

Interview with Dr. Will Somers for the Boston Hemophilia Center Oral History Project, A Gift of Experience, by Laura Gray, September 28, 2004.

GRAY: Okay, I am sitting with Dr. Will Somers in Lexington in his home and it is September 28th, 2004 and I want to thank you for agreeing to be a participant in this oral history project, the Boston Hemophilia Center called the Gift of Experience. So here we are, and Will, I'm going to start by asking you where did you grow up? Now, actually, I'm going to start by asking you what kind of hemophilia do you have?

SOMERS: I have a factor VIII deficiency and when I was younger, I was a 2% level, so fairly mildly effected.

LG: So it's moderate.

WS: Moderate to mild, although now it tends to come into the realm of 10% level for whatever reasons.

LG: Do you have any other chronic illnesses?

WS: No.

LG: Okay. So let me start by asking—how old are you?

WS: Forty.

LG: You're forty years old and your birthday is?

WS: February 11, 1964.

LG: Where did you grow up and who did you grow up with?

WS: I grew up in England in a little village called Lutclade, which is about two hours' drive west of London, with my parents and a brother, essentially. My two sisters were much older than us. They were actually ten years older. They were around when I was very young, but I don't really remember them being in the house.

LG: Does your brother have hemophilia?

WS: No, he doesn't.

LG: You're the only one in your immediate family?

WS: Correct.

LG: Was there any family history of hemophilia?

WS: Yeah, I had an uncle that had hemophilia and obviously he was a lot older than me, but I didn't really grow up with him, see him that much, I think. I do have a nephew who has hemophilia and he's probably in his early twenties at this point.

LG: Did your family know about hemophilia before you were born?

WS: Yes, they did. I mean, my uncle had had it and it was sort of well-known at that point. They didn't know I had it until I had a vaccination and got a bruise from that and I guess my mother's mother said, "Well, I recognize that and we probably ought to have him tested."

LG: So how old were you at that time?

WS: I think I was pretty young. I think I was two or three, something like that.

LG: And so that's when you imagine you got diagnosed, when you were two or three, due to this bruising that you got?

WS: Yes. Right. Right.

LG: Okay. Tell me a little bit about your parents. Where are they from? What was their education? What were they like?

WS: My parents were from the northeast England. So they used have a Newcastle accent, you know, sort of strong Jordie accent, although I guess the result of being in the south for so long, the accent's faded. My father was in the air force.

LG: What does it mean when you say “they had a strong Jordie accent”? Being an American, I have no idea what that means. Does it mean like a strong Irish accent here?

WS: Yeah. I mean, it’s the equivalent of that. I think if you were to visit there, you’d run into people you had a hard time understanding because the accent’s so strong.

LG: Do you have that kind of accent?

WS: No. No, I have a very standard middle-country of accent.

LG: Okay.

WS: So my father was in the air force and he joined when he was very young and was actually flying bombers in the war, Second World War, and was flying transport planes after the war. My mother brought us up essentially, and she was I guess some kind of secretary when she was younger. Then after she had children, she stayed at home.

LG: And their educational level?

WS: My father was—both of them finished high school. My father was trained to be an accountant, and when the war started, he chose to join the air force instead. But back then I don’t think many people went to university.

LG: What is your first memory of hemophilia?

WS: Phew. I’m not really sure, well, probably bruised ankles, things like that, that would cause me to limp around for some period of time. I think they were more conservative with treatment back then and so sometimes, you know, things would be, you know, left longer than they should have been. I can remember being hit by swing and I remember going to the hospital for that.

LG: What do you remember about going to the hospital?

WS: Actually, very early days I can remember being on a drip.

LG: A whole blood drip, do you mean?

WS: No, it wasn't whole blood. It was whatever came after whole blood, I guess.

LG: The cryoprecipitate?

WS: Probably cryoprecipitate, I would guess. But it was, you know, a very large bottle, kind of a drip for quite a long period of time. It was quite a large volume, and I can remember that. I remember when they started using syringes and the volume of liquid was greatly reduced and that's when it was certainly a much better situation.

LG: Did you have to go to the hospital much growing up?

WS: I don't think so. I think it was probably a couple times a year, or something like that.

LG: And what would happen? What do you remember about your body and hemophilia?

WS: It was usually a result of an injury. You know, I was basically doing all the same sports as everybody else at school. In England that's soccer and rugby and these kinds of things.

LG: So you were doing all those things?

WS: Yeah. Yeah.

LG: So your parents put really no restrictions on your activities?

WS: No. No.

LG: How come?

WS: I don't think they wanted me to be treated any differently and so as I result, I basically just did what everybody else did. I didn't

particularly enjoy playing rugby or soccer. I wasn't that good at it, but certainly I didn't want to be considered as being different in any way. Everybody else was doing it, so I should do it, too.

