

Interview with Clifford Deschenes for the Boston Hemophilia Center Oral History Project, A Gift of Experience, by Laura Gray, September 15, 2004.

GRAY: It is September 15<sup>th</sup>, Wednesday, 2004 and we are actually sitting in the Brigham and Women's Hospital conducting this interview. So, welcome, Cliff, and thank you for coming.

Tell me a little bit about where you were born, who you grew up with, when you were born and how old you are today.

DESCHENES: Let's see. I was born in Lawrence in 1954.

LG: Lawrence, Massachusetts?

CD: Lawrence, Mass., and my parents were Henry Deschenes and Theresa Deschenes. I have two sisters, Linda and Debbie.

LG: Younger or older?

CD: I have one older, one younger. The older one is three years older than I am; the younger one is one year younger than I am and right now I'm presently fifty years old.

LG: And what are your diagnoses?

CD: Let's see. I have classic hemophilia, factor VIII deficiency, severe. I'm HIV positive. I have arthritis. I also have Hepatitis C. That's pretty much all of it.

LG: So, Cliff, tell me a little about your parents. Where did they come from? What was their education? What were they like?

CD: My parents, they were brought up in Lawrence. They were born in Lawrence. My mom finished high school. My dad, at the time, that was during World War II, so I think he did finish and then he signed up right after.

LG: So he fought in the war?

CD: Well, he was in the war. It wasn't that he really fought in it. He was in the Navy and he was on a transport most of the time, so he'd go across, bring supplies and then come back. That's most of the time what he did.

LG: Are you the first person in your family to have hemophilia?

CD: Yeah, first person and they basically tried to trace it back and they couldn't find any trace back.

LG: No family history.

CD: Couldn't find it.

LG: When do you first remember having hemophilia?

CD: Well, they told me I was about two years old.

LG: And what was the story they told you?

CD: Well, my younger sister at the time, fooling around with her and she had a small plastic shovel or a small steel shovel at the time and she hit me, and my chest all bruised. So my parents were concerned, so they brought me up to the hospital to have it checked out and they ended up keeping me in the hospital, not for the bruise on the chest—that was all taken care of—but when the doctor went to grab my hand and I pulled away, come to find out, I had a sore wrist. So they put me in the hospital to treat the sore wrist at the time.

LG: And what hospital was this, do you know?

CD: More than likely it was the Children's, Boston Children's Hospital.

LG: And did they actually know that you had hemophilia once you were treated?

CD: I think by then they knew I had it.

LG: What are your first memories?

CD: When I was in grade school. I was in the hospital quite often. It was at least every other month I'd be in the hospital and I'd be in the hospital anywhere from a week to two weeks for a bleed.

LG: With what? What was going on?

CD: Oh, either I blew my knee out or I blew an elbow out or you throw your shoulder out. [chuckles]

LG: So you spent part of your life during your school years in the hospital.

CD: Pretty much.

LG: Which hospital?

CD: The Children's Hospital.

LG: What was that like?

CD: Eh, it just became a routine after awhile, because that's what you had and at the time they didn't have the treatment that they have today. So if you had a bleed, you had to be admitted into the hospital because to treat you at the time they had to use plasma. So it was so much volume that it just took hours and hours for it to drip through.

LG: And would you have the plasma every day you were in the hospital for hours and hours?

CD: I would get it twice a day. I'd get it in the morning, a dose, and then at nighttime get another dose and do that for the whole time I was in the hospital.

LG: Were you stuck in bed getting this?

CD: Well, you were stuck in bed, but you weren't stuck in bed because they had a modified wheelchair to put you in. You got one of

those and you had your IV pole and you learned how to maneuver it.

LG: Would anyone be with you when you were in the hospital? How did that work?

CD: Basically, my dad would always be the one to bring me in.

LG: Your dad would?

CD: My dad used to always bring me in if I had a bleed. He'd stay with me until I got situated in the hospital. Then he'd go back and do what he had to do. He always came every night.

LG: He came every night?

CD: Every night. He'd go to work all day and then after he got out of work, he would drive all the way back into Boston, stay with me until eight o'clock and then drive all the way home.

LG: Wow. And what about your mom?

CD: My mom, at the time she was working second shift, and she didn't drive. She would come to visit me on weekends with my dad. Sometimes if I had appointments in the afternoon, one of her friends would drive her in and then she would take me in. But most of the time it was my dad who took the time off and we had to come in and do what we had to do.

