

Interview with Stephen Place for the Boston Hemophilia Center Oral History Project, A Gift of Experience, by Laura Gray, September 14, 2004.

GRAY: I'm sitting on Cape Cod with Stephen Place. My name is Laura Gray and he has graciously agreed to participate in the Gift of Experience Oral History Project that we're having at the Boston Hemophilia Center. It is September 14th, 2004.

So, Stephen, let me start by saying thank-you.

PLACE: You're very welcome.

LG: Just tell me a little bit about where you grew up.

SP: Okay, I was born on September 26th, 1954, Oak Bluffs, Massachusetts, which is on the island of Martha's Vineyard. Mom and dad, Jan and Trueman Place, one sister, Cynthia. She's older. Lived on Martha's Vineyard for twenty-two years, all through grade school and high school and four years of college. After that, I moved off of Martha's Vineyard to Philadelphia for a couple of years.

LG: What brought you to Philadelphia?

SP: My girlfriend, and we were married in Pennsylvania and moved back two years later to Cape Cod and have been ever since.

LG: So you've been married for?

SP: Twenty-six years.

LG: Twenty-six years. Now, tell me a little bit about when the word hemophilia came into your family?

SP: I think my mom and dad found out I had hemophilia when I was three years old. Running, like any other normal three year old, and tripped and fell and hit my mouth on the corner of the table, and

the little part that holds your upper lip up to your jaw, and that bled quite a bit. We were on Martha's Vineyard, of course and there was a Dr. Ganz, who was from MGH and he was the pediatrician pretty specialized in hemophilia and that kind of thing. He treated me and they got the bleeding stopped, and that's when they brought me to Mass General and got tested and found out I had hemophilia.

LG: Had anyone else in your family had hemophilia that you knew of?

SP: My mom's brother actually died of a tonsillectomy when he was twelve. So that would have been probably in the late '20s, early '30s when he died.

LG: Now, had he been diagnosed with hemophilia?

SP: No.

LG: So you're assuming that he died of hemophilia?

SP: I'm certain that he died of—he bled to death.

LG: He bled to death?

SP: Uh-hmm.

LG: Did any other family history come up after your diagnosis, other than your uncle?

SP: No, as far as I know all my other cousins have not had hemophilia. I have a nephew that has hemophilia, my sister's son, so that got carried over for her. But she has another son that does not have hemophilia. So it's a fifty-fifty.

LG: Do you remember anything about this when you were three? Do you remember being flown to Mass General?

SP: No, I don't remember. I don't remember anything about it. There are a lot of events in my life, when I knew I had hemophilia.

Probably the most significant was when I was eleven, I had a pretty serious bike accident and still have the scar on my forehead to show.

LG: I can see it, right in the middle.

SP: Fell off my bike, no hands, and my head broke the fall. It was the first thing that hit, and had a huge lump. That's kind of when things—when I was curtailed from doing contact sports, a lot of things that I couldn't do that I normally would do.

LG: From that point on you were curtailed from contact sports?

SP: Yes.

LG: And why from that point on?

SP: Well, then they—I guess some of the doctors in Boston thought, well, I shouldn't be participating in contact sports. I wasn't a real sports nut. I always played baseball and played basketball and played, you know, a little bit of football, but I was never a big sports enthusiast, so it wasn't—it was traumatic. That was probably a traumatic time when I knew I couldn't do things that I normally did.

LG: So let me ask you something. From three to eleven, did the diagnosis of hemophilia make any difference to your lifestyle?

SP: It did. It did a little bit. I was—

LG: What do you remember?

SP: I remember, well, just being a little less active in sports than I might have if I didn't have hemophilia.

LG: By your own choice or by someone's nervousness?

SP: Oh, mom and dad. Mom was very nervous.

LG: Tell me about that. Tell me about your parents. Who was the most involved in your care, or were they both?

SP: Oh, they were both very involved. Mom was a nervous person, as most mothers are, and she just wanted me to take things easy, but my dad was a little—quite a bit more lenient. I always rode bicycles and there wasn't a lot that I didn't do. I just did it maybe a little less than anybody else. I always knew in my mind that I had to be careful, and if I got a cut, I had to get a Band-Aid on it or if I got a bruise, I might have to sit and wait and not do things that I wanted to do.

LG: You say your dad was more lenient than your mom. What do you remember about that?

SP: Well, I had knives.

LG: Okay.

SP: I was a hemophiliac, but I had a pocketknife collection. I had tons of them and I just loved it. It wasn't—my hemophilia was always said considered borderline. Was always considered mild. A lot of these words that it wasn't significant. If I cut my finger, I put a Band-Aid on it, like anybody else.

LG: So you had mild. Factor VIII or IX?

SP: Factor VIII.

LG: Okay.