LG: Did you see doctors during that time for your hemophilia?

WS: Well, I don't think they ever told me not to get involved in school sports. I mean, they told me not to go scuba diving and not do to these kinds of things.

LG: What other things, other than scuba diving? Do you remember any restrictions, other than scuba diving?

WS: Scuba diving, wind surfing they were concerned about. There was some—there was some discussion—I was trying to get a pilot's license. In the UK they had something called the Douglas Bader Scholarship Program for people with disabilities or whatever, and somehow I managed to join. I felt like a fake going in for this thing because I always felt like I was perfectly healthy, compared to the other people who were there. But anyway, I got this scholarship, learned to fly and there was a restriction placed on me that I had to have somebody else in the cockpit which is ridiculous because, you know, I was perfectly healthy, as far as I was concerned. And so there was a bit more discussion then, you know, whether—the air force doctors were discussing whether I should be allowed to fly kind of thing, but I don't think the hemophilia doctors ever considered that to be an issue. But I think the thing they really told me not to do was scuba diving. I mean, when I started my parents called up the Oxford Hemophilia Center and said, "Do you think he should do this?" and they said, "No." But I carried on and did it anyway.

LG: They called who?

WS: The Oxford Hemophilia Center.

LG: So you remember actually going to a hemophilia center?

WS: Oh, yeah, absolutely.

LG: From a young age?

WS: Oh, yeah. One of the better centers in the UK was at Oxford and the doctors there were really very good and that was the place I always went to. Always.

LG: And do you remember any feelings about the hemophilia at all? I mean—was it part of your psychological makeup as a kid?

WS: I mean that if I really hit my leg or something, I'd be thinking, "Oh, God, now I've got to go up to the hospital," kind of thing and it wasn't like how you ran off and did it. You know, didn't go home instantly. I'd get home in the evening and I'd be like, "Okay, I did this. You know, we're probably going to have to do something about this." You know that was not something that was enjoyable.

LG: What wasn't enjoyable?

WS: Well, the fact that, you know, you have to come to terms with the fact that you're going to have to go the hospital and get the shot and perhaps be limping around for a couple of weeks.

LG: Did you ever miss school or were you ever in the hospital for any period of time that you remember?

WS: Yeah, I'm sure I missed the occasional day. There was one time where I hurt my hip. It was sort of an odd situation. For some reason I didn't treat it for a few days or a week. However, I remember being in the hospital and it really hurting and then

eventually I started treating it and it got better. But I remember that was a long event. It was like three or four weeks, something like that.

LG: That you were actually in the hospital?

WS: Well, I knew I was in the hospital at least a few weeks and certainly out of action probably for four.

LG: And what was it like to be in the hospital in England?

WS: Well, you were in these big wards. I remember that time I was in a children's ward.

LG: How old were you, do you think, when this happened?

WS: I remember actually I got in trouble from the nurses because we had put talcum powder on the beds and then bashed the beds and made all this smoke. So I couldn't have been that old, I don't think. Must have been pretty young.

LG: Probably weren't eighteen.

WS: I don't think so. [laughs] I remember another visit to the hospital they were giving me like chocolate milk shakes to try and get me to drink and eat food. So I guess I was pretty young.

LG: But that's the only time you really remember spending any extended period in the hospital?

WS: Yeah. I mean, certainly I think back then I think I was always reluctant to do anything about it. You know, I'd hit my leg and let's wait a couple of days to see what would happen. Then usually by the time I saw somebody, it was worse than it should have been.

LG: So do you remember your leg blowing up or being swollen?

WS: Oh, yeah, absolutely.

LG: You do remember that. And what would they do for it?

WS: Well, I've had a cast on my ankle, but usually it was just immobilizing it and make get in bed and sit down. You know, get treatment and wait.

LG: Who in your family was most involved with your care?

WS: I would say my mother, I would think.

LG: Your mom?

WS: Yeah.

LG: Because she was home more?

WS: She was home more. My father sometimes would go away for, you know, a couple weeks at a time, but you know, I think he used to come to the hospital, too, but when I was in there, I'm pretty sure my mother took care of me most of the time.

LG: Were parents allowed to visit in the hospital or stay over? What was it like in England—

WS: They never stayed over.

LG: Never stayed over.

WS: But they definitely visited every day.

LG: You remember you got visited every day:

WS: Oh, yeah, absolutely.

LG: And your brother, how was he around all this?

WS: I don't remember him visiting me in the hospital too much, actually.

LG: Is he older or younger?

