

Interview with Jeryl Drummey by Laura Gray for the Boston Hemophilia Oral History Project, March 17, 2005.

GRAY: This is Laura Gray at Jerry Drummey's house on March 17th.

And let me start by saying thank you, Mr. Drummey.

JD: You're welcome.

LG: We're sitting in a fantastic room surrounded by Minnie and Mickey Mouses. And I just want to say what a lovely pleasure it is to sit with all this company here. So Mr. Drummey, it is March 17, 2005, a Wednesday morning. And tell me your date of birth and how old you are and where you were born.

JD: Well, I was—my date of birth was August 8th, 1941. I was born in Brighton, Massachusetts.

LG: And you're how old now?

JD: Sixty-three.

LG: Sixty-three. And what kind of hemophilia do you have? Do you know?

JD: I'm not sure. I think it's called Type A, I believe.

LG: Type A? Do you think it's factor VIII, Type A?

JD: It's factor VIII, yes.

LG: Okay. And do you know the severity of it?

JD: Moderate. I think it used to be, like, worse but I've just learned to live with it. [chuckles]

LG: Okay. [chuckles] Who did you grow up with in Brighton?

JD: No, not much of anyone. I had two brothers then and we just grew up together.

LG: Your two brothers and your parents, you mean?

JD: Yeah, yes.

LG: Tell me a little bit about your parents? What were their names and what did they do and their education?

JD: My father's name was James. He, I believe—it's a long time ago—he worked at the Boston Naval Shipyard. And my mother's name was Marjorie and she didn't work at that time. Later on, like, she started working as a nurse's aid.

LG: Okay, what was their education? Do you know?

JD: High school, I believe.

LG: And were they from Brighton also?

JD: I don't know where my father was from but my mother was from Athol, Massachusetts.

LG: Where were you in line of the three boys?

JD: I was in the middle.

LG: You were in the middle. And were you the only one in the family with hemophilia?

JD: Yes, I was the only one.

LG: What about other people? Cousins, uncles? Anybody else in the family?

JD: Never has been traced. They've tried to and they've looked through but they've never found any trace anywhere else in the family.

LG: So you're really the only one.

JD: That's right.

LG: What is your first memory of hemophilia? Either the word or the experience with—tell me what you remember.

JD: I think my first memory, I was just a small child and my mother says, "Oh, we've got to go to the hospital for a checkup." You know, and I

didn't know why or what or where. That's like the earliest time I find that I could remember that I had to go to hospital for something.

LG: Do you remember what hospital you went to?

JD: Yes, Boston Children's.

LG: And so you remember going to Boston Children's Hospital with your mom and what do you remember about that visit?

JD: I don't remember much about that visit, or maybe I do; I don't know. I just remember I had a lot of visits and they all just work into—you know, all blend in together.

LG: But you had a lot of visits to Children's Hospital.

JD: A tremendous amount of visits.

LG: Tell me what you remember about that. How old were you? When did it start? Or any memories.

JD: Well, I can go back. I can remember probably when I was, like, four. And it wasn't always a very pleasant experience because back then most of the doctors knew very little about it. And, unfortunately, many of the doctors thought they were going to discover the whole new thing about it. And frankly, they didn't know what they were doing.

LG: What do you remember about that?

JD: I remember them trying different things.

LG: Like what?

JD: Well, when I was—actually, when I was much older, when I would have a bleed in a joint, like a knee, they'd want to aspirate it. And they'd keep doing that. They would aspirate it.

LG: And what did aspirate it mean?

JD: They'd take a large-gauge needle and stab it into the joint and squeeze the blood out of it, so they'd get the swelling down.

LG: What was that like?

JD: Extremely painful. They'd give you a little novocaine, which wouldn't do anything. And I mean, to start with, the joint was bad. It was very painful. And to take something and just stab it in like that—and when I say stab it, they'd have to raise the needle, like, over their head and, like that.

LG: You literally remember someone raising that needle—

JD: Oh, yes.

LG: —and stabbing the knee.

JD: Very, very clearly. And then the only problem, they would take the fluid out, then the next day, of course, it would just fill up again.

LG: And then what would they do?

JD: They—often, they'd want to do it again.

LG: And what was this like for you?

JD: Very painful and very—and it was a case that I felt they didn't know what they were doing. And I think in the years that have gone by they've found out that was not the way to treat it. And so there was many different cases like that that they—I wasn't a person; I was a case.

LG: Is that how you felt?

JD: Yes. They didn't think of me as a person. They considered me as something wrong and something they were going to find how to treat.

LG: How come you felt like that?

JD: Well, I felt like that because when I didn't want it done they would keep doing it. And it would keep filling up again and I would be

having the same trouble. The treatment they were giving wasn't doing any good.

LG: What brought you to the hospital? What was your experience with hemophilia? Do you remember as a kid?

JD: Well, what do you mean? Experience?

LG: Did you experience many bleeds?

JD: Oh, yes. No, I had bleeds in most of my joints. I'd have it in my knees, my ankles, my elbows, shoulders.

LG: Often?

JD: Yes, quite often back then. Well—or it seemed like it was to me now. I'm sure it was a lot more often than I have it now. I don't really have that much problem now. I don't know; I've learned to control myself, live with it and know what I'm doing.

LG: Did you know what the heck was going on when you were a kid?

JD: Ah—

LG: Or did your parents? How'd they figure it out?

JD: Well, I guess when I was about—I think it was 14 months old—I was bleeding in my mouth, whether—a tooth was coming in or something. And it just kept bleeding. And it just kept bleeding and—

LG: Your parents told you this?

JD: Yeah, yes. And so they brought me back and then back then, Children's Hospital, there was a—one very good doctor there who did discover it. It was Louis K. Diamond, who was a very intelligent hematologist. And he knew—he was one of the people who knew something about it, where, unfortunately, most of the interns they had was, you know, just a big discovery to them and, you know, something to experiment on.

LG: So at 14 months you were told, “That’s from a mouth bleed.”

JD: Yeah.

LG: How do you remember your parents handling your bleeds?

JD: I would use ice then, as I would now, and you know—and such. But it was often a case of when I was having trouble to go to a hospital. And then I would probably have a transfusion, which—which would treat it pretty well and it would bring my clotting level up and help stop the bleeding and such.

LG: Did you spend much time at the hospital?