SP: And it was just mild, and I just knew it was always—I didn't know any other way of life. In other words, when you have something like hemophilia, you don't know what it's like not to have hemophilia. You know, if you bang your knee or if you bang yourself, you're going to get a bruise. Okay, you've got a bruise.

So I have it for five days and someone else has it for two days. It never was a—it was just a way of life. It's nothing I—it's hard to explain.

LG: So it's not something that was separate from who you were. It was just part of you.

SP: Just part of me.

LG: Do you remember ever having feelings about your hemophilia?

SP: Well, I did. After the bike accident, when I was eleven, this tremendous change in lifestyle, you know.

LG: Tell me about this accident.

SP: It was—well, I had a huge lump on my head. I mean, it was just massive. It was almost as big as an egg and it was just right smack in the middle of my forehead.

LG: What did they do? What was the treatment for it?

SP: Well, the treatment was a compression bandage.

LG: So they wrapped something around your head?

SP: An ace bandage, and lay flat. Aspirin.

LG: No other treatment that you remember?

SP: No, nothing whatsoever.

LG: Just they wrapped your head up.

SP: Wrapped my head up, told me stay, you know, calm and lay down. There was a product, it was a plasma product, but I never got it. It was always in the refrigerator, but I never used it. So there was really no—

LG: Were you in the hospital for any length of time?

SP: Not at all. Didn't even go. No, this is when doctors came to the house.

LG: Okay, so the doctor came to the house.

SP: Came to the house and said, “Yup, he’s got a lump on his head. Just put a compression bandage on it.” Didn’t know about aspirin being an anticoagulant then. So my head hurts, okay, give him some aspirin. But I’m here, I survived.

LG: So you never had further complications, just that big lump.

SP: The big lump. That was in August of ’65 and I went to school in September. I mean it was—

LG: Did you still have the lump?

SP: I had a good-sized scar. I just put a big old bandage on it. Had raccoon eyes because all the blood drained down and went into my eyes.

LG: Did the kids—

SP: Yeah, you got a little teasing.

LG: You did?

SP: Yeah. Oh, always had teasing.

LG: What do you mean, you always had teasing?

SP: Well, I was always the smallest and I was always the littlest guy and so the typical grade school stuff. Yeah, I was always picked on. Teased on. I was always the smallest, but that’s all right. I survived.

LG: What do you remember about that? Did kids call you names? Did they know you had hemophilia?

SP: Well, they did but it wasn’t significant. It wasn’t a big—wasn’t a big part of my life. It was just I could almost use it as a crutch if I didn’t want to do something.

LG: Did you use it as a crutch?

SP: Probably did. I don't remember anything specific, but I could have. I mean, I could not get into the military. That was absolute.

LG: But that's not using it as a crutch. That was just—

SP: That's just part of life, and I never really made it to the physical or to the draft.

LG: How come?

SP: Because that was the year that they stopped it.

LG: What were your thoughts about that?

SP: Thank you, Lord. Absolutely, because I didn't want to go. I mean, you knew guys that died.

LG: For the Vietnam War.

SP: The Vietnam War.

LG: Just let me back up a little bit to your parents.

SP: Sure.

LG: Because I'm interested in sort of the attitude that parents had toward their kids, and how at this point you can look back and say "What affect did that have on me?" You know, how did your parents talk about it? Did they talk about it? How did they treat you? What do you remember about that?

SP: Well, I remember that they were always concerned if I got a cut or got a bruise. They were both concerned. I mean, it's not that my dad wasn't concerned. It was that my dad maybe—he certainly didn't know. He wasn't in medicine or anything but he knew that—you know, some dads worry. Moms and dads worry different levels and moms are always worried about their children and, you know, whatever. As a dad with my two daughters, you know, if they fall down, I said, "Come on. Get up. Let's go," you

know, “Walk it off. Walk it off. Walk it off.” That kind of thing. My dad was a lot like that. He would say, “Don’t worry about it. Don’t think about it a lot.”

LG: So he wouldn’t baby you?

SP: No.

LG: And your mom?

SP: Yeah, she babied me a lot.

LG: Did that cause conflict between the two of them, that you were aware of?

SP: I don’t think so. I think it caused conflict with my sister because I was the special one. The baby is always the special one, to a certain extent, but I had the hemophilia, so the extra precautions or maybe the extra trips to Boston. Kids are very, you know, protective of their territory and their rights and their “it’s not fair,” kind of thing.

LG: Your sister’s name was?

SP: Cynthia.

LG: In what way do you think it bothered Cynthia?

SP: Well, she always thought I was the special one.

LG: She would say that?

SP: I would think she would say that, yeah.

LG: Would she complain to mom and dad about that?

SP: Probably, yeah. “He always gets special treatment,” or “He always gets this.”

LG: What was that special treatment like for you?

