

Interview with Bill Lynch for the Boston Hemophilia Center Oral History Project, A Gift of Experience, by Christine Harland, September 20, 2004.

HARLAND: This is Christine Harland, talking to Mr. Lynch on September 20th. We're here doing an oral history project on your experience with hemophilia, and we're looking at the beginnings of that for you, as well as how it has affected your life. Can you tell me about the discovery of your hemophilia; how old you were?

LYNCH: I believe I was around one, and they found me—my folks found me in a pool of blood. I don't remember exactly what happened. I might have hit my head, and that's when I diagnosed with hemophilia, when I was about one year old.

CH: Was that a surprise to your family or was there a history?

BL: Oh, sure. No, see, we have no history. In fact, I have two younger brothers who don't have hemophilia.

CH: So it was a real surprise to your family?

BL: So it was a surprise, sure.

CH: They took you to the hospital. You were diagnosed. Have they ever talked to you about what that was like for them in those initial days?

BL: I think they never really talked too much about that, okay? They just went on a lot of the physician's advice, but my mother was a nurse, so she might have had some kind of knowledge of that, anyway. But we never really got into those type of things until I got a little older.

CH: I see.

BL: Then I realized that they were going through what I was going through, but when you're very young, you don't realize that. You

think you're it, but then as I got older, I realized when they were going to the hospital, taking me all the time, they were suffering as well as I was.

CH: Of course they were.

BL: Yeah, so—

CH: But we don't realize that.

BL: No, as a child you do not realize that. You think it's just you.

CH: And you are suffering.

BL: And I am suffering.

CH: Can you tell me your first personal awareness of having something unusual happening to you?

BL: Well, I can tell you that I remember as a child I was playing baseball, and I got hit in the mouth. The ball took a bad hop and got me in the mouth and it had happened a couple times earlier where I was in the hospital, but that was the one that was tough. It was very difficult. I had to go to the hospital—I might have been ten, maybe a little younger—saying, “What do I got here?” You know, because I was back in again and that's when it really hit like, “Man, I got a problem here.”

CH: That's the first time your condition really impacted you?

BL: Yes, but it was like, “Hey, I'm sick of this already,” and I was only a kid.

CH: Can you remember the incident? You're hit in the mouth and suddenly you start to bleed.

BL: Yes.

CH: And what did your teammates do? Was it a time that was difficult for you in that regard?

BL: No, I just was only a block from the house, so I just ran back.

That's all I can remember, it was so long ago.

CH: Of course, but it must have been a shock to suddenly realize that that which you wanted to do and had been doing every day was dangerous for you.

BL: Yes, and that's very accurate and I realize that you're very angry at that point because you know you can't keep playing, and you look around and your brothers and your friends, all your classmates, you don't see anything wrong with them. So you think to yourself, "Why me here?" That's when I think it really hit me, "You got a problem. You got a big problem."

CH: And how did you accommodate that psychologically?

BL: That's a good question. I just thought I could play sports but I'd have to be careful. In other words, I didn't write the book off of any sports, but I realized I'm going to have to change. I can't go out and play all the time. Is that what you're looking for?

CH: Yes.

BL: Okay.

CH: Or do you think you began to think of yourself as being different or unwell?

BL: Yes. Yes.

CH: Which does make a change in us.

BL: Yes, you lose your confidence. I said, everybody was out there playing, and you're in the hospital.

CH: Isolated?

BL: Yes, definitely. That's a good word. People like you anyway. Growing up you knew the kids, the kids like you, but it was still pretty aggravating to watch your classmates. For example, gym. I could play touch football, something like that, but like a lot of the other stuff

I couldn't participate in. I had to kind of sit, and that really got me.
You know what I mean?

CH: And you enjoy sports?

BL: Oh, I love sports, even to this day.

CH: Were your brothers very athletic?

BL: Yes, they were. They played a lot of sports. One was a very good baseball player. The other one was a good basketball player. So, my love sports, I just—I had to go out there, until probably high school I really accepted it. I think it was probably in high school.

CH: You stopped fighting it?

BL: Yes, I pretty much stopped and realized, "You got to be careful here." Of course my knees—physically, my knees were going down and I couldn't, anyway.

CH: We're going to back up a little bit and ask you some more about your family.

BL: Sure.

CH: You grew up in?

BL: Fall River.

CH: Fall River. Your mother was a nurse.

BL: Yes.

CH: And your father?

BL: He was a teacher and then became a vice principal.

CH: So he was an educator.

BL: Yes, he was.

CH: And you had two brothers?

BL: I had two younger brothers.

CH: What about surrounding family, grandparents, aunts, uncles?

BL: Well, I never—my mother's parents died very young, so I never

even knew them, but my father's parents lived a long time. And to be honest with you, I don't know—they would visit me. The grandparents would always visit me in the hospital, but I really don't know if they knew really what I was dealing with, when I look back.

CH: In the sense of how difficult it was?

BL: That's right.

CH: They knew what you had.

BL: They knew what I had, but I don't think they really knew what I was dealing with.

CH: Do you think people who don't have hemophilia can understand?

BL: Well, I think people that—you know how the naturally kind people, the ones that have the big hearts, I think they can kind of understand everything. You could have cancer, hemophilia, a bad case of diabetes, I think they have an understanding, but I think the average person, no. I like to think—there's a disease out there that I hate and that's ALS. I don't know what it's like to have ALS. But I hate it anyway. I think it's probably the same thing. I think except for the very few kind people, most people wouldn't know what it's like to have it.

CH: And of course it doesn't show.

BL: That's correct. See, that's another thing. That's true.

CH: It shows in the sense that —

BL: It used to, the way I walked.

CH: It did?

BL: Okay, because I—it got to the point before—I had a couple of knee replacements, but before that, it got to the point where I was literally dragging my legs around.

CH: In pain?

BL: Oh, yes.

CH: How did you accommodate the pain?

BL: I just tolerated it.

CH: You did?

BL: Oh, yes.

CH: Did you take painkillers?

BL: No, Tylenol, but that was about it.

CH: Can you describe the pain? Was it an ache? Was it a sharp pain?

BL: Well, actually there were different pains. You had the arthritis pain, which was a very sharp pain, and it got to the point where it was agonizing. You had to sit down. The bleed is a kind of a different type of pain. It's pressure. You get pressure in there and it got to the point where it was unbearable. If you had a bleed that you couldn't get right away, it was unbearable. But it's funny, you adjust to it, though. As difficult as it is, you adjust to it.

CH: How do you think you adjust to it? Do you become less afraid of it? More familiar?

BL: Well, if they're minor bleeds, yes. You know how to treat it and you treat it, but major you still get nervous if they're major knee bleeds.

CH: You get nervous?

BL: Oh, yes. Oh, you know what I get nervous, too, about? Your treatment? Okay? Maybe about ten years I think it was—time goes by so fast—I ended up with the people I work with, disabled people, and we ended up taking them to Mystic Seaport. Well, I must have banged my leg on the wheelchair, didn't think much of it, but it

exploded on the way. We were in Connecticut. So the choice I had was, do I go back to Fall River and treat it myself, or do I go to a Rhode Island hospital? Well, I decided the best thing was to go to the ER. Well, I would have done better if I went home.

CH: Why?

BL: It's exploding on me and every once in a while—three hours before they treated me. It was a total mess by the time I ended up getting discharged out of there. I mean, it was a terrible decision. I could have gone home and got a huge Factor-8 dose and treated it better than the Rhode Island. They let me lie there.

CH: Can you tell me more about—besides the fact that you had to wait, which is a big complaint about ER, when you got in there, were they sympathetic with your situation? Did they act quickly?

BL: No. I mean, they came out and they put me on a stretcher because at that point I couldn't get out of the parking lot. Okay, so I got in there and, you know, just like a regular patient. One doctor went, "Oh, I've seen that before," keeps going. You know and finally I started getting mad, "Where's the factor?"

CH: Because that's all you needed.

BL: That's all I needed.

CH: And what was the difficulty in finding and giving that to you?

BL: I don't know. Maybe they were too busy. They're a very busy hospital, Rhode Island Hospital. But I know they have a Hemophilia Center there, but I stuck with Boston and that just reinforces it.

CH: Yes.

BL: I mean, all you got to do really is get on the horn and call the hematologist on call. "We got a hemophiliac in here. He's got a massive bleed."

CH: Very simple.

BL: Ahhh..

CH: Straightforward.

BL: Straightforward, but they didn't do it and I lied there for three hours.

CH: I can imagine how angry you were.

BL: Oh, yeah. You know.

CH: How did your parents approach it? Was it secretively? Was there a sense that you should "keep it in the family"?

BL: Oh, no. No.

CH: So they were open.

BL: Yes, they were open about it. I sometimes wasn't. I didn't like telling, "I got hemophilia." I didn't want to say it, you know, but you had to sometimes.

CH: Of course.

BL: You had to. There were certain activities that you really couldn't participate in and you had to tell them why. But I went back to most of the teachers and, oh, they were very nice to me.

CH: And the students?

BL: Oh, very nice.

CH: So you didn't experience prejudice?

BL: Oh, no, I didn't. No.

CH: Good, and that may be quite unusual because most people don't know anything about hemophilia.

BL: That's probably why the prejudice never came in. No one really knows much about it.

CH: So all they knew was that it wasn't contagious.

BL: That's right. That's right.

CH: So you were fortunate in having a good school experience.

BL: Yeah, considering I had hemophilia, I did all right, when I look back growing up.

CH: Did your parents talk to you and explain things to you as you went along?

BL: Yes, but they pretty much relied on what the physician said, you know what I mean?

CH: I know we talked a little bit about how you realized how hard it was for them.

BL: Yes, and I never realized that until as an adult.

CH: Do you think it was economically difficult for them or was that not an issue? Did it change their lives in any way in the sense that they had to move to be near a hospital?

BL: No. I'd have to say, thankfully, no, it didn't.

CH: So they didn't have to make important life changes because of this? Simply within the family they did, but they didn't have to move?

BL: Oh, no, no. The minor things were, let's say they might have had plans to go out and I had a bleed, they would remain home. But that's really about it.

CH: They went to the hospital with you?

BL: Oh, of course, yes.