JD: A lot—yes, an awful lot of time.

LG: What do you remember about an awful lot of time?

JD: Well, for one—for one period of time I can remember I was going in just three times a week just getting transfusions and which they were trying then to see, well, how well this would make me feel and treat me. And it did pretty well but—

LG: How old were you then? Do you remember?

JD: I was 10—maybe a little older; maybe a little younger. I can’t remember.

LG: But still school age?

JD: Yeah.

LG: Mm-hmm. Did you have to ever spend the night in the hospital?

JD: Oh, I’ve been in—probably 20 times or better I was kept over in the hospital.

LG: For long, short, day—two?

JD: It’s hard to say. It seemed like a long time to me now and it was probably like a week or something like that. And it just—as a child, it seemed like a very long time.

LG: Do you remember what it was like when you had to be in the hospital? Do you remember how people treated you? Were you in a big room, a small room?

JD: Oh, it was a ward. It was a ward. In fact, it was not Children's, as it is today. It was in the old—they had the old bungalows out back in the days when they actually could have some property with grass on it. [chuckles] And—but it was like two-floored bungalows which didn't even have elevators. So when they brought you in they had to carry you upstairs.

LG: Oh, my goodness!

JD: It was a—a kick, you might say. But then a lot of things were then, and such.

LG: So you'd go to the hospital. Why would you be taken; who would take you?

JD: My mother usually. And it was because I would be having a bleed or something along that thing. And sometimes they'd want to just keep me to watch over it and such, and that would usually be the case.

LG: Did it hurt?

JD: It hurt—extremely painful.

LG: Tell me about pain.

JD: Pain?

LG: What role did pain have in your life?

JD: It's just a daily occurrence. [chuckles]

LG: Was it?

JD: Oh, yes. And it was—and it was—like another thing that it was at the hospital was one time I was having—I think it was in the knee at that time and I went—and I was having a lot of pain. So at other times

they had given me, like, some codeine, just to fight the pain. And then there was one doctor—I won't mention his name. He tried passing off some sugar pills to me.

LG: Now, how do you know that?

JD: Because he says, "Oh, take these—these will—these will be better. These will—these are very powerful. These will control the pain completely." But then we saw Dr. Diamond later on in the afternoon there and he took a look at those. And he was, like, furious.

LG: Really?

JD: Furious. The doctor who prescribed—who gave me those, within a week he was no longer in that—in the hospital. He was an intern at the time and he was out.

LG: Now, I'm interested. Did you have pain?

JD: Yes. Well, anyone could have looked at my knee and seen how swollen it was and know I was having pain. So it—but it was just—as I say, there was many doctors then who just had their own ideas of experiment, and I wasn't a person; I was a case. And he was going to prove, "Well, I can control the pain just by giving him sugar pills and he'll think the pain has gone away.

LG: Were there other experiences like that?

JD: Oh, there was a lot. It was like—physical therapy was a problem back then. They would often—because my joints would be stiff, but especially, like, I was having a lot of trouble with my left arm, so they keep sending me to physical therapy. Now, the physical therapist did not understand what hemophilia was and what caused problems. And so they would keep forcing me—forcing my elbow and forcing exercise. And usually, by that night I'd have bleeding in it again.

And so where I could only straighten it so far, by the time I got through with them I could straighten it a whole lot less. Still, it will never straighten again.

LG: So your experience sounds like when you went to the hospital either nothing happened or you got worse. [chuckles]

JD: No, sometimes they would do something—you know, treat me good. But I would keep running into, as I say—different people had different ideas in how to do it. And they did not really understand what they were doing. And so it created a lot of extremely bad experiences to me until finally it happened that one time—this was when I was in my old [unclear] that they wanted to aspirate again. And I said, “No, that’s it.” I said, “I’m out of here.” And I left the hospital. I left—[chuckles] [unclear]—I left, like, the whole system for years.

LG: That was it for you.

JD: Yeah, because I was just tired of doing the same thing, which I was saying this was not working. You know, “You’re just going to take fluid out of my knee. It’s going to kill me. By tomorrow it’s going to fill up and I’m going to be in the same place that I started with.” So that’s when I just said—I just said, “That’s it,” and I left.

LG: But what about the transfusions that you said were helpful?

JD: Well, I just had to give those up because I wasn’t going to fight with all these other things that they insisted on doing.

LG: So you didn’t feel that you had control. You couldn’t just say, “Give me the transfusions.”

JD: Right, right. Because, you know, the doctor said, “Well, you know, you’re going to—this is the way we’re going to treat you and this is

how we want to do it.” It wasn’t what I wanted. It was what they wanted and it was more or less—quite often, where the doctor would—there’d be, you know, interns that’d be fresh out of medical school and such and, you know, still learning. And they’d probably never had a hemophiliac before. And all of a sudden, “Oh, boy. This is what I’ve been waiting for and I’m going to really show how good I am by discovering how to really treat this, which no one else, who probably has a lot more experience than me, knows how to do.”

LG: How did your parents deal with your being in pain and having bleeds all the time? Do you remember what it was like in the family?

JD: No. I’m sure they felt very bad for me but I—it’s a long time ago and I don’t really remember.

LG: You don’t remember your father or mother saying, “Don’t do this,” or “Do this.”

JD: Oh, I was told often not to do a lot of things and take it easy and things.

LG: Were you?

JD: But I didn’t always stop doing it but I’m—I would control it.

LG: So when they’d say, “Oh, Jerry. Don’t do this; you might get hurt,” what—did you—were you more careful?

JD: Well—

LG: Were you a cautious kid?

JD: I was cautious but I would do a lot of things. You know, to me, the quality of life is a very important thing in what you can do. I mean, if it’s all—life is all about what you can’t do, then life isn’t too great. It’s more or less what you can do, and usually I tried to do things, even though I was told, “Oh, this is bad for you.” And—because I felt

I could prove, yes, I can do a lot of things, even though people think it's bad for me, I can still do them.

LG: Like what? Give me an example of what you're talking about.

JD: Well, I wanted to fly a plane, for one thing. And so, once I got to be 18 or so, I took flying lessons. And I did get a license out of it, because, you know, people, "Oh, no. You can't. Too dangerous. Too dangerous. Don't do it." But I did and so I learned to fly and that was a fun part of my life.

