

Interview with Robert Jarratt by Christine Harland for the Boston Hemophilia Oral History Project, November 1, 2004.

HARLAND: When your family first became aware that you had hemophilia, what that was like in your family? You have two brothers with hemophilia?

RJ: I have two brothers with hemophilia and one that does not have hemophilia. Let's see. The younger of the brothers who has hemophilia had a tooth extracted. I was probably in college, in the first year of college. And they had a very difficult time stopping the bleeding. Subsequently, he went to the hospital, finally had to take whole plasma to get it stopped. And they really didn't know what it was because no one in our family had been diagnosed before.

CH: And there was no history?

RJ: No, not that we were aware of. You know, we can look back now and see people in the family who probably were affected by it.

CH: But it hadn't been—

RJ: Right.

CH: —brought forward.

RJ: Mm-hmm.

CH: So you were in college when that first became an issue.

RJ: I was getting out of my first year of college. And then I took a break from college and I later went into the Air Force. Let me think now. My brother, John, who had this problem in the hospital with the tooth was the first thing. But they never really found the problem. They just eventually stopped the bleeding. Then my other brother, a few months later—by that time I was in the Air Force—had a problem with a swollen knee joint. And he then went into the hospital. And

then with all the testing they found that Jim had a factor IX deficiency. So when I came home on leave this—our family doctor, or the doctor that had checked on Jim checked me and found that I also had factor IX deficiency. So I went back in to the Air Force and let them know about it. And they ran their own tests and one of the tests turned out to produce a hematoma in my arm. So they decided that they really didn't want any part of me so they let me out then. But I really had not had any incidents that I at that time connected to it. You know, again, looking back I could see things much clearer.

CH: How old were your brothers? How old was John when this tooth incident occurred?

RJ: Let's see. He would have been probably 13.

CH: And the other brother?

RJ: The other brother would have been probably 15.

CH: Why did it take so long to diagnose? Was it simply that you had a mild form?

RJ: Mm-hmm.

CH: So you didn't have the sorts of incidences that other hemophiliacs might have?

RJ: Probably, yeah. Just pretty fortunate, really. I'd never had any type of surgery, never had a tooth extracted, you know.

CH: You never had any bleeds that you could look back and say, "Gosh, that hadn't healed the way it might have?"

RJ: Well, yeah. I remember having a few crashes on my bike, you know, early and my leg turned black. But, you know, I went to the doctor and they said, "Don't worry too much about it; it'll take care of itself." And, you know, it didn't bother me all that much and it took care of itself.

CH: Tell me about your family. Where did all this occur? Where were you living?

RJ: In Tennessee near Nashville.

CH: Can you tell me about your parents? Did your mother work? What did your father do?

RJ: As we were growing up, my father worked. He was a manager of a radio and TV parts department at an electrical supply company. My mother stayed home with us until—until, I think, John got into high school. Then she began to work primarily as a secretary. She worked at the Methodist Publishing House for a long while.

CH: Was either one college educated?

RJ: No. However, my mother began sort of taking courses, going through great books sorts of things. She read everything she could get her hands on and was probably the most well educated person I have ever known.

CH: The reason I ask is to understand how they approached the care and the follow-up and so forth. They had a 13-year-old who was now diagnosed.

RJ: Right.

CH: So your mother was a person who went after information?

RJ: Absolutely. Wholeheartedly.

CH: Did she do that around the hemophilia as well?

RJ: Yes. She—she became as knowledgeable as she could about it and probably better informed than most of the doctors she ran into about it. Obviously, not the specialists but, you know, the general practitioners. She certainly would know what to look for more than they did.

CH: What was her response? Was she depressed at all? Was she

just forward moving?

RJ: I think just forward moving is a good way to put it. I—I didn't know of any depression around it.

CH: What about your father?

RJ: Dad was pretty quiet about it. You know, he, I think, was obviously concerned. But we didn't talk much about it. He didn't talk much about it with us.

CH: Was that typical of him?

RJ: Yes, yes.

CH: But your mother talked about it?

RJ: Oh, yes. But, you know, still, I had probably less problems than either of my two brothers that were affected. And it was really only my second youngest brother who had the majority of the problems as we grew up.

CH: That was John?

RJ: Yes.

CH: What kind of problems did he have? What was happening in the home around him? Did your mother become protective? Did your family alter its lifestyle?

RJ: Well, to some extent. I'm sure it must have to some extent. You know, it—for instance, he wasn't allowed to cut the grass. You know, the rest of us still were even though—

CH: Shucks. [laughter]

RJ: We were probably about as affected as he was but somehow he just had more problems than we did with it.

CH: Did he have many bleeds?

RJ: Not really a lot of bleeds. He had problems with cysts that would have to be drained, and then they would have to be very

cautious about medical procedures which might cause bleeding.

CH: Were his cysts hemophilia related?

RJ: I don't know that they were. I don't think so.

CH: So he really faced a lot more than you.

RJ: Yeah.

CH: Up until then you really hadn't had any issues.

RJ: That's right.

CH: Did you live in a small town?