CH: And you went to the hospital a lot?

BL: Yes, I did. See, it started off, I was treated I believe in Fall River. We had a very good pediatrician, I think, that he had some knowledge of hemophilia, but they don't have what they have now. Okay? In fact, I look back, I'm really amazed I survived back then.

CH: May I ask what year you were born?

BL: Okay, I was born in 1960.

CH: So in the early '60s care was really very rudimentary.

BL: Oh, yes. In fact, I really couldn't tell you when the Factor came out. I know I took it in the early '70s. Maybe about ten, or they might have had it, but it might have been rare. You know what I mean? But the first ten years without any factor, and with the bleeds, the mouth and the baby teeth and all that, I was lucky.

CH: What would happen when you lost a baby tooth? Would that be an issue?

BL: I think you'd have some, a little prolonged bleeding, but I don't think it did any major damage. But that's a long time ago. I can't really be certain on that, but I don't remember being hospitalized for baby teeth.

CH: But you were hospitalized a lot?

BL: Yes, I was. Maybe to other hemophiliacs, maybe not.

CH: How often would you go?

BL: Oh, I would say about once a year.

CH: And you'd stay in there for a little while?

BL: Yes. I don't remember how long, but I know a few times it was lengthy. Yes.

CH: Can you remember what put you in there?

BL: Mouth.

CH: Your mouth?

BL: I believe it was mouth, as a baby and getting hit in the mouth. That's what would I think put me in there. I had knee braces, I remember, as a kid, but I don't really remember how many bleeds I had back when I was that young.

CH: Can you remember the caregivers? The nurses, the doctors?

Can you remember your first doctor, when you were old enough to realize?

BL: I had a Dr. Hughes. God rest his soul. He passed on, but he was a nice guy. I remember going to Dr. Hughes's office. I always think of fond memories, and he's one. He was very good.

CH: He was gentle?

BL: Yes, he was.

CH: And he explained things to you?

BL: Yes, he did, and he was just a nice guy. Caregivers, I remember the people in the ER. What happened was up to high school years, anytime I needed a bleed, I'd have to go to Boston, okay? But then it got better. We ended up going to the old Truesdale Hospital in Fall River. Anytime I needed a shot, I went there and you had the same people. You got to know the people in the ER and they were very nice.

CH: They knew right away what to do.

BL: Oh, yes. They knew what to do. I would bring the Factor and they'd mix it. They were very nice people when I went back, because a lot of times they were very busy. Then it got to the point where they said, "Well, you know"—"Why don't you learn how to do it?"

People started suggesting that to me. "All right." So my senior year in high school, I learned how to, and that lady, she was so nice. She was a nurse. She was in her late twenties. I was eighteen. I thought she was old, but she was so nice and she showed me how to give the Factor, and that was good because it was a local hospital. Another caregiver back in the '70s at the Hemophilia Clinic at Children's, her name was Sandy Sankowsky. I don't know whatever happened, but she also helped me with the shots, gave me some info on it, and she

was very nice at the clinics when I had to go. So those were very, very nice people.

CH: Were there any experiences apart from the ER experience that weren't very nice? Any caregivers who missed it?

BL: Oh, yeah, I remember a physician I thought was kind of cocky, local. Okay?

CH: Local Fall River?

BL: Yes. Back, as I said, this might have been twenty years ago, but he was kind of a smart ass, okay? My father said something to him because we had we were going to go to Boston. I don't remember exactly, but he didn't seem to like that that much, as I recall it. But I didn't like him at all. But he's about the only one.

CH: Initially you went to Boston every time you had to—

BL: Yes. As I recall correctly, yes.

CH: That was a long way.

BL: Yes, it was.

CH: Those must have been some long drives.

BL: Oh, yes, but my folks took me and my father said to me one day, I'll never forget, as a kid, he said, "I'd walk to China for you." So he'd take me to Boston. I got all—it was Truesdale in Fall River, and then I ended up doing it myself, and that was the key to the ER, was giving your own shots now.

CH: As you said, if you'd been able to go home and give yourself a shot, instead of going to that ER.

BL: That's right.

CH: They were just handy.

BL: Yes, and I thought that I'd get the factor quicker. It turned out that wasn't the case.

CH: And did your mother help you learn to do that, too? Being a nurse, she must have helped?

BL: Well, she never—I don't think—no, not really.

CH: She probably left it to the professionals who were dealing with you.

BL: Yes.

CH: Was that a great relief? It must have been, to be able to do your own shots?

BL: Yeah, it was awesome.

CH: Anywhere, anytime.

BL: I just regretted not doing it earlier. I think now the kids probably do it a lot earlier.

CH: Yes. Oh, I'm sure.

BL: You know what was funny is that at first I didn't want to. You know, back in the mid teens, I didn't want to inject myself. As time went on, I thought, "I can do this," and I was lucky enough to be able to do it.

CH: Of course, the caregivers helped with that, too, didn't they? Getting you over that hump.

BL: Yes, they were very good.

CH: So within ten years your life really changed considerably for the best.

BL: Yes, it did.

CH: In terms of having hemophilia.

BL: That's correct.

CH: And that must have seemed a blessing.

BL: Oh, it was.

CH: You went to school in Fall River.

BL: Yes, I did.

CH: And your father was a principal, I gather, in Fall River?

BL: Yes, he was a principal. Vice-principal, I'm sorry, at a junior high school and I ended up going there for two years while he was there. Not good.

CH: Not good?

BL: Not good. No, no. I think he would have sent me and my brother somewhere else, because you can't win. You know, your father's the vice principal, you know what I mean? Then after that I went to Durfey High School.

CH: In Fall River?

BL: In Fall River, and I always liked school. I always liked the camaraderie. Once in awhile you hear people say they don't like school, but I always liked it. I liked studying history, especially.

CH: Did you find other things, once you couldn't do the sports, that you wanted to?

BL: Yes, I did. I played the trumpet.

CH: You played the trumpet?

BL: Yes, I started that in the fourth grade and my senior year in high school is when I pretty much stopped it. I look back at that, because I was thinking about that earlier, it was an alternative to sports, but I still would have taken the sports. But, as I look back, I wouldn't have got anywhere. One, I was too short. Two, I just wasn't good enough, but at least I would have been out there trying.

CH: Both trying it and enjoying it.

BL: And enjoying it, but it was a good alternative. I played in the high school band, the stage band. It was okay. I look back with more fond memories, but at the time, my heart wasn't in it.

CH: Did somebody encourage you in that?

BL: I think my folks pretty much very strongly encouraged me to the play the trumpet.

CH: To do something instead of sports.

BL: So I said, "All right," so I did it.

CH: Looking back, do you think that your family really had a good approach. They seem to have thought this through for you.

BL: Oh, yes. Maybe the medical background of my mother had a lot to do with it, because no one knew anything about hemophilia, you know. But, I have to say I was very fortunate with that.

CH: Because they were doing things like encouraging you to have other activities?

BL: Yes, that's right, even though at that age you don't really want to hear it, but they're right. I knew they were right.

CH: That's probably true whether you have hemophilia or not.

BL: Isn't that the truth, yes.

CH: What about religious affiliation?

BL: We're Catholic and thankfully, they brought me up in the Catholic faith very strongly. That has a lot to do with how I deal with the hemophilia, how I dealt with the ramifications of the hemophilia, and number one to me is my faith. I give credit to my folks right from the get-go.

CH: Can you tell me how you turn to your faith?

BL: Prayer.

CH: And if you're trying to understand "Why me?"

BL: Okay, you know what? As a child you're angry. Okay? Really, God or no God, you're very angry.

CH: Of course you are.

BL: But how I was able to handle that was when I got older I got to see other sick people. When I went to Children's and had my wisdom teeth extracted in the early '80s and back then they admitted you the night before. So I got to see a lot of kids suffering with IV's, with bald heads, and it kind of transformed me, saying, "Man, what are you—you're lucky," and I really have had that attitude, I think, since then. You know, you look at other people that are dealing with worse than you. Whereas, as a kid there's a lot of people you see are fine.

CH: That's right. Most people you see are fine.

BL: Are fine, and so—but the "Why me's" kind of stopped after I looked out and realized what everybody's dealing with.

CH: That must have been revelatory for you to see this population who were suffering.

BL: Oh, yes. I mean, they're out there, but you never saw them. I'm like, "Look at this," and that's when I really started counting my blessings.

CH: So Children's Hospital had healing properties other than—

BL: Oh, sure, they kind of woke me up like, kicking myself in the butt.

CH: How old were you then?

BL: I was twenty-one. I was a junior in college at that time.

CH: When that happened?

BL: When that happened. I still think about that because it really had an affect on me, how I've looked at life since.

CH: That might never have happened for you.

BL: That's right.

CH: Earlier, before that happened, how did you deal with "Why me?" in terms of your faith? Or did you?

BL: I really didn't deal with it, to be honest with you. If I thought of it, it irritated me. I just kind of lived day-to-day with that, because I knew no one was going to answer that. No one can answer that.

CH: I'm going to ask you a very personal question, but do you ever feel that you have been taken along this path for a reason?

BL: Yes. Yes.

CH: Having been to Children's and seen those people?

BL: Yes, but I can't really know—but I don't know what path it is. Is it possible this is all for the best, in other words? You know, from the human standpoint you can say no, but maybe the Lord's way, yes. You know what I mean? It depends—I personally don't know what advantage I had from this. I mean, it was an innocent—you were born with something that's totally out of your control, but as I look back, I think it made me more compassionate. It made me definitely more understanding. Work wise, I can work with the mentally retarded. They don't have hemophilia, but they got some problems, and I have a little more compassion for that. I think it's made me a better person, I think.

CH: I imagine it has.

BL: As I've become an adult. Not as a child.

CH: What about your brothers?

BL: Yes, I guess that's a good question. When I look back, they knew I had hemophilia, but I don't—and they knew I was in the hospital, but I don't think they had a clue what I was going through. Maybe they thought they did. Now they do. As they got older, definitely.

CH: What changed? Was it that you could explain it better?

BL: Yes. Well, I think as they got older, they understood more

about it, you know what I mean? But I'm sure they wondered, "Why is my brother in the hospital?" But I didn't really talk too much about it then. We were all around the same age.