SP: That was great. [laughs]

LG: It was great?

SP: Sure.

LG: So you liked the attention?

SP: Sure, I did, yeah, but I never wanted to be, you know, singled out and be the better one than her. This would not be my nature.

LG: Let me just go back again. You said, “You know, I was a little more careful.” Were you a little more careful?

SP: Yes.

LG: What do you remember about that?

SP: Well, riding bikes. I’ll tell you, once I fell off my bike riding no-handed, to this day I do not take my hands off of those handlebars.

LG: What scared you most about that bike accident?

SP: Oh, the lump.

LG: Because?

SP: Well, it just—I mean, it was, you know, when I felt it, I got up and I went “Ugh,” you know.

LG: It just blew up.

SP: Yeah, I just really picked myself up and walked home and I wasn’t far from home. I was, you know, just down the street, but I think when my sister screamed, I knew I was in trouble.

LG: But did it hurt you or was it just visually so scary?

SP: Oh, it hurt. It hurt a lot. There was a lot of pain. I think and what I wanted to say, one thought that came to my mind, I think when I was—after this lump, after this bruise, after this trauma, I knew that—it became at that point in my life—that’s when it became significant. I knew that I have hemophilia and that I can get hurt, but I decided at that point in my life, and I remember making a firm decision that I was going to respect it, but I was not going to

be afraid of it. I was not going to allow anybody to make choices for me, as much as you can as an eleven or twelve year old person. That I was going to be making choices about what I wanted to do, how far I wanted to venture into whatever area that I wanted to go.

LG: I am fascinated by that. It sounds like there was a real epiphany at that point for you.

SP: Oh, absolutely. I just—I can't remember the day, but I can remember making the decision, "I'm not going to let this make me into a whuss. I'm not going to live my life as not doing things that I want to do. If there's something I don't want to do, I'll use the hemophilia as a quote, unquote, crutch." If I didn't want to play football, because I really was never involved, really, and I really shouldn't do that. You know, I would say I couldn't be a boxer, obviously. I couldn't be in the war or anything like that. So, that's—

LG: I was saying that I was just fascinated by this event and how it was apparently life altering for you, and you said to me, "I can tell you more about that."

SP: Well, I guess from that point on, from when I was very early teens, I decided to do my own. To be able to pick and choose and look at life and say, "Okay, there are certain areas where I'm not going to go in, but there are so much more that I will go to, and I really don't want—I want to be able to make my own choices." I just decided to be able to live life and not be afraid to cross the street or be afraid to ride a bike anymore or be afraid to do anything. But I know I have limits and if I cross the limits, I know I can get hurt.

The change was from the event of the head injury. I had a lot of people telling me what I was going to do.

LG: I see.

SP: But then whatever it was, a year later or something, I decided, "I know my limits and I'm going to go to those limits, the extreme limits. If I cross the line, I could get hurt and I'll pay the price."

LG: I see. So somehow that event made you step up to the plate to take responsibility for yourself.

SP: Exactly.

LG: And not just have your parents decide what was right and what was wrong for you.

SP: Correct.

LG: Do you remember what it was like to have others determining what your behavior was going to be?

SP: Well, as a young child I think you have mom and dad making your choices for you. You know, they let you make choices a little bit. You know, my mom and dad, I think my dad was the one who would be more apt to let me make a choice, rather than my mom. "Well, that's not really good for him," you know, "We have to worry about the hemophilia," da, da, da, da. I never really heard them talking about it. That's one thing, they kept it pretty much to themselves and I'm sure my dad relented to my mom a lot of times. One funny event. He bought me a Swiss Army knife and first thing he did when he came home was he went down cellar, took this brand new knife and dulled it on a whetstone. Just dulled it right down to almost nothing. So the first thing I do, I open it up and say, "Oh, and it's so sharp." [laughs] Now, that's absolutely

what happened because they reminded me about that, but they were—now, see, my dad would let me have a knife, but it would be dull so I'm not going to be cutting my fingers off and do that. So that's kind of the way that my dad would think, "Let him live. Let him have a good life. Let him enjoy himself. Don't coddle him."

LG: How did having hemophilia play out as you got older, in high school for instance, or into after high school?

SP: Well, high school I didn't do any sports, specifically because of the hemophilia.

LG: Did you have alternative interests in high school?

SP: Well, I worked. I worked at a hardware store and I just loved that. That was my passion. I just loved to do it.

LG: Really?

SP: Oh, just couldn't wait. The day I turned fourteen I got my working papers and that's the day I started. So I couldn't wait and I loved it. So I did a lot with my dad. My dad and I were like best friends. We always did things together, build and paint and we went out in a boat because we grew up on the Vineyard, so we were on the boat every weekend. Went fishing, clamming, quahogging, all kinds of neat stuff. He was always there and we spent a lot of lot of time together. So that was very good. It helped me a lot. Helped me develop into who I am today because I always think about my girls and what would my dad do, you know, in every situation?