RJ: At first, yeah. Well, I guess even later. When I was five we moved out of Nashville because Mom wanted to be on a farm. So we moved out to this little community of Ridgetop—had a population of about 300.

CH: That's small.

RJ: Yeah. And we had a small place right next to the school. When we first bought the place there was a general store next to it that we—turned out we owned with the house. [laughter] And—

CH: But never operated it?

RJ: Well, we actually did then.

CH: Did you?

RJ: We began running the store. And when we first bought the house there was no—no plumbing so we had to put that in. The school was across our strawberry patch, and it had three rooms and eight grades and it had no indoor plumbing. So—

CH: The school didn't have plumbing?

RJ: The school didn't.

CH: So you had an outhouse at the school.

RJ: We had two outhouses at the school, which regularly got turned over on Halloween. [laughter]

CH: So on the first of November you had a problem.

RJ: Yeah, that's right. [laughter]

CH: This was an anniversary.

RJ: Yeah, that's true. [laughter]

CH: Did you like it there?

RJ: Oh, I did like it there. Yes.

CH: It was a good community?

RJ: Yeah, it was a very good community. I did enjoy it.

CH: And your mother was happy?

RJ: Mm-hmm.

CH: She was where she wanted to be.

RJ: Yeah, yeah.

CH: Was she a person of great faith?

RJ: Methodists, yeah.

CH: Was faith a big part of their lives?

RJ: Yeah, yeah. It was. Actually, before moving to the small community, they were Nazarene. And there were no Nazarene churches around so they went to the local—

CH: So they became Methodists. Was that very far apart from Nazarene?

RJ: No, not really. I think probably today Methodists are a bit more liberal than the Nazarenes.

CH: And were your grandparents around there?

RJ: Yes, actually. Well, Dad's mother and his mother's sisters and his sister lived together in—still in Nashville. I guess the first place I remember us living we actually lived with them. And then we had our own place in Nashville until I was five. And they stayed in Nashville; then we moved out. It was about, maybe, 25 miles.

CH: So you saw them.

RJ: Saw them. And my other—both grandmother and grandfather lived sort of about 20 miles in the other direction. So we would see them quite often. And then Mother's mom and dad came up and actually ran the general store for awhile.

CH: Oh, that's nice.

RJ: And lived in it. You know, there was a place to live in the store.

CH: That worked out?

RJ: Yeah.

CH: Did they have a bathroom?

RJ: No.

CH: [laughs] Did they ever have a bathroom?

RJ: No. [laughter]

CH: Oh, wonderful. [laughter] Did you put plumbing in the farmhouse?

RJ: Yes.

CH: Was your parents' reaction to be quiet about the news, the hemophilia, or to share?

RJ: Well, let's see. We moved again after that.

CH: After that you moved—

RJ: After that.

CH: —out of this small town?

RJ: We moved out of the small town into a town of probably about 5,000 people. So—

CH: Was that because—

RJ: Well, it was really because they wanted a better high school for me and the rest of us.

CH: And at that point they didn't know hemophilia was an issue.

RJ: That's right, they wanted a better school for all of us. I just happened to be the first one to need it. And so we moved back to Nashville first. And then a year there was, again, not what they wanted. So we moved back to the small town.

CH: The one with a population of five thousand?

RJ: Five thousand.

CH: And your father moved jobs?

RJ: No, he stayed at the same job.

CH: He did?

RJ: Mm-hmm.

CH: He was able to do that?

RJ: Mm-hmm.

CH: That was nice.

RJ: Yeah.

CH: Did he stay there his whole career?

RJ: Yes.

CH: Isn't that wonderful?

RJ: Mm-hmm.

CH: That doesn't happen much anymore.

RJ: No.

CH: Did he like it?

RJ: Yeah, and I actually worked there with him for a while. You know, sort of summers and between college and going to the Air Force I worked with him.

CH: And TV was just coming in.

RJ: Yes. And we were pretty fortunate because, you know, back when we lived in this small town, Ridgetop, you know, Dad had been

working for this radio, TV parts distributor. And the company also sold radios and TVs and serviced them. So on the weekends he would bring the service ones home. So it was not uncommon at all for us to have a living room full of people to watch Ed Sullivan because it was the only TV around for miles.

CH: That's funny. We used to do the same thing.

RJ: Yeah.

CH: Our house was filled with people watching television.

RJ: Yeah.

CH: It was just a social occasion.

RJ: Yeah.

CH: And everybody watched Ed Sullivan.

RJ: Yeah.

CH: And Lawrence Welk.

RJ: [chuckles]

CH: That was the big thing. And drank Moxie.

RJ: [chuckles] That must have been up here.

CH: [chuckles] At Cambridge.

RJ: Yeah.

CH: Yes. So once they had this on their plate, the hemophilia, did they choose to be quiet about it in terms of your brother?

RJ: They—they got very active in the local hemophilia chapter.

CH: There was a local hemophilia chapter?

RJ: Later on, there was. By the time I was out and married and, you know, John was still having some problems with this. He was in contact with the doctors at Vanderbilt quite a lot. So I think through that exposure Mom got to know some of the people associated with the local chapter. And then she became rather active in that.

CH: Did your brother encounter any prejudice at all? He was thirteen years old.