CH: Were you close?

BL: Oh, yes, we were and we still are.

CH: But they were busy with their lives.

BL: Yes, they were busy with their lives, but they showed up at the hospital, too.

CH: They did?

BL: Oh, yes. They were concerned, yes, but I don't think they really knew exactly what was going on, and at that age, how can you? You know what I mean?

CH: Can you tell me a little bit, if you can isolate it, about some of the conversations you've had with them since childhood about what it was like?

BL: To be honest with you, I never really got into that. Not really. They would basically say they're there if they I need them. We never really got into a deep, that I remember, anything real deep.

CH: But they do understand it?

BL: Oh, absolutely.

CH: What do they do for professions?

BL: Well, I have one brother that worked as engineer for the government down in Newport, and I have another brother that works for Fidelity.

CH: So you're in the caring profession and they're in business?

BL: That's correct.

CH: Maybe that's the path.

BL: Yes, maybe.

CH: Interesting that that happened.

BL: Yes, one brother was super with mathematics. I wasn't.

CH: History was always your—

BL: Yes, because my father taught it, so I got an interest in it, especially American history. I wasn't that interested in European history.

CH: Yes, but American history.

BL: You had to take the classes, American, Foreign Policy, World War II, Southern History. That's what I liked.

CH: It's fascinating, isn't it?

BL: It is.

CH: The Civil War wasn't very long ago yet it feels like a long time ago.

BL: Oh, sure, sure.

CH: Not at all. It's really fascinating.

BL: You wonder what would happen if the North didn't win.

CH: Well, absolutely.

BL: And, you know, it's kind of an interesting history, you wonder about that. What would have happened? Would we have two separate countries from that now?

CH: Absolutely. A Northern Ireland and a Southern Ireland.

BL: That's correct.

CH: Yeah, and we don't think about it.

BL: No.

CH: It would make a great paper, wouldn't it?

BL: It would.

CH: To turn history around.

BL: Oh, sure.

CH: And write it the other way.

BL: That's why you get all these different books, interpretations of history become different. The history itself is steady, but geez, maybe that meant different now than it did a hundred years ago or fifty years ago.

CH: Apart from the trumpet, what did you do? Did you read a lot? What did you do to fill the time you might otherwise have been playing football? Did you go to see games? Were you active in sports as an observer, even if you couldn't play?

BL: Well, yes, I was a scorer for the middle school basketball team. Once again, you're thinking, "I'd rather"—you're in the locker room before the game and you want to be on that team, but I did what I could and I did a nice job, I thought, in scoring. It was good. You got to see all the games.

CH: And you were part of it.

BL: And I was part of the team, that's correct.

CH: Good for you. Was that your parents' suggestion?

BL: No, actually it was the teacher. I had a teacher who was also the coach of the basketball team and he asked me if I wanted to do that. I said, "Yes, okay," and I did.

CH: So he brought you in.

BL: Yes.

CH: In a good way.

BL: In a good way.

CH: Any other things like that that you remember?

BL: Offhand, I—I'm trying to think now, but—

CH: Because that was a very good solution.

BL: Another thing that was big was I went camping in the summer

times, from the early '60s—I'm sorry, mid '60s to mid '80s.

CH: So when you were five or six years old?

BL: We started camping.

CH: Your family?

BL: My family and we camped there almost every summer. It was down Sandwich, Mass, down the Cape, for twenty years.

CH: Do you have a camper?

BL: Yes, had a tent, then a camper, then a little bit bigger camper, and those were great days.

CH: All five of you?

BL: All five of us.

CH: You must have had a wonderful time.

BL: But then we ended up taking over the trailer, and that was even better.

CH: The boys?

BL: The boys. Those summers were great, swimming or if you wanted to play shuffleboard. You'd go to all the parties, and it was just a lot of good times.

CH: So you were a close family.

BL: Yes, we were.

CH: That must have been wonderful going off together. You'd go off for two weeks? Four weeks?

BL: Oh, I think what happened was we would go off for a week or two, but as time came on, we kept our trailer there the whole summer.

CH: Oh, I see.

BL: Then it got to the point where we kept our trailer there the whole year. So it was ready when we got down there.

CH: That must have been wonderful to look forward to.

BL: So that was wonderful, yeah.

CH: When you went to high school in Fall River, did you have any idea what you were going to do with your life?

BL: The truth, no.

CH: No?

BL: Even though I started college. Well, I take that back. I was interested in being a vocational counselor for Mass. Rehab. I'm not sure if you're familiar with Mass. Rehab.

CH: Some.

BL: What they do is they help people with disabilities get jobs, but I think all sorts of disabilities. So as a child I was interested in it, because I had gone to Mass. Rehab. As an adult, I applied twice and never heard from them. I'm not really—when I get a survey, I slammed them.

CH: You never heard from them?

BL: Never heard. Two applications. I think one was like in 1995, one was in '98. Never heard, so I slammed them maybe about six months ago when I got a survey asking me what I think. But at least acknowledge my application, and they never did.

CH: Isn't that terrible?

BL: And that was the dream of mine, to become a vocational counselor.

CH: Where did that dream come from?

BL: When I went as a client there, as a kid, I said, "Geez, I wouldn't mind this. Interviewing, taking care of people with disabilities."

CH: So you went because of your—

BL: Because of my hemophilia. I went to Mass. Rehab and they didn't do—they didn't do very much. I'm using a nice word. They

didn't do very much. Even as an adult, when I went there several years ago, they didn't do much. It's almost like I got the degree, you know, nothing. So I made that clear on the survey.

CH: Good. But that was your goal?

BL: That was my goal, the more I think about it—I don't know. I'd still love to do it. State job. I'm working for the state now, but—

CH: But you'd rather do that?

BL: Oh, yes. Desk job.

CH: Keep trying.

BL: Yes, I know. People say that, but after getting twice, two applications, never heard from either one of them.

CH: And how long ago was it that you applied?

BL: Maybe three years ago was the last time.

CH: Where did you go to college?

BL: I went to Bridgewater State College.

CH: What did you study?

BL: I majored in history, minored in psychology and once again, I liked school and I liked it there, too.

CH: How did you like the psychology?

BL: I did. I took an abnormal psych class, but I did some projects on child psych. I'm trying to think, there's another—experimental child psych. There were two different ones. A course in drugs and human behavior. That was a good course, but the teacher was lousy. There was no point to go to class. You lost interest pretty quickly. He went by the book, so half the class wouldn't show up.

CH: That's too bad.

BL: That's too bad, yes.

CH: Did you live at school?

BL: No, I didn't. I commuted, but we had a big carpool. We were all friends. That's why—I had a chance my sophomore year to get a room, but we had people carpooling and I said there was no point to it, so I commuted.

CH: How was college for you? You had a good time?

BL: Yes, I did. My senior year I wouldn't take away for anything.

CH: Why is that?

BL: Well, there were part of history majors and there was like over thirty of us that went to Jacksonville, Florida. St. Augustine, historical and two vans. Oh, it was a living hell to drive, okay, but we had a great time when we got down there.

CH: Living hell because you were tired and it went on and on? Or for you personally?

BL: Oh, no. Once you're there, it was great, but the drive just kept going. I did have one experience where I had a bleed. No big deal, and I went to mix the factor and it was expired. So I thought, "I can't use this," but in retrospect, I might have been able to. So you're on the horn. The local hospitals don't have any factor. So I finally got in contact with a hospital in Jacksonville, which was about an hour away. So three of us, two people went with me and we went to Jacksonville. Well, I got to the hospital. They had the factor. They have to take the blood test to make sure I got hemophilia.

CH: Oh, gosh.

BL: I didn't understand.

CH: Like you're going to go and ask for the factor just for the fun of it.

BL: Oh, yes. So I had to take a blood test and I had to wait for the blood test to come in. Finally, they gave me the factor and off we

went.

CH: How long did that take?

BL: A couple of hours, but it wasn't as bad as Rhode Island was, in all fairness.

CH: And were the guys happy to go and wait with you?

BL: Yeah, it was a lady and the guy who ran the trip and me. Yeah, they were very, very happy.

CH: Very supportive.

BL: We were listening to the radio and having it blaring going up to the hospital, so—

CH: Do you remember what happened that caused the bleed?

BL: No. See, a lot of times you get what they call spontaneous bleeds that happen for no reason. Most of the time, however, if you really bang it hard or fall, then you're going to get a bleed, but sometimes believe it or not, you might walk too much, and you might get something minor like that.

CH: You must have a moment when you think, "Oh, no." You know, here you are. You're having a wonderful time. You're almost where you want to be and you think, "Ahhh."

BL: It happens quite a bit throughout my years where you say that.

CH: That you feel—

BL: "Oh, why now?" Yes. But you deal with it best you can and try to get to the factor the best you can and that's that.

CH: What can you do?

BL: See, that's the problem I think with the hemophilia and other disabilities you don't have answers. So you pretty much got to try to meet it head on and go for it, you know what I mean?

CH: When did you come to that?

BL: I think it was over a period of time. I don't think I ever sat down one day and said, "Bang, I'm grateful, bang, I can deal with it." I think it was little by little. More people you meet, how—what kind of bleeds you had and how you treated them. It was kind of a lifelong experience to come up to this point. It wasn't anything automatic.

CH: You gained wisdom.

BL: Yes, I did. I got a little smarter, I think, as I got older.

CH: Yeah, as we do about all things.

BL: In all things, yes.

CH: But some people remain angry.

BL: Oh, yes.

CH: You let that go.

BL: Yeah, but you know what's funny? Once in awhile it comes back, but not as often as it used to.

CH: Can you give me an example?

BL: All right, I'll give you an example. Hepatitis-C, okay? You know, all the blood borne problems with us. You say, "Enough is enough." You know what I mean, because dealing with the hemophilia is enough. Now you've got all this other stuff. That's when it opens up, you know what I mean?

CH: Did hepatitis-C affect you?

BL: Oh, I have it. Yes, and I'm being monitored very closely and I'm doing very well.

CH: Good.

BL: But I went on interferon. I don't know if you're familiar with that? Okay, that was brutal.