LG: Do you remember your parents' attitude toward this?

CD: Hard to say, really.

LG: Hard to remember, or hard to say?

CD: Hard to really remember because basically they were just doing what they had to do to get by.

LG: Were they anxious? Were they protective of you?

CD: Yeah. They were probably protective because basically it was, “Don’t do this. Don’t ride bikes. Don’t play sports. Don’t run.” So there was a lot of restrictions that you had to abide by. If you abide by them, you probably didn’t get a bleed as often. If you didn’t abide by them, you ended up with a bleed more often. So it was—[laughs]

LG: Did you abide by them or didn’t you abide by them?

CD: Most of the time I abided.

LG: You did?

CD: Yeah. Once in awhile, you’re a kid, you’re going to, “I’m going to try it anyway,” and you paid for it.

LG: But it sounds like you paid for it no matter what.

CD: Because I was just a severe bleeder and I would get a joint bleed and back then, if you got a joint bleed, like on a knee or an elbow, they would aspirate it, put it in a cast and you’d have it in a cast for four weeks.

LG: Were you in a cast often?

CD: Oh, yeah. I have pictures at home where I have like a double leg cast and an arm cast on or two arm casts and a leg cast, but it’s just something that had to be done. When you go into the hospital, you always seen somebody who was worse than you were, so it was like, “Okay.”

LG: Let’s go to the hospital for a minute. They must have known you.

CD: Yeah, they got to know me very well. [chuckles]

LG: And you them.

CD: Yeah.

LG: What were they like? How were they toward you? Do you remember?

CD: Yeah, most of the people were fine. Tthe doctor at the time who was in charge of hemophilia was Dr. Strauss and they had the others below him, but when I used to go in and they used to have to set up an IV, a lot of the times the doctors couldn't get an IV started because at the time I was fat. I was in the second grade and I weighed a hundred twenty pounds. So I was as high as I was wide and Dr. Strauss says, "You don't need all that weight." It don't do it you any good. So I just cut out a lot of stuff just to make it through. I never really lost weight, I just grew after that. But any time I used to go in and the doctors couldn't find the vein, they'd try once, maybe they tried a second time. Then my dad would say, "That's it, no more. You don't get a third shot," you know.

LG: So what would happen?

CD: Well, they'd call Dr. Strauss down then and he would take the time and he would always get it on the first shot.

LG: So your dad was really there to advocate for you, to protect you.

CD: Yeah, they got two shots. After that, it was like, "Hey, get somebody else."

LG: When you had to go into the hospital, do you remember how you felt about it?

CD: Well, most of the time it was you didn't really want to, but it was like, "Eh, got no choice." Nobody wants to go to the hospital. Its, "Well, no. I'll hold off. I'll hold off," but the more you held off, the longer it stayed, so it was like, okay.

LG: So you just knew it had to be.

CD: It had to be, but a lot of times you wouldn't really see you had a bleed. In other words, you tried going through it yourself.

LG: What do you mean by that, you tried going through it yourself?

CD: Just be quiet.

LG: Not tell?

CD: Not tell, but after awhile they'd notice because either you couldn't use an arm or you weren't walking too well and it was like, "What's bothering you?" "Oops." [laughs] It was kind of tough.

LG: But you would try to keep it a secret.

CD: You tried.

LG: How were the kids to you at school?

CD: The kids at school were fine. I was just another person to them. I had crutches. It didn't matter. It was like, "Okay, so you're on crutches." So most of the time the kids were fine. Every now and then you'd get somebody who'd be a little wise guy, but there was always one in the crowd. But for recess and stuff, I used to stay in the class.

LG: You didn't even go out?

CD: I didn't even go out for recess. We only lived a block from the school so it wasn't like I had a long walk or anything. So for recess a lot of the time I would just stay in the classroom and the main corridors of the hallway, I would be on crutches and you aren't supposed to run in the hallways. So I was racing kids up and down the hallway with crutches. [laughs] But it was just something I had to do, and I just did it, and it wasn't anything else.

LG: What was it like? I'm just going to hop back to the hospital for a minute. What was it like being a kid alone in the hospital for such periods of time?