LG: Would he talk with you about the hemophilia?

SP: Not really. No, it wasn't—I think he knew that I knew what it was and to take it easy and I knew my limits.

LG: So then what happened after high school?

SP: Well, I got into college.

LG: And where did you go?

SP: I went to Cape Cod Community college for two years, got an Associates Degree there. Continued on to Western New England College in Springfield, got a Bachelor's Degree there. Started graduate school at Plymouth State in New Hampshire and I went one semester and I was done with school at that point. Through high school, college I had a fair amount of injuries, mostly knees. My knee would blow up or I'd hit it, hit wrong and then I'd have to sit for a week.

LG: What do you mean you'd have to sit for a week?

SP: Well, when the knee blows up, you just sit for a week and try to let it heal.

LG: No medicine? No anything?

SP: Not in high school. Not in grade school. Not in high school and not in college.

LG: No cryo?

SP: No cryos, no factor VIII.

LG: No nothing.

SP: Nothing.

LG: So you'd just bite the bullet and let the swelling go down.

SP: The swelling go down.

LG: Tell me about pain. What do you remember about pain?

SP: Never really a lot of pain.

LG: No?

SP: No, just boredom and “Can’t stand sitting here.” The hardest thing for me to do is to sit. I can’t sit, ever.

LG: But you’d sit.

SP: But I’d have to sit. Well, that’s what the doctors would tell me to do. “You’ve got to sit.” My knees all blown up and I’m just going to sit until this thing gets better. Then it would get better and then I’d be on my way.

LG: So it would take a week or so, as you remember?

SP: About a week for a knee, yeah.

LG: And how often would that happen in your life?

SP: Not often. Not very often. I know that the first time that I got factor VIII was 19—I’m trying to remember now. 1981 when I had—1982 when I had a half a kidney out. I got my first shot of factor VIII and the only—and then I got a lot of cryos at that same time, too, so they could make sure it stayed healed and everything else. The only thing I did get out of that was some hep-C. No AIDS, which I’m very thankful for. I had a factor VIII company, it’s called—it’s down in Connecticut. Can’t remember one of the name of it. One of the ladies there told me, she says, “Probably the reason that you didn’t contract AIDS was because you grew up on Martha’s Vineyard and there was no hematologist. There was no factor VIII readily available.” She lost her son to AIDS because he was a hemophiliac and he got, “Oh, boy. This brand new product comes out. Boom, I’m going to give it to you and you’re going to be able to live life like a normal person,” and no one knew about it and it claimed a lot of lives.

LG: What was that whole period of time like for you? Do you remember what you thought about it when you started hearing about it?

SP: About the AIDS?

LG: Yeah.

SP: Oh, yeah, I remember.

LG: Tell me.

SP: I remember when I heard about it and it had to do specifically with factor VIII and everything else, and I waited and waited a couple of years and then finally I decided to get a test, and I got the test.

LG: So you waited a couple of years wondering?

SP: Yeah, and then I waited. Then it was—I got the test like say in the middle of the week and I called, you know, for—the test results would be available, you know, such and such a date. Well, the doctor was out of the office for the whole weekend, so I had this terrible horrible week. Almost a week. It was horrible just waiting, but he said, “You’re clean and you’re clear.” Of course, they didn’t know about hep-C then either.

LG: Did having hemophilia affect your love life?

SP: No.

LG: Not at all?

SP: No.

LG: Was it an issue in your thinking, “Will a woman want to marry me?”

SP: I don’t think so.

LG: Did you tell your girlfriend and wife about it?

SP: Oh, sure. Oh, yeah.

LG: What do you remember about that? Was it something you were worried about disclosing?

SP: No. Not, with my wife, no. Not with Carole, no.

LG: Had she known about it? Did she notice it or did you have to tell her?

SP: Oh, I had to tell her. I have no physical signs at all of hemophilia at all. Nothing. I don't have any lines or any—you know, where I'd been giving myself Factor at all. I mean, the only time I use it as necessary. Treat as necessary.

LG: No limping. No really bad joints.

SP: No. No.

LG: When you married your wife, was there ever an issue of children or a discussion around that?

SP: We talked about kids and we knew that I was—you know, I had hemophilia and that I could give it to my daughters as a carrier and that their sons might have a fifty-fifty chance. They will definitely be a carrier because it's on that chromosome and it's a fifty-fifty chance if they'll pass it onto their sons. But we know from all the doctors we've spoken to, it will never be more severe than mine. We know now that there are factor products that take care of it, you know, very quickly.

LG: What's your relationship with factor now?