RJ: No.

CH: No? Good.

RJ: No, I don't think—

CH: Not at school?

RJ: I don't think people were generally aware of it. You know, I think our close neighbors would know that he was being a little more careful than they were. But, you know, again, although I had far less problems than he did, I think he had far fewer problems than the rest of the hemophilia general population.

CH: Well, he had thirteen years when not much happened.

RJ: That's right, yeah.

CH: He hadn't had these bleeds and joint issues.

RJ: That's right.

CH: That most people have starting with infancy.

RJ: That's right.

CH: But it's still a bitter blow for somebody thirteen years old—

RJ: Yeah.

CH: You haven't grown up with it as part of your life.

RJ: Yeah. Except, you know, when he needed to have treatment—when he had to go to the hospital for something he didn't take factor as a regular sort of thing.

CH: Only when he had a special—

RJ: Right.

CH: And how do you think they found the quality of the medical treatment in that area? Did they go to Vanderbilt?

RJ: Yes they went to Vanderbilt.

CH: And was that a fairly well informed center?

RJ: Yes, it was. I think certainly for that area they were pretty much on top of it. Certainly, as much as anyone would have been at the time. I mean, when you realize that—that factor IX deficiency or Christmas Disease wasn't really officially diagnosed until the '50s. And this wasn't a long time after that.

CH: That's right.

RJ: They knew about it pretty well.

CH: Going back to you. Here you are; you're in the Air Force. How did you feel when suddenly they didn't want you. That must have been a blow.

RJ: Yeah, it was, actually.

CH: Hurtful and irritating.

RJ: Well, disappointing, I think.

CH: Disappointing?

RJ: Because the first year of college I hadn't done so well.

CH: Which was where?

RJ: Vanderbilt.

CH: And why was that?

RJ: I think I just, for whatever reason, just wasn't ready for—for that level of study, just had a hard time concentrating on it. Now, Claudia will tell you I have ADD. But—and so probably that was a factor.

CH: Did you do better the second year?

RJ: Excuse me?

CH: Did you do better the second year?

RJ: I—well, I went to the Air Force.

CH: Straight out of school, after the first year?

RJ: After the first year. After the first year I worked for the summer with Dad and then went into the Air Force.

CH: So you pretty much decided after the first year that college really wasn't for you.

RJ: I knew that—at the time it wasn't for me, Yeah.

CH: What were you planning to study? Or did you know?

RJ: In—

CH: At Vanderbilt?

RJ: At Vanderbilt. Yes, I was—I wanted to study chemistry because I'd had this chemistry set that I'd played around with. And I was really pretty interested in it. And I found out pretty quickly that as a hobby it was one thing and as something to try to pursue as a career it was totally different. So I was doing a lot of rethinking about what I really wanted to do. And I thought that I wanted to do something more mechanical, maybe, you know, work with cars or motors or things like that. So I went to sign up for the Air Force and took all their tests. And I scored okay on the mechanical stuff but I scored pretty high on the electronic stuff. And they said, "Well, you'd be crazy not to go into electronics because that's where our best schools are." So I did.

CH: And you were going to be an electrician in the Air Force?

RJ: Right.

CH: And you had been there one year when the issue of hemophilia came up.

RJ: About a little less than a year.

CH: And how did they handle the severance?

RJ: It's—they were really pretty good about it. It was not like there was any choice on my part. But the—sort of our company—I don't

know what he was called. Just the head of our—the group that I was in spoke to me to me as I left and said he was sorry that it had to work out this way and wished me the best and sent me on my way.

CH: Do you have feelings about that decision? Do you think that they should have kept you?

RJ: Well, I—we had the hematologist at Vanderbilt write them and we told him to let them know that I wasn't wanting to get out, that what I wanted was them to assign me to a job in a location where I could get reasonable medical care. And they said they could not always guarantee that. So they got me out.

CH: That must have been a blow.

RJ: Yeah, it was.

CH: Now, you were at a loose end again.

RJ: Mm-hmm.

CH: At that point, what was happening to you physically? Anything different? Did it change your life at all? Or were things were going on as they always had?

RJ: Still had no real incidents [unclear].

CH: Did you bleed?

RJ: I would bruise. But I didn't think—you know, it was—it was never bad.

CH: And had you had any infusions at that point?

RJ: No.

CH: Did it worry you?

RJ: Well, yeah, I guess to some extent it did. I began seeing this girl. We got serious and were talking about getting married. But there was the issue of hemophilia there. So, you know—

CH: When did you tell her?

RJ: We had actually started going together before I left for the Air Force. So when I found out I told her and said, you know, “This is certainly going to affect my life later on and so we can call this off if you want.” But she didn’t and we didn’t and then later got married.

CH: Do you think that affected your relationship?

RJ: I don’t think so.

CH: What did you do? You leave the Air Force. Where do you go from there? Life has changed.

RJ: Life has changed. I worked—went back to work for a while with Dad. And then Mom found out about a—either a career day or a college recruitment day back at the high school that I guess Jim was going to then. So she arranged with the principal for me to be able to go back and talk to some of these college recruiters. So I talked to a fairly local, smaller state engineering school there. I had come out of Vanderbilt with a fairly poor record. But they were willing to let me in and have another try at it. So—and with the electronics training in the Air Force I went back in and went into electrical engineering.