CD: Well, you were never really alone because you were never really in a private room. You were in a room with probably five, six other kids because a lot of the rooms back then were like six in a room or four in a room. So there was always other kids in the room. They may not have had hemophilia, but they had their problems, and by seeing other kids with other problems, I used to say, "I'm not too bad because he's worse than I am."

LG: You remember thinking that?

CD: I remember thinking that because there was one kid in there, I forget what disease he had, but if a feather hit him, he could break a bone. Now, his bones were that brittle and he was in the hospital and it was like, "He's worse than I am, so I'm not that bad."

LG: Did your parents ever get mad at you for getting a bleed?

CD: No.

LG: So they didn't ever blame you for getting a bleed?

CD: No, got a bleed, it just got to the point where, "Okay, you got a bleed. We got to go into Boston, got to take care of it." If they resented it a little bit, they never showed it.

LG: What about your sisters—how were they around it, do you remember?

CD: Oh, my sisters were fine.

LG: They were?

CD: Yeah, we got along fine.

LG: How did it affect your being able to do your schoolwork, missing so much school?

CD: Just one year they brought a tutor in to keep me up with it, but I had no problem staying with the class.

LG: You didn't?

CD: Because I remember one time I was out for almost two weeks when they were learning a whole new section in math, and I ended up going in on a Friday and they were having a test that day and I said, "Look, I'll take the test." They says, "Well, you don't know it." I said, "Have somebody show me what you did in the last two weeks and I'll take the test." So they said, "Okay," so they showed me and I took the test and I passed the test.

LG: So you were a capable student.

CD: Yeah, I just didn't apply myself all the time. I applied if I wanted to, and that was the subjects I liked, like science, math. Those I liked, so I would apply myself, but Englishes and histories, it was just something to, "Okay, you have to take it."

LG: You know, you talk about this as "Hey, I just took it in stride," but when you describe it, it really affected your quality of life in the sense that you were pulled out of your home, pulled out of your school often and put in the hospital.

CD: Yeah, that's right.

LG: How do you explain just sort of going with the flow?

CD: It just either you go with the flow, or drive you nutty. So you have to either accept it, and if you accept it, then it's just a way of life. If you don't accept it, then it's going to cause a lot more problems. That's the way I ended up looking at it, and that's how I always

made it through. It was “I’ll take today as it is, and however tomorrow brings, I’ll deal with it.”

LG: Do you think that came from a family attitude or was that just you?

CD: Eh, probably had to be part of the family because whenever they did anything, I was always included. It wasn’t like I was excluded because I had the hemophilia. If they did something, we all went. It was the whole family went. If they went to the beach, I went to the beach and many of the times I was on the beach, I had casts on.

LG: The hemophilia never stopped you or your family?

CD: No, it was, “Hey something that you have. Something you got to live with, so you just”—like anybody else who has any other disease. You learned to live with it and just keep going.

LG: Do you remember what the caregivers were like to you, the doctors and nurses?

CD: Oh, they were all great.

LG: You don’t have any specific memories about any particular hospitalization?

CD: No, they were all good, all good caregivers. I got treated, like I said, anywhere from a week to two weeks, until the bleed subsided enough so I could go home, and go home on crutches and casts. Then go back to the clinic like every two weeks to get checked out. “Okay, this bleed’s all set.” Then they get you off that and you throw your other leg out, so then you’re back again and you start the thing all over again. So it was like a routine.

LG: So it was just really part of your routine?

CD: Just part of the routine after awhile.

LG: Cliff, when you were in high school, were you in and out of the hospital all the time?

CD: Well, by then I knew my restrictions and you start abiding by them a little bit more than when you were younger. So I had fewer bleeds.

LG: You did have fewer bleeds?

CD: Yeah, I had fewer bleeds, but I would still be on crutches more often, and back then that was about the time I got in high school they started offering the prophylactic care, but that was being treated every other day, but at the time, you couldn't do it at home. So every other night my dad and I would drive all the way into Boston, Children's Hospital. I would go up and at the time I was getting cryoprecipitate, which they were using. So I used to get my cryo, go up to the blood bank, talk to the people up there because they knew me on a first name basis. They knew when I was coming in and it was like, "Okay, yeah. It's over there in that refrigerator."

LG: So you would get cryoprecipitate on a prophylactic basis?

CD: That's how they started it originally.

LG: Oh, tell me about that.

