sonny Story’s father’s car because Sonny Story might get hurt and then his father won’t be able to drive him to the hospital.” You know, there developed a whole—I ended up having a whole different lifestyle because I was the freak, you know.

LG: What was that like for you?

FS: Well, I would used to—I would have to say, probably resent it, you know, because there’s so many things I think of in life that come to things—well, like in Sunday School, and I forget which level of Sunday School, but it would have been I might have been nine or ten, but at our little Christmas party when, you know—like I said, the community is small, so there might have been in my class four boys and myself, plus four girls we’ll say, you know. So the boys for a gift, they all got a jackknife and then I, like one of the girls,

got a coloring book because I couldn't have a knife because I might hurt myself. And probably, maybe to this day, for some strange reason, I always carry a pocket knife, you know. I have problems now with travel, if I was going to fly somewhere, but I used to have a bigger pocket knife than these. But I've always—even amongst our grandchildren, it's always if somebody needs something, someone says, "Oh, go see Grampy, because he'll have a pocket knife," you know. But it was always that type of thing.

LG: You were different. People treated you differently.

FS: Right, and when we had like recess in school, I for awhile thought that—we had a game called Snatch the Eraser. I thought I was probably the best player in the class for Snatch the Eraser because nobody could catch me and then later on I found out, well, they've all been told not to tag me too hard because I could get bruised, you know. It sounds like a sad sob story. I don't mean it that way, but growing up in the school, it was just a three-room school and there was two classes per room. So the first and second grade were in one room and the third and fourth in the other, and the fifth and sixth. So that was we called the Centerville School, and so in my class there was probably twelve of us in the first grade when I started, twelve or thirteen, and when I moved on from the sixth grade, by the time I moved there, there was like six of us in the sixth grade, and I was the only boy at that point and there were five girls. Of course, in the '40s, but it was like in the whole community everybody knew, like I say, that I was a bleeder and they treated special, and I always tried to avoid it.

LG: Tried to avoid what?

FS: Avoid the tag ‘a bleeder.’ I tried to do just the opposite. When I went out, you know, I wasn’t supposed to play baseball because you’d get hit with a baseball, and it probably ended up, like I tell the grandchildren now, in terms of as far as baseball, I really don’t enjoy the game of baseball. They all love baseball. My wife, Mae, loves baseball, too, but I didn’t enjoy the game of baseball probably because I couldn’t play it well, you know. I wasn’t supposed to play it, but I used to sneak off and play, but I was always afraid of the ball, you know, because I had drilled into my head, “If you get hit with that ball, you know, you’re going to end up going to the hospital,” or something, you know. So I was always trying to catch the ball to the side or something, rather than address it straight on. So—

LG: So on the one hand you tried to rebel.

FS: Right.

LG: And do these things anyway.

FS: Right.

LG: But on the other hand, it was you couldn’t fully enjoy it.

FS: That’s right. Like I became pretty good at hockey because none of my—

LG: Field hockey or ice hockey?

FS: Ice hockey. Of course, we didn’t have the rinks and everything that you do now. You’d go down on a local pond and shovel it off, shovel the snow off and get a group together and skate and play hockey. But I played hockey and I played fairly well, but my parents didn’t know what hockey was. It was like they thought it was something like figure skating, you know, so I was able to get

away with it and I did until one day I really got whaled with a hockey puck and then there was no camouflaging it after that.

LG: And what happened to you when you got whaled with a hockey puck?

FS: My leg swelled up like a balloon, you know. I got it off the shin and then I went through, you know, not being able to walk on it, you know. Have to go and see the doctor. You know, the whole thing but they—

LG: What was ‘the whole thing,’ actually?

FS: Well, before I move on that, then we can—

LG: Okay.

FS: Yeah, I was going to say at the sixth grade level, after I left the Centerville School, because then they transferred us down to the center of Beverly into the larger school system. So when I went to the larger school system, I was like a total stranger. I was moving in to the seventh grade, but nobody knew me. I was the only boy coming in from the Centerville School, so there wasn’t anyone to walk around and say, “Hey, you know, Sonny Story”—so I got rid of the Sonny, as well as I—in the seventh grade I got rid of the Sonny and became Fran and Frank and I got rid of the tag ‘hemophilia.’

LG: And what was that like?

FS: It was wonderful. It was like a whole new world, but I still had to duck a few issues here and there. One, my parents would get involved. I would try to keep them in the background, so they wouldn’t tell anybody, type of thing, but it developed a whole thing for me in life where I didn’t talk about my hemophilia. I felt

that maybe it was kind of like a badge of dishonor or something, and I didn't want to be looked upon as being different or an oddball. So I didn't talk about it. I avoided—probably avoided as much as I could, any reference to it. It was like a whole new life at that seventh grade that opened up for me. Yeah.

To come back to the question that you had asked me before. Before—oh, what was it like—oh, what was—

LG: When you said, “Oh, it was the whole thing.”

FS: Oh, the whole thing. Yeah, the way—when I would get injured from—well, how I was bothered with hemophilia would be through bad bruises, extremely bad bruises, nose bleeds, wicked nose bleeds.

LG: Wicked nose bleeds in that they just wouldn't stop?

FS: Just poured. Wouldn't stop. The doctors would take huge wicks and stick them up my nose and you could, instead of stopping, what it was doing was stopping it from running down your nose. You could feel it running down your, down your throat, you know. But they would put these wicks in and put them in and out of my nose. I would have—and I believe the correct word is thromboplastin, which is an injection. They would—I'm not sure if you were there, or whether it was someone else when the doctor that—Dr.—

LG: Was it Marks or Ewenstein?

FS: Ewenstein. Dr. Ewenstein. When we mentioned this, and right away he knew what it was. He said, “Oh, yeah, that.” But they used to, in order to stop some of the bleeding and that, they would give me these shots there. They would give them in the arm, and it

was more or less just like a normal, like a normal shot. I'd get them in the arm or get it in the fanny, and that supposedly would help stop some of the bleeding.

LG: Did it?

FS: Yup, as far as I—as far as I know, you know. It might be, you know, in like when I ran into an accident or something, I would have to go and have the shot every day for five days, let's say, or depending on the severity, I guess it might be just one shot. It would be “Well, if the nose stops bleeding,” or “The bruise starts going down.” But it was bruises and nose bleeds and then problems with the teeth, you know.

LG: What problems with your teeth?

FS: With the teeth. Whenever you got, like we'll say an abscessed tooth or a toothache or a tooth that needed to be extracted, you couldn't really just go and have it pulled out, you know. It would—if your tooth had to be pulled, you know, and I had a couple of teeth that—well, here again, I guess let me back up a little bit with the teeth. We're back at a time where, like I say, in the Depression and that, and people really aren't taking care of their teeth. They don't have the money, and so you would go to the school dentist, and the school dentist would get you out of school for the morning, and put you on a bus and take us downtown and for ten cents, you would sit in the school dentist's and they would do fillings or what have you, on the teeth that needed to be done. But it was just cursory type of care, and when you ran into a bad problem where say a tooth decayed or something and it had to be extracted, then they would send you to a

regular dentist. Then the dentist would do the x-rays. Most of the dentists would look and say, “Oh, geez, with a bleeder, with a bleeding problem we don’t—and the way the tooth is hooked to the jaw and that, we don’t want to tackle that.”