CH: Tell me about that.

BL: I think I tolerated it pretty well, I guess, to a lot of people, but

for two weeks I was a zombie. I'm driving home, you know, they gave me the first one and showed me how to do it. Driving home, "Hey, this isn't bad." When I got home it started. Like if you have the flu, that's pretty much what you feel like.

CH: Headache?

BL: Headache, oh, the whole thing. Yes, antsy, you know. I took two weeks from work off and I still tolerated it quite well. I went to work after that. I had my nephew played—he was one game away from the Little League World Series, so I went to Connecticut feeling miserable, but they played in Connecticut and the ride was a disaster. It was like go here and go there. It wasn't straight through, but I made it and I saw him play. But you just felt—you didn't feel right. Luckily, I kept my appetite going. That's, when you're going through that, you're saying, "What? I didn't do anything to deserve this."

CH: And you were angry?

BL: Oh, yes.

CH: How old were you when you discovered you had hepatitis-C?

BL: Oh, I found out in 1991, okay?

CH: What were the symptoms?

BL: Oh, I don't have any.

CH: You didn't?

BL: No, still asymptomatic.

CH: So there were no symptoms.

BL: I just said, "Check it," and they did, but back then they couldn't do anything. Zero. So I said, "Ah, the heck with this, I mean there's nothing." But the last few years I've been monitored, blood work every three or four months and they wanted a biopsy, liver biopsy and that's the only way they put you on, and I told them, "No." I'll go on

interferon, I have no problem, but I said, "I'm not going to go for a biopsy right now."

CH: Why was that?

BL: Biopsy? Because what can they do? You know what I'm saying? They could find—other people who listen to this maybe they do know, but all right, so they find out fifty percent of the liver is damaged. What are—medically, what can they do? Nothing. So I thought, I'll deal with the iffy. Some day I'm sure I will, but they let me go through it, anyway.

CH: Well, it allows you to be hopeful.

BL: Yeah, exactly.

CH: And optimistic.

BL: And optimist.

CH: Which you might as well be.

BL: Yes, and I don't think—I know what could happen, okay? But you don't have to live with it every day, you know what I mean? Because you've got a life out there you have to live, but it's always in the back of your mind and I felt a biopsy's going to bring it to the forefront.

CH: Yes, particularly if the news is—

BL: If the news is not good, you know, if they could do something for you, then I'd go in tomorrow to get it done. But there's not much they can do right now. I think in a few years they told me. In other words, they're coming along now I think and I think in a few years they're going to come up with something. But right now, except for the Interferon, and the chances of that working aren't good.

CH: No?

BL: No, because I have the common genotype A. Most people, it

doesn't work as well with A. So they told me it was less than fifty percent, and it knocked out some of it, you know, and I think it did some good in it cleanses your liver, but in terms of what we want, it didn't do it.

CH: So you had the two weeks and that was it?

BL: Yes, I was able to manage from there on and off, you know? I think some people are so sick they have to come off it, but I was able to hang on almost the full thing.

CH: Good. Was that through Children's Hospital?

BL: Brigham and Women's now.

CH: Brigham and Women's. That must have been a day, when you got that news?

BL: Oh, it was awful.

CH: Can you tell me about the day?

BL: Sure. Well, I'll back up a little bit, okay. As you know, the HIV crisis was even more of a concern, so back in '85, I thought the impression was, if you have the HIV, you might only have a ten percent chance of getting it, which sounded like hepatitis-B, actually, to be honest with you. All right, test me. They never called me with the results. Never called me, positive, negative. This was in 1985 when the test came out.

CH: '85?

BL: '85.

CH: No one called you back?

BL: No one called me back, so you don't know what to think of that.

CH: Did you call them?

BL: No. No, in fact, we looked subsequent years later and all they

had was I was tested. They didn't have the results. Now, after that, back toward the late '80s, all hell's breaking loose now.

CH: Now, just backing up, why do you think there were no results?

BL: Don't know. The doctor wasn't on the ball, that's the only thing I can think of.

CH: That's interesting.

BL: You know, whoever ran the office—

CH: Didn't do it.

BL: Didn't do it.

CH: So that was a nonevent.

BL: That was a nonevent, then.

CH: So then what happened?

BL: As you know, after that, that's when all hell started breaking loose. Actually, before that, but mainly they realized if you had hemophilia, severe, you're in trouble, okay? So as time went on, I refused to get tested. I stayed away from the hemophilia clinic, okay, for that reason.

CH: Out of anxiety?

BL: Out of anxiety because I know they're going to test me, and understandably, if I worked for them, I'd definitely want to test people. I mean, you want to let them know. And I wouldn't. I wouldn't. I went up there in the late '80s and I let them do a T-cell count, which is the basis of the immune system. It was very good, so I still didn't get tested, okay?

CH: And did they push you to get tested?

BL: No, not at that point, although they really wanted me, but they were very nice about it.

CH: They left it to you.

BL: They left it to me.

CH: Even going up for the T-cell count took some courage, didn't it?

BL: Well, I let them do it. Yes, it did, but that's why I don't think they pushed it because it was sky high at that point, okay? But I think it was 1991, I think it was, where I let them do a T-cell count in May I believe it was, of '91 and it went down. You know, I knew what it was at that point, you know what I mean? So I said, "Test me."

[end of Side A, Tape 1]

CH: Can you remember that day? It is really hard, isn't it?

BL: It's awful because I knew what it was.

CH: You did, yeah? You just had it to hear it.

BL: Yes. Yes.

CH: So you got the worst news you could get at that particular point.

BL: Yes, and back then they had nothing, you know? They had the AZT and that was really about it. You know, my mother was a nurse. I think my father—they both have so much faith, but my father, I think—and he never told me this, it's just my gut feeling, I think he hoped like hell that maybe I was one of those five percent or something that tested negative.

CH: Of course he did.

BL: Because he had such good faith in prayer, and so he cried on the way home. I was numb. That was the word, numb, you know what I mean? Because it wasn't unexpected. So—

CH: And the person who delivered the news to you, was he—

BL: Dr. Ewenstein, the physician.

CH: Ewenstein?

BL: Ewenstein, yeah.

CH: And he was?

BL: Hematologist.

CH: Did he offer you any hope?

BL: Well, I had the nurse practitioner. I had the social worker.

CH: In the room?

BL: In the room.

CH: So you knew.

BL: So that's how, yeah, but the nurse practitioner, social worker, "Anything I can help outside the physical area?" Dr. Ewenstein was really the physical area. So, every area you had somebody if you wanted to talk to them and everything like that.

CH: And they were supportive?

BL: Oh, very.

CH: Hard news for him to give.

BL: Oh, I'm sure it is.

CH: So you're driving home and your father is devastated, of course. Did he ever speak to you about whether it challenged his faith at all?

BL: No, not that particular, but I know things challenge his faith. Anytime I suffered, that's got to challenge his faith. No doubt that diagnosis challenged his faith, but he rocks on, you know. Both of them, they keep going. They got some friends now that are diagnosed with cancer and major heart surgery. The faith just keeps going, no matter what's thrown at them, and that's what, you know, I admire.

CH: How did your mother react when you got home?

BL: Fine, you know what I mean? In other words, not in front of me. She didn't lose it in front of me. I don't know what happened at other times, never asked her, but she was stable.

CH: What happened in your family then? You're in a whole new ballgame.

BL: Okay, well, you have to think. You got to be careful who you tell, okay? Even now most people don't know, and how I think I've lucked out with that is I'm healthy. You know, I've been lucky I haven't had an infection related to HIV yet. So I'm going to work. You know, I look healthy. Putting on weight, exercising, and so people don't know, but I told a couple of my closest friends, okay, and there's no problem because they know you've got hemophilia. There's a close friend of mine that I never told because he has a big mouth and he might twist the whole thing around. So anybody I knew with big mouths never knew. People that didn't, at my request, they never told anybody. That's why—and my brothers are very supportive. One brother I have has three kids, and “Come over for dinner.”

CH: So they're not—

BL: Not one bit. They invite me over there all the time. I go, kick back and watch the games and thank God there was no problem. And other people that know, no problems. I've been very lucky. Now, back then, I don't know. I bet you there would have been at work because I work with retarded. I think all hell would have broke loose, back in '91. Now, I'm not so sure. It's much better now, and I did tell them about hep-C because I was out for a while and no problems at all.

CH: Did you tell them about the HIV?

BL: No. No.

CH: So they don't know?

BL: They don't know about the HIV because I still don't know what

the reactions are going to be.

CH: Right, and it's too late once you've told.

BL: Yes, that's right. You've got to be very careful, I think. Not as bad now. It seems to really—people have mellowed out with it, it seems, but back then, oh, boy, I can hear it now.

CH: But even if, say, your supervisor understands, there may be people around who don't understand.

BL: Yes. With the hep-C, you wouldn't know a difference, you know.

CH: Tell me about the early days and HIV, because it is so different now. What kind of responses did you get back then? What kind of responses did you get from people about the HIV situation?

BL: The people that knew, they were very nice. Okay? And, you know, I'm not saying—I'm not prejudiced or anything, but I think getting it through blood might be a little different, we'll say, than getting it the other ways. So you might get more sympathy from people, okay? And I'm not saying that against anybody, but I think it's true.

CH: Oh, I think it is true because there's no moral component. It's only a physical component.

BL: That's correct. In other words, remember how they used to say how to prevent HIV when it first came out? But the bottom line is, hemophiliacs, we follow the moral rules and the moral laws, we're still going to get it. So they kind of irritated me, those ads because there are people. Let's say somebody needed surgery. Got in a bad car accident, needed whole blood, they could get it. Or someone with any type of cancer surgery, they need the blood, they got it. So that's not—that's very misleading to say you can prevent because some

people couldn't prevent it.

CH: They didn't get that across back then, did they?

BL: No, they didn't. Now I think they have, but back then they did not.

CH: Right. It made a real change in your approach because prior to that, secrecy had not been an issue, had it?

BL: No.

CH: So suddenly you're in a situation where you're having to make the decision to be secretive.

BL: Yes.

CH: Did that feel different for you? Was that harder?

BL: Oh, it was hard.

CH: Because you strike me as a person who would want to be out there and straightforward.