CD: Well, that was when they were thinking if they brought the levels up, that it would help people lead a more normal life. So I was one of the first ones they asked if I wanted to go on that type of program.

LG: How do you know you were one of the first ones?

CD: They told me. A lot of the stuff, anytime they would do a trial, they'd ask me if I wanted to try a trial and nine out of ten times I

said, “Yeah, okay. I’ll try it. I’ll try it.” I’m still doing the same thing today. I still—sometimes I fight them, but I still end up saying yes. So I used to go in every other night after supper.

LG: From Lawrence?

CD: From Lawrence. My dad would get out of work, pick me up. We would drive into Boston. Go down, see the Emergency Room at Children’s. Go up to the Blood Bank because in the Emergency Room they’d give me all the paperwork. I’d go up to the Blood Bank, get my cryo, bring it back to the Emergency Room and then I had to wait around for a doctor. I did that for two or three years.

LG: Two or three years?

CD: Two or three years because I think I started that when I was a sophomore in high school. Junior year, that was the year I got my license for six months while I was on my permit, I was driving in and out with my dad, but I was driving. So the day I turned sixteen and a half, I got my license and he handed me the keys and says, “See ya. You’re on your own.” So I would come in every other night and it was just a routine. It was just, “Okay, got to go to Boston.”

LG: So your social life was sitting in the Emergency Room at Children’s Hospital.

CD: Well, back then because I used to wait for a doctor and then there was one particular doctor that happened to have duty that night and she asked me, she said, “Would you like to learn how to do it yourself.” She says, “This way here you don’t have to wait for any doctor down in the Emergency.” You can come in, find a room

that's open. Just take the room that's open, do your injection and then out of here.

LG: But with cryoprecipitate?

CD: With cryo because the cryo was much more concentrated than the plasma, but it's not as concentrated as the—

LG: The factor.

CD: The factor now. In other words, the Cryo probably for adults it would probably take thirty c.c. syringes. So for injection time it would probably take you like ten, fifteen minutes.

LG: I see. So she taught you how to do it?

CD: She asked me if I wanted to learn and I says, "Sure." So she says, "Here." She gave me her arm and she said, "Here, put the needle right there." So I put it in, put it in on the first shot and she says, "Okay, if you come in in two days, come and see me," and she says, "I'll let you do it yourself," and after that it was I started doing it myself every other night, and then because I didn't feel like coming in every other night, I started pushing it to every three nights. Then every four nights and I got off the prophylactic care because I just didn't like time restraints. If I would have stayed on it, I probably wouldn't have had as much joint damage as I got, but it was something that did improve my life when I was doing it that way, but I found I was able to also push the timeframe up further and further.

LG: So you were able to start negotiating with the doctors. Whereas, before you used to just say, "Okay, I'll do what you say."

CD: Right, and so once she showed me, any time I went into the hospital, I got my own stuff and did my own injection.

LG: How did this affect your social relations in high school? Did you still have friends?

CD: Oh, yeah.

LG: Did you date?

CD: I didn't really date until probably senior year. I had friends. You know, I was always out. I was never home. I was always out with the friends, playing, hanging around, just doing what kids do.

LG: But you were just on crutches or in a cast.

CD: Yeah, either that or I had crutches or I had a cast on, but it didn't really stop me. You know, but when I got in high school, I didn't have the bleeds as often because I was treating it much closer. I would realize I was having a bleed and get it treated before I ended up into a major bleed.

LG: Did your parents or anybody ever go, "Oh, poor Cliff."

CD: Oh, you get that.

LG: Did you?

CD: Yeah.

LG: What was that like?

CD: Eh, sometimes I'd say, "What do you mean poor me?" They'd say, "Well, you got all this wrong here." I says—well, like my mom will once in awhile still say it. She'll say, "Oh, poor you." I says, "No, not poor me." I says—because we believe in God because we are Catholics so basically my belief in God, so he wouldn't give you anything that you couldn't handle. In other words, if he gave you something it's because you could handle what he gave you. So that's how I got through it because I was brought up as a Catholic and one of the things of a Catholic is you

believe in the God, and so I got the attitude that if I couldn't handle it, He wouldn't have given me what I got.

LG: So that never challenged your relationship with God, to say "God, why did you give me all this stuff to handle?"

CD: Oh, yeah. Sometimes you do curse and say, "Hey, why me?" but you get over it and you say, "Okay. All right, I can handle it. So I guess it's all right."