CH: Did you like it?

RJ: I did like it, yeah. It took awhile to really get into it but I did like it.

CH: Did you like the school?

RJ: Yeah, it was a good school. Yeah.

CH: Two years? Four years?

RJ: Four years.

CH: Uh-huh. Why did it take awhile to get into it? Was it just that you’d lost speed with all the changes?

RJ: I think so.

CH: Because you had a lot of changes in two or three years. Big

news.

RJ: Yeah, mm-hmm. But I think, you know, in the end I was doing reasonably well.

CH: And they stayed with you?

RJ: They did, mm-hmm.

CH: Good move for you?

RJ: Yes, it was a very good move for me.

CH: Did you live there?

RJ: Yeah. Lived in the dorms for a couple of years and then got— then I guess I stopped for awhile and got married. I worked for—

CH: You stopped school?

RJ: Stopped school for awhile. Got married, worked for maybe six months to a year. I don't remember right now. And then went back to the same school. Judith and I got an apartment and we finished school there.

CH: Did you have children?

RJ: No.

CH: May I ask what happened to the marriage? Did you remain married for a long time or did you—

RJ: Yeah. We—we were married for close to 20 years.

CH: Did she want children and that was a decision not to—

RJ: No, we eventually did, just not then did we have children.

CH: Oh, I see. You did eventually have a family.

RJ: Yes, mm-hmm.

CH: You graduated from college?

RJ: Right.

CH: And then what did you do?

RJ: Graduated from college, moved to, first, Illinois.

CH: For a job?

RJ: For a job.

CH: Which was?

RJ: Worked for Magnavox doing—working on some government projects that were associated with Sonabuys. But worked there about a year and a half and, you know, working on government contract work was just not what I wanted to do. So then I found a job at Heath Company in Michigan. It's the company that used to build the kits and that sort of thing. And I got into their scientific instrument group there and have actually been in that line since.

CH: With that company?

RJ: Not with that company.

CH: I don't even know if they still exist.

RJ: We moved from Illinois to Michigan and had been there about a year. And we were trying to have children but were not able to at first. And we had started an adoption process. And when that was almost complete, then Judith got pregnant so we had a son. And, you know, medically, fortunately it was a son and then he wasn't affected.

CH: That was your only child?

RJ: Yes.

CH: Did you have a lot of conversations around whether to have children or not to?

RJ: Yeah. But I think—we wanted children and I think probably rationalized it that, you know, by the time they would be—that I—you know, since I really hadn't had that much of an issue with it that we were hoping that they wouldn't either and that, you know, medical science is going to progress and some day this will continue to get easier.

CH: And you're right.

RJ: Yeah.

CH: You were right. All this time that you're working and developing your career, were there any things that occurred? Hemophilia-related incidents? Or did it remain fairly benign?

RJ: It remained quite benign.

CH: So not many bleeds?

RJ: Not many. Didn't really have joint problems. A few instances of bleeding from my kidneys. I never had factor. I had to take whole blood once or twice in some of those instances but mostly just wasn't an issue.

CH: Is bleeding from your kidneys a result of a bruise or was it some sort of auto bleed?

RJ: I think it must be sort of auto bleed because first time it happened, you know, they ran all sorts of tests to be sure my kidneys were okay. And everything was okay. And then I guess it's common enough that, you know, that it's just not a worry.

CH: Did Judith educate herself? Was she interested in the details of it?

RJ: Not so much. Not nearly to the extent of my mother. But she didn't really have to because, you know—

CH: Day to day it wasn't an issue.

RJ: Day to day it was not an issue, whereas with Mom day to day it was more of an issue with my younger brother.

CH: Let's back up and tell me, if you would, what was happening with your two brothers during this time.

RJ: Jim went on to school, did very well in school. He was pretty much an A student except for phys ed. [chuckles] And I—I don't

know of any serious incidents that he had at all. John, again, continued to have some problems, some with joints but mostly he had terrible acne. I did as well, just not quite as bad as he did.

CH: Hemophilia related?

RJ: No, but it caused problems with cysts, which did have to be drained, which then became an issue.

CH: That's heartbreaking.

RJ: Yeah, yeah. Mm-hmm.

CH: So he had a tough time.

RJ: He had a tough time.

CH: All the way through.

RJ: Pretty much.

CH: And what happened to him?

RJ: John was much more centered around the arts so he went to Memphis State, got his—eventually got his MFA degree and—but, as with artists, that's not—that's not a financially secure career path. [chuckles] So I actually, you know, I don't really remember all the details but he eventually got connected with Hemophilia Health Services. So he now works with them, or rather the company they were sold to. He does a lot of their retreats and planning and does a lot of patient overseeing now. So he's very active.

CH: So he found a good spot for himself.

RJ: Yeah, mm-hmm.

CH: And where does he live?

RJ: He lives in Nashville.

CH: So he landed on his feet in the end.

RJ: Yeah.

CH: Did he have many infusions as he grew up?