In order to have a tooth extracted, you had to go to the hospital. So I naturally didn’t have health insurance and things at that time, so the tendency was then, “Well, let’s see if you—let’s see if we can take care of it by soaking it in, say, warm water and salt,” or things of this type, and see if eventually the tooth will improve. Well, you end up with teeth that have to be extracted, but they’re sitting and saying, “We can’t extract them,” and so they end up in—I had a couple teeth that they did them by piece. So they would take a little piece at a time out. Like on a molar, you know, if they had like four roots on it that hook around, well, they would split the tooth and take a little piece out a time, but you’d develop these terrific clots in your mouth and it was—one of the—the dentist that—the dentist that I go to now, I had gone to his father and his grandfather. So it’s been three generations in the same family of dentists, but I always would say to my current dentist, I’d say, “You know, you and your father, we used to live together for like a week when I came down to have a tooth extracted.” He was willing to do it, and then recognized that he was going to have to spend a lot of time with me, you know.

LG: What do you mean that “we practically lived together for a week”? What would actually happen?

FS: Well, the—once you extracted the tooth, the normal healing, the tooth would bleed and start to clot and so for the first day it would

have all the traces of what would take place, let's say, if you had a tooth extracted. Maybe into the second day, you and I might be the same, you know, but midway through maybe the second day, the clot would start to grow because it didn't have any strength to it. And the clot would grow and grow and grow, and it would keep growing to the point where I would have a whole mouth full of blood clot, and then call the dentist and I'd go back and they'd have to scrape it all down and start over from scratch again, you know, on the clot process. Each time this would happen, and it would happen day in and day out for almost a week, until finally you were able to get inch, fraction of an inch by fraction of an inch of the cavity where the hole came, where the tooth came from, patched up and the clot to hold, you know. But it would be, like I say, the dentist would know once we did it that, you know, if it was Saturday or Sunday or if it was ten o'clock at night, that gee, I'm almost choking on the blood clot and there's blood all over the pillow, "Look, better come right down to the dentist, to my office. I'll be there," you know. So that tooth extractions were really bothersome.

LG: What was it like for you to go through this? Do you remember what you thought about it? Did it hurt? Was it scary?

FS: Yeah, well, the teeth really hurt. Yeah, that really bothered. But—and the joints, like my knee, my right knee, to this day I have problems with that, and that was just from the frequency of falls on that knee. It would always seem like when you were going to fall down, that was the knee you would fall on, you know, and if you were going to fall, that's how you'd try to protect yourself, I guess.

LG: And when you'd fall on your knee and you knew you bumped it, would you tell your parents?

FS: Probably most of the time I wouldn't.

LG: You wouldn't?

FS: No, and then—

LG: Why not?

FS: I just knew that suddenly there'd be a lot of concern and restrictions and "I told you so," and the whole group of things. Then probably a lot of the time, I probably was doing things I shouldn't have been doing, you know. Maybe I was out running around playing tag football or something and so, you know, just to avoid—and there were so many different restrictions and things, that I'd get—you know, just inclined not to.

LG: Who put the restrictions on you?

FS: Oh, my father or my mother.

LG: Both of them were involved?

FS: Yeah, both. Yeah, both of them were involved.

LG: Did they have different attitudes or the same attitude? Was there a different way they approached it with you or were they a unit?

FS: Different ways they would approach it, I would say.

LG: How did your father approach it and how did your mom approach it?

FS: Well, my father was pretty much—oh, the other thing we haven't talked about was—well, yeah, we did talk about the nose bleeds. The nose bleeds, when they would start and they would occur in the middle of the night or things like that, and I would call to my mother and she would come in and she'd get panic liked. I could

understand why she would, and then naturally you would run out of handkerchiefs and things, so she would end up tearing up sheets and tearing up pillow cases or just to have to—but my father would always say, “Margaret, you better take care of it, because I can’t stand the sight of blood,” you know. So that was—when we reached him, it was—that was more or less always his—[phone rings]—“I can’t stand the sight of blood,” so if it was the blood. [tape off/on]

I know—I’m making it sound like my father’s the heavy, and I don’t mean it like that. Life was so different then, and the struggle to put food on the table and that, and men worked six days a week. They didn’t have Saturdays off. So, I mean, he was out of the house to go to work, you know, before seven in the morning and he’d get home from work—he’d come home at noontime for lunch, and then he’d come home, you know, shortly after five. He was a hard working person, and I imagine—and I think at this stage of life or so, I look back, and in many ways I probably was a big disappointment to him, in that he as a cabinetmaker and working around sharp tools and things of this type, I couldn’t have been the son that he probably dreamed of having. You know what I mean? So I don’t want to make it sound like he was a heavy, but as far as my bleeding and that type of problem, my nose, as far as the visual sight of blood, it was always, you know, “I can’t stand the sight of blood,” you know.

LG: Why do you imagine—you’re saying from his perspective now, you imagine you were a disappointment to him. Did you ever get a

sense when you were growing up that you were a disappointment to him?

FS: I can't truthfully—truthfully say that, but he really wasn't one, I think, to show his emotions. I—I—I am critical of him because of the fact that my mother and he separated, I guess, and I am critical of him. I know, as a family man and I think as a good family man, I don't think it was whether my mother's fault or my father's fault, but for the life of me, I can't see giving up a child. Whether—if one of my children ever said, you know, "Gee, I want to live with someone else," I'd say, "Tough cookie. You're going to live with me. You're my child." I just—so maybe in the sense that, you know, not—you know, basically giving my brother away. But I don't know.

But I know, you know, he was—I mentioned earlier my mother was English, my father was Swedish.

LG: Were they born in America?

FS: Yes. My father was the first born in this country. He had a brother, older brother that was born in Sweden, and then his mother and father came across, brought his brother and then he was the firstborn in this country. They settled in Gloucester. My grandfather was an old Gloucester fisherman, who I've always been intrigued by. I really didn't know him, and that's another whole thing. I didn't know him because he was always off at sea, and you know, and when I did see him, I was frightened of him because, you know, he was just rough and gruff and burley, like you would picture fishermen would be.

LG: Do you ever remember him talking to you about the fact that you had hemophilia? Was that ever mentioned?

FS: No, no. That was—that was never, yeah. But my father, see, would be—he would work, like I said, six days and on the seventh day, the seventh day was always devoted to go see his mother. So it was—and it was always we as a family would have to get in the car and ride to Gloucester and then we would have to sit in the parlor while he would sit with my mother and visit with his mother, you know. It was always—I grew with a life where his first priority was his mother. He was never able to separate himself from her. So—but that's like another—

LG: What about your maternal grandparents? Were they in England or were they here?

FS: No, they—they passed away when my mother—when my mother was—I believe she lost her father when she was like at the age of ten, and lost her mother at the age of eleven and she was brought up by her grandmother. But we're going spin off on a little different area because a area of confusion for me, because my mother was a twin and she had had an identical twin sister and they were brought up their grandmother. She had two other sisters, one who never married, and another sister who had married and had two sons. The sister that married and had the two sons, they did not have hemophilia, and they—we were never close and very seldom saw each other, but the few times in life that we did see each other, you know, I just knew from their lifestyle and the things that they did—one went off to go in the Army and another was on the football team or something. But I mean, that—and I

was always told, you know, that there was no problem there. So I could understand that, knowing the way it runs in—hemophilia runs in my own family.