SP: As needed. I have it down cellar in our refrigerator down cellar and if I get a bump, or a bang, or a bruise or something I feel that's significant, I'll grab it. Go to Cape Cod Hospital and say, "Here. This is how you do it."

LG: You don't self infuse?

SP: No. I could. I suppose I could, if I had to.

LG: But it's not something you've had to do that often and therefore you never learned.

SP: I've never self-infused. I imagine I could. I'm sure I could. I can do just about anything. I'm not afraid to do anything like that. I have, you know, syringes and the factor down cellar and that kind of stuff, and I carry a little thing in my wallet that says, you know, "If I'm unconscious, the factor VIII's at my house. Get it. Get me to Cape Cod Hospital." I have a doctor. I also have a doctor, a hematologist right here on the Cape.

LG: So you do have a hematologist now?

SP: Right, but I've only seen him once. Just as an initial visit, and he's kind of there in my back pocket, in case I need him.

LG: How does your hemophilia affect you in life now? Or does it?

SP: A little—I'm a little more careful than the normal person.

LG: Physically?

SP: Physically. If I am doing something, I look at a couple of important points. Head, knees, elbows. If I bump, bang or something, you know, fairly good rap, I'll run right up and I'll get some of my Stimate. Shhh, Shhh, a couple of squirts, put in the back in the fridge and right back outdoors doing whatever I was doing.

LG: So the Stimate is really something that's helped you?

SP: It does. It brings my factor level up to fifty percent. That's what they tell me, which is great. Which makes things heal a lot faster and be a lot less severe and a lot less down time sitting and waiting. I asked Dr. Marks a long time ago if Stimate was

something I could use every day and he thought the—I don't know what the word is, but it would not be as effective if I used it every day.

LG: So you use it on an as-need basis.

SP: Just as needed, yeah. If I'm going to go out and I'm going to be working, like I've been reshingling my roof, and what I do before, I do it preventatively. I do it prophylactically. First thing in the morning I'll just put a couple of squirts in there and I'll go out. So I have that. As a hemophiliac, when you have that little extra less chance of being hurt or little less chance of a bump being significant, it's much easier to work because you're not worried about getting hurt. If you're not worried about getting hurt, you're more relaxed and you're less apt to get hurt. Do you understand that concept?

LG: Uh-huh.

SP: It's when you've got your seatbelt—when you get your seatbelt on in the car, you don't mind going down the road, but if you don't have a seatbelt on, you're going to be nervous and you're going to be looking around and an accident is more likely to happen when you're nervous about stuff.

LG: What about your daughters and the fact that they're obligate carriers.

SP: Sure.

LG: Do they know about it?

SP: They know about it, and they will, when it's time—you know, when they get married, they'll have to disclose that to their fiancés and say, "You know, this is a chance," and they have to go on that

way. But I believe and I read a little bit in my *HemAware Magazine*, they are working on genetically engineering to be able to eliminate it, and I think in my lifetime it will be eliminated.

LG: Do you?

SP: I sure do. They're doing other stuff. Other medical science has come out, which is amazing.

LG: Have treatment advances changed your quality of life?

SP: Never thought of that. Yeah, sometimes I wish I didn't have it, especially when I'm sitting down in a chair for a week with a bad knee of something. But now, since the factor is pure and if I did ever, you know, really mess up my knee, I'd get some factor into me. I would leave that line in there and I'd probably do it for two or three days, and then instead of being a week sitting down, I could do it for a couple of days. So that does make the quality of life much better, knowing that it's there.

LG: So in some ways it's not as much of an intrusion.

SP: Right.

LG: Was it much of an intrusion on your life, as a mild factor VIII person?

SP: I suppose in some things. You know, there were things that I couldn't do. Like I couldn't do sports. Even if I wanted to, I couldn't do it. So my choices were a little bit more limited, but then I guess I made a decision, "Well, that's okay." Maybe that's why I'm not such a sports, crazy sports fan because I never really could participate in sports for any extent.

LG: Do you think there were benefits from having hemophilia?

- SP: Probably still alive because when you're a teenager you're crazy. There were times when I said, "Well, if I drink too much and I'm driving home and I get into a car wreck, I could really die. So maybe I'm not going to quite drink so much so if I won't get into a car." I mean, that's being pretty basic and pretty honest.
- LG: How did you become so reasonable, do you think?
- SP: What do you mean by reasonable?
- LG: Well, by this whole business of "I'm really going to take this into account," versus, "Oh, I hate this thing and I'm going to do whatever I want and the heck with it."
- SP: Well, God made me—honestly, God made me this way, so I'm going to take what he's given me and make the absolute best I possibly can out of it.
- LG: So that's how you thought of it, that God made you this way.
- SP: Sure, absolutely.
- LG: Tell me about God and you. Is there a relationship?
- SP: Oh, a very good relationship. I'm born-again Christian and came to faith in—actually, my wife gave me the Gospel, Jesus Christ as personal savior, and I accepted him as my savior—this is back when I was twenty-one, twenty-two. I always had a good relationship, I thought, with God, but this is a relationship with Jesus is much better. It really is. And from then on, just kind of dedicated my life to do whatever I can to serve Him, and to know that, you know, there's going to be tough times. Just because you're Born Again doesn't mean that life's going to be a bowl of cherries.
- LG: And how does your faith help you in tough times?