LG: So in some way, it sounds like, despite the possibility of really getting hurt or doing something that might end up in the hospital, you had some ability to take risks nevertheless.

JD: Oh, yes. Yes.

LG: What do you make of that? Where do you think that came from?

JD: I don't know. It's—maybe it came from a lot of people telling me I can't do this, or I can't do that. And in my mind I figured, 'I can do it.' I even spent one week up in Canada learning to ski, which wasn't—

LG: How old were you then?

JD: I was in my, I'd say, probably early 20s.

LG: And this was before—this was during the period you were not getting treatment or anything else.

JD: That's correct.

LG: Did your brothers tease you? Were they nice to you? What did they make of you? [chuckles]

JD: I don't think they thought—it was just the way things were and I don't think they thought—no, they were good to me and, you know, it was just the way things were and they were just used to it, I guess.

LG: So you don't remember them bringing hemophilia up much in relation to you?

JD: No.

LG: Didn't play that much of a role in your relationship with your brothers?

JD: No, not really.

LG: What about with your mom and dad? Do you remember? Did they talk about it much? How did you even come to understand what it was? Or did you?

JD: Well, I came to understand what it was by always going to the hospital and listening to the doctors and everything, knowing what was going on 'til, you know, I think I got to the stage where I think I knew more than they knew. And I think I did, for most of them. I mean—I mean, don't get me wrong. There were a lot of very good doctors who I would say did a lot of very good things for me. But there were a lot of—unfortunately, you remem—remember the bad ones a lot easier, like one time I had an infection in my foot. I—this was way back when you could actually go swimming in the Charles River, believe it or not that there was such a time. But even then it was getting pretty polluted [unclear]. And I had cut my foot and I was treated but I guess it got infected. I had to go to the hospital. The infection was bad; they admitted me. And then it was the way they treated that. They woke me up in the middle of the night and all of a sudden they were lancing out my foot without any kind of anesthetic. [unclear], you know, this kid, he won't—he won't understand. And so all of a sudden they were just holding me down, cutting into my

foot. So that's why I have a lot of bad feelings about [chuckles] hospitals and doctors.

LG: Did your mom stay over with you?

JD: No, I would be alone.

LG: So you were left there alone and whatever happened to you happened to you.

JD: Yeah. That's—something like that, but that's why I say I learned what I could about what was wrong with me. And, of course, most people know their own bodies and their own selves pretty well. And so you learn pretty quick. It's just a way of—way of life, I guess.

LG: What about school and friendships?

JD: I never went to school. I had all my schooling at home.

LG: How come?

JD: The school system was afraid to take me because they knew I was a hemophiliac. I went probably six months—yes, I went about six months to kindergarten. And—beyond that—but the school systems were afraid of—something would happen to me and they might be responsible and such. And so the city of Boston had a school system with home teachers and such. And so I went through all 12 grades at home.

LG: I am amazed that they wouldn't let you in. So your brothers went off to school and you stayed home every day.

JD: That's correct.

LG: What was that like for you?

JD: Well, that was what I knew so—

LG: That was what you knew.

JD: You know, that's the way it was and, you know, when you're used to doing something that's the only way you're doing it, you know, that's—you just do it and you don't think too much about it [unclear].

LG: And what was it like being home-schooled? Did you have the same teacher over the years?

JD: No, maybe—I would have the same teacher for a few years and I'd change to another one. I guess—I guess—and the teachers were—you know, so it was certain grades and different grades.

LG: How did you feel your education was?

JD: Well, I think I finished high school, I was—I think it was okay because I was still like—I was only 16 or 17 when I finished high school. So I was actually probably a little ahead of—ahead of my usual age group.

LG: Now, did you go any further in school?

JD: No, I didn't.

LG: You stopped in high school?

JD: Yeah. Mainly, my family did not have much money at that time and it was a question of to go further it would have been more money than we had to spend. We just did not have much—

LG: What about health care and paying for that? Was that ever an issue with your family? Were you ever costly to your family or did you feel you were?

JD: I think at some points I probably was, yes. But there was never too much talk about what that was.

LG: So you were never made to feel—

JD: No, no. No, I was never made to feel that I was any kind of financial burden or anything.

LG: Were you ever made to feel—or did you ever feel badly that you were causing problems in your family’s lives—did they ever make you feel bad for getting a bleed?

JD: No, no. No, I don’t think so. Not at all. No. As I say, this was just—to me it was just a normal way of life. This is the way all my life I was and so I just never thought, ‘Well, gee. It could have been different.’ This is the way it was.

LG: So you just accepted, this is who I am. This is what it is.

JD: Well, yeah, because [chuckles] there’s not a heck of a lot you can do about it. If you don’t accept who you are and try to do what you can with what you are, you’re not going to go anyplace.

LG: But I’m always fascinated, as someone who actually has not grown up with a chronic illness, and I always wonder, you know, how did people accept it? Didn’t you hate it? Didn’t you wish you didn’t have it?

JD: I’m sure I did but I never—I never really talked that much about it to people. It’s just what it was. It was my problem, not theirs. So I didn’t usually put it on anyone else.

LG: Did anybody tease you when you were a kid?

JD: No.

LG: Or ask you, “Why are you limping?”

JD: Yeah, yeah. People would probably ask me some of that. But usually would just shove it off and it wasn’t really a problem.

LG: Were you disabled as a kid with all these bleeds? Could you still walk and run?

JD: I could walk, yes. No, I could—you know, at times I’d be quite normal. Everything would be quite good. Other times, I would not be

and just some joints were worse than the others. And at one time, actually, one leg I even had a brace put on it because it was really very bad, very weak and such.

LG: Brace on what?

JD: On my leg. My knee was getting very—very weak in the muscles so they did—I did have a brace made and I wore it for a couple of years.

LG: For a couple of years. That's a long time.

JD: Yeah.

LG: Were you ever in crutches, a wheelchair, that sort of stuff?

JD: Oh, yes. I had a wheelchair and I was often in the wheelchair and I did have crutches and I got very proficient on crutches. Yes.

LG: So it was very visible to people.

JD: At times, yes. Well, you see, it's a very strange thing. Sometimes, you know, you look, oh boy. You're having trouble; look at him. He's on crutches [unclear]. Other times it could be a month later and I might be walking around just fine. There's no sign of anything. And it was like—like, I mean, it was bad enough what the doctors didn't understand. Most people knew even [chuckles] less than that. So it was just a very strange, strange thing. The people—people just didn't know what hemophilia was.