LG: So your faith did play an important role?

CD: Yeah.

LG: And does it still?

CD: Yeah, it has to. Because you've got to have that extra. If it's just physical, you can't deal with it.

LG: What do you mean if it's just physical you can't deal with it?

CD: If it's just a physical thing. You got to be able to have something in your mind that helps you get through it. Now, it may not be a God, it might be something else, but it's a spiritual thing. You've got to get to a different level to handle it.

LG: Do you remember when you got to that different level?

CD: Probably some time in high school. But even when I was younger, before high school, I would be in the hospital and I always had a smile on my face. So it was something that it was always me.

LG: Tell me about pain. Were you in much pain?

CD: Yeah. You know, it's pain, but that's where the next level came. You had to get to a point where you could block it out.

LG: How do you block pain out?

CD: It's tough.

LG: Can you actually do it?

CD: Yeah, until it gets to a certain point and then I can't block it out because then it's beyond my threshold and once it goes beyond my threshold, then I can't do anything with it.

LG: And then what happens, when it's beyond your threshold?

CD: Then that means I've got to get something taken care of. Then I see a doctor and get treated for it.

LG: So sometimes you wouldn't attend the bleed until it went over your pain threshold.

CD: Yeah, sometimes.

LG: And then at that point it just pushed you.

CD: It pushed me over.

LG: And then once you went to get treated, weren't you still in pain?

CD: Yeah, but now you know what was causing the pain because actually it happened just this past year.

LG: Tell me.

CD: I had hurt my hip. I was putting a floor down for a couple of days and I got a bleed into a hip. I was controlling the pain, but I wasn't sure what was wrong with the hip. So I had a doubt. So I was taking pain medication and the pain medication wasn't really doing what it was supposed to because I didn't know exactly what the hip dislocated or whether I had a bleed or whether—because I've got an artificial joint—whether the artificial joint deteriorated and let go. So I got to the point after three days I was in doubt of what was happening because I treated it as a bleed, but—

LG: You weren't sure.

CD: I wasn't sure, so that left a doubt. By leaving the doubt, my pain got to the point where it was like "I got to go get it treated." Then

after they checked it out and said it was fine, then I was able to—the pain didn't really go down. I was able to say, “Okay, this is what's causing the pain, so I can maintain it now.”

LG: Now, that's interesting. So somehow tolerating pain has something to do with knowing what it is or not.

CD: Yup. A lot of times.

LG: Explain that to me. Somehow doubt makes pain worse?

CD: Yeah, I think so. Now, because most of the time I'll have pain, but there's—as the hospital has, they have the little pictures, in other words, what level of pain. Even people at work will say, “Oh, your pain threshold is much higher than mine.” I says, “Yeah, that's because I've lived with it all my life?” So what you would classify as probably a five, I'm classifying it as a one. So it's just an aspect that you're looking at it as okay, you're in pain, but how much pain is it? It's hard thing to quantify. Sometimes I can tell I'm having a bleed actually before the pain really kicks in because I feel something that's not quite right.

LG: But somehow you feel more in control of the pain, if you know what it is?

CD: Yeah. If you know exactly what's causing it and if you know you can treat what's causing it, then you maintain. You can drop the pain.

LG: I see, but if you don't know what it is, then that anxiety—

CD: The anxiety makes it worse.

LG: So pain isn't only physical. Pain you're saying is mental, too.

CD: Pain, a lot of it's in the mind. It's physical but you can control a lot of it with your mind. You can't eliminate it, but you could make it less severe.

LG: Okay. Did you take pain medication a lot as a kid?

CD: Nope.

LG: Why?

CD: Because I don't.

LG: Why not? Or as an adult, let me put it that way.

CD: Even as an adult, I don't take it that much.

LG: How come?

CD: Just because once I start treating it and if I realize I can treat it, and it's not interfering too much, then I just won't bother. Like last week I had a bleed in my wrist. I woke up at twelve thirty and it was throbbing, so I says, "I'll take a couple of Tylenols with codeine." So I took that. It took care of the pain, but I also had a reaction to the Tylenol and codeine because once in awhile it just don't agree with me. So if I don't need it, I try avoiding it.

LG: I see, and so you just somehow integrate the pain into your life.

CD: Yeah.

LG: And you said you've lived with pain all your life. Have you?

