

Interview with David LePage for the Boston Hemophilia Center Oral History Project, A Gift of Experience, by Christine Harland, August 11, 2004.

HARLAND: I'm here speaking with Mr. David LePage. I'd like you to tell me a little bit about yourself, where you grew up, where you were born.

DL: Saugus, Massachusetts. I grew up on School Street.

CH: On School Street?

DL: Yeah, in a three-bedroom house. Quiet neighborhood. My mother noticed a series of things happened to me. My easy bruising, results of my hemophilia and my mother probably got some dirty looks because—results of the—because of the bruising that I had because of my hemophilia. I had a hard time. I fell down one time and cut my lip and it took several times of stitchings to heal that lip because of the bleeding that's caused by my hemophilia. The doctor thought it might be leukemia at one point, or something like that. I didn't have that, so they checked out my hemo—they checked out my Factor VIII level and it was low, so I was diagnosed with hemophilia at the age of two.

CH: Do you have brothers and sisters?

DL: One sister.

CH: Who was older than you?

DL: Was three years older than me. After they found out I had hemophilia, my parents decided not to have any more children because of that, the risk of possible carriers in my family or others that might have hemophilia, or sisters that could be carriers. So my parents decided not to have any more children.

CH: Was there a history in your family?

DL: I think my great uncle might have had it. My mother was a carrier.

CH: Did she have inkling that she was a carrier?

DL: No, she didn't.

CH: Tell me a little bit about your parents. What did your father do?

DL: He was a draftsman. He worked forty hours a week at Sylvania.

CH: At Sylvania?

DL: Yeah, he was a machinist draftsman.

CH: Did your mother work?

DL: Probably a little bit here and there. I was brought up at home, you know. I was allowed to do many of the things any other normal person was able to do.

CH: What were your parents' educations? Did either of them go to college?

DL: My father didn't go to college. He just—yeah, he went to night school to further develop his career in drafting.

CH: How would you characterize your parents? Were they good decision-makers? Did they work together when they had to face this new development?

DL: Very supportive. Yeah. I mean, I used to have to go twice a week to Boston at the Emergency Room to take care of a variety of things, either swollen ankles, or fingers, or a elbow, or even a bleed in my back, or a swollen knee. I wasn't allowed to take karate, or to wrestle, which I wanted to do.

CH: I wouldn't think you remembered much at the age of two.

DL: No.

CH: But can you remember when you first became aware that you

were somehow dealing with something different than the children around you?

DL: Well, I used to have to take transfusions, which I used to probably not like to take.

CH: I'm sure.

DL: And I probably didn't like having swollen ankles, swollen parts of my body. You know, I would go to school on crutches, and the next day I would be walking and the kids would say that I was faking. You know, they didn't understand the disease of hemophilia, that you could be on crutches one day and not on crutches the next.

CH: Would you say that they were cruel? Did you experience a lot of isolation as a result of your hemophilia?

DL: No, not really because I was always outgoing and friendly. One time I was running towards a picnic table and I hit my eye on the edge of the picnic table, when I was a kid, and my eye swelled up and I had to spend a couple days in the hospital taking whole blood. You know, daily trips to the Emergency Room were not uncommon.

CH: Did any of the people around you at school make an effort to learn more about what was happening to you?

DL: No, not really. I pretty much kept it to myself. Sometimes if I had a swollen knee, I'd be in a wheelchair, you know, so the teachers were protective of me. You know, watching out for me to make sure I didn't get hurt on the wheelchair. I don't remember much of my childhood. I mean, I was a kid that used to take his bike and used to go off ramps, so that didn't challenge me. When I was a teenager, I fought my parents to take karate, which I did, but I ended up having swollen ankles and every time I blocked a punch, it would swell up. So it was kind of discouraging because I wanted to be a black belt at

karate and take wrestling. I wanted to be able to protect myself against the world and having hemophilia was an obstacle for that. I wasn't able to do those things. So—

CH: I'm getting the impression, though, that your parents went as far as they could to let you do what you wanted.

DL: Yeah, until I found out it was impossible to do it.