But the one that I was closest to was my mother's twin, who had a boy and a girl and the boy supposedly—his name was Buddy, and he was my closest cousin and I used to see him. He lived in Boston, but I would see him on, you know, four or five times a year maybe, and those were always big occasions. To me, Buddy was like—he was like the apple of my eye.

LG: And did he have hemophilia?

FS: Supposedly he didn't. I say supposedly because he—it was like he didn't have it, because he never had nosebleeds, you know. But I had it. But to me it didn't make sense. But then at the age of thirteen, he was reprimanded for doing something—doesn't make any difference what it was, but his mother's way of reprimanding him was to lock up his bicycle and so she padlocked his bicycle so he couldn't ride on it for a week, we'll say. So he went out with his friends and he rode on his friend's bike by sitting on the handlebars. I don't know if kids even do that nowadays, sitting on the handlebars. But he was sitting on the handlebars of a friend's bike, and a friend drove the bicycle. They got hit by a car and my cousin flew off the handlebars onto the hood of a car, of the car, and they took him to the hospital and he bled to death. So I always felt that he must have, yeah. He must have had hemophilia.

LG: So that was a huge loss for you.

FS: Yeah.

LG: He was your closest cousin.

FS: Yeah, yeah. So—

LG: Did you put two-and-two together for yourself at that point?

GS: Yeah. Yeah. It's never been said that he did, you know, but I just almost have to think, but then his sister—her name was Martha—she married and lost track of her and her family, but she had two sons, I believe, who have hemophilia and later on life, through my brother, he had made contact with her because he was involved with the New England Hemophilia Center down in Dedham. But I always felt, see, being identical, it just had to be there, but it was either somebody was living a life, you know, masking it over or it maybe just, as I've been told, your body goes through a change every seven years and like my brother didn't really have the symptoms of hemophilia at a young age, but when he got to be like fourteen and fifteen, as I was growing out of the stages and wasn't having nosebleeds and wasn't having the bruising problems, and they seemed to be diminishing and I'm sitting there saying, "Oh, gee, maybe I will grow out of it." Every seven years my problems were a certain type when I was—up until I was seven, and then between seven and fourteen, there were a different set of problems associated with the hemophilia. Then when my brother didn't have anything, he was going the other way, it was almost then—like by the time I got to be like up in high school, like I'm almost sitting and saying, "I don't have hemophilia because I don't have nosebleeds any more, and I don't have bad bruises. I have bruises, but I don't have them anything like I used to, and there must be something to this body change, and at twenty-one, gee, I'm"—

LG: I wonder if it's a body change or was it just a change of behavior, where when you're up to seven you're falling and bumping and awkward, you know.

FS: Yeah. Right.

LG: It was the trauma in some ways that caused the problems, although I'm not sure about the nosebleeds.

FS: Yes.

LG: But that was your experience?

FS: Yeah.

LG: Were you ever hospitalized?

FS: No. No, I—well, you mean as a youngster? No. No, I wasn't.

LG: For the hemophilia, did you ever have to go to the hospital?

FS: No, I never was—I never was in a hospital until after I was married, and my experience in the hospital there, I had picked up a problem with a knee. The left leg, they never really resolved what it was, but the doctor finally had me admitted to the hospital, Salem Hospital, to do a spinal tap. That was my first experience ever going to the hospital, and it wasn't a pleasant experience because the doctor forget he had had me admitted, and I was there for a whole day waiting. At that time—I don't know what they do now on a spinal tap, but they admit you. You can go in and they'll do it outpatient, but at that time, you had to be admitted and stay over night and that. So I was there the whole day and stayed overnight and the next day, and no doctor and finally the calls went, "Oh, I forgot," you know. "I forgot." So that was my only experience in a hospital.

LG: Did you tell them you had hemophilia?

FS: Yeah.

LG: Or did you not mention that?

FS: Yeah.

LG: So you always did mention it.

FS: Yeah, on this particular case the doctor was a hematologist that had me admitted.

LG: So your experience wasn't so much going to the hospital or being stuck in hospitals growing up, but it was more the nosebleeds and the bruises and being called 'the bleeder,' and having the whole community relate to you differently.

FS: Yeah. Right.

LG: Because you were a bleeder.

FS: Right, and the other thing with the bruises and the joints, they would treat it by way of bandages, like Ace bandages. They would bandage you up or put a splint on your leg, like for the knee and stuff. If you didn't—it would keep swelling and swelling and swelling.

[end of Side A, Tape 1]

FS: They would straighten your leg out the best they could. A lot of times you couldn't get it really straight, and if you put a splint on it and then bind it up with a tight Ace bandage, and then you'd be bedridden. You had to keep it elevated, maybe for a week, two weeks.

LG: Would you have to do that often?

FS: Oh, I did it quite a few times, yeah.

LG: You did. So you were in bed with your leg up.

FS: Yeah, yeah.

LG: What did that do for school and your studies? How did—did it impact your education?

FS: I'll tell you, I didn't get the best of grades, but I can't blame it all on that, either, you know. Probably a lot of times I just—I just didn't care for school and there was nobody there encouraging me to study hard. My own fault. I mean, I just ended up in life that I short-changed myself and I spent quite a few years going to night school and all of that to make up for what I didn't do.

LG: So it wasn't the hemophilia, per se, that got in the way of your doing well in school.

FS: No, but I was absent a lot. I was—yeah.

LG: What did you think about your hemophilia?

FS: Well, I pretty much just tried to put it out of—I—see, once I moved—once I moved down from the sixth grade to the seventh grade, which like I say, brought me from the country to the city, you know, then I felt I could carry on a new life and I really didn't talk about it.

LG: Did you think about it still, or did you just put it out of your mind?

FS: I just put it out of my mind.

LG: You just got rid of it.

FS: Yeah, yeah. Right, right, and, you know, we were going through a whole—see, that would put me in '41, you know, so say start of the World War II, so you know, everything kind of shifts and you know, there was always talk about, you know, people that are 4-F. It would be like, well, I didn't want to be labeled 4-F because I was going to go in the Navy, you know, and I was told, "You never will be able to go into the Navy because you have hemophilia," but

then I later on—you know, I'm getting up into the high school level now. Then I'm getting up into an area where I'm saying, "Well, if I don't say anything. If I go and sign up in the Navy and I don't say anything, they're not going to know. They're not going to know until I'm in," so I guess that's—you know, from my standpoint, you know, I'm saying "I'm one of the guys. I'm the same as everybody else that I'm in school with that's going off to war," you know. You know, deciding that they're going into the Air Force. That was the whole thing in our school, you know, during that whole period, through the early stages of the war, I mean, everything is geared—you have your neighbors and classmates, older classmates and things that are leaving to join the service and that's the patriotic thing to do.

LG: Did you do that actually?

FS: No, by the time I—when I graduated—see, I graduated in '46 and the war ended in '45. So it ended up—

LG: But you would have considered trying to go into the Army and not telling them, so you could be one of the guys?

FS: Yeah, trying to go into—yeah.

LG: And what about the risk to you of getting hurt?