CD: Pretty much. Always something sore [laughs]—always had a joint that was sore. Like most of the time I got a wrist sore now or I got an elbow that's sore. Back then it used to be my knees or elbows.

LG: We talked about how you had to spend a good part of your life in the hospital. Then as you got older in high school, cryo came and you went on prophylaxis, so you just spent every other night in the

Emergency Room. And then you actually could infuse yourself, so you didn't have to spend quite as long in the Emergency Room.

CD: Right.

LG: Then what happened?

CD: Then from there, that's when they started with the factor and they said, "We can let you bring the stuff home, if you want."

LG: What was that like?

CD: I said, "Super!" So now instead of having to go to the hospital every other day, like I was, I would go to the hospital every other week because that's where I was picking up my supply. I was going to the Children's Hospital and picking up like six doses, so I'd have it at home for when I needed it.

LG: What was that like? Did that change your life?

CD: Yeah, because it cut down a lot of time coming to the hospital just to be treated.

LG: How was it to infuse yourself with the factor? What was that like?

CD: I picked up on it quick and never had a problem.

LG: So the amount of time that you had to go to the hospital, did that change?

CD: Oh, yeah. When I got in high school, my time in the hospital had dropped almost to maybe once a year I'd end up in the hospital, if that, because I was being treated outpatient wise.

LG: So it made a huge difference?

CD: Made a huge difference for hospital time and once I started to take it at home, the only time I ever went in the hospital after that was if I had something that had to be done. Like when I had my knees replaced and my hips replaced, or a bleeding ulcer. Stuff like that,

then you have no choice. You got to go to into the hospital because you can't take care of that.

LG: But for the actual bleeding episodes, you no longer had to come in any more.

CD: Never came in and so I would see the doctors like every six months. Just come in and say, "Hi."

LG: I think that's what's been fascinating about men who have grown up in your timeframe of spending so much time in the hospital to really getting to the point where you hardly ever came in.

CD: Yup.

LG: Did you ever reflect on that and go, "Wow, this is different"?

CD: Well, back then they didn't have the treatment that they have today. That was the whole thing. Because it was a new science and just that it progressed that far in the last fifty years.

LG: And for you it really made a difference in your lifestyle.

CD: Yeah.

LG: Now, tell me about dating and meeting your wife. Have you been married just once?

CD: Just once.

LG: Okay. When did you meet your wife?

CD: Twenty-six years ago.

LG: Twenty-six years ago?

CD: Right, through my ex-girlfriend. [laughs]

LG: So you dated and the hemophilia never got in your way?

CD: Yeah, I dated. I went out, did what I wanted. My wife, I met her, like I said, through my ex-girlfriend. Me and one of my friends were going up to one of the clubs at the time, and we went up to

the club, they introduced me and I ended up going out with her.

First thing you know, I married her. [laughs]

LG: What about the hemophilia, was that ever a concern of yours?

CD: Not really because I knew kids my kids—my son's—couldn't have it, so that was one plus. Only draw is if you have daughters, the daughters become an automatic carrier. So it has its drawbacks, but overall it's fine.

LG: Did your wife have any worries about it?

CD: Sometimes she gets a little anxious about it, but most of the—

LG: About what?

CD: Eh, more concerned, really.

LG: For you?

CD: Yeah. "When are you going to do something about it? You've got to do this about it. You should go see the doctor."

LG: Now, did you have kids?

CD: Yeah, we have two kids. I have a son, he's going to be twenty-three years old, and I've got a daughter who just turned fifteen.

LG: So your daughter's not even close to the marrying age.

CD: No. So, it's a long way off, yeah.

LG: So she's the one who can pass it down.

CD: She's the one who could pass it along.

LG: Have you ever talked to her about it?

CD: Yeah, she actually did a report last year for school. She had to pick a disease, so she picked hemophilia. So she did her research and she asked me questions. She aced the report.

LG: Is hemophilia something that's talked about in your home?

CD: No, it's just there.

LG: Do your kids ever ask you about it?

CD: No, they know if I'm having a bleed or something. "Okay, dad's got to take his medication." No, it doesn't really bother them. It may have bothered my kids a little bit because I probably couldn't do a lot of other things that other people would have done with their kids. Like probably bike riding, but when I grew up, it was "Don't bike ride. Don't run. Don't do this." If I were to stay on prophylaxis, then I could have probably did that, but that wasn't what I did. I got to the point where I'd use it on demand only. So they know when I'm not feeling well.