SP: Oh, because I can go to God and say, “Help me through this time,” and He always has. Every time. Never been a time that God’s let me down. Never.

LG: At twenty-one you let Jesus into your life. What about before that?

SP: Always had a relationship. Always great, yeah, right from when I was very young. Knew that God was there and knew that God would help me. Always prayed.

LG: So faith has played a very central role in your life.

SP: Absolutely.

LG: Did the faith make it easier to handle hemophilia? Oh, I imagine it makes it easier to handle any challenge.

SP: Any challenge. Still hard, though. There’s still time. I’m a very impatient person.

LG: In what way?

SP: Like I don’t like to sit around. I can’t sit. Want to do everything now. Get everything done right away. My theory is to do today what you could do tomorrow because when tomorrow comes, there might be something better to do.

LG: Do you think having to sit with a swollen knee has anything to do with that?

SP: Sure. Because it just—when I had my half a kidney out, I was in the hospital for almost a month. Everything was fine and I came home after two weeks and got a little bit too crazy trying to do something and everything broke apart in there and I had to go back in and get more cryos and sit for another two weeks. So I’ve always done that. Whenever I’ve had an injury, I’ve always tried to get back into it too quick and paid the price. I had a hernia

operation and got back into it a little too soon, so it hurt for almost a year, and other injuries and stuff.

LG: But you can have surgeries and have your bleeding managed now.

SP: Yes, with the factor. Works well. I don't want anymore surgeries. I really don't.

LG: You have two daughters?

SP: Two daughters, yes. Stephanie is sixteen. Meredith is twenty.

LG: Is Meredith married?

SP: No, lives at home.

LG: If Stephanie or Meredith were to have a child one day who had hemophilia, what would that be like for you, do you imagine? Do you ever think of that?

SP: That wouldn't hurt me.

LG: Wouldn't hurt you?

SP: No, I'd say, "Let's go. This is just one little thing and we'll go through." I'll also mention we have in our family something called neurofibromatosis. Are you familiar with that at all? Okay, neurofibromatosis is a genetic neurological disorder where the—it's a sheathing that's on your nerves. It's like a wire, like the plastic coating on the wire. Well, it gets enlarged, and Stephanie, on the right side of her face has a neurofibroma on the side of her face. That's one thing that neurofibromatosis causes. I have little fibromas like all over my body and my neck, these little dots and these little things. It also caused a brain tumor in Stephanie when she was four. It was in her thalamus. It was inoperable. Brigham and Women's had a brand new treatment called stereo tactic radiation, and where the radiation comes in, instead of a brain bath

for the entire head, it comes in and energized when the two beams come together. So they can treat a pea-sized tumor, and it was developed back twelve years ago. So we went through that. She's also—she just had some surgery on her ear because that fibroma closed up her ear canal, it got so big. Meredith had scoliosis and up at Children's she had a rod put in her back to straighten her spine. She also had a long bone in her leg that wouldn't heal. All these things that can be caused by neurofibromatosis, it's NF1. There's an NF2, which I don't have a lot of information on. So I have it, but the only affects that I've had are just these little fibromas around my body, which don't really slow me down too much.

LG: So you've had to deal with a lot of medical stuff and a lot of stuff that's been passed on.

SP: Right. We made a lot of trips to Boston.

LG: It sounds like they've also benefited from some advances in science.

SP: Oh, absolutely.

LG: What about healthcare professionals? What has your relationship been with them? Do you have any memories of nurses or doctors or even social workers?

SP: Well, there was Dr. Ganz, who was this—he was at the Mass General. He was pretty important, pretty high up for MGH. He had a summer home on Martha's Vineyard, which is why we got to know him, through a doctor there. We'd see him every couple of years or something. Go up and give me a physical and he was very—he was very stern. You know, one of these old, stern type

doctors, but a nice guy and he would, you know, say “Well, I don’t want you doing this,” or, “I don’t want you doing that,” and I’d probably go home and do it anyway. [laughs] But he was the one that probably had a lot to do with my early healthcare. Some of our local doctors on Martha’s Vineyard, they were just general practitioner kind of guys and they just kind of muddled through most of everything that happened.

LG: Do you remember having positive or negative feelings about how people treated you back then, or even now?