FS: Yeah. I could, you know, at that point, you know, I'd gotten into a couple of boxing matches, which I shouldn't have. I mean, just some different things. But what—probably a good defining area of this is—probably one—I went downtown. Then I was approached about joining the Boy Scouts and have very, very fond memories of the time that I was in the Boy Scouts, but then there was a big question in my family whether I should be allowed to join the Boy

Scouts or not because, you know, they chopped wood and they had knives. You know, they hiked in the woods and you could trip and fall and all of this stuff, and then for your different badges and things, there was different things that you had to do that could be classified as dangerous for somebody with hemophilia. So I wanted to join the Boy Scouts and my father and met with the governing counsel or whatever it was of the troop, you know, to say that I wanted to join, but he thought there should be certain things I should be excluded from because of my hemophilia, which, geez, I didn't want it to have happen, you know. But they finally agreed to accept me without the exclusions. I mean, I was going to have to do the same thing as everybody else.

LG: And your parents agreed to that?

FS: Reluctantly. At that point, I guess they know how important, say, it was to me, but then it was for me to make sure that when I got to that certain point, like maybe I could be a Tenderfoot, but never be a First Class because I wouldn't do the wood chopping, or whatever it was, you know. So I said, "Okay, well, when we get there, you know," but I had every intention of becoming—well, to me, I wanted to become a Eagle Scout, you know, but never made it. But that-I got in and I was with a group of guys, you know, and did participate and do everything. We went off camping for the week and things and was off in the woods playing Capture the Flag and everything else, you know, taking the bumps and grinds with everybody. If I got a bruise, I didn't talk about it, you know. I would have to say that that was a big turning point for me.

LG: Because?

- FS: Because that started me on a whole different thing with the guys. Before—before, my whole social life was up where I lived in Centerville, you know, where everybody knew “Don’t run after him,” or “Don’t tag him,” or “Don’t this,” or “Don’t that.” Where I’m down with, I’m just like any new guy coming into the troop and got to go through initiation, like everybody else, you know?
- LG: So you felt normal?
- FS: Yeah.
- LG: One of the guys. Whereas, before you were always sort of an outcast, as the bleeder.
- FS: Yeah.
- LG: Do you ever remember being teased or was it more you were just—everybody was cautious with you?
- FS: No, I don’t ever—
- LG: No one was mean to you?
- FS: No, no. I never had anything like that, yeah.
- LG: Let me just get back to your mother, because you told me about your father.
- FS: Yeah.
- LG: What was her attitude about the disease, other than a certain pride in it? Do you remember how she handled it or her attitude toward it? She was very cautious, it sounds like.
- FS: Yeah, very protective. Protective of it. I just think of her as a comforter.
- LG: She was a comforter?
- FS: Yeah, I think of her. Anytime I ran—she was sympathetic when I ran into problems and stuff like that. It was never, you know, like

[unclear] or “you deserve it,” or “you didn’t do what you were supposed to do.” No, she was—

LG: She never blamed you.

FS: No, no.

LG: Well, let’s move on a little bit. Now you’ve been through high school, okay, and you were one of the guys.

FS: Let’s see, wait a minute. We’ve got me up to—we’ve got me up to the seventh grade now.

LG: Okay.

FS: Because about at that point I joined the Boy Scouts. But at that point, I wanted to have a bicycle.

LG: When you were in the seventh grade?

FS: Hmm. Everybody else—everybody else had a bicycle, but I wasn’t allowed to have a bicycle.

LG: By your mom and dad?

FS: Yeah, and particularly my father because I was going to fall off the bicycle and get hurt. So I wasn’t allowed to have a bicycle. Plus we didn’t have any money to buy a bike, you know. But then, I mentioned my cousin that had gotten killed, well his bicycle that had been padlocked, my mother asked my—unbeknownst to my father, my mother then asked her twin sister if I could have his bicycle, you know, which they agreed to. So they shipped it down, you know. So one day the Express truck showed up, my cousin Buddy’s bike, which was mine to have, which created a—you know, some tension at the family at the time and turns out that I sure was going to get hurt riding the bicycle. But I learned how to

ride it and didn't get hurt and went onto many bikes afterwards, you know.

I just mention that. That was a big—

LG: It must have been a big event in your life.

FS: That was a big event in my life, too.

LG: And it's interesting that your mother wanted that bike for you, despite the fact that you had hemophilia.

FS: Yeah.

LG: Somehow she thought your having that was more important than the potential danger of having the bike.

FS: That's right. Yeah, yeah. That's why I wanted to feed it in at this point, that maybe I'll tie in. And at that point, you know, in the seventh grade, at the start of the seventh grade moving into the eighth grade, you start to get into organized sports. We had junior high football teams and junior high baseball teams, but rather than go the sports route, knowing you know, that—well, I wasn't good at any of them, and I don't think I put so much thought in terms of, "Well, I could get a nosebleed or something," but I just said everybody else was further ahead than I was, you know, just knowing at recess time if you were out tossing a ball around, you know, I couldn't throw the ball as far or as far as somebody else.

So when you got into the organized sports—so, I got involved in music and so I—and I didn't know which way to go, but I knew that I wanted to play an instrument and I'd always had an interest in the drums. But at that time, you know, it was a period of what they called the Big Bands and the Benny Goodmans and the Tommy Dorseys and all these, and different people, they'd

become our idols, just like Joe Lewis or Ted Williams or, you know, in sports, the musicians and the developed—you could look back and you could see that during a certain period, everybody, every youngster wanted to play the clarinet and it was because of Benny Goodman or Artie Shaw or something. Then there'd be a period where everybody, all the young students wanted to play the trombone or something, and it was because of Tommy Dorsey. You could see how the development in different instruments would come along.

So I was always interested in the drums, but I also said, "Well, gee, maybe I might like to play the piano, too, or a wind instrument." But I was told, "Well, rule out like the trumpets or the trombones because you have hemophilia," because blowing into the instrument could start a bleed internally. I mention this only in that the crazy things that, you know—it was like you don't do those.

So then I said, "Well, maybe I'll do the piano," because we had a piano. But then I was told, "Well, there's been money spent. Your two older sisters have taken piano lessons and nothing has ever come of it, and we don't want to waste anymore money on piano lessons." So I said, "Well, then I've down to—I've always wanted to play the drums. I guess I'll play the drums," and there was a question. "Well, why waste the money on lessons?" or something, "to play the drums," but I really wanted to play them. So I had a little side job working in the gardens and stuff like that, so from seventh grade on, I started taking drum lessons with my own money and I took drum lessons for years. In fact, went on and

played the drums and I played them very well. At one point, I was interested in becoming a fulltime professional musician, but I took all of my energy and interests, instead of putting it into the sports area and that, it went into the music area, you know. Like up through high school and all this, I had high school orchestra and played the high school dances and stuff like that. But I mention it only that—where this came from in terms of hemophilia, “people with hemophilia shouldn’t play wind instruments,” I’ll never know, but it was—

LG: That’s interesting. But in a funny way it was because of the hemophilia that led you to this love of drums.

FS: Yes, right. Yeah.

LG: When you were thinking of relationships or meeting your wife or dating, was hemophilia ever a concern of yours?