WS: He's younger. We used to fight a lot and so, you know, I mean I think it was a normal sort of relationship between two brothers. You know, used to compete and fight and I don't think he held

back because I would end up in the hospital or anything. I don't remember ending up in the hospital as a result of fighting, but then I certainly received a few injuries from time to time.

LG: Was hemophilia talked about at home?

WS: No, I don't think they really talked about it. I mean, obviously if I was injured, we would go off to the hospital and get treatment, but it was not something we ever really discussed.

LG: So neither parent said, "Don't do this, Will. Don't do that." There was none of that when you were growing up. "You might get a bleed."

WS: No, there was never that.

LG: None of that?

WS: No.

LG: Okay. And when you got a bleed, was there ever any comment about it?

WS: I don't think so. I think it was just a question, "Okay, we've got to deal with this. We've got to get you off the hospital and get you seen to."

LG: There was not a lot of drama around it.

WS: No. No.

LG: Uh-huh, or fear, per se?

WS: No, there was no real fear. I mean, as I said, I mean if I got an injury it was sort of like, "Oh, God, I've got to deal with this kind of thing."

LG: For you?

WS: For me, yeah. There will be a couple of weeks when I can't run around or I can't do what I want to do. There was more that kind of feeling from me, [unclear].

LG: Did kids know that you had hemophilia?

WS: I don't think so, actually. No, I don't think they knew.

LG: So in school you never had to deal with any peer relationships around the fact that you had this?

WS: No.

LG: Chronic illness or this chronic disease.

WS: No, because I mean, looking back, I mean, I certainly got in as many fights as anybody else and, you know, did everything everybody else did. I'm pretty sure that nobody knew.

LG: And rugby strikes me as a very heavy-duty contact sport.

WS: Right.

LG: Did you get bleeds from playing that?

WS: You know, I never really got anything serious from any of the sort of sporting related things I ever did. It was usually, you know, walk into the corner of a table or something like that that would cause an injury. None of the sports I've ever done have ever really caused any, any injuries. I mean, I think part of the way to deal with this is to, you know, to get fit and be as active as you can.

LG: Was that the philosophy you remembered?

WS: I don't think it was ever anyone ever told me that. It was something I just did. I always was running around doing things, wind surfing, and certainly I noticed that the more in shape I became, and the fitter I got, the less trouble I had to deal with.

Certainly, you know, once I got off to university, you know, literally it would be once a year or once every couple few years when I had to deal with it. I mean, it really was very infrequent at that point.

LG: And what do you make of that?

WS: What do you mean?

LG: That it seemed so frequent once you got into university.

WS: I think gradually it just got less and less as I got older, and you know, obviously I'm not getting thrown over my brother's shoulders anymore into things. I really think a lot of it has to do with how fit you are and how at university I'd be lifting weights and swimming and windsurfing and scuba diving and doing all this kind of stuff. You know, I was in pretty good shape back then.

LG: So you went to scuba dive, anyway, even though at some point it was contraindicated?

WS: Yes. It would just make no sense to me that I couldn't do it, given all the other things I'd done. I mean, actually I could go for maybe a couple of years without even needing treatment. It made no sense that I couldn't scuba dive. I actually was an instructor after awhile.

LG: Did you know other kids who had hemophilia?

WS: I didn't know anybody else, actually, that had it.

LG: Nobody else?

WS: Uh-hmm.

LG: Even when you went to the hemophilia treatment center?

WS: I met the people, but we didn't know them. I knew my sister was more involved with the Hemophilia Center when she had a son

with hemophilia, but I wasn't. It wasn't something I felt like I needed to be part of particularly.

LG: It's not something you particularly identified with or felt like you needed support around?

WS: No.

LG: Yeah. Was there at any point a time when you wished you didn't have it or had any feelings about it?

WS: I tell you the worst thing that happened actually was when I had two or three years in the university, I had a bleed into my sort of stomach area and that was something that went on for a couple of months.

LG: Did you even know it was a bleed?

WS: Oh, yeah, yeah. I mean, I was feeling dizzy, but I had no money and walked to the pharmacy. I was going to get some iron tablets. I knew I had lost some blood and I could see I was pale, and the price of the iron tablets are what made me go to the hospital. When I got there and they're like, "Okay, don't move. We're going to get an ambulance," and they gave me blood and everything. So, that was probably the most serious thing I had. So, you know, after a couple of months of that, I was thinking, you know, this is something I don't need to be dealing with. You know, I'd much rather not have to deal with this, but most of the time it wasn't really an issue for me. You know, I guess when you're lying there and you've got a sore ankle or whatever, you'd rather not be ill. But if you have something that affects you once every couple of years, it really became less of an issue.

LG: Let me just go back to the treatment that you remember because you're forty years old, so that would bring us back to the '60s. There really wasn't any factor at that time.