CH: But they weren't over protective of you.

DL: No. They thought I was a mild hemophilic when I was a kid, and when I became an adult, they checked my factor level again and it was a severe hemophiliac.

CH: So it changed over time.

DL: Yeah.

CH: Were your grandparents living at the time?

DL: I had my grandparents growing up. Of course, my grandfather died when I was a boy, three years old, but I had grandmothers that were always part of my life. I came from a very supportive family where I had a happy childhood. You know, a very good upbringing in a nice house and a pool and I got to swim a lot.

CH: Did your family do much to explain to you or to help you think about how you could deal with your hemophilia?

DL: They gave me a book about it to understand how it's passed from woman to child. Actually, all my daughters would be carriers. All my sons wouldn't be carriers or hemophiliacs. If I married a hemophiliac woman, then I would have chance to have a hemophilic son.

CH: So they helped you to understand what was happening to you?

DL: My limitations and what I could and couldn't do. Yeah.

CH: I assume that with his job your father had health care?

DL: Yes, they covered eighty percent of the costs of my blood, which can run into the thousands of dollars. So my father found out that they can get help with crippled children at Children's Hospital, Boston. That's the hospital I went to growing up is Children's Hospital. So—and in there I learned how to—my father learned how to give my transfusions when I was a kid, and I as a teenager learned how to give myself transfusions.

CH: Which meant you didn't have to run off to the Emergency Room every time.

DL: Right. When Factor VIII concentrate became developed during my teenage years and I was able to give myself transfusions.

CH: That must have made a tremendous difference in your life.

DL: Yeah. The blood supply became contaminated, 1978, which first with Ryan White and other hemophiliacs got infected with HIV and hepatitis. I didn't get diagnosed with HIV until 1987, and I knew that I had hepatitis in '81.

CH: That was the first sign you had?

DL: Yeah, I was very sad and devastated when I found out.

CH: I'm sure you were.

DL: Knowing that chances for girlfriends would be very difficult, but I couldn't let it affect me as a person. I became a Born Again Christian in 1982, where I read the Bible every day. For twenty-two years now I've read the Bible every day, and my faith has helped me get through the difficult times with hemophilia and HIV and hepatitis. And then learning more about HIV and the complications, the T-cell count, the risk of infections, pneumonia, cancer became almost real in my life, even though I'm asymptomatic at this time. But the fear of getting cancer, pneumonia or bacterial pneumonia or fungal infections

or candida or thrush are daily concerns with me now, even though I don't have any of them. My T-cell count is 600. It's been as low as 260. Below 200 is AIDS and since 1987, when I was diagnosed with HIV, I've been fighting the complications of dealing with this disease, as well as hemophilia.

CH: And the fear.

DL: And the fear.

CH: So, the physical and the mental complications.

DL: Not only myself, but keeping others safe, too, from this disease. Taking the necessary precautions not to infect others with the disease. So—

CH: I'm just going to stop a minute and ask you about that early care at Children's Hospital. From the time when you can really remember it, did you feel that the care was compassionate, that it was all it could be?

DL: It was necessary to get me through each day, yeah.

CH: But did you feel that your caregivers really helped you? Was that experience, given that it wasn't a very nice experience to start with, as good as it could be?

DL: It was very good, and then when I found out I had HIV, the level of care intensified, where I got support from social workers at Children's Hospital and Brigham and Women's Hospital. I found that I could go there to deal with my HIV and hepatitis, so I could go there once a week and get counseling and very helpful.

CH: When you finished high school, what were your goals? What did you do out when you left high school?

DL: Well, I dropped out of high school because of mental illness. I had schizophrenia and depression at the age of sixteen, seventeen and

eighteen and continuing until now, and I'm forty now. So I've had severe mental illness since I was sixteen and I've been on disability since I was eighteen. So I did have health insurance for my medical conditions.

CH: From the time you were a junior in high school?

DL: I dropped out of high school.

CH: You dropped out of high school, and what happened then?

Were you hospitalized? You were now facing another issue and the need to stabilize that.