FS: No, no. No, it was never. It wasn’t even part of my vocabulary, and I—see at this point, my brother, who never had signs of it, started to develop signs, and got obsessed with it. Well, who’s to say somebody’s obsessed, but from my standpoint, at this point in time, somebody who doesn’t want to talk about it, doesn’t want anybody to know, doesn’t—you know, I just “I’m a normal human being,” to my brother is into “Let’s find out more about it, and let’s check into this,” and went on to—we always used to joke about it, like when my brother and I did get together or something, he’d always want to sit around and talk about some studies he’s participated in or doctors he’s seen or any combination of things. He’d have in his wallet, he’d have all kinds of identification that he has a hemophilia and he’s wearing all kinds of badges. He died

last—a year ago, at the age of seventy, and he went through open heart surgery. He was up at Beth Israel. He was involved in a bad accident, a work-related accident and it blew part of his head off. Peeled his scalp back. He survived that, and he was up at the New England Medical Center up by Tufts. He participated in a study at Emerson Hospital, which he called and asked, for comparison purposes, if I'd be willing to go up and donate some blood, which I did do. That was years ago, but he had an entirely different tact and it was so strange that, you know, we started out life and he has nothing that relates to hemophilia and I have a lot. And then later on in life, it's just the reverse.

LG: But it's interesting in that you had no desire to seek out company in talking about the disease.

FS: No, right.

LG: That wasn't a comfort to you.

FS: Right, right.

LG: Quite the opposite, in fact.

FS: Yeah.

LG: You wanted to distance yourself from it.

FS: Right, right. Then the—if I could back up.

LG: Sure.

FS: When we were talking—the thromboplastin and bandaging the knees. The other thing that they did would be a heavy diet of liver. So whenever I had a nosebleed it was like, well, I'd have—my mother would be cooking up liver like crazy and it would be almost raw. Put it in the frying pan and flip it over, flip it again and then you'd have it, and you would think that I would hate it,

but I enjoy liver, to this day even, cooked that same way. I'll like have liver medium rare, which I know you shouldn't eat that way now. But I'd have liver, cod liver oil. They would feed me a lot of cod liver oil and liver extract, which is the worst tasting medicine in the world. Terrible, terrible, but it was a steady diet of liver. Evidently, there's a lot of iron in liver and it was to get the iron level up, you know. I think it was.

LG: Now, I wonder if doctor's told your mother to do this, or this was just her home remedy?

FS: I believe the doctors did, yeah. Yeah. I really didn't—I really didn't talk about my hemophilia, hemophilia problem. Of course, when Mae and I started dating and that, we didn't talk about it, but later on, as we got serious about our relationship, probably had commented on it. But the interesting thing there is that—I forgot one thing I wanted to mention.

LG: Okay.

FS: Okay. Back when I started school, in the first grade you had to have a Smallpox vaccination and they didn't vaccinate me because of the fear that by scraping the arm, as they did then. Remember the vaccinations on your arm, when they would scrape your arm and create a scab, that they wouldn't be able to stop the bleeding. So I've never had a smallpox vaccination. That was—I had made note of that. I just thought that was interesting. That was just to show you some of the concerns that were out there by different people.

And I thought of this because it leads up to the next thing. When Mae and I got married, and I'm talking '48 now, when Mae

and I got married, at that time, they would do the Wasserman Test. You know, for venereal disease? They would extract blood, but they wouldn't take any from me. So the doctor signed a certificate showing that he had been my doctor of eighteen years or nineteen years and vouch for the family. But even back in '48, they were afraid that if they put a needle into me, into my vein to extract the blood, they wouldn't be able to stop it. So—

LG: So every step of the way, your hemophilia came up for you?

FS: Right, it came up in so many—

LG: Even though you wanted to shed it and not deal with it, you couldn't.

FS: Right. So then we—I had an opportunity to go to work for the—Mae and I got married.

LG: Do you remember telling Mae about having hemophilia? Was that an issue?

FS: No, and Mae's an RN. You know, in fact, we kid that I went through nurse's training with her, you know. Only that when we had just started to date when she enrolled, started her first year of training, and then all the years of training were, you know, we dated. At that time, on nurse's training they went three straight years. They didn't have the summer off or anything like that, and then they would—because she went to Boston Psycho for six months and then Communicable Disease down in Rhode Island for six months. I forget where else, but they would move the students around. So I'd go visit her and, you know, you'd have restrictions. You could see each other for an hour and have to be back, and they really worked them hard.

And then for the state exams and that, we studied together for them, but at some point along the line I know we had talked about. I can't specifically say that we sat down and said, "Hey, gee, I don't know. Should we get married or shouldn't we get married? Should we have children or shouldn't we?" I don't think it was ever anything like that, you know. It was just—just a regular just a fluky type of thing. So, you know—but we—

LG: But it was never an issue for you that you could pass it on? Or did you understand you could pass it on?

FS: Yes. Oh, yes, I understood it could be passed on.

LG: But that was never something that you felt you did or didn't want to do? It wasn't an issue for you.

FS: Yeah, it wasn't. It wasn't an issue. But there probably was as much misinformation on the passing on, as the information on passing on. This is just—and we find in our travels and talking with different people there still is tons and tons of misinformation about the passing and the severity or the passing on and the—it's just strange the way it will show up in the family. We're still amazed at the way that's, you know—the two little boys you saw today, now, they don't have it and Nancy has one other son that doesn't have it. But then we have I think five or six that have it, and five that don't. It's really weird. I went to work at the Holyoke Insurance Company over in Salem. I was working at the bank in Beverly and then playing in different orchestras.

LG: After high school, did you go to college or did you go right to work?

FS: Went right to work.

LG: And you were playing in bands.

FS: Yes, right, and—

LG: Considering being a professional musician.

FS: Yeah, and when I was in my senior year in school, the—I forget what was the guidance department, what you'd call it at the time, came to me and recommended me for a job at the bank, part time job at the bank after school and vacations. So I went to work at the local bank. Well, at this juncture in life, you know, it was like if you could get a job at the United Shoe or work in a bank, I mean, you've got life made. You've got life made. So as a senior in high school after school, you know, I'd hightail it down to the bank. Up to that point, I had different jobs working on estates cutting grass and weeding and things like that.

So I went to work at the bank and I really never cared for it. I just plain didn't care for it, but I did a combination of different things and worked my way up to—eventually I was in the teller's cage and I hated it. I just hated my work, you know. You didn't get paid well. The pay was miserable, but what was really keeping me going was the money I was making playing in orchestras, and I had my own orchestra.

Well, I'm at a teller's cage and people are coming in and cashing their pay checks and everything, and the—my name was appearing on the street on different signs, playing different dances and stuff and the head of the bank told me that I should learn to live within my means. I shouldn't have the two jobs because I just said, you know, "Well, I can't live on twenty-eight dollars a week," or whatever it was I was making, you know. So with that, I

ended up—I got an opportunity to go to work at the Holyoke Insurance in Salem, which is a small company at the time, under a trainee program. That’s the purpose of my going through this.