WS: Right.

LG: What do you remember there being? You mostly just remember volume of drips.

WS: Yeah. Right, right. It's just a very large volume you were getting and it would take a long time to put it into you. I just remember that. I remember on the bed just waiting for it to happen, you know, but that's all I really remember from that. I certainly remember the time I went in and they had these giant syringes instead. That was a big step forward.

LG: What was it like to go from the big, big bags to a giant syringe?

WS: It was just much quicker, much more efficient when you went in. There still wasn't any home treatment, I don't think. Certainly I didn't have it, but they were just much easier. It was convenience, basically. You go in and you'd be out of there very quickly.

LG: Did you always feel like, "I have to be near a hospital"?

WS: No.

LG: You never had that sense?

WS: No. I mean, I remember my parents, you know, if we would go on vacation to other parts of Europe, I mean, they would get a book that had all the hospitals in case we needed them, but I don't think we ever did. I used a hospital visiting a place in north of England one time. I don't think on any of the trips to other countries we ever visited anywhere else.

LG: Who taught you about hemophilia? How did you learn about it?

WS: I have a feeling it was just these trips to the hospital and talking to the doctors. I don't really remember.

LG: Do you remember your impressions of the doctors and nurses? How they treated you? Your feelings about them?

WS: The doctors at the hospital were really good, actually.

LG: What do you remember?

WS: I remember there was a senior guy, Dr. Ritzer, who seemed to be very knowledgeable. You know, I guess in the country, he was one of the people who people looked up to. Seemed to understand what was going on and the nurses were very nice. Very nice to the patients that come in. I think it's very different when I came to hospital here. The first time I visited a hospital in the States at UCSF, I remember standing in a corridor. They were giving me a shot and there were people that seemed like they were homeless people walking around across the corridor talking to you while this was going on. You know, in England it was a very nice hospital. They were all very friendly. It just seemed like a very pleasant environment in comparison.

LG: So it was a real shock coming to the States and going to San Francisco for the first time.

WS: Right, and then dealing with health insurance and everything else, seemed kind of an odd situation.

LG: You never had to deal with that in England, the whole health insurance issue.

WS: No, you just go along and they take care of you. Go into any hospital and they take care of you.

LG: You don't have to show anything?

WS: No.

LG: You just walk in and they take care of you?

WS: My son was sick last Christmas and the doctors saw him, we never heard back.

LG: Your son was sick and what?

WS: He was sick over Christmas vacation and we went to see a doctor and my wife said, “Well, where we do pay.” I said, “Well, you can’t pay. There’s no mechanism of paying.”

LG: Oh, this is in England?

WS: Yeah. It’s actually a nice system to deal with. The people at Oxford are really very, very good.

LG: Do you think having hemophilia affected your relationships in any way? Did you tell friends that you had hemophilia? Was it a secret? Was it not? Or was it just a non-issue?

WS: Well, it was certainly not something I wanted to talk about with most people. I don’t think any of my friends ever knew about it. They still don’t know about it.

LG: Really? Still don’t know about it?

WS: Right, right. If I entered into a relationship with somebody, you know, eventually perhaps if it was going somewhere serious, I would tell them.

LG: You would?

WS: Yeah.

LG: You mean a female? A female?

WS: Yeah, but I think in the normal day-to-day relationship I don’t think there was any need for people to know.

LG: When you limped at school or—

WS: Oh, I didn't limp back then. Oh, oh, when I'd hurt myself? I think they just assumed that I'd hurt myself. You know, kids occasionally hurt themselves and it was just like, "Oh, okay. He's hurt himself."

LG: So it didn't happen often enough that people sort of went, "What's with this guy"?

WS: No, I don't think so.

LG: Or if you disappeared into the hospital for three weeks, they didn't wonder, "What the heck is this about?"

WS: You know, it's funny. I just don't remember, so maybe they did.

LG: You just don't remember.

WS: I just don't remember that people ever treated me any differently and I'm sure people didn't even know. I mean, I can't imagine they did know because occasionally—well, in England, around birthday times it's pretty tough. People will come and pick on you and, you know, kick you and all this kind of stuff. I don't remember anybody not doing this to me. They treated me as badly as everybody else.

LG: So tell me this again. In England when it's your birthday, what happens?

WS: When you're a young kid in England, the school I was at, you get a thing called the 'bumps' where a lot of people catch you. Probably like fifteen people will get around you, grab an arm and a leg each and then throw you up in the air and kick you on the way down.

LG: And kick you on the way down?

WS: So obviously, you don't want to let anybody know it's your birthday, but every year someone finds out and then this happens

to me. So I don't remember them sparing me in any way, so I can't imagine that people knew.

LG: And do you ever remember coming home with a bleed on your birthday?