BL: Oh, that's me.

CH: And that's hard for you, I'm sure.

BL: Yes. I just like balance both out. You know, I'm sure there are people out there now that don't know that I probably should have told by now, but you know, they would be very nice, okay? Other people, I just don't have an answer. I don't know if they'd be nice or not. I'm sure—

CH: I think you're right to follow your instincts.

BL: Oh, yes, and it was instinct to keep my mouth shut. The only thing I worried about was let's say I had gotten sick and I was in and out of the hospital knowing you got hemophilia, they might say, "Wait a minute," and if they have any knowledge—if they have. They might have read it in *Newsweek*, *Time*, whatever it might be, then they might come to a conclusion, but I've been lucky that I've

been asymptomatic. So I don't think anybody I work with—I mean, they might think, “Geez, this guy might have got this, but maybe he didn't.” So I've had no problems with that.

CH: Do you feel less fearful now that you've lived with it for almost ten years?

BL: Yes. Oh, actually it's been more. It's been thirteen. Thirteen but to be honest, I probably had it several years before '91.

CH: So you must be a little less fearful because you've lived a normal life—well, with the hemophilia, but that hasn't affected you so severely.

BL: Yes, I can handle it a lot better now. You know, and I think I still feel comfortable not saying too much to anybody. You know, if they asked me, I'd probably tell them now, if I could trust them.

Whereas, I never would when I found out. So you know, there's hope with HIV because there's so much medication out there now. When we first started, there was nothing, and I'm not on anything right now and I haven't been on anything for two years. Now, I do realize that the T-cells are going to come down and I'll have to go back on something, but to give my body a rest two years, I'm very grateful.

So I'm almost trying to expect now that one of those days I might go up there and say, “Okay, it's dropped now. Let's put you back.”

CH: And they'd put you back on?

BL: Oh, I don't know what they're going to do.

CH: But you're ready? I mean, mentally you understand—

BL: Mentally I'm ready.

CH: That may happen.

BL: Yes.

CH: Hope is really important, isn't it?

BL: Yes.

CH: Has that happened over these years, that you can feel hopeful.

BL: Yes, you felt you didn't have any hope in '91. You know what I mean? You had zero, but now there's hope with that, and what I think a lot of me and my colleagues, I think we're hoping that hep-C—because to be honest, that worries me more than HIV. You know what I mean? It really does.

CH: Because it's working quietly?

BL: Yes.

CH: Did you participate in the trials at all?

BL: No, I'll tell you a story about that. What happened was I was ready to go. It was back in '91 and '92 and they'd do a T-cell count, you know, and they'd check it. You have to do a minor physical, little things before you go in the study. Well, they do my T-cells and we're ready now. If they go below a certain point, I'm going to start. They went up. They went up. I blew the study. That was the end of the clinical trials. You know, and I don't think they—it had to be like five hundred or below and mine went to like seven hundred or something. That ended that.

CH: So you were disqualified.

BL: Yes, no more study.

CH: What about the legal aspect of all of this, did you participate in that?

BL: No. I did what I had to do, you know, in terms of filling out the proper paperwork and things like that, but I never went to any court dates or anything like that.

CH: How did you feel about that, what the drug companies ostensibly did?

BL: Honestly, I feel that they—I don't think they knew a hundred percent that they were sending out [unclear] factor. I'm trying to be objective, honest to God with myself, I don't think they said, "Oh, this stuff's infected, we're going to send it out." But I think they knew they had a heck of a potential and they should have recalled the stuff.

CH: And they overlooked it.

BL: And they overlooked it, okay? I also feel that the factor VIII that we were taking, we had to take it. Okay? If we knew this lot's infected, okay, let's say we knew one hundred percent this lot of factor's infected, but you had a major bleed at the same time, what do you do? I'm not talking a minor bleed. Forget it. I'll do what I can, but if you had something that was life threatening, what do you do? You know? I think I would probably say take the factor and [unclear], but we were encouraged, I think—I remember, so long ago, that take the factor if you need it.

CH: So you would probably say "If there was that chance, I'll live without it. I'll do what I can without that."

BL: Yes, but I mean, you're taking the factor, you knew that there was potential. I think they knew there was potential and they sent it out anyway.

CH: But in those days, as you say, the word was, "Take factor VIII."

BL: Yes. As far as I know, yes, if you really need it, and I think—to be honest with you, I think that we should have done better, okay? I think the settlement should have been a lot higher.

CH: Yes?

BL: The blood product settlements that they gave us. The federal government also gave us some money. The Ricky Ray Hemophilia Act, but I believe that the blood product companies, one, should have

admitted guilt. They should have. They never did.

CH: They should have.

BL: Guilt. They should have admitted guilt. I don't think they ever did.

CH: They should have admitted guilt?

BL: Admitted guilt, and they never did, as far as I know. Two, there are other countries, I think, hemophiliacs did better deals than we got, you know. I don't think financially I should have a worry in the world. But I commend the people who worked so hard, the hemophilia people. I commend them. The word thank you doesn't describe it. That's how grateful I am to them. They did the best they could, because I guess if I went alone, I probably would have lost, you know what I mean? So I think they did the best they could, but it will never be over, in my opinion, until they actually say, "We made a mistake. We were wrong." I mean, why would you give a hundred thousand dollars to every hemophiliac and not-and so it turns out to be I don't know how many hundred million, and actually say, "No guilt." You're not going to dish out three hundred million dollars for nothing, but I commend the people that did it, though. They did outstanding work.

CH: During that time, did you feel anger at the drug companies?

BL: Oh, yes. Oh, yes.

CH: Powerless?

BL: Oh, powerless. Oh, absolutely. Yeah, but I will say something about the blood companies now. If another virus came out in the blood, which is possible. Trust me, it is possible, right? I won't fall down because I think now they're doing what they should have done twenty years ago, thirty years ago. They're doing everything possible

now to prevent. So I wouldn't fault them at all if something came through, because they really are doing what they can.

CH: Let's go back to college. We left you going to Florida. You said your senior year was a wonderful year for you. What did you do after that?

BL: After college, you mean?

CH: Yes.

BL: Well, no, I went out and I subbed for a while. Substitute taught for a couple of months, which you know, I had the elementary schools. I kind of liked that. Then I got hired at Paul Dever. Paul Dever's like a—used to be a State Institution for the Retarded, but now it's closed because they moved a lot of these people into the community. But back then Dever was, there might have been a thousand people who lived there. Or maybe eight hundred. It was a little city, and I started there and I worked there until early 1990 and I went into group homes. I worked in a group home in Fall River, in Carver, Mass, and Somerset now. So I've spent twenty-one years working with the mentally and physically disabled.

CH: Did you find right away that you responded to that first experience?

BL: That's good—very good. I walked in there and said, because we had a dining room full of people and I said, "I'm not going to. I don't think so," but I did it. I don't know what it was. I think it was the state gives you good benefits, health insurance, usually, which I really need.

CH: So at first it was a practical decision?

BL: Oh, yeah. Yeah, but as time went on, I got to like what I did. I got to like it, and I guess after twenty-something years now doing it—

I was a supervisor and case manager and human rights officer.

Different positions, but most of it was direct care.

CH: Did you come to understand that population better and therefore find working with the retarded folks easier? Did you feel that you came to understand better what their lives were like?

BL: Yes, you realize that they weren't blessed. A lot of them, I can't be sure, but I think some of them were just natural birth defects, okay? But a lot of those might have become—had the retardation right after. I'm not really that sure about it, but that's when you say, "Oh, boy."

CH: Just a—

BL: Just like a weird thing. You know, a lot of them are very special people, though. You got to know them and what they like and what they dislike and the state, to its credit, has done really a fantastic job with them. Putting them out in the communities and the institutions are closing down.

CH: They all have hearts and souls.

BL: Yes, they do. Yes, they do. It's just sad a lot of them, though, are physical, got a lot of physical problems. One of my positions is I give out medications and we have to be certified to do that, and they're on a lot. Some of those guys are on a lot. Seizure medication, behavior medication, you realize once in awhile that it's kind of too bad.

CH: Yeah, it is. It's living in a kind of—not a real world.

BL: No, that's what I mean, but we give it our best shot and we make it as—they just got back from vacation. I took them to the Cape.

CH: You did? How many did you take?

BL: Four. I work in a house with four people.

CH: Did they have a good time?

BL: They did. Right on the water, you know. We give it our best shot.

CH: Good for you. And you feel fulfilled in what you do?

BL: Honestly, I think I would if I moved up, and that was my goal. A manager or a director of one of those houses, but I watch what they do and I'm not impressed. You know, with the responsibility they got.

CH: You mean what the managers do or don't do?

BL: Exactly. In other words, I would go for it in a heartbeat, but I don't know. Some of the jobs they're responsible for, I'm not interested in. And that has prevented me from moving up the ladder.

CH: Your own choice?

BL: Yes.

CH: And what are some of those jobs that you would not want to do?

BL: Well, they have two houses to run, not one, and one is enough, trust me. You know what I mean? If they have one house, then I'd go for it. I think I'd really go for it. I'm not that familiar with the Medicaid laws and all those, but they're involved in all that.

CH: Bureaucratic?

BL: Yes, and they're involved with a lot of that, those type of duties, too, which I'm not sure—and a lot of responsibility with them. In other words, back when I was at Paul Dever, they had the social workers. They had like the program directors. They had the psychologists. They had them all. Well, they got rid of a lot of them, so now the house managers have a lot of those responsibilities. I

don't know they never leave well enough alone, but they did that. Running two houses, and medically, the medical responsibility with the house manager is so—and with us, even when we're on duty.

CH: And less patient contact.

BL: Yes.

CH: And probably less chance to make a difference in some ways.

BL: Oh, yes, and we go to these trainings and they help but you got to work with those people, okay? You have to work with them to really understand them, and understand a lot of their goals, okay? If I can sit at a desk here and I'm way, way up there, now, some of those people don't have a clue what's going on in the homes, and you got to. I wrote a paper on that, too. I still haven't shown it because I was taking a course in organizational theory and I like to show them. The instructor that I show my paper to them.

CH: So you haven't shared it yet?