RJ: You know, I guess not a lot compared to what someone with severe hemophilia would have.

CH: And HIV and hep C—

RJ: Yeah.

CH: —didn't become an issue?

RJ: Hep C did. HIV did not. He's been very fortunate to not be affected by HIV. All of us are. But he—he has had bouts with hepatitis and he's—he does have liver problems now.

CH: When was he diagnosed with that? Do you remember? The early '90s, maybe?

RJ: Yeah, that's probably about right. Mid to early. Yeah, early '90s was probably about right.

CH: Do you remember that period when it began to appear that HIV and hep C were real issues?

RJ: Yeah.

CH: Can you tell me what that felt like? Were you very concerned? Of course, you hadn't had a long history of infusions.

RJ: I hadn't had a history of infusions.

CH: John—

RJ: John had some. And—but, you know, it's interesting because that word didn't get out to us, I think, until—you know, it was almost over with by the time we really were aware of the real dangers involved with that.

CH: Did any of you go for testing?

RJ: Yeah, yeah.

CH: All of you?

RJ: All of us.

CH: Were you concerned or did you feel fairly at ease because of

your history?

RJ: Well, I think, since I knew that I'd had no factor, and I felt pretty safe about it, you know.

CH: Of course. John?

RJ: John I'm sure was nervous about it, although, you know, we didn't live in close proximity. So, I mean, we didn't talk about it on the phone much.

CH: Was your mother still—

RJ: She was still—she was still—

CH: Alive and—

RJ: Very active still. And I'm sure she was concerned about it as well.

CH: I bet she was. That was a tough time.

RJ: Yeah.

CH: So you worked and you had a son with Judith. Can you say whether the hemophilia affected you personally in any way during those years? Would you say it affected either your life or your relationship?

RJ: I don't think that it did. I really don't think that it did because there just were not any serious incidents.

CH: Right. You weren't in pain?

RJ: Yeah.

CH: You weren't restricted?

RJ: That's right.

CH: What happened then with Judith? The marriage just ended?

RJ: Yeah. And, you know, we—we still talk to each other. She's on the West Coast now. And then I eventually met Claudia, actually through my son.

CH: And life started again.

RJ: And life started again. Yes.

CH: Did you tell me your brother, John, married or not? Did he?

RJ: He married. Yes, he did marry and they adopted a son from Korea. And then he later divorced and—

CH: Do you think that affected his marriage?

RJ: I think it probably did.

CH: I'm just interested in the—

RJ: Yeah.

CH: —in the way the disease does affect—

RJ: Yeah.

CH: —some relationships.

RJ: I'm sure—

CH: And whether you know much about that.

RJ: I don't—it wasn't talked about directly a lot. But I do know that John being affected by this so much affected his employment, his ability to earn money to support his family. His wife was a schoolteacher so she had steady employment—she was able to keep them going with that. But still, it was not a comfortable situation with John having heavy medical expenses and not being able to produce an income.

CH: There are all kinds of things to consider, and then having a family—

RJ: Yeah.

CH: —can be an issue.

RJ: Right.

CH: Had they decided not to have children or did they—

RJ: I don't know. I suspect that they did decide not to have

children.

CH: Your other brother?

RJ: My other brother never married.

CH: Do you think that was because of the hemophilia?

RJ: I don't know. But I don't think so. He is living with his roommate from college now still.

CH: Your mother must have been remarkably modern.

RJ: She was.

CH: And intelligent. And she was in a very small place, very Methodist.

RJ: Yeah.

CH: She really had a lot of verve, didn't she?

RJ: She absolutely did.

CH: What was her name?

RJ: Fay.

CH: Faye.

RJ: Actually, Gracie Fay.

CH: Gracie Fay.

RJ: But it was Fay.

CH: As a family, talking intimately didn't seem to be something you did.

RJ: No, we didn't.

CH: Not a surprise.

RJ: Yeah.

CH: Lots of families in the '50s were that way.

RJ: Now, I should also say that we're pretty certain now that Mom was also affected by this, even though, you know, at the time people said that just didn't happen, that women were not affected. But they

realize now that, indeed, women are affected.

CH: In what way? What would you say, looking back, were the ways in which it affected her?

RJ: Well, I mean, from a physical bleeding standpoint because—I guess I don't know any real incidents she had but—but she was aware of it and told us that she felt that she also was affected by this.

CH: Was she ever anemic?

RJ: Yeah, yeah.

CH: I didn't know that they had found that women—

RJ: Yeah.

CH: —exhibited some symptoms.

RJ: Yeah, mm-hmm.

CH: You were lucky in having her, weren't you?

RJ: Oh, absolutely.

CH: And certainly your brother was.

RJ: Yes.

CH: Your father was quieter.

RJ: Mm-hmm, but very supportive.

CH: It sounds like a nice family.

RJ: Yeah, it really was.

CH: You had surgery eight years ago?

RJ: Eight, yeah. I guess about eight years ago.

CH: And obviously, Claudia knew that you had—

RJ: Yeah.

CH: —hemophilia.

RJ: Yeah.

CH: You told her.

RJ: Mm-hmm.