DL: A combination of the five. Schizophrenia and depression and hemophilia and hepatitis and HIV. I had to juggle all of them diseases at once. You know, I tried to take my life when I was eighteen, a few times. I ended up in the hospital, Westford Lodge in Massachusetts and in a variety of hospitals, all my years since I was eighteen up to now. I take medication for my schizophrenia and depression.

CH: Does that help you?

DL: It helps me quite a bit.

CH: Good.

DL: And I go to Tri-City Mental Health and Retardation for my mental health work. And then I go to Brigham and Women's Hospital every three months for my hemophilia and HIV care. My T-cell count is 600 and viral load is undetectable. During the '90s, they found out I had cirrhosis of the liver because of my hepatitis and I went through an interferon treatment, which proved to be successful.

CH: Which what?

DL: Proved to be successful.

CH: Good.

DL: And I don't have hepatitis for a year now.

CH: Good.

DL: I'm free and clear and I've been cured of hepatitis.

CH: But you're putting out a lot of fires.

DL: Yeah. I have to take my medication every day, faithfully, and so far I'm asymptomatic. During the early '90s I did have neuropathy where the virus attacked my nerves in my hands, but when the viral level went down to none, the neuropathy went away.

CH: That must have been a relief.

DL: Yes.

CH: It's very difficult when you—

DL: Even with the smallest symptoms, the symptoms of HIV can be disabling.

CH: When did you move out of your parents' home?

DL: When I tried to take my life my parents gave me the option of going to a rooming house or a group home. I chose to go to a group home in Lynn for the period of September of '82 to February of '84.

CH: A year and a half.

DL: And I've been living on my own for twenty years now, juggling all my diseases, as well as the mild—mild anemia, too.

CH: Are your parents still living?

DL: My mother passed away in '85 of lung cancer.

CH: In '85?

DL: Before she—before she knew I had HIV, and she suspected something was going on during the early '80s, and when I found out in '87, my father, it kind of shook him up, rattled his cage when he found out I had HIV.

CH: Did he pull away from you?

DL: No, he didn't.



CH: Good. Why did your mother suspect something was up?

DL: Oh, I'm not really sure.

CH: She just had a feeling?

DL: Yeah, she was hearing things that was going on. Maybe in the news.

CH: So that period of the '80s, '81 to '85, when you lost your mother, those were really very difficult years, weren't they?

DL: I took my mother's death well. I knew she was a Christian, so that reassured me.

CH: Were they always Christian, or was this something that she discovered later?

DL: Later on in life.

CH: Did you learn the power of religion from her?

DL: Well, she learned it from me.

CH: She learned it from you?

DL: Yeah.

CH: So it was a gift you gave to her.

DL: Yeah.

CH: Isn't that wonderful.

DL: Yeah.

CH: And I'm sure it brought her a lot of comfort.

DL: Yeah.

CH: And where did it come to you? Where did you discover that?

DL: Well, when I had my breakdown of schizophrenia, I had to reach out to a higher power that I could draw strength from in my difficult times of mental illness in '82, before I knew I had HIV. I knew I needed help somewhere through my faith, I became a Born Again Christian and I've been going to the church since '82 until now.

CH: May I ask you—you don't have to answer, but I'm wondering how you think about all the things that have happened to you, in terms of your faith? Do you feel that there's a purpose for you?

DL: I think I'm happier.

CH: You do?

DL: I'm more content when I'm a Christian. Instead of being angry and bitter and having fits of rage over my illnesses, I try to be peaceful and gentle and take care about other people. To be pure. It's a tough—tough thing to juggle, but me not working, and really I'm not employed because of my disability, mental disability, and it just helps me to take care of myself because I have all I—I have all I can handle to handle all my diseases without working. So it's helpful to just take care of myself, without the added pressure of working.

CH: Do you feel that God gives us only that which we can bear?

DL: Yes. He—I think I—in 1990, 2000 I met another Christian girl named Kristen and we became engaged and then we were just going out and she died in February of 2004.

CH: Of what?

DL: Of heart attack.

CH: My goodness.