SP: Well, a lot of people, you know, they hear hemophilia and they just automatically think the worse. “Oh, my gosh, you don’t want to bump or bruise him,” that kind of thing. Then when I would explain to them, “Well, it’s very mild, and it’s not a real serious thing, unless I’m in an automobile accident, unless I’m having surgery or something. Then I need to really, you know, be careful.”

See, I thought of something else when I knew you were coming. I’ve always had mild hemophilia, but I’ve never known anyone with serious hemophilia, so I really don’t know what someone with serious hemophilia goes through. I just do—even with me for mild hemophilia, it’s hard for me to conceive of what they have to go through every day. You know, giving treatment, factor every day. Every day. You know, have to do this. It’s like a diabetic, you know, every day they have to, you know, get some kind of medicine. I hate taking medicine. I’ll take a Tylenol once a month, maybe.

LG: Really?

SP: That's it.

LG: You're resistant to taking medicine.

SP: I'll just, you know, maybe a decongestant or something if I get a headache and that kind of thing.

LG: And pain? Just sort of tough it out?

SP: Tough it out. The headaches, the sinus headaches are about the worst part of my life, but they don't happen that often. So if I can treat them fast and get them going real fast, then I'll be fine.

LG: Were your politics affected at all with the whole AIDS crisis?

SP: No.

LG: No. No feelings about that?

SP: No, I knew that it was, you know, that AIDS was a very terrible thing and just a very small percentage of the people affected with AIDS—it was ninety, over ninety percent either illicit sex or illicit drug use and that's where it came from. It was just [unclear] and the amount of people that were affected outside of that category were very, very small.

LG: What about getting hep-C through the factor?

SP: Well, when I first—remember, I was up at Boston Hemophilia Center and I had blown out my knee for some reason or other, and they did some blood tests. They came back, "Gee, you've got antibodies for hep-C." Okay. All right, well, that just kind of is a thing. It's non-A, non-B is what they used to call it before they made it hep-C. So I knew about it and didn't really think a lot about it, and I saw a doctor at Brigham, a Dr. Grace, back in '99 and he did some tests. He said, "Well, this level's good. That level's a little high. Your count is very low." He said, "You're

probably going to die of something else, other than hepatitis-C.” He was a very old school—Dr. Grace. I remember him. He was very good. So I kind of ignored it for awhile and my regular—then I went to a gastro guy down in Hyannis and didn’t really care too much for him, so I kind of ignored it for awhile more, and see my regular GP and he tests the levels every six months or something like that, and they’re still pretty low. I did see another gastro kind of guy, gastroenterologist just recently and my levels are still very low on that. They said you could treat. It’s Genotype 1-A, which means if you treat Genotype 1-A, you treat for forty-eight weeks and you’ve got a fifty-fifty chance and it’s—my brother-in-law went through it and it’s pure hell. My sister told me it was terrible. Terrible for him and it didn’t do a thing for him. Now, my nephew, her son, also got hep-C from factor and he—

LG: How old is he?

SP: Adam—I think he’s twenty-eight or twenty-nine, and they say he got cured. He was free. I don’t know what genotype it was, but he only did it for twenty-something weeks. So couldn’t have been a Genotype 1. Now, my brother-in-law got it from drug use back in his early days, his teenage years or twenties or something. So right now I made the decision I’m not going to do it.

LG: Adam has mild hemophilia. Has he ever come to you about it?

SP: No, we really have never really talked about it much. There was a time in our lives, as a lot of family’s have, where my sister was kind of apart from the family. So those were his younger years, but, you know, we talk on the phone once in awhile.

LG: Were you ever that interested in meeting other guys with hemophilia? Was that something you ever wanted?

SP: No, never really thought about it.

LG: Never really did?

SP: No, I never really—it never was such a significant thing that I would join a care group or a help group or, you know, one of those groups. You know, when people have cancer or people have different things, they'll join a support group. Out on Martha's Vineyard, I don't think—there may have been one other person with hemophilia. It's not anything I have any desire to do. I'd like to help anybody I could.

LG: In what way, when you say that?

SP: Just my philosophy is to—again, is to respect it but don't be afraid of it. Respect the disease, but don't be afraid. Don't be afraid to do things. Don't be afraid to stretch yourself a little bit. You know, stretch it right to the limit and if you get by, great. It builds your self-confidence, builds everything up. Builds your whole self-conscious and self-esteem. Builds yourself right up.

LG: You're saying do that?

SP: Oh, yeah. Go to the extreme. Now, don't push the envelope too much because then you're going to do something stupid. Because then you're going to get hurt. Then it's just—I mean, I've done things that are stupid. I'll show you my scar. Right there.

LG: Oh, yes.

SP: That's a good scar.

LG: It's a scar on your left hand.