LG: Was that hard for you ever as a dad?

CD: Sometimes.

LG: Sometimes—in what way?

CD: Well, sometimes you'd like to go out and play catch with your kids, but you know if you go out and play catch, you're going to end up paying for it afterward. So you sort of go, "Oh, can't do that."

LG: Did that change the way you related to your kids at all, do you think?

CD: No, we have a good relationship. I don't think that really affected it.

LG: Let's move on to the whole period of the early 1980s, the AIDS period. What do you remember about that?

CD: Well, back then they came and they were saying you could have HIV if you got any types of transfusions or—

LG: Who said it? How do you remember hearing about this?

CD: The hospital.

LG: Had you been reading about it in the paper before that?

CD: Well, I probably read a little bit about it in the paper, but mainly it was from the hospital because at the time my knees were getting ready to go and I had my knees replaced back in '89.

LG: So how old were you then?

CD: I was thirty years old. At thirty years old I had to have bilateral knee replacements and before I had the knee replacements, that was when they were having this whole thing HIV and AIDS. Back then it was, well, if you were getting blood products, the odds are you're infected.

LG: That was the first time you heard about it?

CD: That was the first time. "You're infected."

LG: What was that like to hear?

CD: It was like, "Okay, so I'm infected." They weren't sure and they says, "Oh, you should get tested," and I said, "Why should I get tested? You're telling me I'm already infected, so I'm not." I fought them on getting tested for years.

LG: You didn't want the test.

CD: I figured if I was positive already, why are they going to take a test and tell me I'm positive? That's what it came down to. Well, what ended up happening, my wife got pregnant. What was it? Let's see. Let's see, the knees were done in '814. My wife got pregnant in '88. We lost that one.

LG: You lost that child?

CD: We lost that one.

LG: How come?

CD: Just miscarriage. That's all.

LG: I see.

CD: So doctors at the time says, "Well, if you want a kid, you should definitely make sure that you're okay." So finally I said, "All right." This was in '88 I finally said, "Okay, I will have the blood test. Get it out of the way." It came back, I was negative. This is back in '88 and I was already told for five years that I was positive. So they came back in '88 and said that I was negative. So I said, "Fine." My wife got pregnant again. We had my daughter in '89.

LG: Now, you'd already had your son?

CD: Already had my son because my son was born in, let's see. He's twenty-three, so he was born in 1981.

LG: So this was before the whole HIV business came up? He had already been born.

CD: He was already born and the HIV started out, it was about '82, '83, in that timeframe.

LG: So they told you that you were negative in '88.

CD: Then my wife got pregnant again. We had my daughter in '89, July, and in October they said, "You should do the test again." I says, "Okay, fine, I'll do the test again."

LG: Why did they want you to do it again?

CD: No idea. So I said, "Okay, I'll take the test again." Took the test, it came back positive.

LG: What was that like?

CD: It was like, "Wait a minute. You told me all these years I was infected. It shows up negative and then I have another kid and now I'm positive." "Well, you got to go on treatment," and I says, "No." I says, "Why do I got to go on treatment?" They says,

“That’s what we recommend.” I says, “Well, I’m not going to go with it,” and I fought them on that for, oh, five years.

LG: Why?

CD: Why? Because they couldn’t give me any real reason why to go on it.

LG: You mean they couldn’t say, “We can make you better”?

CD: They couldn’t give me any answers. They couldn’t say, “Okay, we can do this,” because it was still experimental.

LG: I see.

CD: And I just said, “No.”

LG: Was your wife afraid that she could get it?

CD: Yeah.

LG: How did you two handle that?

CD: It was rough for awhile.

LG: In what way?

CD: Eh, we grew further apart for awhile—so every year she was going in and getting tested.

LG: Were you upset that you initially got a negative and then a positive?

CD: No, because they said, “Oh, we get those a lot. We get negative readings. Then we get positive readings.”

LG: So it caused some real tension in the family?

CD: Yeah, for a bit. For a bit.

LG: What was it about the HIV that caused more tension than hemophilia?

CD: Well, the hemophilia, you can't give it to your wife. The HIV, you can give it to your wife, you know. So it's one of those. It's a different type of disease that you have to deal with.