DL: And this is the card that she gave me.

CH: What a huge loss for you.

DL: When I was in the hospital, she wrote to me, "I hope you get well very soon. I miss you very much. I love you very much, love, Kris," and I still have that card that she wrote.

CH: All those years later.

DL: Well, she died in February of 2004.

CH: She died this year?

DL: This year.

CH: Very young.

DL: Forty-four.

CH: Of a heart attack?

DL: Yes.

CH: I'm so sorry. But you have the love that she gave you in your heart.

DL: Yeah. She gave me that, too.

CH: Did she give you the bunny?

DL: Yeah.

CH: Does the bunny have a name?

DL: No. Kris.

CH: I'm very sorry. That's a real sadness, I know.

DL: Right. I do. I have found, not that it's too soon. It's been six months since she died. Yeah, and then there was an issue of, you know, justification of how I caught HIV. I receive some compensation from all the pharmaceutical companies. I won't name them, that gave me the HIV in the blood that came from their blood products. The pharmaceutical companies, four of them in all, each gave each hemophiliac a hundred thousand dollars. I guess they were being sued too much, so they couldn't afford the cost of being sued, so they offered each hemophiliac a hundred thousand dollars. It's a small payment. I feel like I deserve five hundred million and that would just take care of all my needs the rest of my life. I didn't believe in suing, since I was a Christian.

CH: I see?

DL: Didn't believe in suing, since I was a Christian.

CH: So suing really went against your ethics.

DL: My faith, yeah.

CH: Did you then become part of a class action suit?

DL: As a member of it, yeah, even though I didn't sue, and received a hundred thousand dollars in January of 1998, and there was the Ricky Ray Law that they offered another hundred thousand from the government, who failed to protect blood supply from us hemophiliacs and other people that received transfusions. I received another hundred thousand dollars March of 2001. I've enjoyed the money. I appreciate the compensation they gave. It makes my life a little easier. I can eat a little better, take care of myself a little better. Pay for my medications a little better. I've been fortunate, since I was disabled with schizophrenia and depression in '82 to receive, you know, Medicare and Medicaid, which pay for my medications. I'm on—I was on AZT.

CH: Expensive medications.

DL: Yeah, and now I'm on Viracept and Epzicom, and that can run up to thirteen thousand dollars a year. Then the medical costs and each lot of Factor I take is two thousand dollars.

CH: And they cover that for you?

DL: Yes, they do, practically.

CH: Good. Tell me a little bit about the discovery that you were HIV positive.

DL: [coughing] Well, they tested me for it and I became concerned. A week later, you know, they gave—when I came back to the hospital, they gave me the test results and of course I was practically crying.

CH: Of course you were. Your mother and father were with you? Your father?

DL: My father—

CH: —HIV was really something people didn't know a great deal about then, either. I believe.

DL: And they were just handing out the pamphlets on HIV and I was just living in an apartment in Saugus and I found out I had HIV and it rattled my father's cage. My uncles and aunts were shocked. My sister was terrified.

CH: Was she married with children by that time?

DL: Divorced.

CH: But with children?

DL: Yeah.

CH: And when you say they were upset and terrified, did they accommodate the news?

DL: They were very supportive.

CH: They were? So they learned about it.

DL: And then, unfortunately, I was living in a one-bedroom apartment in Saugus and I was not afraid to tell anybody about the disease or the complications, I told my landlord and they forced me out of the apartment.

CH: They did?

DL: Yes.

CH: I see.

DL: And I ended up living in Lynn in '87—it happened in 1987, where I was forced out of my apartment, and I found a one-bedroom apartment in Lynn and learned not to tell my landlord. [laughs]

CH: You learned honesty isn't always the best policy.

DL: Right.

CH: Not a good lesson.

DL: Umm.

CH: What was going on at the hospital all during this time? What were they doing for you and with you?

DL: I received one-to-one counseling once a week or whenever I wanted. Very supportive. I mean, I've been hospitalized several, maybe fifteen times since 1987.

CH: Fifteen times?

DL: Yeah.

CH: What for?