LG: How do you think that affected you psychologically? I'm fine; I'm not. I'm walking; I'm in a wheelchair.

JD: I think it made me think a lot more about how to do things and I—I will have to look at what the risks are and what I can achieve by doing it. And is the risk worth what I want to do? And I think that just—you look. You have to weigh everything and then you go ahead and do what you want to do, if you can.

LG: So it wasn't so much your parents making those decisions for you that you remember?

JD: No, I think it was me. It was me. I think I got into it, you know—I think I got into it quite early when I could see that these doctors are trying to make decisions for me and—

LG: What kind of decisions?

JD: Well, as I say, like giving me treatments that I didn't want.

LG: I see.

JD: More like that. And so that's when I think I got into the point where I've got to make my own decisions on most things and figure out what's going to be the best thing for me to do and not what's best for someone else.

LG: So it must have really affected in some ways your relationship with authority figures. Did it?

JD: No, I don't think so.

LG: No?

JD: Because, well, like, I don't consider, like, a doctor an authority figure.

LG: You didn't? Not even as a kid?

JD: Well, maybe originally as a kid I did but I think I learned more because, as far as I can see, like, a doctor—if I have a doctor, he's working for me. I'm not working for him. And his job is to do what I need. My job is not to do what he needs so I don't really consider him an authority figure. And I think I've got to use his intelligence and what he wants to do. But I have to use it in the context of what my needs are and what I really require, not as a patient but as a person.

LG: Do you think it led to more independent thinking for you?

JD: Yes. Yes, I do.

LG: You do? In what way?

JD: Oh, because I will—I mean, I will—I would say, well, it probably—again, as you say, authority figures. If someone tells me this is the way something is, I will think about it and try to figure out, well, is this really the way something is or how something has to be done? Or can it be done differently? And I will not just take anyone’s opinion on how—how to do something until I think about it myself and say, “Well, you know, I agree with them,” or I disagree with them. But I’ll want to give thought on my own about what it is.

LG: Mm-hmm. I’m skipping around a little bit, but when you were in the hospital or when you were in a wheelchair, or when you were kind of physically unable to run around, what would you do with your time?

JD: I would read.

LG: Were you a reader?

JD: I was a reader, yes. I would—I used to like to draw at one time. When I was very young, I used to draw a lot and do things like that and plan ahead. That’s—that’s probably when I first thought, ‘Gee, I’d like to learn to fly and I’d like to fly.’ In fact, that went for years and years thinking, ‘That’s what I’ve got to do,’ and, ‘That’s what I want to do.’ In fact, I never even—I never even was in an airplane until I took my first flying lesson.

LG: There’s just something about the freedom of flying that you wanted to do.

JD: Because I wanted to do it. I wanted to say, “I can do this.”

LG: What happened after you graduated from high school?

JD: After I graduated—well, I got a job for awhile in a bookstore. I like to read so I worked in Boston at the Old Corner Bookstore. And I worked for 10 years there.

LG: What'd you do there?

JD: Well, I started out in the stockroom and then I ended up being a sales clerk and actually running a couple of departments in the bookstore.

LG: How were you working in the stockroom with hemophilia, carrying all those heavy books?

JD: I decided I wanted to do it so I did it.

LG: And it didn't cause you to bleed?

JD: No, occasionally I would have some trouble but, as I said, with most things, if you weigh how to do things then you can find a way of doing things and—

LG: Did you tell people you had hemophilia?

JD: Not too many people. Just—just those like when I worked in the bookstore, the manager knew it, but no one else knew it.

LG: Did you ever tell anybody about it and feel there were negative consequences to telling?

JD: No, I don't think so.

LG: No? That was never your experience.

JD: I don't think so, no. I mean, most people that I have even told—and a lot of people, even still nowadays, know very little about it. You know, they—a lot of people have heard about it and, you know, they go back to the Russian czar and they knew it was there. And they've heard things here and there. But most—very few people really understand it, what it is and, you know, that they can't understand that, well, at one time you could be in very bad shape and a couple

weeks later you could be, you know, just fine and have no signs. And people won't even know you even had any trouble, except I do have stiff joints. A lot of—I'm sure arthritis has set in and such—but—but, no, most people don't really understand it yet.

LG: I want to go back to the pain issue for a minute because a lot of kids have to manage pain today. And I'm just wondering how did you do it? What was it like? Do you remember what went through your mind?

JD: Yes, I wish it would stop hurting. [laughter] Yeah.

LG: Would you know when a bleed was coming on?

JD: Oh, you—you get the feeling when it's starting. As I say, you get to know your body pretty well and when something is starting to go wrong you can usually feel it. And that's—you feel it start coming. The fortunate thing about pain is, pain, you can forget a lot. You remember pleasure very well but pain—fortunately, the mind blocks a lot of it out. You can remember that, "Boy, I had a hard time. I couldn't sleep for three days," and such because there was so much pain. But you don't really remember exactly how the pain feels. That's—

LG: Once it's over, you mean?

JD: Once it—yeah, once it's over it sort of just, you know, fades away and you're just glad when you don't have it. So you don't really—your mind sort of blocks it out and you don't really think that much about it.

LG: What do you think your relationship is to pain today?

JD: An old and disagreeable friend.

LG: And why do you say friend? [chuckles]

JD: Well, enemies don't hang around that much but, you know, the pain stays. I've had it for some 60 years in one form or another. So, you know, even though you don't like it, you have to sort of consider it your friend because it sticks with you.

LG: What about pain medication?

JD: I take as little as possible.

LG: How come?

JD: Because I don't want to get so I'm dependent on anything, you know, like that. I'll take it when I need it. I'm just sort of achy some days and, you know, not bleeding or anything—just sometimes I might be achy so I'll take some Tylenol or something. And that'll be fine and—but then when I—really sores up, I will take, like, a Percocet and such, which by not taking it too much, it's quite effective and it really helps. But it—but I know it only helps if you don't take it a lot, because sometimes when I've had, like, a long session of pain and you're taking them a little more regularly they don't—they sort of lose their effect on you.

LG: Kind of build a resistance to it.

JD: Yeah, exactly. So it's best to take as little as you have to.

LG: How did having hemophilia affect your love life, or did it? Dating?