SP: I held a board and I held a razor scraper that you clean your windows with. I needed to trim a little piece of wood. I could have gone down cellar and got the right tool. It would have taken me a minute at the most, but I held that thing there and all I wanted to do was trim that little piece of wood. Now, I've got a clear thought in my mine, "Steve, if this thing slips, you're in trouble," and it slipped. So it was rush to the hospital. Get it stitched outside—just missed an artery. Stitch up the outside and I spent, again, a week and it hurt. So to save sixty seconds, I put myself out of commission for a week. Again, that was stupid.

LG: Do you think your father's encouraging you to go out and do affected your feeling that you could do things?

SP: Oh, sure.

LG: Because oftentimes parents wonder how careful should I be? How protective should I be? You know, it's such a hard balance. Do you have any thought about that?

SP: Learn your limits and go right to the limit.

LG: How do you know what your limit is?

SP: Trial and error. If, you know, you get hurt, you say, "Well, next time maybe I won't do it, or maybe I'll do it a little different." I have power tools. I have every power tool in the world. I mean, if I cut my hand with a power tool, I'm in serious trouble. Anybody who does is in serious trouble, but if I do, I've got that little extra bit of seriousness. So I think before I do stuff. "Okay, I'm going to cut this board and this part's going to go here. That part's going to go there. What's going to happen? What's going to be the end of this little adventure, this little thing that I'm doing here?"

LG: What is your work, Steve?

SP: I'm a salesman for Harvey Industries. We sell doors and windows. You might have seen our signs. We're quite big up in the Boston area. I've been in this kind of business, the building material business for twenty-five years, and built most of my house myself. Most of the rough frame, the house part was done, but hung all the doors and did all the painting and all the trim work. All the painting, and built the decks and the shed.

LG: Very impressive.

SP: So if I'm—I always wanted to do more than someone—
[end of Side A, Tape 1]

LG: All right, I've just turned over the tape. You were just saying to me you always wanted to do more.

SP: Do more.

LG: Because of your hemophilia. What's that about?

SP: [laughs] I just—I don't want to be held back by it. I probably always wanted to live a normal life, but with that little—that little thing in the back of my mind, "Well, okay, how are you going to accomplish this, even though you have hemophilia? Do you want to go up on the roof?" Just a little more careful and a little bit crazy. I have to say, "Okay, Steve, if you fall, then it's going to take longer to get the roof done." [laughs] "Because you know you're going to get hurt, and you're going to get better. Then you're going to have to go back up there."

LG: So hemophilia, in fact, even though it's been mild, has been a real entity in your life, a real relationship that you've had to negotiate.

SP: It's there every day.

LG: It is there every day?

SP: Oh, sure. Yeah. I use an electric razor. I used to use a blade, but every once in awhile I'd cut myself, and said, "Ah, this is such a pain. Now I've got to slow down and now I can't run right out of the house." So I just said, the electric razor does a lousy job, but I say, "Okay, I'm going to use the electric razor twice a day, rather than use a blade once a day, but I'm not going to get cut." So that's one little cut that I don't have to deal with and I don't have to mess around.

LG: You wanted to live a normal life. What does normal mean to you? Were you not normal because you had hemophilia?

SP: I guess I just had to take extra time or I had to be a little more careful.

LG: Okay, but the whole concept of "I am normal or I am not normal"?

SP: That's not really. I want to be able to just keep on going. I don't like to waste time.

LG: Okay.

SP: Time is very important to me.

LG: Okay. So you didn't feel somehow that you were abnormal?

SP: No. That was just me, and I had to do things that other people didn't have to do, and I couldn't do things that other people did. But that was who I was, so just deal with it and make the best of it.

LG: Steve, have I not asked you something? Are there any thoughts that I have not tapped into or any memories?

SP: No, I think I told you about everything because, you know, the concept of pushing yourself to the limit, but being careful. Being aware and respecting the disease, but just don't be afraid of it.

Don't be afraid that you can't do something because there are a lot of things that people can do, especially with the Factor now.

People with hemophilia can probably—people with serious hemophilia can probably do more than I can do because I'm not being treated and I still have that, whatever that magic number is twenty-five or thirty percent of factor. There are probably things that they can do that I can't, but that's okay. I'm not going to be infusing myself with hundreds of thousands of dollars worth of material that I don't really need. I can manage my life and do ninety-eight percent, ninety-nine percent of what I want to do. I can't really think of anything that I'd like to do. Maybe I could twirl knives or something, I don't know. [laughs] But I do everything—I do everything that I want to. Very comfortable. Very happy with what I do.

LG: Well, I want to thank you then.

SP: You're very welcome.

LG: I so appreciate your putting aside this time for the oral history project, and it's been marvelous meeting you and talking to you.

SP: Great talking to you, too.

End of Interview