So I started there and liked what I saw and instead of making twenty-eight dollars a week, I’m making thirty-three, but they had acknowledged that they didn’t have any problems with my playing in orchestras and things. And I’m on the job probably five or six months and they put in a new program where they were going to provide life insurance, a thousand dollars worth of life insurance for all of their employees. Everybody was all excited about the program, and so lo and behold, I signed the application for the insurance and everything, but there was a medical involved, you know. So I went to see the doctor for the medical and, you know, going down through family history and blah, blah, blah, blah, you know, and then “Is there any bleeding disorders?” or something, and I said, “Look, you know, I have hemophilia.” And, “Oh, oh,” okay? And that was the end of that and then about a week later I got called into the office and hey, everybody in the company and at this time we’ll say there’s forty people in the company, “Everybody in the company has had approval on their thousand dollars’ worth of insurance except you, and it’s because you have hemophilia.” Right away I said, “Oh, geez, does this mean I’m going to lose my job?” you know, because the fact that I’m—suddenly a red flag has gone up about my medical condition or something. But it turned out I didn’t lose my job. I went on and became the head of the company, but I mean, they raised this concern.

Then Mae and I had had, at this point Pammy had just been born, so we were saying, “Well, I don’t have any life insurance now,” and that thousand dollar policy was going to be important to me. So we talked with some friends about it and they said, “Well, gee, maybe you ought to search around and see if you could get some term life insurance or something to protect yourself so that at least you have some income coming in if something happens to you. So that Mae and Pammy would have something to live off of. This is a serious situation for you, so you better explore it.”

So with that, I went to a company Phoenix Life—it doesn’t make much difference what the name of the company was. They came and interviewed me and they went down through the whole thing and they said, “Well, we might entertain taking you, and rating you up, but we would like to know a little more on the severity of it. So we will pay for you to go and have the severity checked.” So they sent me to a doctor in Boston. His name was Dr. Alexander, and he was up in around Symphony Hall some place. A very fine gentleman, and so he—this was my first exposure to really getting into the severity aspect of it, you know. So he told me at that point that they could only break the blood down into thirteen parts, so that if you fell under that thirteen, you kind of were in the severe group, but beyond the thirteen parts, you wouldn’t really know somebody had hemophilia, unless you told them. The tests they did on me, he said, “We really wouldn’t know unless you told us.”

LG: So it really didn’t come up on the test they had at that time.

FS: Yeah. Yeah. So they would classify me as mild, but he said, “What we would like to do is include you in our studies, so as we come into new areas where we increase the number of steps that we can break out, you know, that we might—we’d like to include you, but it would mean you’d need to come in and donate the blood and stuff.” I said, “Oh, count me in,” you know. So it was at that point through Dr. Alexander that I got fed into a program and I got the life insurance that I needed. The company was willing to pick me up, and I got twenty-five thousand dollars worth or something. That was rated up, but it was reasonable, you know, but the loss of that thousand dollar free coverage led me into the study that brought into the fact that it wasn’t of a severe nature and got me the life insurance that I needed to protect my family, you know.

LG: Did that have any political ramifications for you at all?

FS: No. No. I thought—there was great concern on my own part. There was a big concern on my own part that it was suddenly going to put a damper on my business career, you know, politically. You know, “We can’t have him doing this,” or “We can’t have him doing that.” You know, take him out of the training program. But it didn’t, not at all.

LG: Were you, as an adult, treated for hemophilia much? Did you bleed much as you got into adulthood?

FS: No, as I—the nosebleeds pretty much disappeared at say twelve and thirteen. I haven’t had a nosebleed for years, and the—the only problem, as I said, was continuing to injure my right knee.

LG: Were you seeing a hematologist? Once you met Dr. Alexander, did you get regular checkups for your hemophilia?

FS: No, I didn't want to get into that. I—I found that the minute that I mentioned to any doctor that I had hemophilia, I would get sent into the revolving door. It was—and you'd never get out of it. You would be put through test after test. You'd be—I had one—I had injured the knee and I was giving it the same treatment that I always did. I bound it up. I'm trying to think how many years ago this was. Anyhow, my daughter Jane was being admitted to nursing school at Children's Hospital, so I bound it up and got off of it. Treated it the way we normally did.

LG: Which was to bind it up and keep it—

FS: Keep it elevated.

LG: Not ice? You never did ice?

FS: No. Or walk around on crutches, whenever I had to. But it wasn't getting better, and so I was—my daughter Cindy, who is the second oldest daughter, was at the Leahy Clinic in Boston at the time, and you know, children were always after me, "Well, do this. Do that," and I'd say, "I'm not doing anything. I am taking care of it myself." Well, I ended up this particular day when the—I'm picked up under the armpits by my wife and my daughters and lugged out to the car and put in the back of the car and driven to Boston up to the Leahy Clinic and said, "You're getting that taken care of, you stubborn old coot." [chuckles] But I went in and saw the doctor and he looked at my knee and then he fed me into the revolving door, and I got sent from this one to that one, to all around, and I'm in there for my knee and they're doing a thousand and one other tests and everything, and I went out the door. Never to return again.

At one point, just a couple years back, some of these—my name came up somehow or other on something and said, “Oh, we have record of him there, but he came and he went to this and then that, and then for some reason or other, he never—we never checked him out,” or signed him out. What have you, but it’s just, as I say, I said, “Oh-oh, I’m in the same old thing,” and I just always found that out. That it was like I’ve never—I’ve never seen a doctor will take you, but it’s so rare. It’s like I’ve never seen another patient with hemophilia.

I had a bad accident this winter down in Florida. It could have been a lot worse, but you know, what we went through, it was like people were coming into me and said, “Geez, I’ve always heard of hemophilia, but I’ve never seen anybody with it.” Then I heard somebody say, “You know, he’s the oldest—he’s the oldest living person with hemophilia in New England. You ought to go down to that man in that room.” [chuckles]

LG: That’s what they’d say?

FS: Yeah, yeah.

LG: How would they know that? [laughs] So your experience was that medicine really didn’t help you?

FS: No, no.

LG: You were just a rarity no one really knew. You’d go through all these tests and nothing would come out of it for you, so you figured, “Better I can treat myself.”

FS: Right, right, right.

LG: Even with your brother looking into everything that was available, did he ever find a hemophilia treatment center or try to send you that way?

FS: No. No. Well, he had some tests—well I guess I mentioned, at Emerson Hospital.

LG: Right.

FS: Yeah, and I participated in that. Then later on, he had participated in a study at Framingham, a study on heart, but because of the hemophilia aspect, and he wanted me to participate in that. I did participate in that, but—

LG: But you never had a desire to try to find other people with hemophilia? Quite the opposite. It wasn't something you wanted to identify with at all.

FS: No, no. Only time I really started talking about it, all right, sounds strange, but is with the outbreak of AIDS. Then there was the whole thing on AIDS and I'd never had a transfusion.

LG: You've never had a transfusion?

FS: No, and then there was—the rare occasion you'd hear of somebody who had AIDS that it came from a transfusion and they had hemophilia, and I suddenly started saying, “Hey, I'm going to talk about it a little bit. I have hemophilia and if I ended up at some point, some point, you know, having AIDS, I want people to know that I had hemophilia.” I don't know if that makes sense.

LG: You mean, you wanted to be clear if—

FS: I wanted to make sure that nobody thought that—

LG: That you were a drug user or you were gay.