JD: No, I don't think so. I didn't date a whole lot and such but I guess I was waiting for the right person to come along, which finally did come along. And I don't think hemophilia affected it.

LG: You weren't worried, 'Oh, I'm limping. Some woman isn't going to want me.' Or 'I bleed.'

JD: No. No, that—as I say, you've got to play the cards you're dealt.

[chuckles] And the worry about something you can do nothing about

is just like a—you know, a waste of time. You know, what is is and if you can't handle it, then you're going to have a problem. So you have to just say, "This is the way it is." That's when you start thinking, 'What can I do with this? How can I handle this? What's the best course for me to take?' That's the way—it gets—you think a lot about what course to take.

LG: What course did you take?

JD: I just—was me.

LG: So you didn't identify yourself as, "I am a hemophiliac."

JD: No.

LG: You were Jerry—

JD: I was Jerry Drummey.

LG: —Drummey.

JD: That was just something like, you know, you have brown hair. You know, just another thing and then, you know, [unclear]. I was me and this is me. And so first you have to like me; then you have to like or dislike any of my problems.

LG: Tell me about meeting women or your wife.

JD: Oh, well. Actually, I met my wife up in Canada, or going to Canada. I worked awhile with this pilgrimage group. This was as a volunteer. My mother had me go up and there's a pilgrimage up at Saint Anne de Beaupré in Canada.

LG: What's a pilgrimage?

JD: It was a religious Novena that they have in July. There were—a lot of handicapped people would go up to the shrine.

LG: A lot of handicapped people would go up?

JD: A lot of handi—people would go there and my mother had me go there.

LG: For what purpose?

JD: Well, because we're devout Catholics and such and it just [unclear] and some people are hoping for a cure and such [unclear] that. But—

LG: All right. Now, educate me because I don't understand. So you would go on a pilgrimage to Canada—

JD: Yeah.

LG: —in hopes, perhaps, that some healing could occur.

JD: Yeah.

LG: And who would do the healing?

JD: Well, no—no one. It was just praying to, you know, God and singing and such. And it—you know, you don't really see any people. But I think it was good for the people who learned to live with what they have, maybe. And so I went on that as a child. And later on, I was like a volunteer and helping them and working [unclear] and helping a lot of the other afflicted people and, you know, people in wheelchairs and such. And I would work along that. Then my wife—she wasn't my wife then—she volunteered. She was a—actually, a student nurse down in Holyoke, Massachusetts. She volunteered and she went along. That's when I first met her. I met her up in Canada like that. So that's when we first got together back then. Then we ended up being married up in Canada there.

LG: And tell me a little more about this—about religion and what role that played in your life. Was that a resource to you?

JD: I think so. I think it's a solace and a comfort when things are really bad and everything, you know, just seems to be going wrong and

things aren't working. It's just sort of a comfort, something you can lean on a little bit.

LG: Like what?

JD: Well, it's just—

LG: In the sense that you'd pray or—

JD: You'd pray—

LG: —you'd have a philosophy?

JD: You'd probably pray that you can handle what you are being dished out, and I think mainly like that. And just to give you the intelligence, the common sense, the ability just to handle what's—what isn't working right, or even sometimes maybe just to be thankful for what is working right. You know, it's just—just a peace of mind you can get by, you know, having—having something to believe in.

LG: Did you ever see healing go on in any of these pilgrimages?

JD: I believe it has happened. I can't really say I have ever really seen it. I know—it was like at the beginning of that. That's when I had a—had a brace and by the next year the doctor didn't think I required a brace now. I think a lot of it was just that I was improving and I was making myself work better and such.

LG: I think some people might say, "Oh, I don't want to associate with other handicapped people." What did your heart say about all of this?

JD: [chuckles] Say, "But for the grace of God, it could be me." You know, and at times it probably was me. So, no, I sort of welcomed the chance to just help other people that may have had a problem, and something I could do to help them and make their life a little bit better.

LG: Did you think of yourself as handicapped, having hemophilia?

JD: Well, yeah, I guess somewhat. But then we're all handicapped in one way or another, you know. You know, if you had to go out and say, "I'm going to go in a prize fight, you'd be handicapped against a professional." So, yeah, I guess in some ways but in—you know, where you are weaker in some areas, you probably get stronger in other areas.

LG: Well, that's an interesting statement, where you're weaker in some areas, you get stronger in others. Are you defining hemophilia in some ways as the weakness that maybe promoted you to be stronger in other areas?

JD: Yeah, perhaps. I wouldn't say just hemophilia. I would say anything where you're, you know—that would have been—probably for me it would have been hemophilia. But anything where you're weaker in one area, you improve in another area.

LG: We touched upon it a little bit, of you're saying you think you're a more independent thinker, or you had to be more pragmatic in how you approach things with the risk benefit. Were there any other ways that you can identify where having hemophilia made you stronger?

JD: No. No, I don't—I don't really think of anything.

LG: What about the down side of hemophilia? Was there any part of it that you really resented?

JD: Well, I think there's always a problem of when you really can't do something, like you're having trouble with your legs and you can't walk, and you can't go someplace, or you can't do something. I think that's sort of the downside. That's why I think often now I will do as much as I can. When I'm feeling fine I will sometimes push it very hard just to enjoy it because that's the upside of it. And so you

just enjoy all the good moments you have so that way you don't have that many bad moments.

LG: I see. So your sense of appreciation has been heightened, perhaps.

JD: Oh, positively.

LG: Positively? Does that ring a note for you?

JD: Oh, yes. Positively. I—when I can do something, and I do many things, and I really enjoy what I do. And I get a lot of pleasure out of things I like to do because I'm able to do them.

LG: What about the whole '80s period with the HIV and Hep C? Where were you in life at that time?

JD: I was a free and easy person. I was—

LG: You were what?

JD: A free and easy person. I was not going to the hospital. I was—let's see. I was—well, I got married in '70.

LG: You got married in '70?

JD: In 1970.

LG: So you were with your wife, Kathy, when all this starting coming up?

JD: Yes.

LG: Did you identify with that at all as far as, "Oh, my—I have hemophilia."

JD: Yes. It was sort of slow because a lot of stuff was very slow and they didn't know where it was coming from and what was happening. And it was like—it was sort of like the experiences I have gone through because you had a lot of—a lot of doctors not knowing what they were really doing. I mean, not that it was their fault but they just didn't know. And I was, fortunately, on the sidelines there.