CH: Having met her, I wouldn't think that it would be a big issue for her.

RJ: No, it wasn't. [laughter]

CH: A challenge, maybe. [laughs]

RJ: Yeah.

CH: But not an issue. What happened with the open-heart surgery?

RJ: Well, I went in. No, I guess actually what happened, Claudia went in to our cardiologist. And, yeah, I'd been seeing him on and off just to—for general health reasons. And I think in one of the—one of the tests that he had run, just as a general screening test, an echogram indicated that I had a bicuspid aortic valve. He said at the time I just need to watch this as it goes on because they're more prone to calcify than others. And that was pretty much it. Then Claudia was in one day to see him and treated her. And as she was leaving he said, "I think you should get Bob back in here because I've been doing some reading and it turns out that this may be more of an issue than we had first thought." So I came back in. They ran more tests and found that—that, indeed, the valve wasn't working properly and that there was an aneurysm around the aorta at the opening to the heart. So he sent me home and, you know, said, "We need to schedule surgery pretty quickly and in the meantime don't exert yourself. Don't lift anything." Claudia was not in the office when I was told this first. But then she came to the doctor's office while I was there. And she said, "But he can't be operated on like this." And the doctor said, "It will be fine. They'll work it out." And he was right.

[end of side 1, tape 1]

RJ: I don't think he knew all that was involved with it.

CH: She was right.

RJ: Well, I think that the doctor was right in that it certainly worked out. But there were issues that had to be dealt with that I think that he wasn't truly aware of.

CH: How did they deal with it?

RJ: Well, what happened after that was that Claudia got on the phone with the New England Hemophilia Society, talked to Cathy Cornell. She suggested I see Dr. Ewenstein at the Boston Hemophilia Center. He managed the whole thing. He set me up with then Dr. Lawrence Cohen, who is the chief of surgery there, and Dr. Ewenstein, the hematologist, also picked the anesthesiologist and that team. So everything was pretty well set up for me. And they got me in the day before, started giving me factor. And then, just before the surgery they took some of my blood to later then give back to me after the surgery. So they were really on top of it all the way.

CH: Were you afraid? Nervous?

RJ: I was, yeah—well, certainly I was nervous.

CH: You'd be nervous anyway.

RJ: Yeah.

CH: It's a difficult surgery.

RJ: And, yeah, I was afraid. And I think the really most depressing moment of that came when I asked, what's the lifetime of this valve you're going to put in? And my cardiologist said, "Well, they can last a lifetime because it's an artificial valve." But I then found out, because of my hemophilia, they couldn't use that type of valve, because that type of valve requires blood thinners to be taken with it. So what that meant was that I would at some point have to do it again.

CH: Oh. You had to have an older type valve.

RJ: Yeah.

CH: Older-fashioned.

RJ: Mm-hmm. Well, or at least different. One that doesn't have an unlimited lifetime. So that to me was the most discouraging part.

CH: Were you in the hospital by that time?

RJ: No.

CH: It didn't give you pause about having the surgery at all?

RJ: No.

CH: You never reconsidered—

RJ: No, that wasn't the issue. I mean, we were just waiting to get scheduled by the surgeon at that time. So just—

CH: How did you get over that discouragement or did you just move through it and have the surgery?

RJ: Yeah, I think so. And certainly, Claudia was very supportive. And it's not like there was a choice, you know. It—if I had to do it again, I would have to do it again.

CH: Well, the choice was don't do it at all and—

RJ: Yeah.

CH: —do it this way.

RJ: Well, that wasn't a choice either. I mean, not doing it really wasn't—the way it was described to us—wasn't a choice.

CH: Did you then or at any other time seek counseling or talk to other men with hemophilia or go to any kind of group that gave support?

RJ: I didn't. No. I talked to—I talked to the doctors but I didn't talk to anyone else.

CH: Are you a person of strong faith? Was that part of what

supported you?

RJ: I think I'm—have a pretty strong faith. It's not a traditional sort of faith. I'm a Unitarian, wouldn't call myself a Christian anymore. But yeah, I—yeah, I still believe that I have a strong faith.

CH: It must have been quite a shift for you to say that you don't call yourself a Christian anymore. That must have been quite a change for you.

RJ: Yeah, yeah.

CH: Certainly from then to now.

RJ: That's right.

CH: May I ask if that happened overnight or—

RJ: No.

CH: —was it just a growing—

RJ: I think it was just a growing.

CH: —change.

RJ: Mm-hmm.

CH: Philosophically you changed?

RJ: That's right. Yeah.

CH: As we should and do. That's not a bad thing.

RJ: Yeah. I think—you know, there was awhile after Judith and I first got married that we didn't go to church much. Then as David starting growing up I think we both felt the need to get him back into that environment and expose him to that. So Judith had been a Baptist growing up. I had been a Methodist growing up. I mean, while were dating we went to both churches. I mean, we were so churched.

CH: [chuckles]

RJ: Oh, it was. [laughter]

CH: My goodness!

RJ: [chuckles] And so by that time we were living here. David was, I guess, about four.

CH: You had joined the company you work for now?

RJ: No.

CH: You changed companies?