FS: Yeah, yeah. So that I would talk about it, but—and it's amazing, absolutely amazing how closely people associate hemophilia with AIDS. In a minute and you can see it in people's eyes, you know, I'll say to Mae—like a lot of times Mae will say in some conversation, she might, "Because, you know, Fran has hemophilia," and you can almost see sometimes people recoil, but you know, and it's not my imagination. But people do. People do.

LG: And what is that like?

FS: You just—you just—now I know what it's like for some other people that—

[end of Side B, Tape 1]

LG: You were telling me before about the AIDS piece and how for the first time you had an appreciation of how society would respond to someone.

FS: Right.

LG: What were you saying to me?

FS: I was I guess trying to say like, you know, for years I went—I've come full cycle. I went from years that people, I didn't—in the neighborhood I grew up in, everybody knew that I was a bleeder, had hemophilia, and I should be treated different. It was like a stigma to me, and I wanted to get away from that stigma, so as I entered into, say, the teenage of my life—from a teenager on—I was able to travel in circles where it wasn't a subject. It was not like a deep, dark secret, but it was just something I didn't talk about because I didn't want people treating me differently than they did anybody else. I wanted to be one of the guys, you know.

Then I went into another setting, we'll say as a family person, becoming aware that I couldn't totally and completely sweep it under the rug. I had to live with it, but other people's lives could be affected by it, not only through the passing on to the grandchildren, but the need to provide for my own family and the difficulties that I could have, whether it would be somebody looking upon my future advancement differently because I might—because I have a medical problem. And over to a later in life aspect that because society was drawing a close parallel between hemophilia and AIDS, and the gay issue, that—and not wanting to be labeled as a gay, I built up certain interests in terms of letting people know that I had hemophilia. It went full cycle from not wanting people to know to suddenly—

LG: So you wanted to let them know you had hemophilia to make sure they knew you weren't gay, in case you got AIDS.

FS: Yes. Yeah, yeah.

LG: And you were saying people would recoil when they'd hear hemophilia. What was that like?

FS: Well, I don't want to—by the recoil, it would be—

LG: About the AIDS.

FS: Not that they'd be, say, afraid to shake hands or something. You could see in—you could see in the eyes and it would—it would almost lead to some questions about the hemophilia aspect of it, and you'd almost know the line of questioning, what was in the person's mind. Like "Do you have—have you ever had a blood transfusion?" or "Have you"—I don't know if that makes sense to you or not, but—

LG: But you've sensed they might be afraid of you.

FS: Yeah, yeah. Right. Right. Yeah, and I think Mae is aware of that, too. You know, now, as I pointed it out to her, she can see sometimes, you know.

LG: Did you ever get tested for AIDS?

FS: No.

LG: No, because you never had a transfusion so you don't have to worry about it.

FS: Never had a transfusion, never had—

LG: So you knew in yourself you didn't have it, but society didn't know that, just because of your label of hemophilia.

FS: Yeah, right. Right, yeah. Yeah.

LG: What was it like for you, Fran, to have grandsons with hemophilia? Did you worry when your daughters got pregnant, for instance? Was that a concern of yours?

FS: No. No, no. No, it was—I guess we've run into a few cases where it has been suggested, mentioned, you know, the availability of an abortion or something because of the hemophilia issue, you know, but not in our family. I mean, the whole abortion issue is strictly something we don't believe in, but I mean that subject has come up in terms of—in terms of passing it on and that.

LG: Were you ever worried about your daughters having kids with hemophilia?

FS: No.

LG: Okay.

FS: No. Yeah, no.

LG: Because?

FS: Well, I guess probably because we've lived a life and—a good life, and except for a few aches and pains, you know, haven't really had—it hasn't affected our lifestyle or anything.

LH: Uh-hmm.

FS: And there's big improvements in terms of how it's handled, how it's treated, how it's, you know, diagnosed today, in contrast to what it was, you know. When I think in terms of—that's the bridge I have to get over is this, you know, gee, the minute you think you—you see, when you do get an injury, it doesn't show up right away. Be something like you'd bang yourself and right away you start bleeding. You can—you can take an awful whack and not be affected by it at all, or you can take just a minor hit and think nothing of it, and a week from now you say, "Oh, geez, I can't even move my arm. It's starting to swell up. I wonder how I did that?" you know. So when something does happen, it's just amazing to see, you know, how quickly everything is put together.

Like with the accident I had, how quick they got the factor. Even though they didn't have it at the hospitals, they were able to find a supply and find the factor and to find it to be the synthetic, so that it's pure and then there's no problem with it, in contrast to what you had before, you know. I had—back—I banged up this knee again in a serious injury fifteen years ago, something like that, and I ended up going to the doctor over in Salem and a hematologist there, and said, "Well, we've got two courses we can take. One, you know, we can bind it up and put a splint on it and get you off of it, or we can give you factor, but I don't recommend you taking the factor because of the"—

LG: The safety of them.

FS: The safety of it, and he said, “There risk there is too great.” He said, “I feel the risk there is too great, and that you’re better off to keep it bound up.” So that’s what we do. Where today it’s so much—you should always have some in the refrigerator, so that if you do get hit, don’t wait.

LG: You know, given your experience of how people responded to you or tried to protect you or define you by your hemophilia, do you have any thoughts for your daughters in how they should have or could have approached it with their sons?

FS: No. No. I just feel that each one—and each, the daughters that have children with it, it’s very interesting to see how they all approach it a little differently, and I think that’s the way it should be in life. I don’t think we should sit and take—everybody’s their own individual and I think you need to take the course that’s going to fit your own—not just physical, but your own mental needs. I mean, I have one daughter that is very protective of her son and doesn’t let him—he’s always—well, he’s out of college now, but has always steered him away from any type of heavy physical encounter and has steered him away from, you know, like even cutting the grass and things like that because he could get hurt.

LG: Not so dissimilar from your experience growing up.

FS: Yeah. Right, yeah, and to—her sister taken the opposite with, “Hey, get out. Do anything you want to do,” and you know, you look at Pam and her two boys and think of Ben off hiking the Appalachian Trail all by himself with backpack and away from civilization, and Chris rowing on the college rowing team, and

they're off skiing, you know. Who's to say what's right, the right approach and the wrong. You have to do what—I don't think anybody should be—the interest, the desires should be stifled by it. I think they should just live with it, and if it shortens your life, so be it. I mean, you know—like I figured I was going to be lucky if I could live beyond twenty-six, and like I mentioned earlier, I'm seventy-six. I've had fifty years, you know, and pretty much doing my own thing.

Now, whether that's the right approach. Whether that's the approach for everybody, doing as—like we talked about with my brother, doing your own thing wasn't his thing. I mean, his thing really come down to being closely watched and guided and, you know, and making sure that everybody knew. He went on to become a Shriner and was in Shriner parades and stuff, but I mean, if anything happened to him, boy, everybody knew, you know, where he was to go and how he was to be taken care of. I know, they got after me. They got after me. I was traveling and—and rightfully so because I was traveling on a plane. We were in some rough weather and I was strapped in and I went one way and the plane went another way and I ended up bruising a, bruising a rib, and I was in wicked pain. I was out in Indianapolis and I sat on the edge of the bed all night and seven o'clock in the morning, I was on a flight to come back to Boston and I called Mae and said, "I'm headed back home." So they met me in Boston and took me right to the hospital, but I had locked in my own mind that I didn't know what was wrong, but I said, "No way am I going to get stuck in a hospital in Indianapolis. If I'm going to be stuck in a hospital, it's

going to be a local hospital,” and maybe that wasn’t the smartest thing to do, but I did it. But the doctor got after me and at that point he said, you know, I didn’t have a medic alert on me. I didn’t have anything in my wallet that said I had hemophilia. I didn’t because like I say, I just didn’t carry a badge around any place. So he really got after me at that point and said, “Hey, you might go through and do your own thing, what you’re talking about doing and stuff, but at least you got to have something on you.” So I started wearing a medic alert.