[end of side 1, tape 1]

LG: By the sidelines, which means you weren't taking factor during this period.

JD: Well, this—well, we didn't have factor in those days. It would have been whole blood or plasma. But I was not seeing doctors at that time. I was just watching out for myself.

LG: But actually, there was factor now.

JD: There was cryoprecipitate that they were starting into and such. But they didn't really have factor VIII then.

LG: Okay. And anyway, you didn't have any factor.

JD: I wasn't having anything.

LG: Okay. Were you going to hospitals at all at that point?

JD: No.

LG: Not at all.

JD: No, I had—as I say, I was on the sidelines. I had stepped out of the system because I had too much—it wasn't working and I just stepped out and left it.

LG: You just decided you were going to tolerate your bleeds, period.

JD: Right, because—and there was—

LG: And nurse them yourself?

JD: Yeah, and it was more or less—I could say probably some of the doctors helped me decide that because they more or less were saying, “This is the way we're going to treat you and you have to do it our way.” Right.

LG: Take it or leave it type of thing?

JD: Yeah, so I left it.

LG: Wow! So, therefore, you avoided the co-infections then.

JD: Yes.

LG: Is that what you're telling me?

JD: Yes. I was just clear of everything. And it was even—you know, like several years went on 'til they really figured out that, oh, people are getting this through transfusions. And fortunately, I wasn't getting any transfusions. So I think so many people, actually, my age, just aren't here now because they stayed in the system.

LG: No question about it. Have you ever had any thoughts about that, just—those bullets that you dodged?

JD: Well, I think that maybe you saved [unclear]. Maybe, you know, God is watching over me. [chuckles] You know, maybe it wasn't all my decision. Maybe He helped me make it or whatever. But for some reason, I made the right decision and I went the way that I felt was the way to go. And it wasn't even knowing anything about HIV. It was just other things were not right and it was not being treated right. That's why I left and I just picked the right time to do it. Maybe it was luck. Whatever it was, I'm glad I made the decision then.

LG: Now, you're married to a nurse.

JD: Yes.

LG: How did she feel about your not [chuckles] participating in what medicine had to offer?

JD: Well—

LG: Did this cause difficulty?

JD: No, because, as I say, first she had to marry me. Then she had to marry hemophilia. [chuckles] It was me first and I—I was what I was, and what I decided—how I was going to live my life and how I

was going to do things. This was what I was. And other things—you may occasionally agree, not agree. She—I had no problems. She understood this is the way I wanted to do things and she went along with it.

LG: So it wasn't really a point of discussion.

JD: This is the way—this is what I was, yeah.

LG: This is how you were going to manage yourself.

JD: Yeah, right.

LG: Okay.

JD: And at that point, obviously, I probably knew a lot, [chuckles] and I probably still do know a lot more about hemophilia and what—the effects it has on people than, you know, she does or most people. Most people, unless they have it, they don't really know what it's like. They can say a lot of things and read a lot. But until you have it, that's when you know what it does, and what it can do and what it can't do, and what's a myth and what's not a myth. And some people are very afraid of everything. I can remember once when I was a child I was going to a hemophiliac meeting and such.

LG: Oh, so you did go to some of those as a kid?

JD: Yeah, as a—and I—

LG: At Children's?

JD: It was through Children's, yes. They—I think—I'm quite sure it was, but it wasn't held at Children's. They would have it at different places and such. But I got fed up with a lot of it too because I could remember just one thing that always stood out in my mind where I was at one of these meetings, and there was parents of someone who had it. And they were—I guess it was a—doctor was a speaker or

something. And they came out, which I thought was the most ridiculous thing I ever heard, or so it seemed to me at that time. They asked the doctor, “Well, my child has hemophilia. Now, do you think it would be a wise thing, so when he eats, make him use a spoon, not let him have a fork because he may hurt himself with a fork.” Which, you know, you may hurt yourself crossing the street but you’re not going to not cross the street. You know, you do what you want to do. And I think that’s why—after that—I think it was soon after that I took up as a hobby of knife collecting. [chuckles] You know, I said, “Yes, you know, knives can be dangerous but only if you cut yourself with them. And if you don’t cut yourself with them, they’re not going to hurt you at all.” But I always remember thinking that a poor kid is going to, you know, grow up eating with a spoon and not a fork.

LG: So this sense of overprotection was really—

JD: Yes.

LG: —very unpleasant for you.

JD: Extremely unpleasant because you just can’t do it. You’ve got to—

LG: What do you think are the negative effects of over-protecting a person?

JD: I could—I think if you over-protect them, then you’re not going to do anything. You’re going to just hide from everything. Every problem that comes along, you’re going to back away from. And you’re just not—you’re not going to face it; you’re not going to face life unless you go out and do it.

LG: Let’s move on to—you worked in the bookstore and then what? Were you able to work in your life?

JD: Well, oh, I worked in the bookstore for 10 years. Then I became a—I got married and the bookstore was a lot of fun but it didn't pay anything. [chuckles] You know, I got a lot of books; I got to read a lot. And so it was fun. You got to meet a lot of interesting people but it didn't pay anything. So then I was going to get married so then I went in with the company as a distributor for women's clothing, which wasn't all that interesting but it paid okay. [chuckles] So I did that for, like, a—what, say about [unclear]—oh, like, 25 years there. So I worked for, like, 35 years. And I kept doing that and I probably would have still been doing it but they went bankrupt and so—

LG: Was insurance a concern throughout your life, keeping your health insurance?

JD: No, it wasn't because I—my jobs I was in had insurance and it all went—like, when I was working in the bookstore I wasn't having any—really, going to the hospital or anything. And I had insurance and I wasn't really using it. I think the only time I ended up using it was working in that job was I got a very bad strep throat. And then my whole throat was swollen and I ended up in the hospital for about a week with that until, you know, the medication set in and cured the strep throat and my sore throat [unclear].

LG: So how long did you actually stay away from medicine?

JD: Twenty—

LG: Or let me put it this way.

JD: Twenty, twenty-five years. Thirty years.

LG: When did you go back?

JD: Well, I went back when—then finally, I was having some kind of a GI bleed on something. And then I went back and, like, my blood level,

the crit was way down and I was having a bleed from something. And I think it was probably I had an ulcer working on me and I had to go in the hospital. And so then I started getting connected up again.