DL: Depression. I got pneumonia once, but it wasn't related to my HIV. I think I caught pneumonia twice, bacterial pneumonia and another type of pneumonia. But—so—

CH: Then you found this apartment.

DL: Found this apartment. I'm very happy here.

CH: I should think so. It feels very much like a home.

DL: Yes. I've been going to Tri-City Mental Health, Retardation since 1999, where I have a nice doctor, a respite I can go to any time I want to get support. Medication adjustments. The medication I take makes me have diarrhea, which can be a problem if I don't take Imodium. So—

CH: So you have to take something, and then something else to cure that.

DL: Right.

CH: But you're very faithful, I think, about your medications, aren't you?

DL: Yeah.

CH: Good.

DL: At the most, I miss it once every three months.

CH: Apart from Tri-City, do you belong to or participate in any support groups with people who share the same diagnosis?

DL: Yes, I do.

CH: And how are those for you?

DL: Very supportive. I see a—my case manager, John Rider, from the Committee of Ten Thousand and DMC, where he takes care of my overall HIV case management and helps me with my care, home health aide if I need one, which I don't know. When I was on the interferon I needed a homemaker because it made me sick. When I was through the treatments, the interferon for my hepatitis would make me sick, so I needed a homemaker at that time. I go to a support group in Brockton with all the hemophilics that have HIV. Out of the 9400 hemophilics that are infected, 5000 have already died.

CH: Five thousand have died?

DL: Yes.

CH: So 4,500 are left.

DL: That are still alive.

CH: And how are you finding their response, as compared with yours, when you go to the support group?

DL: It was a large portion of people there when I started the support group.

CH: Who aren't there anymore.

DL: Who aren't there anymore. There are about two or three left, and I'm one of them.

CH: That's chilling.

DL: Yeah.

CH: The two or three of you who are still meeting must have a very special bond.

DL: Yeah, [unclear] a lot of the people that have passed on from hemophilia or HIV, and it's very sad. A lot of the people didn't even get compensation before they died, before 1998, and the blood companies have not accepted responsibility for giving us the virus because they could be sued.

CH: So they settled, but don't take responsibility.

DL: Right.

CH: I see. How do you feel about that and about what they did?

DL: Well, you know, there's a book that says "Dying in vain and cry bloody murder." And the murderer of thousands of people. That's what it is.

CH: That's what it is. Do you see your father very often?

DL: I talk to him every day. He supports me. He's my rep payee. I'm disabled with a chemical imbalance. Some people may not know it, because I hide it very well through my faith. Being disabled, I just can't handle the pressure of work, when I'm working I fall apart. All I can do right now, being disabled to juggle my diseases is to take care of myself and, as you can see.

CH: You keep everything so nicely in your apartment.

DL: Yeah, I've still got a lot of work to do in this apartment, but—

CH: And, as you say, there are all the things you need to do to follow up.

DL: Yeah.

CH: Are there ways in which you wish, from the time you were young until now, that the healthcare providers had done a better job for you? Other ways in which you wish they had responded?

DL: Oh, be more supportive.

CH: And how would that manifest itself?



DL: Take a more active part in my life in support. Call me once in awhile, see how I'm doing.

CH: So that you felt they really cared?

DL: Right.

CH: That you just didn't go in, have an appointment and leave.

DL: Right.

CH: That you were assigned a counselor and then you left.

DL: Right.

CH: So there is this distance, isn't there?

DL: Yes, there is.

CH: Do you think they've answered your questions adequately? Do you feel that you get the time you need and want?

DL: If I ask them to, they will.

CH: But you need to be proactive?

DL: Yeah.

CH: Have you found that in fact you've needed to really take charge in your care giving experience ?

DL: Yeah, I take a passive-active role in it, you know. I may be passive, but I'm also assertive. So I don't ask too much of my providers, I just—I just go with the flow.

CH: Unless you need something specific.

DL: Right.

CH: And you let them know when that is?

DL: Yeah, which I haven't had practically any symptoms at all, so it's more like it's been a passive role for me, just sitting back. But I do have a nurse coming over here once a week to check on me, see how I'm doing, from the Lynn VNA.