WS: I don't think I ever did.

LG: You just never did.

WS: But maybe I did, I can't remember.

LG: Anyway, you started telling me very early on this interview that because of your hemophilia you were able to apply for this special scholarship, was it, to learn how to fly?

WS: Yeah, I think it was called the Douglas Bader Scholarship or something. They probably still have it going on actually but, you know, most of the people there were pretty badly disabled and I kind of felt like kind of a fake going into this thing. Everybody was, you know, clearly had problems to deal with, but I was, you know, definitely very happy to be learning to fly for nothing.

LG: I see. So it's a way of getting into flying without having to pay the price.

WS: We all lived at a flying school for eight weeks and went flying every day for nothing. So it was quite nice.

LG: Did you have absences from school that effected your school work?

WS: The only time it ever became an issue was I think it was second year university where I actually ended up missing certainly several months of the school year.

LG: Several months?

WS: Right.

LG: From this internal bleed that you had?

WS: Right, right.

LG: Now, tell me a little bit about that. Is it that you didn't really acknowledge that it was a bleed for the longest time or you didn't know?

WS: I think no, I just think it was something that took a long time to heal. I mean certainly I ignored it probably for the first few days, I would imagine, but it was just something that I didn't really know what the problem was. Of course, they were discussing whether they should have this in surgery and in the end decided not to and it eventually resolved itself, but it just took a long time.

LG: Did you get any treatment for it to stop the bleed?

WS: Oh, of course. Yeah, yeah.

LG: You did?

WS: Right, right.

LG: So were you always forthcoming with physicians or your medical people with the fact that you had hemophilia?

WS: Oh, yeah. Yes, of course.

LG: Were you always thinking in terms of hemophilia whenever you had any kind of physical ailment?

WS: Oh, no, I mean, obviously, you know, there are times when you know if you've got a swollen knee or whatever, you know what's going on. You know it's not something else.

LG: So you pretty much knew when you were having a bleed, even though you are a mild and didn't have to deal with bleeds often.

WS: Right.

LG: But you would know what it was.

WS: Absolutely, yeah.

LG: And what you were telling me growing up is sometimes you'd try to ignore it and sort of say, "Let me see what happens here before I really let anybody know about it."

WS: Right, I guess I've always sort of done that.

LG: Even today, you mean?

WS: Well, not so much today because the factor VIII's sitting in the fridge and it's very, very easy now. Certainly, even when I first moved out here, doctors at the center in Boston would give me a hard time for coming in too late. You know, I'd come in with some massive bruise and they'd be like, "Oh, my God, you know. Why didn't you come in sooner?"

LG: So that trend continued with you through the years, even up until this point.

WS: Right.

LG: But now you're saying, "Gee, there's factor in my refrigerator, so I can just infuse myself." Do you infuse yourself?

WS: Oh, yeah. Yeah. I've done that since I was probably in my early twenties, I would say, something like that.

LG: Tell me about the treatment changes. I mean, what do you remember about how things got easier and easier? Are there certain points in your life that you can identify?

WS: Well, at some point I think in my early twenties it got to the point where you could give yourself home treatment and that's when it became much easier. I mean part of time with the university, I was at home just giving myself factor, and at that point certainly the volumes have got lower than they were back then but, you know,

essentially it's the same kind of treatment and I guess companies are working on trying to make it more convenient. But at that point it became pretty good. I don't know why I still avoid using it. I guess maybe I didn't always have—I must have had Factor 8 around the time. I don't really know why I avoided it. I mean, now I'm better about keeping a reasonable supply sitting there, and if anything happens, I just take care of it usually.

LG: But what you're saying is for the longest time it seems like you did avoid treating yourself.

WS: Yeah, because a lot of things just get better. You know, with the sports I do I tend to get a lot of bruises, small bruises, and a lot of them I'm thinking, "Okay, well I'll wait a couple of days and see what happens," and most things just get better. I don't feel it's worth dealing with the factor VIII, and I guess that's probably still the case now. I'm probably a little more proactive now if I have a feeling it's going to get worse or it is getting more, I'm more realistic about dealing with it quickly now.

LG: Do you think it's a matter of being more realistic? What do you mean by more realistic?

WS: Well, like just rather than hoping it's going to get better and then realizing a few days later it's not going to.

LG: I see, and does it get better if you give yourself factor?

WS: Oh, yeah.

LG: So you find there's an immediate response.

WS: Unless I let it go for a long period of time and it's something huge at that point, but certainly if you get to it pretty early, it's pretty easy to take care of.

LG: Now, you're married.

WS: Uh-hmm.

LG: And how old were you when you got married?

WS: It was only a few years ago.

LG: Is this your first marriage?