LG: And where was that?

JD: I think then I went to Beth Israel.

LG: To the Beth Israel.

JD: I think it was the Beth Israel, yeah.

LG: And were you introduced to factor at that point?

JD: That's when I first—in fact, I think one time before I might have had—I think I had a pulled groin and I had some cryoprecipitate a little earlier than that. You know, I was just in very bad shape and I had to go. And I went to Beth Israel then and I think they gave me some cryoprecipitate. But then when I had the GI bleed, that's when they started with the factor. Yeah, I'm pretty sure.

LG: How old were you? Do you have any idea?

JD: It was—I was in the 40s. I was in my 40s; yeah, I'd say in my 40s, about 20 years ago.

LG: So in the mid '80s, do you think?

JD: Mid '80s, that's—yeah, mid '80s would be about right, yeah.

LG: So you dared try the factor in the mid '80s.

JD: Oh, yes. Well, because then I went and I talked to doctors. And obviously, they had learned a little bit in my absence. And it was obvious they had learned a little bit from my absence, because they knew, like, the things I was talking about that I didn't agree with, they had all said, "No, those things did not work." And obviously, they had learned, and then talk about factor and how—control they had [unclear] and how well they had tested and then—

LG: You asked about it?

JD: Oh, yeah. Yeah, and they called me and, obviously, they knew what they were doing at that point.

LG: What was it like to get factor?

JD: Like getting anything else, I guess. I've had more needles shoved into me than, you know—that a needle—I don't even wince if someone shoves a needle into me, because it doesn't—you know, it's just—my veins aren't all that good. I've only got a couple that are really good; they're so scarred up. But it was—it was actually easier than fresh frozen plasma. When they put plasma in, you could feel it when they shoved it in. You could feel it go right up you. When it was still cold you could feel it right through your gums.

LG: Oh, my God!

JD: [chuckles] But, in fact, it was just like—like nothing.

LG: I guess what I'm trying to get to was, did you feel, "My goodness! It stops the bleed."

JD: Yes, okay. I think the fact of the effect of factor, because here, finally they knew what—what was missing in my blood. In the earlier days with hemophilia, they didn't know what was missing; they just knew something was not working. And they had no idea what was missing in the blood. Obviously, at this point they had got it all separated and they knew it was factor VIII that was missing. And they tried it on me and it worked quite well—very well. It was [unclear]. That's how—so it gave me a new confidence in them because here—I can sometimes make a good judgement if these people are right, or these people are wrong. And these people are obviously right at this point because they were talking intelligently. They were giving me

something that was obviously working and they knew why they were giving it to me. They weren't giving it to me because, "Oh, we're going to try this out and see if it works. You're going to be the guinea pig. We're going to just watch." But they knew what they were doing at that point.

LG: So it was a whole new ballgame.

JD: It was a whole new ballgame and then it was—and what happened about, oh—about 10, 11, 12 years ago when finally the place I was working for—my legs were really getting—my hips were, like, going at that point. It was arthritis and such, [unclear] and such. And my hips were hardly working. My legs were hardly working. My knees were getting pretty bad. But I kept on working because, well, the company I was in weren't the nicest people. And I knew if I went out to have something done, I—they would have got rid of me some way, because they had done this to other people in the company and such. So at that point, well, they did go bankrupt. And I said, "Well, this is time to have something done. And I was going to BI at that point. And the doctor I had said, "Well, we could send you to a guy who does, you know, replacements on it," because he could see what shape I was getting. I was sort of getting to the point where I was using—using the cane most of the time; even sometimes I had to use crutches back then too. It was getting bad. And so he said, well—oh, he made an appointment for me with Dr. Brick at Brigham. And so, okay, fine. I went over to him. Actually, about a few years earlier I went to someone about my knee. My knee was giving me a lot of trouble at that point. And he couldn't promise me much at that point. He says, "Yeah, we do hips okay." But knees he'd been very unsuccessful at.

So he says, “We could try to do something for your knee but it’d probably end up worse than you are.” So I just said, “Well, let’s forget that.” Yeah. But at this point, so he sent me in to see Dr. Brick. And it was mainly my hips were, like, really bad then. And Dr. Brick looked at my x-rays and checked me over and he says, “I can fix it for you.” Dr. Brick is one of the few doctors from the beginning I had a lot of faith in. And he was—his manner, the way he was talking, what he was saying, he obviously knew what he was talking about, I thought. And he says, “I can fix that for you.” He says, “How would you like to handle it?” And I said, “Well”—right then it was like the hips were very bad. He says, “Well, we could do everything.” He says, “But that’s very hard to recover from.” [chuckles] And he—so he says, “We could—why don’t we do your hips?” And he said, “We could do it one at a time or we could do it, you know, one—one week and a week later do the other one.” He says, “Or we can do them both.” So I opted—I said, “Well, maybe you could really do it—you could do it both. You know, get it done,” because actually, my mother had hip surgery and she had one one week and one a week later. That was sort of rough going through that. Once you get one done, you don’t want to do the other. [chuckles] And—but she recovered very well from her surgery and her hips were pretty good. And I said—and he—Dr. Brick gave me a lot of confidence and we started—then we clicked up with hematology there. And they started saying more about, yes, with factor we could do it and it’ll all work. You don’t have to worry about the problems of an operation. Like earlier in life, an operation was just—you didn’t do it on hemophiliacs; it was a no-no. And so that’s when I started

finding out more and more about factor and such. And so I had the hips done and such and it worked out very well. They [unclear]—

LG: Did it work out well?

JD: It worked out excellent. You know, I had both hips done. It was rough. I hardly remember coming out of the anesthetic. The first thing I said to the nurse, “Did they do both of them?” [chuckles] “Because I don’t want to go through this again next week.” And she says, “Yes.” And they worked out well and then I finally found out after that was done was that they—physical therapy had improved, that there are physical therapists who know what they’re doing and know how far they can push something. And they understand something about hemophiliacs and you can cause bleeding, and you can’t overdo it. And I was fortunate where I’ve had a home physical therapist who was a friend of the family, because my daughter was going to school with her kids. And she was a friend of the family and she was very good. In fact, she ended up—she was only supposed to come, like, two or three times a week, but she ended up coming seven days a week to me because she was a friend and she lived nearby and she would come. And I called her Attila because she put me through torture, but it was for a purpose. You know, you can go through torture if it’s for a purpose and it’s achieving what it’s supposed to achieve, maybe do it. And she did a great job. And then it was like a—my hips really got good. And at that point I realized how bad my knee really was, [chuckles] because, you know, the hips are so bad you sort of miss the other thing. And my right leg, I only had about 10 degrees of bend in it. I could hardly move and it was not straight; it was like this. So it was in very bad shape so then a year later Dr.