RJ: I changed companies. So we went to the Baptist Church. Well, that was an experience here. You know, not having been in church for awhile and, you know, sort of having a bit broader view of the world by that time, there was this Baptist Church here in New England talking about how wrong it was to teach evolution in school.

CH: Still?

RJ: Still. How it was immoral for women to wear slacks, you know.

CH: In Massachusetts?

RJ: In Massachusetts.

CH: That's what I would have expected in Tennessee.

RJ: Yeah. [chuckles] I said, "This isn't the place for us."

CH: You both agreed?

RJ: Yes. Judith had been sort of exploring other spiritual paths. And we tried the—we tried the Unitarian Church. We lived in Groton at the time. We tried the Unitarian Church there. And they had a part-time minister that was, you know—felt like a part-time church. But then they got a new minister and I went back by myself for awhile. And the new person was just really in tune with what we felt we believed. And so we got David involved in the church school there and sort of continued with that.

CH: When you applied for different jobs, did you speak about being a hemophiliac?

RJ: Yeah.

CH: You did? Did that ever affect your getting a job?

RJ: No. You know, the only issue would have been insurance so—

CH: But that wasn't an issue.

RJ: But that turned out to be not an issue. I've never had any absenteeism because of my health.

CH: Did you find that kind of nerve-wracking? Here you were, a job interested you? Did that ever cross your mind?

RJ: Yeah.

CH: Because it had to have affected you hugely. It must have been tempting—

RJ: Yeah.

CH: —to just not go there.

RJ: Yeah, I guess I was afraid to not go there. You know, afraid of the consequences of that more than I was afraid of facing it up front. And fortunately, it wasn't an issue with anyone that I worked with so—

CH: Have you been happy with your career?

RJ: Yes, I've been very happy with it. I've been—actually been with the last company for 19 years now. So—

CH: So hemophilia really affected you twice primarily. One was in the Air Force when it really changed the whole direction of your work.

RJ: That's right.

CH: And then with the valve surgery.

RJ: That's right.

CH: Those are the two big things.

RJ: Mm-hmm.

CH: Do you ever think about life would have been like in the Air Force if you'd stayed on that path?

RJ: I've thought about it, yeah. And it's sort of hard to imagine what it would have been like, now looking back at that. Certainly would have been different—wouldn't have had the opportunities that I have now, I think. There would have been a different set. I truly don't know.

CH: Do you believe in destiny?

RJ: [unclear].

CH: It's not a question—

RJ: No.

CH: —I'm probably supposed to be asking.

RJ: No, that's quite all right. I don't. No, I don't think so in any strict sense of the word. I think—I think we are to a very large extent in control of the direction that our lives take. Now, what you just pointed out, that I was—certainly in those two instances I wasn't in control.

CH: Right.

RJ: But certainly there was some level of control about how each of those was handled.

CH: That's right. That's where this wonderful Chinese saying that “Character is destiny,” comes in, which is what I think I believe. Something happens that you could nothing about. Your character dictates what you do with that information and that occurrence. And that's destiny, really.

RJ: Yeah, that's good.

CH: That always appeals to me. It's sort of right in the middle of self-direction and—

RJ: Yeah.

CH: —self-determination.

RJ: Yeah.

CH: And how would you say your brothers have ended up vis-a-vis the hemophilia? How significant has it been? Certainly, for your younger brother more than for either of you.

RJ: That's right.

CH: It has affected his life, hasn't it?

RJ: Mm-hmm, it has. I think in a very large way. And he still—he still has medical problems with it. But at the same time it brought him into a career that he likes. And he is very actively serving the hemophilia community.

CH: So it's brought him to a good place in an interesting way.

RJ: Yeah, yeah.

CH: Into a caring profession—

RJ: That's right.

CH: —for a sensitive individual. And remind me what your other brother does for work.

RJ: My other brother was an engineering physicist, worked for Martin Marietta Missiles. And as soon as he made enough money to retire, he retired. So he's living in the hills of Asheville, North Carolina.

CH: The beautiful hills of Asheville, North Carolina.

RJ: Beautiful, yes.

CH: With his friend.

RJ: With his friend.

CH: Is his friend retired?

RJ: Yes. They worked together.

CH: And they have a great—

RJ: They have a—

CH: —a great life.

RJ: They have a great life. They help their neighbors. They are involved in all sorts of charitable things.

CH: How wonderful.

RJ: And they live very frugally but very well.

CH: As your family did.

RJ: Yeah, yeah.

CH: You learned to do that—

RJ: Yeah.

CH: Is there anything else you'd like to say about the experience of hemophilia?

RJ: Mm-hmm, sure.

CH: How all the other aspects of life are impacted as well.

RJ: Well, sure. I think after—after my surgery I was just deeply aware of how caring the hemophilia community is. And, you know, the—the doctors I met, Cathy and the people at the hemophilia treatment center, the home care people that we had.

CH: Any other patients?

RJ: I didn't really know any other patients.

CH: So that connection wasn't made.

RJ: Right.

CH: But that group came forward—

RJ: They did.

CH: —and gave you support and encouragement.