WS: Uh-hmm.

LG: Was having hemophilia ever a concern of yours in meeting women or thinking about getting married?

WS: No, not really. No.

LG: Was there any issue for your wife when she heard about it, as far as having kids?

WS: I think when people first hear about it, I don't think they really know all the implications when they first hear. They're like, "Oh, okay." When I met my first wife she'd scuba dive with me and I'm teaching her to windsurf, and we're hiking and camping and everything, it's like "Well, big deal. This isn't really a problem," and I think that most of the people I met were through something like scuba diving, so I don't think people assumed it was ever going to be really an issue.

LG: So therefore you think just in watching you with your lifestyle, she would think, "What to worry about?"

WS: Right.

LG: And since you've had children, have there been many discussions about the hemophilia?

WS: Well, my mother's comment was, "Oh, you've got a son. That's good. He's not going to be a carrier, and that's a good thing." I mean, I don't particularly worry either way, whether we have a girl

or a boy or whether or not they are a carrier, but she's made that comment.

LG: Tell me about your mother. Did she have any feelings about the disease, having seen another generation have hemophilia before you and the real lack of treatment back then?

WS: No, I don't remember. I'm sure she wasn't happy to find out that I had hemophilia, but I don't really remember her being—I was pretty young when she found out, but probably by the time I remember, she's already come to terms with it.

LG: So it pretty much was just a matter that people took in stride in your family?

WS: Yeah. Yeah, I think so.

LG: Tell me about the '80s, when there was the whole issue of the blood products and HIV. Do you remember that period?

WS: Oh, yeah, definitely.

LG: What do you remember about it?

WS: I was absolutely, you know, I was following all the headlines that were coming out about HIV and everything.

LG: Were you in England at that time?

WS: Yeah, yeah. It was also a time when I hadn't had any treatment for a couple, few years and so I was thinking, "Well, this is probably a good time not to be getting treatment." At some point there was a real concern about the supply of factor VIII and that was the time when I had this bad bleed, internal bleed, so I went to the hospital. At that point, they said, "Well, you have two choices. We have this National Health Service material which we think is higher quality than the American factor VIII, or we can have the heat

treated American factor VIII, which we think is safe.” So it was a little bit scary because at that point there didn’t appear to be any real hard data about which option. I mean, even the doctor didn’t seem completely convinced about which way to go, and this made it worse, actually. Oxford seemed to disagree with the Leeds Center. I started out treatment in Leeds in north of England because that’s where the university was, with American heat treated material, and I got down to Oxford, they were like, “Well, we prefer to switch you onto the National Health Service Factor”—I guess it was from a small pool of donors.

LG: So you had been using one factor in Leeds where everybody was saying, “This is the factor to use,” and then you move, and they go, “Umm, we’re not sure.”

WS: Right. Right. So obviously it was a concern and I certainly remember going and getting tested. They gave you test every six months back then. I guess they weren’t sure how long things would take to show up, so I think every six months or so I would go in for a test.

LG: They tested you every six months in the center just to make sure? Did you have to seek it out? Did they seek you out? How did that work, do you remember?

WS: I don’t remember. I remember they set up appointments and told you to come in.

LG: Yeah, but you must have remembered waiting for the results.

WS: Oh, of course. Yeah.

LG: But your lottery came out negative. Did you know people who were affected by that?

WS: No. I mean, obviously I was following the headlines, and I consider myself pretty fortunate.

LG: But it sounds like you knew that the factor could have been contaminated.

WS: Oh, of course.

LG: For the longest time in America people weren't putting it together.

WS: Well, I think this happened at a time when a lot more was known about it. I mean, it was in the headlines that this was an issue. I must have known because I remember going to the hospital thinking, "Oh, my God. This is not a good time to be doing this." So I wasn't happy with the idea of having to get factor VIII at that point?

LG: And did you get it anyway?

WS: Oh, of course. I had it, I mean, literally every day for a couple, few months. Probably a couple of months, I would think.

LG: Because of this bleed that you had going on.

WS: Right.

LG: And no hep-C involvement, either?

WS: Back then there was no mention. When I was young, I remember the doctor saying to me, "Well, we're going to give you a hepatitis B vaccination," and I was thinking, "Okay, fine. That seems okay. You can do that," but then I didn't really have any comprehension that hepatitis was particularly serious. You know, they gave me the vaccination, I didn't really think anything of it.

LG: Did your lifelong involvement with doctors and hospitals affect your educational or professional pursuits?

WS: I was thinking about going into medical school and my mother wanted me to be a doctor in medical school, and eventually I studied biophysics.

LG: Do you think because you had had experience with doctors that you were familiar with hospitals, that you'd consider medical school? Was there any association, do you think, or not?