Brick said, “Now, we can fix that too.” And he warned me. He said, “It’s a lot more pain than the hips—a lot more pain.” And [chuckles] he says, “Well, we can fix it.” You know, both my knees weren’t too good but one was really bad and really had—something had to be done. And so he—I agreed and he did my knee. And he was absolutely right. It was a lot more pain. [chuckles] But after about six weeks of really heavy pain, and then it starts getting better and better and better. And now it’s probably my best joint I’ve got, actually, because it was really wonderful. Of course, the other one—he understands why I don’t get it done because—and he—like an intelligent doctor, he agrees. It’s my decision to where I think it’s so bad it really has to, because it’s not so bad that most of the times I don’t even notice it, that I’m just used to it and it’s fine. And he agrees. And even my therapist agrees. He has to go—because it’s a lot of stuff to go through to have it done that, is it worth doing it? And right now, I’d say no.

LG: So your experience with medical providers has really gone from night to day.

JD: Oh, yes. Yes. No, I—for the most part. For the most part. Well, no. I have a primary care physician that’s—with the bedside manner of a dead codfish [laughter] and such. Then, you know, he’s like, disappointed, I think, sometimes when I come in because he doesn’t find something wrong with me. It’s like he wants [chuckles] to find something. But I only see him a couple times a year and it doesn’t really matter because we just have a checkup and that’s it, you know, and so on. You know, he’s okay because he’s not really doing much of anything for me, and just checking on my blood pressure and

blood—occasionally blood counts and cholesterol and whatever, which all seems to be pretty good.

LG: How many kids do you have?

JD: One.

LG: One daughter.

JD: One daughter.

LG: And how old is she now?

JD: She'll be 34 in January.

LG: And her name is—

JD: Anne.

LG: And is she married?

JD: No, she's not.

LG: No children then.

JD: No children. No.

LG: Do you have any feelings about if Anne were to have children or a child with hemophilia? Have you thought about that?

JD: Yes. I think I have probably thought a great deal about it. I guess she has too because she has been tested and she is—she would be a carrier and a very good chance. I think under today's conditions—I think a hemophiliac would be off to a much better start because, you know, knowing exactly what's missing in your blood is a whole lot different so it's not like they have to experiment. They would know exactly what to give someone. So, you know—but, as I say, you—you have to play the cards you're dealt and so when those cards are dealt, then deal with it. But—but, no, she knows what the whole picture is and she knows what it is. Right now she's not going with anyone she's intending to marry yet but, you know, it could happen. And she

probably hopes some day she will get married and such. But, you know, that's something we'll deal with when it comes.

LG: Do you have any advice for families today? It's a broad question, I know.

JD: Yeah. Find out what the child wants to do in life. I mean, you know, [chuckles] what they want to achieve. And don't just be too quick to say, "You can't do that." You know, control the stupid things but control—let them find out, say, "I want to do that. Can I do that?" And, "Why can't I do that?" Because you can do that. And don't be overprotective. You just say, "No, your life has to be different than anybody else. Everybody's life is different but you've got to be able to do what you want to do or, you know, what are you living for?"

LG: I think so many parents are terrified of having their children hurt or have a bleed.

JD: Hurt is a part of life. You know, you're going to get hurt sooner or later. I mean, the biggest part of life is death because everybody's life is going to end in that sooner or later. And you can fight that all you want but sooner or later it's going to happen. People say, "I shouldn't go on an airplane because it could be dangerous." Actually, I have had an airplane crash with my wife and child and I lost power flying a plane. And we had to go down and I had to put the plane down without any power into a cornfield, which tore the wings off the plane. We rolled over and were, like, stuck in the plane for about five minutes until people got through the woods, helped get us out of it. But that's all a part of life. And we all walked away from it. I was bruised up from [chuckles] my shoulder to the—here I had two black eyes where my face went into the dashboard and such. My daughter

was—well, she was asleep at the time so she just sort of tore her pants. I think she scraped her knee a little bit, but we all walked away. I was sore for a while but, you know—but that’s just it.

You’ve got to go for what it is and you have to take the chances. I mean, it wasn’t because I did that—“Oh, Jeez. It was terrible.” You know, “Should never have been doing it.” No, this is part of it.

LG: Is there anything that I haven’t asked you or touched upon that you thought about before my coming here?

JD: No, because I didn’t know exactly what you wanted to know.

[chuckles]

LG: But is there anything else that I haven’t asked you that you think would be useful, either to families or doctors or social workers?

JD: Well, I think the only thing the doctors and social workers, the—

LG: Nurses.

JD: —nurses, the family is to remember, first of all, it’s a person and not a hemophiliac. First, it’s a person and so you can’t just treat hemophilia. You’ve got to treat the person and the person has got to know what they want, and what they want out of life and what—how they want to do things. And that’s got to be very primary. You can’t—you can’t just ignore that part of and just say, “We’re going to treat hemophilia and that’s the only thing that counts.” Because it’s not because, you know, if the treatment gets more—you know, more than the life of the person, then the treatment isn’t worth anything. The person’s quality of life is the important thing. So they’ve got to do that. So, you know, you can’t just tell people they can’t do something because how do you know they can’t do it unless they try? Maybe they can do it because most people can do a whole lot more

than they think they can, and I'll just make it too soft for them because life isn't soft. [unclear] you've got to play the cards you're dealt with and you've got to play them the best you can. You can't just—just say, “Oh, I'd better not do that because that's not easy.” Find out if you can do it.

LG: Or if I could get hurt.

JD: Or if you can get hurt but you can get hurt doing anything. You can avoid everything and a plane could fall on your head.

LG: Well, Jerry, I think this has been great.

JD: Well, I hope it's [unclear].

LG: And I want to thank you and I appreciate your participating in this oral history.

JD: Yeah, I hope it'll be a help.

End of Interview