RJ: Yeah. So I wanted to do something. So I got back in touch with Cathy. And so pretty much since then I've been involved with

their newsletter committee. So I work with them a few times a year.

CH: Any work again with, say, children?

RJ: I haven't been. I mean I would but that opportunity hasn't really presented itself.

CH: Their issues are so different than your brother's.

RJ: They are. Yeah, they really are.

CH: It's a totally different world, isn't it?

RJ: Yeah.

CH: Do you think your brother's ever resentful, sad about that difference of 30 years or 20 years really made such a difference for him?

RJ: Oh, I think for John very definitely because there isn't any doubt about—I mean, it made his life a struggle for a large number of years.

CH: And you have the only grandchild.

RJ: That's right. That's right.

CH: When did your mother pass away?

RJ: Let's see. It's been about four years ago.

CH: Not too long.

RJ: Not too long. Hm-mmm.

CH: So she certainly knew her grandson.

RJ: Yes.

CH: Well.

RJ: Mm-hmm.

CH: Do you think it affected her long term or did she just did the best she could and accept that?

RJ: You know, I think—yeah, I think she certainly just did the best she could with it. I don't think she anguished over it but I think she

just, as with everything, put her whole self into it and did all she could about it.

CH: Did it impact them financially?

RJ: Yes, yes.

CH: In a big way?

RJ: I think in a very, you know—

CH: Substantively?

RJ: Not—yeah.

CH: Did your father have health care?

RJ: Yes. But, you know, after, of course, John got to a certain age that wasn't effective anymore. So it—it strained them. There isn't any doubt about it.

CH: When did your father pass away?

RJ: He's still living.

CH: Is he?

RJ: Yes.

CH: How old is he?

RJ: He is 83.

CH: And healthy and hale?

RJ: Quite healthy, yes.

CH: In Nashville?

RJ: In Nashville living by himself in his house.

CH: Isn't that wonderful? Keeping busy?

RJ: Keeping busy, yeah. Just in his own way, you know, with his, just, routine every—

CH: Yes?

RJ: So—

CH: I just wanted to ask you. You said looking back, you could see

there might have been signs of—

RJ: Yeah.

CH: —this affliction in—in the family in the past. What was the nature of that? Did your mom remember—

RJ: Well, yeah, my mother remembers people in the family who had—would have problems that could—that she now would recognize as possible. And her own brother—

CH: But they didn't know?

RJ: And didn't know. And her brother had serious problems with—with bleeding, internal bleeding.

CH: And nobody diagnosed it?

RJ: Nobody diagnosed it.

CH: Did he die prematurely?

RJ: Yeah, he did. It was exacerbated by alcohol. But he did die—

CH: So he probably had a very tough life because of it.

RJ: He had a very tough life because he also was not able to maintain employment.

CH: So there's the answer right there, isn't it?

RJ: Yes.

CH: Her brother and yet nobody really—

RJ: Yeah.

CH: —really observed that.

RJ: That's right.

CH: It wasn't very long ago, was it that—

RJ: It was not all that long ago.

CH: —that that wasn't recognized. I was just rereading about Czar Nicholas and, of course—

RJ: Yeah.

CH: —his son. That changed the course of history. Rasputin came on the scene. And they did know what it was but there was nothing they could do except be careful.

RJ: That's right. Yeah.

CH: And there but for that went the Russian Revolution.

RJ: [chuckles] Yes.

CH: Is there anything else that you'd like to add? I will just go back to what Claudia said. Did you feel that your attitude towards care changed?

RJ: Well, I think what she's referring to—I never saw the need before that to keep—store factor on hand, to—to even have checkups at the Hemophilia Treatment Center. So I guess in that sense there was some denial but it's—I'm—I don't know it's so much denial as is just not considering it a problem.

CH: It wasn't in the forefront, was it?

RJ: Yeah, yeah.

CH: So now you do keep factor?

RJ: Yeah.

CH: And do you go for checkups?

RJ: About once a year, yeah.

CH: Why not? And of course you have the added issue of the heart so you want—

RJ: That's right.

CH: —to be sure that all is well and that you're ready if something happens.

RJ: That's right.

CH: Isn't it fabulous that they can do these surgeries?

RJ: It is amazing.

CH: Because for a lot of people I talk to, small occurrences—

RJ: Yeah.

CH: —were such an issue.

RJ: That's right.

CH: And you're having open-heart surgery and we're talking 40 years, 45 years.

RJ: That's right. That's exactly right. I mean—

CH: That is really an astounding advance.

RJ: Certainly, 20—maybe even 15 years ago I wouldn't have lived through it.

CH: That's correct. So timing was on your side.

RJ: Yes.

CH: And that they take the chance and are so brave and courageous to undertake that.

RJ: Exactly.

CH: You know, people can talk about healthcare litigation but people are still taking on the high-risk places to go.

RJ: That is—yes. And that—that takes an investment.

CH: Yes, it does. Absolutely. Certainly a commitment. So I ask you again. Is there anything that I've missed that you would like to add?

RJ: I can't think of anything.

CH: I really appreciate you talking to me.

RJ: Well, it was very nice talking with you.

CH: Thank you.

RJ: Thank you, Christine.

End of Interview