WS: No, not really. In England you have to make the decision when you're eighteen or nineteen and it seemed like a reasonable thing to do, and the grades weren't good enough because I had goofed off in school too much. Actually, eventually my grades were good enough, but at that point I'd been offered a course in biophysics, and that seemed like an interesting course, so I decided to do that. At the end of that, I was offered the chance to do a Ph.D., so I did the PhD.

LG: In biophysics?

WS: In biophysics, too. It actually turned to be a pretty good career move at the end of the day, but it was one of these things I sort of drifted into, I guess.

LG: What brought you over here to the United States?

WS: You know, I'd been in north of England attending university for seven years and I really wanted a change, and I imagined that California was this beautiful place with beautiful beaches. So I applied to schools in California to do a post-doc. It's a two or three year period after you finish your Ph.D., and ended up going there for a few years and then after you've been in the States for a few years, it's pretty hard to move back.

LG: It's hard to move back to England once you move here?

WS: Yeah, because the money over in the States is so much better than in the UK.

LG: I see.

WS: I actually looked at the jobs in the UK and they were offering me perhaps even say less than half, maybe a third of what the jobs out here were paying. So it became very difficult at that point to move back.

LG: Really? So you touched upon the difference of going into a hospital in San Francisco, versus your experience in England. Are there any other things that have struck you about getting care for your hemophilia here?

WS: I think it's just the financial situation, where you know how much the factor VIII costs. You know, you go to the hospital and I mean basically the hospital's seemed obsessed with getting your insurance card and all this kind of stuff. Certainly when I first arrived out here, I was like, "What is this system?" When I first arrived here, I actually moved house, so my bill went to the wrong house. So the first thing the hospital did was trash my credit rating. I had no credit rating, but they sent a collection agency after me for the forty-dollar co-pay or whatever it was. So that was my welcome to the US healthcare system. And, in fact, for the next five years, I couldn't borrow money to buy a pillowcase, thanks to the bad credit rating. Because when you first move here, they don't know about you. You have no records. So when you're only record is a bad record, it's really not a good situation. So I think whereas in England, you literally don't deal with any of this. I mean you have no concept what factor VIII costs.

LG: Is the relationship between patient and doctor different here than it is in England, or patient nurse?

WS: You certainly don't see them much here, but I think in England I always viewed these people as somebody I knew. I mean, I saw Dr. Rizza certainly probably all the time I was growing up was at the hospital. I mean, he seemed to be there before and he retired, and it seems that people here move around a lot more. I mean, it's certainly hard for me to keep track of the people that I'm supposed to see at the center here. I mean, basically you go in and they see you. You get that thing dealt with. You leave. Often for me by the next time I go in, there's a different set of people, anyway. So certainly I've never stayed in the hospital in the States since I got here. Usually they try and get you out of there as quickly as they can, because I think in England it doesn't seem to be as big a deal having you stay over.

LG: I don't know if you were aware that there was a huge class action suit against the drug companies in the '80s around the HIV infection. Were you aware of that?

WS: Yeah, I heard a little bit about it. Obviously, I didn't involved because I didn't have HIV. I did have hepatitis-C.

LG: Oh, you did have that?

WS: And so I just actually started finding out more information about it.

LG: Did that change your politics at all around your relationship with doctors or medications? What was that affect, if any?

WS: Well, you know, actually I just read the report from the plaintiff's lawyers. It's from the lawyers representing the people that have been affected.

LG: For the hep-C?

WS: For the hep-C and if what they say is even half true, it's pretty shocking what the pharmaceutical companies were doing to try and maximize their profits. Particularly in the States, buying blood from prison and these kinds of things. So having said that, I work for a pharmaceutical company which is on the other end of some litigation—not this particular litigations—so I have mixed feelings about it. Certainly if these guys, you know, were buying blood from prisoners when they were told not to, then they deserve to compensate people and it's pretty outrageous what they did. But I don't really know enough to know whether the lawyers in this case are telling the truth.

LG: But for you, just reading this new suit that's coming up around the hep-C, it's sort of making you think, "Whoa!" Whereas, you weren't as involved back then because you didn't have HIV.

WS: Right. Right.

LG: Yeah. Yeah. You know, when you think of kids who are born with hemophilia today, would you have any thoughts or suggestions for those kids or their parents in how to prepare them to deal with it?

WS: I would say that the key is to have them have as normal life as possible and try and keep them, you know, as active as possible and encourage them to be as, you know, physically fit as possible. I really think there's a correlation between being physically fit and not having any problems. I mean, obviously I was fairly moderate to mild, but I think that really the better shape you are, the less you have to deal with this. You know, the other thing I think is

keeping joints in good condition. I think that if you get any joint bleeds, that you should deal with the factor VIII as quickly as possible. I have a sore hip now that I think was caused by that, you know, one time in hospital where I didn't receive treatment for a week or so. So I think that's the only thing I really have to deal with.