CH: And with all the new things, what's happened with the

hemophilia? Is that really not an issue any more?

DL: Not too much of an issue anymore. I don't injure myself because I'm not in any high-risk activities. I might have a transfusion every three months or every six months, which is nothing.

CH: Can you do those for yourself now?

DL: I do them for myself.

CH: Was that difficult to learn to do?

DL: No, not really. Very simple. Just like when I inject my hepatitis shots to get rid of my hepatitis.

CH: What changes in the care and information about hemophilia do you feel have really made a difference? That's one of them, I assume, being able to self-transfuse.

DL: Oh, I don't know. Just call the doctor when you need to.

Yeah. Being assertive without being aggressive.

CH: Going back to when you were thirteen or fourteen years old, how was it? Did you feel that you were leading a fairly normal life, apart from not being able to do karate?

DL: Well, it was difficult in school, going up and down the stairs on crutches. You know, they didn't have elevators. I was, you know, carrying my books, so it was difficult. I had to have somebody else carry them for me. Of course, they probably didn't have backpacks back then, so—

CH: So, the infrastructure at school really didn't make it easy for you.

DL: No, it didn't at all.

[end of Side A, Tape 1]

CH: What about friends, connections? Did you have anyone in particular, a teacher or a young person, who made you feel less

lonely?

DL: No, not really. Just my active faith in God. I didn't feel lonely because I knew God was with me.

CH: When did that develop for you?

DL: 1982 when I was eighteen.

CH: That's right. What about your younger years, thirteen, fourteen, nine, ten.

DL: I really didn't have any girlfriends or any—

CH: Boyfriends? Any young fellows that—

DL: I had a friend, John, where I used to get into a little bit of trouble with. [laughs]

CH: That's good and healthy.

DL: So—but, never a terrible person. No. I just hung out, you know, maybe had a couple beers when I was a teenager.

CH: I think we can forgive that.

DL: So basically just a quiet teenage life.

CH: Did you feel very different than everybody else?

DL: Well, the psychological problems made it difficult.

CH: When did you feel those coming on? When were you aware of those?

DL: Probably when I was sixteen. Fifteen, sixteen.

CH: The depression?

DL: Yeah, made it very difficult to work.

CH: I'm sure it did. It must have been difficult to concentrate.

DL: Right, and to be able to work. But my supportive parents were always there for me.

CH: Isn't that wonderful.

DL: So if I had any close friends, they were probably my parents,

where I could talk to.

CH: Your sister?

DL: My sister was nice, too. Yeah, she went to be a nurse.

CH: She became a nurse?

DL: Yes.

CH: Do you think that what happened to you influenced her in that decision at all?

DL: No, because I didn't find out I had HIV before I was twenty-three.

CH: I meant the hemophilia and—

DL: Well, I'm not sure.

CH: May have?

DL: May have, yeah.

CH: She probably had an awareness through your situation. I mean, your life really was very hospital-oriented.

DL: A little bit.

CH: More than most.

DL: Yeah.

CH: So she had that awareness.

DL: Yeah.

CH: As a family, did you take vacations in the summer?

DL: Oh, yeah, just to see Disney World and Orlando, to South Carolina and Maine and New Hampshire or whatever. So—then Horseshoe Falls.

CH: When the issue of the class action suit came up, did you take any part in that at all, or were you just included per se?

DL: I was just included. They offered it everybody, even if you didn't sue. So I took it. I was more than happy to take it.

CH: I'm sure.

DL: I'm the one that wouldn't sue. I'm glad that if they offered me the money, I could buy things that I normally wouldn't be able to buy, like my big screen TV.

CH: Which I'm sure brings a lot of pleasure and the cat likes being in front of it.

DL: Yeah. So, I'm going to be—I'm waiting for a new living room set.

CH: Good.

DL: Coming on later on this month.

CH: Wonderful.

DL: So—

CH: That will bring you a lot of pleasure.

DL: Yeah, it just has to be delivered.