BL: Shared. That's what I'm looking for. I haven't shared it yet, but I will.

CH: Good, and you're pleased with your paper?

BL: Oh, I'm very happy.

CH: Good, I absolutely think you should.

BL: I just think there's—I guess my paper theory was there's got to be less of a gap between upper management and staff. You know, it's got to be closer.

CH: Particularly in this very emotional setting.

BL: If they come down to the houses and work down there for a while, they'll have an understanding, but in all fairness to us, we have to go up there and see what they're dealing with. So it worked both ways. So I thought it was pretty good.

CH: It is. It's a very fine idea.

BL: Because there's a lot of bitterness I think if people think they're getting orders from people that don't have a clue. You know what I'm saying? But if they have a clue and they've done it, I think it's much better. Much better.

CH: Which is why you would be very good at it.

BL: Right, that's why I would be good. I better get moving.

[laughs]

CH: Maybe you should give it a try.

BL: You know what's funny, too? I'm going for another Associate's at PC, Providence College.

CH: Another Associate's Degree?

BL: Yes. I have a Bachelor's in history, but I'm going for an Associate's now in Business, and I got one of my brothers at Fidelity. I know I have several references, so I think I could get in, but I'm worried about insurance. Hemophilia, you need the insurance and I feel trapped sometimes because they don't have the insurance that I want, I don't think, and would they find out, would they say, "Sorry, we can't cover this guy."

CH: So in that sense hemophilia really did change your life?

BL: Oh, and that's one of the reasons—

CH: Maybe that's the biggest one.

BL: Why I've stayed with the state, but work like nine-to-five, weekends off. I've never seen that. You know, I would have several, four or five people I could put as references down at Fidelity and I think I'd have a good shot. I explained to my brother about it, about this, and he said, "Well, I understand." But at first he didn't understand. "Geez, why don't you get an application in there?"

CH: So your brother invited you to do that?

BL: Oh, yes, "Get an application in there."

CH: And what would you do at Fidelity?

BL: Customer Service Rep. I think you'd have to take like three months' training and you have to taken an exam. That was another doubt. The exam's very difficult.

CH: You'd be very good at it, though, because you're very outgoing.

BL: Well, I love talking to people on the phone.

CH: That's right. You would be very good in that regard.

BL: Yes, I just like people in general to shoot the breeze with, but I'm afraid of the insurance and the HIV, and the hepatitis, would I have to tell them? I don't know. I wouldn't want to tell them.

CH: That's another consideration.

BL: See, all these legal things and all I need is to leave the state, and "We can't do it," because that happened once, and it broke my heart.

CH: Tell me about that.

BL: I got a job at *New Bedford Standard Times*, the newspaper. One of my former teachers got it for me.

CH: When would this have been?

BL: Oh, I'm sorry, early '80s, maybe. 1980-81. Maybe earlier than that. I got the job. All it was sorting newspapers. That's all it was, but I thought, "Just get in there," right. I could become a sports reporter, journalist, something, you don't know. Well, before I started, you go for your physical and a lot of times back then they were kind of amazed with hemophiliacs. They thought you were doing very well, and found it odd almost to talk to a hemophiliac, you know. So I went for a physical and I passed the physical, okay? You fill out a form. I fill out the form. Now, you're not going to do either one,

unless you're hired. Okay? Then I forgot what happened, but I didn't get any calls, and I called them back. You know, I didn't hear anything. Well, it was the hemophilia, why they didn't hire me for that job and it was because they were afraid if something happened to me, then I'm not sure if they knew the insurance would cover it, and I didn't get in. God, was I mad, and that's what really, even though it's a long time ago, you're afraid something like that might happen at Fidelity.

CH: Of course.

BL: So I have to admit that, yes, you mentioned something that it is a big hindrance, your hemophilia, when it comes to getting jobs, except the government, the state, maybe the city, you'd have a chance because the government, they got disability laws and I think the state's got them where they almost promote that somebody with a disability comes in.

CH: It's really not the company so much as it is the health insurance?

BL: Okay, that's what I think what it was they were afraid of the health insurance.

CH: But also there are companies that are going to back off from a potential problem.

BL: Of course, it's like life insurance. You know, I can get it through the state. In fact, they had an enrollment.

CH: You can get it?

BL: Yes. They just had an open enrollment for the state and I grabbed the whole thing. I grabbed as much as I could.

CH: And they'll give that to you?

BL: Yes, they will. No questions asked. The other ones, they're

going to ask you questions.

CH: So that is a great advantage with the state.

BL: Yes, see, and that's why I'm kind of hesitant, and I explained all that to my brother and he understood.

CH: But it's very restricting for you as a person.

BL: Oh, it's terrible, to be honest with you. I can't leave the job because of my insurance and that's basically—

CH: You're trapped.

BL: I'm trapped.

CH: I understand.

[end of Side B, Tape 1

BL: —a my heart, and it made me angry, and that was the end of it.

CH: It changed your life, didn't it?

BL: Yeah, it really—it really—and that's why everything, insurance was number one.

CH: Was that one of the first times you'd come up against—

BL: Yes, because you want to know something, though? When I look back, in the summer times I started working young. I was fourteen doing painting at schools. It was part of what they called the Youth Resource Agency. They were very nice to me those people, and they hired me. I worked at the Venus DeMilo. Okay, the Venus DeMilo was a fancy restaurant in Swansea, Mass. You got all the weddings and a lot of the big banquets there. They hired me. The only thing is the owner said, "Just watch out for broken glass."

CH: So he knew.

BL: Yes, and he hired me, and I stayed there. I used to get out the hot soup. See, some people will hire. At Bridgewater State College they realized that—got a part time job, a part time librarian, student

librarian, and the only thing is, the owner wasn't smart. The director was smart and said, "I don't want this guy lifting heavy items." So they found something else for me to do. So those people that were outstanding. It was the *Times* that really—I've always been very cautious ever since the *New Bedford Standard Times*.

CH: You hope that the people who gave you those chances understand what a gift they gave.

BL: Oh, yes. Yes, if I ever saw them again, I'd tell them. I really would.

CH: They probably don't realize how special that was. It's funny how the bigger companies that really have much less to lose because they're so big, are much more hesitant to take the chance.

BL: Oh, yes. I can understand, to a point, to be honest with you, but you know, if you have a good work history? I think I could get recommendations now, and I got them for the Mass Rehab. It would have been like we're sitting here right now with a nice computer here and I would interview people and see if I could help them out getting a job. But like anything else, they get a huge workload, though. They might have a hundred people, but I think that would have been what I really wanted. I would have been very happy, but it didn't work.

But, yes, you brought up something I would have never thought about, and that's the insurance and how it does trap you. Then people ask, "Why don't you go into business? Why are you going to school now?" That was the reason, but now I'm having second thoughts that, "Geez, I might not be able to get in there." Maybe I'll try to move up, but I think I'm better off with the state.

CH: You're safer with the state.

BL: Safer, that's the word.

CH: When you learned you had HIV, was there any issue at all with the health insurance with the state? Did you tell them?

BL: No. No.

CH: You didn't tell them?

BL: I figured they got to know by the Brigham and Women's, you know what I'm saying?

CH: Do you think so?

BL: Oh, yeah. In other words, they know I have hemophilia because I went to some program, they were supposed to tell me about how to manage my hemophilia. I did that for four years and I was like, "Okay. You do what you want."

CH: Through the health insurance?

BL: Yes, through the health insurance.

CH: Did you go?

BL: Oh, it was a phone thing, but now I'll get a nurse call me every few months to see how I'm doing, but I pretty much know how to manage it, you know what I mean? I've had it forty-four years, but the HIV, I don't know. But in all fairness they probably do because the Brigham and Women's, they have to send health records, I'm sure.

CH: Are they self-insured?

BL: Like hepatitis-C they must because I had to go on the interferon.

CH: Is the state self-insured or do they use a company?

BL: Oh, they use Tufts. They use everybody.

CH: Oh, they do. So they spread it around.

BL: They spread it around. I got Tufts. You know, in the past I had John Hancock. I had Blue Cross, but the state, they switch, you're automatically in. They don't take anybody out.

CH: But there's a lot of freedom other people enjoy that you can't feel.

BL: Oh, yes. You know, somebody resigns, we'll say and they go get a better job, you're kind of envious because you know you really—if you're realistic. If you dream, I could, but no, it's too bad.

CH: If you don't mind my asking, tell me about your personal life. How does all this affect your decisions about relationships.

BL: Oh, yes. Be honest with you, I've been kind of a guy that has a date here and there. I've never really been at the point where I wanted to get married or anything, and do I think this has something to do with it? Yes. I think—would I get married, absolutely, but you'd need somebody real, real special. Okay? Because who wants to marry somebody with HIV and hepatitis-C? Now, I know there are exceptions out there, but if I got the exception, then, yes, but to me, what a tough thing. I feel bad for the guys that have been married. I don't know how they manage with it, you know.

CH: And then they discover that HIV is an issue.

BL: And then they discover. It would be tough enough to me to find out when I'm single and then tell somebody you want to worry. So, no, I've never really met any yet that are in that category.

CH: And that dates back to when you were—

BL: Yes, to me that would be a tough, tough thing to do, but you have to tell them. You've got a moral obligation to tell them.

CH: Have you ever met anyone you felt that way about?

BL: Oh, yeah. Yeah, but you don't really take it any further.

CH: Is that a source of sadness?

BL: Yeah. Yeah, you know what it is, though? I'm kind of a choosey guy, anyway, you know what I mean? I'm not the type of

guy that's going to go out with anybody for the sake of going out, you know what I mean? But to me I think it would be a project for me to fall in love and get married because I got those two viruses and hemophilia. But I know it's been done, but I don't think it's easy. You'd really need somebody to love you back with something like that.

CH: I suspect it gets easier as you get older and the women around you are more mature.

BL: Okay. Yeah, okay.

CH: More understanding.

BL: But don't you think—let's say you're in their twenties now, okay?

CH: If you're in your twenties.

BL: Yes, let's say you're in your twenties right now. It must be tough. So you go to a good nice club. Okay, a nice club, have a few beers or something, you might meet somebody, but you tell them that—see you got also the choice of when to tell them. You got to tell them. You got to tell them soon, but that must be—I feel bad for the kids that are in their twenties now, because we really got a strike against us. No matter what age, but especially down there.