LG: Is this limp that you have from the hip bleed.

WS: Yeah.

LG: You had said, "I think if I could tell a kid to lead as normal a life as possible." What do you mean by that?

WS: I mean, that means that even though obviously I'm sure parents would be concerned about the idea of having their kid playing soccer or playing baseball, they should do everything every other kid is doing.

LG: But what if they get a bleed?

WS: Well, I think they should have some factor VIII and move on from there? The reality is, I think the less you do and the more you protect the kid, the more out of shape they'll become and the more bleeds they'll get. I actually think that it really is a key to be as physically fit as possible and really I don't think it helps to try and protect people.

LG: You don't?

WS: No, I don't think so. I mean, certainly my nephew is less physically fit and I think he has the same factor levels as me, and he certainly doesn't seem to get away with it as much as I do. I think even now I can feel that when I do more exercise, when I get bruises, they're much less severe.

LG: So you think living as normally as possible and not protecting kids from themselves or from getting bleeds is beneficial because on some level you feel like that would encourage them to go be more physically fit.

WS: Yeah.

LG: What about psychologically? I mean, is there anything that you felt helped or hindered your coping with this? I know that's a pretty broad question. Were you ever afraid of it? Did you ever feel like, "Oh, my God. I shouldn't do this or I shouldn't do that" or, "Hey, I can do anything"?

WS: Actually, I think the only thing that ever concerned me was, you know, one time I went traveling a little bit when I finished university, and so when I went into the remote part of China or Thailand or somewhere, you know, you sort of think, "Okay, I'm perhaps a little more isolated than I might be otherwise. I'm certainly some distance away from being able to get reasonable treatment." But that's really the only time I've really—I've ever been concerned about it. I mean, certainly not when I'm in any situation here.

LG: But I think it's interesting what you say. It's probably not that helpful to protect kids, in the sense of making them worry.

WS: No, I don't think that helps at all.

LG: Is there anything that I haven't touched upon that you've been thinking about at all? Any memory that I didn't tap into?

WS: Yeah, I guess the only thing is that for me—it's hard to know whether hemophilia was part of this. I've always been very determined just to go and do things and not let things get in my

way. Certainly I think that that sort of helped me in my career, if anything.

LG: Really? In what way?

WS: You know, just people, you know, with work or university or whatever, let things—let obstacles get in the way, whereas I’m someone that doesn’t let that happen. I’ll always just try and find a way to get something done, and ultimately that helps you. So, you know, I’ve done fairly well.

[end of Side A, Tape 1]

LG: You’re saying that hemophilia led to your attitude of “I’m not going to let things get in my way.” So do you think that actually harkens back to a voice in you when you were growing up, saying, “I have this, but I’m not going to let this get in my way. I’m going to do what I’m going to do anyway.”

WS: Yeah, I think it does. Yeah.

LG: And did that play out more when you were younger around exercise or sports?

WS: Yeah, you know, in high school you just want to be like everybody else, so I don’t think I was going out to try and be better than anybody else. So I was just basically doing what everybody else was doing. I think when I got a little older, I wanted to be, you know, very physically fit and very determined to go out and be good at things.

LG: But there was a psychological piece of you that said, “I’m not going to let this get in my way.”

WS: Absolutely, yeah.

LG: One last thing, and my question is pain. Has pain been constant in your life?

WS: Oh, my hip hurts now when I walk around on it too much, or when I've been windsurfing or kite boarding or whatever. I come in and my hip will hurt after that. So this relates to keeping joints in good condition, but I mean clearly there was, you know, pain associated with these bleeds when I was younger. But it's just one of the things you sort of forget about. I certainly don't look back and think I was in pain all the time when I was growing up, you know. I more think, you know, the bleed and the swelling and whatever, but I don't really think about the pain. Clearly, it hurt at the time.

LG: But it was time-limited, you mean. Do you remember how you dealt with it or how you deal with it today? Do you think you have a different relationship to pain than someone who hasn't had to deal with it through their lives?

WS: I don't think so.

LG: Imagine if you had a daughter and your daughter had a son with hemophilia. What do you think about that?

WS: Right. I think these days it's much easier than when I grew up and it didn't slow me down very much. I think that, you know, really the only thing that I'm dealing with today is a few joint issues and I think that there's no reason to have to deal with that these days. So I really—I really don't think that it's a problem.

LG: You don't perceive it as that big a deal?

WS: Right.

LG: All right. You know, I think that's it.

WS: Okay, good. Thanks.

LG: Thank you.

End of Interview