LG: You did?

FS: Yeah. Yeah, and I have it on the back of a bracelet, but he said, “You’re just plain foolish that way.” He said, “Because there’s nothing on you that would indicate that you have it, and if you say became unconscious and they had to take you to the hospital and operate on you, you know, you could have been dead.” So I mean, I took that advice.

LG: Was there anything that was particularly helpful or harmful to you, do you think in coping with hemophilia?

FS: Helpful or harmful?

LG: That either helped you cope with it better, or helped you not cope with it so great.

FS: Well, I think my ability to block it out I think—

LG: Was?

FS: Helpful.

LG: Helpful.

FS: Yeah, helpful. I think if I had dwelled on it, there would have been so many avenues in life that wouldn’t have been open to me.

Things wouldn't have been possible for me. We talked about, when we started, how I got into sailing, you know. I was told "You better not get into sailing because"—

LG: Oh, you were told that?

FS: Because the boom could come across and hit your head, you know. You know, and you run into all kinds of things.

LG: So you really fought against those words of caution: Don't do this. Don't do that. You didn't want the hemophilia to get in the way of what you wanted to do in life.

FS: Right. Right.

LG: And your philosophy more was "I want to do what I want to do, and if it shortens my life, so be it."

FS: Yes. Right. Yeah, yeah. But you can't be foolish about it, you know. I suppose—but I don't want to jump out of an airplane. I don't want to parachute, you know. There's certain things in life I just don't want to mean, so I mean—[phone rings] I wouldn't want to say, "If I didn't have hemophilia, I'd parachute." I really can't—I'm trying to think of anything that I really wanted to do, you know. I probably would have been—I probably would have been really disappointed if the wall hadn't have been—if I had wanted or felt the need because everybody else was doing it, to go in the service and got a 4-F label, I would be—that would have bothered me because I wouldn't want to be labeled that way. I guess that's it. I guess that's probably the big thing right there. You just don't want to be labeled in life, you know, and have a Scarlet Letter.

LG: [chuckles] Do you ever talk to your grandkids about it? Is it a subject that comes up within the family at all? Do they ever ask you about it?

FS: It comes up every once in awhile, just as a passing comment. Like, “Oh, Grampy, you’re just like us,” or “just like me.” You know, every once in awhile I might say something, but I can’t really think of cases where, you know, we’ve sat down. They might have asked me, but I can’t think of anything.

LG: Is there anything you’d want to say to your kids, your grandkids, about having hemophilia in life? Any advice you’d have for them particularly?

FS: I don’t think so. No, I guess just be yourself and do your thing, you know. Live out your dreams, you know. I’ve just never let it hold me back. But like I say, I haven’t really ran into a situation where it’s really has come up and said, “You know, okay, you’re 4-F,” you know. You might want to go in the service. You might want to protect your country. You might want to, but you can’t do it, you know. I haven’t run into any situation where—

LG: Although you ran into that a lot when you were in elementary school.

FS: Yeah, yeah.

LG: constantly.

FS: Constantly, but--

LG: And somehow that didn’t define you then. You didn’t become this timid, “I can’t do this. I can’t do that.”

FS: Yeah.

LG: In some ways you reacted against that by saying “That’s it. I’m not going to let this define me.”

FS: Yeah, yeah.

LG: You didn’t find that caution and careful and treating you different helpful to you.

FS: No, but I think probably at that age and everything at the time, I didn’t recognize it, you know. I really, really thought I was faster, swifter. [laughs] More agile. I mean, that sunk in slowly, so maybe, maybe I was a slow learner.

LG: Is there anything that I haven’t asked you?

FS: No.

LG: That I should ask you? Or anything in your notes that we didn’t cover that you’d like to say?

FS: No, as you can see, I made—made—a whole list of bullets here, and we covered—we covered every, every one of them. I can see every one of them, and Dr. Alexander, Leahy Clinic, yeah. Oh, on the life expectancy, I put life expectancy of twenty-six and the seven year cycle that I was led to believe. You know, and so maybe by the time I’m twenty-one, at that point I’m married, that you will have outlived your hemophilia, you know. We know nowadays that doesn’t happen, you know.

LG: But in your mind maybe you thought, “I’m just going to outgrow this. This isn’t going to be part of me anymore.”

FS: Right.

LG: Yeah.

FS: And my cousin Billy who died at twenty-six, and my cousin Buddy who was thirteen, and my brother Lawrence at seventy. So there’s

my brother Lawrence at seventy, and I'm still going at seventy-six. So I would say that's pretty normal.

LG: [chuckles] Well, I want to thank you.

FS: Oh, well, it seems like I've been chatting away here for—but I was really happy to sit down and go over and just discuss some of the things that—these are thoughts while shaving or, you know, however we want to label them. Life's been good. Life's been good.

LG: Life's been good.

FS: Yeah, really has.

LG: Yeah.

FS: Really has. Life's been wonderful. Yeah. I think in terms of I've had six marvelous children, and I have a son, too. We have five daughters. I have a son who does not have hemophilia.

LG: Right.

FS: Who has gone through ranger school, is a DEA agent, lives quite the different type of life than I do. He's off on drug raids and jumping out of planes.

LG: Wow. You know, the only thing I didn't ask you is do you think that hemophilia gave you any sensitivity that you might not have had, having to deal with something different or a disorder? Do you think it gave you any insight or appreciation?

FS: I don't—I don't think so.

LG: Okay.

FS: But we are, and hadn't always been, but we are very involved with our church.

LG: Has faith played a big part of your life?

FS: Faith has played a big part of life.

LG: It has?

FS: In the latter part of my life. Earlier part, I would say was with my wife more so than myself, but we brought the family up, you know, with involvement in the church and that. But in the—I had a heart attack in '91 and at that point faith started to play a big role, and as we—through our involvement in bible studies and that got to become more aware of the need to be more sensitive to people, and to people that have different problems and different lives, different issues in life, and I look upon things completely different now today, as I did say when I was running a company.

Probably—and I think I did a good job running a company, but I had a couple of hundred employees underneath me, but I like to think I probably would be more sensitive today to certain issues, particularly the health issues, as they relate to different people, different things.

LG: You think you'd be more sensitive due to your bible studies, rather than the hemophilia?

FS: Yeah. Yes.

LG: It was the bible studies that opened you up and made you more sensitive to other people's issues.

FS: Right, right. Yeah. Yeah. But like I said—probably—I'm starting to repeat myself now, but probably the hemophilia issue was probably in my hip pocket and you know.

LG: All right, Fran. Why don't we stop here, then?

FS: Okay.

LG: Thank you.

FS: Well, nice being with you, Laura.

End of Interview