CH: Apart from your religion, which is so important, did you or do you have special interests? Did you have something that you had hoped to pursue?

DL: Oh, just—no, not really. No, just being able to try to live a normal life. You know, I'm happy with. Maybe have a special relationship here or there. Yeah, with somebody special.

CH: Tell me if there are one or two people who really stand out for you in the care experience, like that nurse? Have there been one or two people who've really been different? Very special?

DL: Only my girlfriend, Kris.

CH: What about in the healthcare situation? Have you come across anyone who stands out?

DL: Well, Laura Gray is very nice, too. So she's kind of nice. See how you're doing, as well as the other social workers that have been

there for me. Kathy Ives. So—and just having somebody to talk to through this whole experience having HIV.

CH: I'm sure.

DL: Which has been a tremendous help through the years. So—

CH: There's a lot to deal with with it, isn't there?

DL: Well, the best is yet to come. [chuckles]

CH: Are you fearful of that?

DL: I know I'll be taken care of, no matter what. They're not going to let me fall through the cracks, or else I won't let them.

CH: No? Good for you.

DL: Yeah.

CH: And you're still here and healthy and thriving.

DL: Yeah, I'm still asymptomatic and healthy, you know, so I'm taking a proactive role taking care of myself so they don't have to.

CH: Have you done much reading about either the HIV or the hemophilia? Did your parents learn a lot?

DL: I know a lot about hemophilia, but I also, you know, have my little pamphlets on hemophilia and AIDS and stuff like that. The different drug treatments, the side effects, options, you know. How to take a proactive role in taking myself and not exposing myself to different diseases, whatever.

CH: When you were young, did your parents learn a lot about it?

DL: Yeah.

CH: Was it a very active approach?

DL: Yeah, I mean, we used to—we got a book on hemophilia and we read it. So, yeah.

CH: That must have been quite a blow because it came relatively out of the blue.

DL: Yeah.

CH: They had to deal with something brand new.

DL: Chronic, yeah.

CH: Something chronic.

DL: Yeah. You know, I think of my favorite verse in the Bible, which helps me get through every day is, you know, “Fear not, for I am with you. Do not dismay. I am your God. I will strengthen you and help you and uphold you with my righteous right hand.” I guess that’s my favorite verse in the Bible. “Fear thou not, for I am with you. Be not dismayed, for I am thy God. I will strengthen you and help you and uphold you with my righteous right hand.”

CH: It’s a beautiful verse, isn’t it?

DL: Yeah.

CH: And it gives a lot of strength.

DL: Yeah, and God is my refuge and strength. A help in trouble.

CH: Did you go through a period of anger?

DL: Probably, yeah. I learned to deal with that through the Bible or to get rid of all anger, bitterness, fits of rage. Yeah, cease from anger, forsake wrath. Fret no wise to do evil.

CH: Say that again?

DL: Cease from anger. Forsake wrath. Fret no wise to do evil.

CH: It’s wonderful to find those verses that speak to us.

DL: Yeah. It helps me with my coping skills. You worry about your life, you know. God knows what you need of, you know.

CH: And it feels so unfair, doesn’t it? It can.

DL: My grace is sufficient for you. God says, “My strength is made perfect in your weakness.” So—

CH: Do you go to church?

DL: Yes, I do. Twice a week.

CH: Do you have a community there that's very supportive?

DL: Yes, I do.

CH: Isn't that wonderful?

DL: Born Again Christian/Baptist.

CH: That's the local church here?

DL: Here in Lynn, yeah.

CH: And you speak openly about your own situation?

DL: Yes, I do. I don't make it an object to talk about it because I don't want to make anybody feel uncomfortable.

CH: But you also are direct.

DL: They—they know. Yeah.

CH: It's nice to be accepted as we are, isn't it?

DL: Yeah.

CH: Without secrets.

DL: Right.

CH: It feels good.

DL: I can't be afraid of what man can do to me, you know.

CH: No, you can't.

DL: Then they have power over you.

CH: Man has done enough to you, if you will.

DL: Yeah. [laughs] You know, the fear of man is a sneer to your soul, so you can't be afraid of anybody. No.