CH: Have you been in the position of telling a young woman?

BL: No. No. I've never been that close to somebody, a woman that I'd have to tell them, you know. I think the only part of that, I might deny it, but I really think part of that is preventing me because you know really, it's almost like I don't want to even get in that position to have to tell. You have to tell them, "Geez, I got hemophilia."

CH: And they say, "Bye, bye."

BL: Which they might not physically say "Bye," but you won't hear

from them again.

CH: That's a kind of a threat, isn't it?

BL: Oh, it's a big time threat.

CH: It's like the doctor and the newspaper—

BL: You know what's funny, a lot of people—I don't want to say a lot, but a lot of people say how come you're not married? They'll ask you. "You're a good guy, why aren't you married?" and you just kind of—I do like being single, by the way. You know, I like it because my brothers are married and sometimes it takes—you go to Atlantic City and things like that, I don't know, a million dollar watch or something to get them there. In other words, they're restricted. I'm not. So I like it, but you have to kind of "Well, I like the single life." You can tell them excuses like that. You're not going to mention the HIV, but to be honest, even like I think about it now, it really has an affect more than I thought it would, you know.

CH: Tell me about that.

BL: Oh, because you just don't want to get close to anybody because you're going to have to tell them. So if you're not that close, you're avoiding a huge problem if you don't get close to anybody. But some day I might. So the choice is get close to somebody, get married and you got to tell them, or stay single and not tell them and right now I'm really kind of at the single side.

CH: I suppose someday there may be a person who knows that and still—

BL: I'm sure. It's unlikely, but I'm sure it's going—yeah. But I think that—I like to bet once in awhile, and I don't bet on that.

CH: But you don't think about it all the time?

BL: No, you got to go on, you know what I mean? You can't—

CH: Are you happy living at home?

BL: Yes, I am. Why? Because that's another thing, you think you might get sick of living at home, but I live my life. My folks live their life. When they're not around—they're retired now, so they like to travel occasionally, I'm there to take care of their home. In other words, what I'm saying is it kind of works both ways. I'm independent. You know, I know some people at home that are "mama's boys," I guess you'd call them. That's not me. You know, I could move out, like this. Financially I could do it, but I'm content.

CH: I don't find it odd.

BL: But do you think a lot of people do thought?

CH: Well—

BL: You know, this—speaking of girls, that could be a big downer.

CH: I guess, except it's really community, isn't it?

BL: Yes, but I got to admit, the people I know and work with, they don't—they don't take that against me whatsoever, but I do know there have been people that do. But, I'm just—I'm pretty content there. If I was restricted in any way, I would go, and my folks, we've always got along, and they do what they do and I do what I do. So I don't see much of a problem in it.

CH: Do you talk very much with them about things that are happening for you, the concerns you have?

BL: Oh, I'm kind of quiet. I'm kind of quiet but sometimes I do, like work we discuss. The HIV crisis we discussed, I don't know how many times. Normally I think parent-son conversations.

CH: Where do you go to talk about all of those madnesses or frustrations?

BL: I don't. Oh, I don't really say too much.

CH: No?

BL: No.

CH: You don't go to any groups with people who are—

BL: Well, I'm a member of a couple of clubs, but I haven't attended them recently.

CH: But I mean men with the same issues that you have.

BL: Oh, no. Be honest with you, I never really got friendly with other hemophiliacs. There's another family that lives in my town that we've contacted once in a blue moon. One of them lost their son, so there is only one hemophiliac now. I went to one of their meetings years ago at the Hemophilia Association, Rhode Island, but that's been really about it. I talked to a guy who's also at Brigham before I had knee surgery and he was great telling me what to expect and what's going to happen. He was great, but I never really got into the meetings. A lot of it, though, had to do with it's a hike. You know, it's a hike to drive from Fall River to Dedham. Like, today, I guess it's about the same drive.

CH: It's not easy to do that all the time.

BL: Yes, but that's partly my fault, too, for not being enthusiastic because a lot of times I don't like to talk. Hemophilia, I don't like the word sometimes, you know. Be honest with you, the people I've known all throughout the years, they don't have it, so you really don't discuss it.

CH: And that feels better.

BL: Yes. I feel better not talking about hemophilia than I do talking about hemophilia.

CH: Otherwise, we can be defined as a person with hemophilia, and that isn't true. You are a person and you happen to have hemophilia,

so you don't focus on it.

BL: True. That's right because, as I said, you can make yourself selfish, but I look at other people who are dealing with a lot worse and I think the kids that are being born now got a good shot. With the synthetic factor they got now, the more they know, they got a good shot.

CH: Do you ever feel, not resentful, but do you ever feel wistful? These young people are really not facing the issues that you faced, which were must more complicated?

BL: Honestly, I'm happy for them. I'm happy for them, but I don't trust the blood supply. You know, even though it's much better and I'm still taking blood, factor VIII, you know, because I'm doing so well on it.

CH: Not synthetic.

BL: Starting when I run out of this dose I got now, I'm going to start the synthetic.

CH: Are you?

BL: Yes.

CH: Is that because you're anxious?

BL: They've recommended it now, and I said, "Okay." It's going to be easier shot wise, too, I think. You don't got the big needles sometimes. It's going to be smaller needles. So I decided to take that, but I do think that—I'm happy as hell for them that they can do well and they can get up there and play sports now.

CH: Yeah, they can.

BL: Except for football, which even the average person, those guys take one heck of a chance when they go out and play. But I can see basketball, baseball, swimming, bowling, I mean anything they want

except for football. So I'm happy for them but I wish them well with the blood products, if they can get off of them because I don't trust the blood. They're talking like West Nile.

CH: Do you feel uneasy every time you take it?

BL: Oh, no. No, I don't because I have a lot of faith in them now, but I think that they'll do okay. Let's hope, pray, that they don't get—there's nothing in the synthetic stuff that we wouldn't even imagine right now, but in twenty years, you know. I mean, and that—

CH: We don't know.

BL: No, we don't. Okay, there could be something in the synthetic now that twenty years from now will pop up. I think what—me, I would have liked—it won't happen in my lifetime, but that you take a pill. “Oh, my knee's up. What the hey?” Pop one, but I don't think that's worked. They might have tried that, but I don't think that's going to happen.

CH: Even before the HIV issue for you—

BL: Hep-B.

CH: Did you have feelings that you did not want to have a family in the sense that you could pass along the hemophilia?

BL: I don't think I felt that way in my younger days, okay, but as I was saying, when the—except hep-B. I got hep-B back then, but you develop an immunity, some people, and I was one of them. So when they have shots, I get hep-A. I didn't need B. So that's—no, I think hemophilia didn't have an—now it does, with the blood borne viruses, but back then I think if the right girl came along, there was no such thing, then I would have taken it. But at that point, no. You know what I'm saying? That's pretty much—then I waited and then I'm in a position where it's not a good one with that.

CH: It's changed.

BL: It's changed now.

CH: I don't want to keep you too long. I just wanted to ask you what your body feels like now. I mean are you in pain? Do your knees hurt now?

BL: Okay. Thank you. Actually, the knees are much better. That was the best thing that I ever done, was having them replaced.

CH: Did you have both replaced?

BL: I had both. One in '98, one in 2001.

CH: Three years apart.

BL: Three years apart, and it was a lot of hard work and physical therapy, but I worked my tail off both times. I did what they asked me to do. I couldn't get my knees to bend as well as I wanted, but everything else, I've got more muscle tone. I'm walking like three miles every other day now. You can see the muscle tone on my knees getting bigger now. So the best thing I ever did was to get that done.

CH: It's good that your knee's getting better?

BL: Oh, yes. See the more muscle tone, the more secure the replacement will be.

CH: Was it a hard decision to make to have them?

BL: By that point, no. I had had it with it, you know what I mean?

CH: You were in pain.

BL: Yes, I was in pain.

CH: All the time.

BL: All the time. I walked terribly and I held out until my late thirties, so I did all right. Health-wise, I was a good candidate for it. I was healthy, so they did it, and otherwise, I do have a problem with the elbow occasionally, but nothing compared to what these knees

were. So I still have my left elbow, and health wise, I've got a great appetite.

CH: What do you do to keep fit?

BL: Walk.

CH: You walk a lot.

BL: Yes, and I said, "I'm going to do something," so I started walking and, you know, a mile became a mile and a half, became two, and the other day I hit three and a half miles.

CH: How long does it take you to do three and a half miles?

BL: Hour and ten minutes.

CH: An hour and ten minutes.

BL: To do three and a half. So I think going an hour is good. I think if I go an hour and go three miles, or two and half, then I'll be fine. I'd like to join a gym so I can keep this up so I don't go, because then you're achy by the time you get back in April doing it all over again.

CH: Are you going to join a gym?

BL: I'm going to join a gym and I love the Stairmaster they got. Oh, I'll go on it and go and go and go. When I had physical therapy, that's when I used that and they've got those at the gyms. Maybe do some—

CH: You find that really helps you?

BL: Yes, but actually it's weird because the first time I went for therapy on my left knee, I went on it and I loved it, but they wouldn't put me on it at another place of therapy for the right knee. So I really got to talk to the orthopedic guy and make sure that it's okay that I can do that. But I loved it. Up and down, up and down, up and down. You're getting a good workout with your heart.

CH: So day-to-day now, you're not in severe pain?

BL: No.

CH: That must be a huge relief.

BL: Oh, it's nice to walk. I couldn't walk very long before the surgery.

CH: Sitting?

BL: Very uncomfortable. It got to the point where it was very—I'd be moving around and I'd be—

CH: Because of your knees?

BL: It took like ten minutes to straighten out the knee. So, no, that's gone now.

CH: You must be very sympathetic with people with arthritis these days.

BL: Oh, it's tough. Any type of arthritis. I don't—I think they've got Celebrex. You know what's helped me? I take once in a blue moon is Vioxx.

CH: Do you?

BL: But Vioxx is excellent. You've got to be very careful with it because it's a blood thinner. So we can't just pop Vioxx, but if you take them once in a blue moon, it really is good. I think a lot of these people that are taking this—anybody who's got arthritis, I don't think that's really the answer is to take Celebrex and all those long-term.

CH: They do have side effects.

BL: That's what I mean.

CH: Just one last question. Looking back, is there anything that you would have done differently? That you wish someone else had done differently?

BL: That's very good. I think as far as the treatment for hemophilia,

no. I think our family, we went to the right people. We gave it the best shot. Oh, except I would have learned how to give Factor earlier.

CH: To yourself?

BL: To myself. Maybe at age fifteen or sixteen, as opposed to—I think that's one minor regret.

CH: To gain some independence.

BL: Yes, and to save all those ER visits in high school. But the way I treated it and my decisions for knee replacements, I think I did the right things with that. I think if I had a chance in my younger years, I would have been less bitter. You know, I think I—there were times when I was angry I couldn't play certain things. Like one time I was playing football. No, no, I was stupid, okay, I'll admit it, but I wasn't really into the game too much. You know, I was kind of playing outside. In other words, I was playing a position that there wasn't much contact, okay? But I had pads on and my father came down and took me out. Oh, was I mad! Back then you're incredibly mad, but now you understand.

CH: Think how hard that must have been for him.

BL: Oh, for him. Was he right? Sure he was right, but even now I guess the hemophiliacs can't play football and you can understand. Concussions.

CH: In fact, probably nobody should play football.

BL: No, concussions and they got a couple of major spinal injuries. They can't walk anymore, so, no. But I would recommend any other sports for these young kids, except for that one.

CH: How did your parents handle the bitterness, or did they? Did you talk about it?

BL: I talked about it, you know what I mean? No one—none of the

parents have the answers. They did, I think like most of the good parents do try to get you to like something else, maybe, and teach you to be moderate. Whatever you do, just—which I would recommend, even if you’ve got somebody with hemophilia that’s fourteen right now, but he’s a gifted athlete. What I would tell him is, “Play hard.” You can’t go out there and not play hard, all right? You really can’t, but don’t play stupid, you know what I mean? Play hard, but if there’s a ball that you know you’re not going to go for, don’t dive for it or things like that. Play smart. But to play, just say play, it’s lousy. You want to go one hundred percent when you’re playing those games, and I couldn’t. I really couldn’t.

CH: And you had to accept that.

BL: And I had to accept it and it’s very difficult, until you get old. Until I had that experience at Children’s Hospital that time.

CH: That was some experience, wasn’t it?

BL: Really, and you realize what experience it is as time goes on, what it meant.

CH: Because probably at the time you didn’t quite understand how it was going to alter your life.

BL: No. I’m thinking, “I’m back in the hospital,” although I was lucky. I had a hip bleed in 1973, a bad one. You know, and I’m even saying, “Why are you giving me all this factor for?” “Well, don’t worry about that. Just worry about getting better.” You know, I don’t know how many things of factor they—this is the Children’s Hospital, right? Until then I went to the ER a lot, but I wasn’t admitted until that time, you know, in ’81 when I had to get the wisdom teeth out. So when I saw those people, I said, “What do you have to complain about?”

CH: And you meant it.

BL: And I meant it.

CH: Have priests been any help?

BL: Oh, yes.

CH: Have you talked to them?

BL: I had a priest, that he was one man that I had just become a Eucharistic minister.

CH: You had become a minister?

BL: Yes, right now I'm a Eucharistic minister and I go and I give Holy Communion out in a nursing home.

CH: How wonderful.

BL: Okay, I didn't want to do it in the church, but I do it in a nursing home. He found out right away in '91, and he was very supportive. Never said, "Well, I wonder if you should give out communion." Never. One hundred percent support. Never said anything, and I know I'm in his prayers. This was back thirteen years ago and he was super, and now he's struggling with diabetes in and out of the hospital. He had a blood clot. He's suffering now. He's been in and out of the hospital.

CH: You've been to see him?

BL: I went to see him the last time, when he broke his foot because I, you know—but he was super to me, support. I'm on the Parish Council, which really haven't met much because he's been sick.

CH: Did this priest have diabetes, do you think, at the time?

BL: I don't think he had it ten years ago or something. He was in good health back in '91. You know, he also had a problem with alcohol we just found out about and he took care of that. So things are slamming him, but he keeps fighting back.

CH: Well, he understood you.

BL: Back then he was very, very understanding.

CH: A person facing his or her own difficulties understands better.

BL: Isn't that the truth, but we're all flawed in some though, you know.

CH: Well, we are but—

BL: Well, if you don't think you are, then I think you're going to have a problem.

CH: But if you're troubled yourself, it's easier to understand someone else's trouble.

BL: Oh, definitely.

CH: Did you ever consider the priesthood?

BL: Yes, I did.

CH: And why did you decide not to pursue that?

BL: Honestly? I like Sundays off. No. [laughs] I do like Sunday's off, all kidding aside, and to be honest with you, they're lonely, okay, because there's not that many of them anymore. So you see a lot of these big rectories, there's only one person in it.

CH: And you're very gregarious.

BL: Yes. You know, and I think it would be real lonely. I know some of them are really busy. They have schools. They've got funeral masses, weddings and all that, but I also think a lot of them need camaraderie, and I don't know if they get it or not.

CH: They do but in a limited way.

BL: Yeah, I guess. Yeah. On the weekends.

CH: I think they are much more in the world in the early days in Boston when they went to parties and they went here and there, but now they're pretty set apart.

BL: And now, unfortunately, their names have been thrown in the mud because of the few scum bags. So that doesn't help matters trying to recruit priests.

CH: Do you're think your outgoingness, which is very apparent and very appealing, do you think you developed that partly because you had to overcome so many things?

BL: I don't know. I think in school, even as a teenager, I was kind of—I liked to joke. I just liked to kid around and laugh, so I'm not sure about that. Even now I've always loved sense of humor, and I have a stupid sense of humor, all right? One that you'd get kids of fourteen or fifteen would do, you know, and my coworkers just accept me, you know, despite all my jokes. So I don't think so. I think it would have been me anyway.

CH: They enjoy you, I'm sure.

BL: Oh, yes. I do think that adults—you know, stupid things. I just do stupid sense of humor, which is me. It's me.

CH: Would you characterize yourself as optimistic?

BL: No. No.

CH: No?

BL: Honestly, no, but I wouldn't consider myself pessimistic. Kind of in the middle, I think. I think in some ways, yes. Other ways, no. Optimistic, for example, a cure for HIV, yes. Optimistic for a cure for hemophilia, no. I think they'll come a long way, but I don't think, when it comes to genes, I just don't think it will happen. Maybe in two hundred years, you know what I mean?

CH: I'm going to ask you one last question and then if there's anything you'd like to add—

BL: I think I've pretty much let it all out here.

CH: But I wondered about your sense of mortality. Knowing how your faith is important to you and you've certainly had to look at mortality, where are you with that?

BL: Okay. Mortality, I definitely have looked at and looked at it a lot.

CH: Straight on.

BL: Yes, and to be honest with you, I wouldn't want to say every day, but almost every day you think about it. But you think about it to the point where it doesn't really affect you, you know what I'm saying? I'm trying over the last thirteen years to prepare myself to get sick. I'm lucky in that I had that chance. That I didn't walk in there in '91 and I'm near death at that point, you know what I mean? So I consider myself very fortunate to have lived this long to be able to prepare myself. If I do get sick, I think I'm better prepared now than I would have been ten years ago. I think my faith has a lot to do with that, plus a lot of people that you think will outlive you because you had the HIV back then have died. So a lot of people that you thought would outlive you, haven't. So I think as far as death goes, for a guy forty-four, I'm handling it the best I can. In other words, it won't be a shocker, you know. I've kind of been able to learn to take it one day at a time and knowing that, "I might get sick. Hepatitis, I might get sick," but I look at it as I'm preparing myself for that.

CH: In a conscious way?

BL: In a conscious way.

CH: Do you read? Do you talk to people?

BL: No. To be honest with you, I don't like to read articles about hemophilia. Even less about hepatitis-C and HIV and hep-B. I just don't—I never liked to read about it, unless it's good news, and as

you know, back twenty years ago, it wasn't.

CH: I think we can get used to most anything, and you've had a long period to get used to your situation.

BL: Very fortunate.

CH: And we do get used to things.

BL: Yes.

CH: If we let ourselves.

BL: Yes. It's like I'm used to it. My folks are used to it. My brothers are used to it. I think some of my friends, they don't even think about it anymore because I've had it for so long, you know what I mean? But you don't know what other people that don't know right now what they would think of it. They might go through what I went through twelve years ago.

CH: And you're so used to it, that it's not news anymore.

BL: No, it's not.

CH: So it's easy to tell them and think everyone else is going to be that accepting of it.

BL: That's correct. But I think in general I've handled it very well.

CH: I think you have.

BL: Even though it was incredibly difficult in '91.

CH: That was the hardest point, wasn't it?

BL: Oh, awful. That was like you hit the bottom, when I found out both of those things in '91. But the main focus was HIV. It wasn't really hep-C then. It was brand new, hep-C, almost.

CH: How long did it take you on that occasion to begin to pull up again? To heal a little bit?

BL: I think probably when I hit forty. You know, in other words, I think I've been pretty much at peace the last four years. Whereas, you

didn't know what—before that it was up and down.

CH: Do you feel at peace now?

BL: Yes, for the most part.

CH: Good. As much as any of us does.

BL: You just can't—oh, exactly. You just can't let the HIV thing get to you, you know what I mean? As I said, you've got to accept it and it's very difficult to accept it when you get it from blood, but no matter how tough it is, you have to. You have to, you know, because the day you accept it, I think you go on your life a little easier.

CH: It doesn't ruin every day.

BL: No, that's right and I've been lucky. Very incredibly lucky to be healthy still because I would never—you told me in '91, it was 2004 and I'd still be healthy, I would have laughed at you.

CH: And here you are.

BL: And here I am.

CH: And some aren't and some are.

BL: Yeah.

CH: Is there anything you'd like to add that we haven't talked about?

BL: No, I'd just like to thank you for interviewing me.

CH: Oh, my pleasure.

End of Interview