CH: Not at all.

DL: Without hurting it. Without going—with being nice to them. Not fearing them, but being nice. Yeah.

CH: Are there any other things you would like to tell me about this whole experience for you, questions that I haven't asked you?



DL: I don't know. Well, I don't know. Just taking care of yourself each day is enough fulfillment—is enough of a fulfillment for me each day.

CH: You've certainly achieved a lot for yourself.

DL: Yeah.

CH: Life is hard work.

DL: As long as you have someone special in your life, it makes life a lot easier.

CH: And a special cat!

DL: Two of them.

CH: Two special cats. Cats make a lot of difference, don't they?

DL: Yeah.

CH: Did your father marry again?

DL: Yes, he did. He's living in Wakefield for the last five years.

CH: And his wife has accepted you?

DL: Yeah.

CH: That's nice.

DL: They call me a miracle because I'm still alive.

CH: You are a miracle.

DL: Yeah.

CH: That must be very interesting, to feel yourself a miracle.

DL: I hope so. I want to be—not that I want to be selfish, but I want to be the longest living hemophiliac that has HIV.

CH: Well, there's a goal for you. If I was going to ask you about a life goal,

DL: That's my goal.

CH: There we are.

DL: That would probably be it. Not to be selfish, though. Not that I

want anybody to die.

CH: I understand, It's a positive goal.

DL: Right.

CH: It's not a negative goal. It's a positive goal.

DL: Yeah. Probably that they might have a cure of AIDS some day.

CH: Absolutely they might. Do you feel that you have a good quality of life within the parameters of the issues you have to deal with?

DL: Have a very good quality of life.

CH: Good. Do you think that perhaps—I know it's sort of a strange question, but do you think that all you've been through, the hemophilia and the AIDS, has actually enhanced you at all as a person, has brought things to you?

DL: Trials produce character. Character, perseverance. Perseverance, hope. So I still have hope.

CH: You do?

DL: And love. And that's what matters.

CH: Well, you've certainly handled it in a very proactive way for yourself.

DL: I try to, yeah.

CH: Good for you. I'm very, very touched, and this is a very generous gesture, sharing with people what that experience is like.

DL: Yeah.

CH: That's the whole point of the history is that sharing.

DL: Yeah.

CH: Is there anything else that you'd like to say? Is there anything that you would like to add?

DL: No.

CH: I think it was a wonderful interview.

DL: Thank you.

CH: And it was a real pleasure for me to meet you and to share that with you.

DL: Okay. Yeah.

CH: Thank you.

DL: Thank you. [tape off/on]

CH: I wondered whether you have found any connections through your computer? Do you communicate with people that way at all?

DL: No, I don't.

CH: Not on this subject.

DL: No, I don't. No, I do have a book on it.

CH: Yeah, but you don't go to websites or—

DL: No.

CH: For information or connection?

DL: No.

CH: Do you think people do? Do you find the people in your support group use the computer to get information?

DL: I think my case manager, John Rider, is always encouraging us to do that. In fact, he gave me a book on AIDS and the internet. So, yeah.

CH: But you decided not to do that.

DL: No, because I feel I know enough. That I'm educated enough.

CH: Yes. Well, you certainly seem to be.

DL: Yeah. Right here?

CH: Yes. And do you feel that everybody is different in this, too? That in fact your experience is different than other people's experience?

DL: Probably.

CH: So, in fact, reading about them, you all have to handle it in your own way.

DL: Yeah, the sickness develops differently in each person, in some ways, yeah.

CH: Was the mental illness that came on you directly related to your hemophilia, or was it just a completely separate—

DL: Totally separate.

CH: Probably separate.

DL: Yeah.

CH: Because there was a chemical change in your?

DL: Yeah.

CH: So that was not something you could say—oh, look—came to you as a result of having hemophilia?

DL: No.

CH: I just wondered if the depression was a result of it.

DL: Oh, the depression might have. I've had the depression since I was sixteen, but the HIV has probably when I was a twenty-three year old.

CH: Right, of course.

End of Interview