LG: So she was afraid she could get it?

CD: That was one of the biggest things, that she could get it. Years just living together and after awhile you sort of sort things out. That's all.

LG: Were you afraid that your daughter could have gotten it?

CD: Well, wasn't afraid that she was going to get it because I was negative when she was born.

LG: I see.

CD: So it was—I got tested after she was born.

LG: So let me ask you, how did you feel when you were diagnosed with HIV? How did you handle that? What do you remember of that time?

CD: Oh, I cursed it a little bit. It was like, "Why? Why do I get this?" But then, like I said, I got back to the attitude where, "Okay, I can handle it," so that's what I was doing and doctors kept saying, "You should go on treatment," and I says, "Why?" They says, "Well, because your T-cell count is at 500," and I said, "Well, it was 500 three years ago, so give me a reason why I should be treated?" "Well, a normal person's supposed to be around 1500 for the T-cell count." I says, "I got 500." I says, "I've had 500 for as far as possible." So I says—they kept asking and my T-cell count at the time was going down. It got down into the 200's, so finally I told them, "I'll go on treatment when my T-cell below the 200. Then we'll discuss treatment."

LG: I see. So that's when you realized your body was changing and you thought that you had to do something about it?

CD: It wasn't that I was seeing any change. It was just my blood count was changing, because I was never sick from it. So it didn't affect me.

LG: What about the hep C? When did that come rolling down the pike?

CD: Who knows. Somewhere along the line, I don't know how many years ago, but it showed up. A couple of years basically they had me try one of the trials and said, "Oh, well, try this," and basically it was a one-year trial.

LG: And?

CD: And it worked for a bit and then just before the trial ended, it didn't work anymore. So it was like, "Okay." So the hep C they're saying, leave it alone. It's not doing anything. It's just sitting there, so it's like "We won't treat it anymore right now."

LG: I'm just struck how you keep such an accepting attitude instead of saying, "Ah, this is horrible, this isn't fair," you know?

CD: Eh, just it's my personality. That's the biggest thing.

LG: Yeah, and it's your faith?

CD: Yeah, the faith—there are days you're going to have your doubts, but your faith is what gets you through a lot of times.

LG: But you think it's true, just your personality? You were born with this?

CD: I was born with the personality that I accept stuff.

LG: What about the class action suit? The feeling that the manufacturers maybe knew? How did you deal with all of that?

CD: I just got in the class action suits. You know, they sent me all the forms. I just filled them all out and just had to see what happened, and it worked out. I got the money from it, but part of—the first one that was against the pharmaceuticals, that one there, I had to get a lawyer after awhile, go through paperwork. That got bogged down on this end because the lawyers wouldn't touch it and the judges wouldn't touch it. You went to court and they'd say, "Well, what are you doing?" "I'm doing this." "Well, you can't do that. You can't take your kids' rights away." So it's like, okay. So finally they handled it out on the other hand. In other words, they said, "It's all settled, here," because my kids were underage. So I wasn't supposed to be able to take their rights away, that they could sue the pharmaceuticals. So the lawyers on the other side of the country, they took care of it because they had all the forms that were all signed and they says, "We'll dispense of it from here."

LG: What was it like to get the money?

CD: Eh, paid off a few bills and then just put the rest of it away, in case something does ever happen. Mainly just paid off some old medical bills. Didn't really do much. You know, it wasn't so much the money. It's just the fact that the pharmaceuticals realized they screwed up. They made a settlement.

LG: How did you come to terms with pharmaceutical companies?

CD: Well, the way I looked at it was there's always a chance of getting something, if you're taking something, and if you want to treat what you've got, there's a chance that you might get something else. So it's like, it's one of those, if you do, you're damned; if you don't, you're damned. So you've got to go down the road and

say, "Well, this is what I've got to do now and hope it works."

[laughs]

LG: I see. How about the rest of your family? Did they have feelings about all of this, of your getting more problems?

CD: Eh, probably a little bit more. Probably my parents—  
[end of Side A, Tape 1]

CD: Yes. They probably showed more concern. That's because they're family.

LG: Did that bother you? Did you want them to be concerned?

CD: I didn't want them, but they have the right to know.

LG: So you accepted it, but you didn't want it.

CD: Right, because it took me awhile before I told anybody in the family.

LG: Oh, tell me about that.

CD: Well, at the time they were saying you don't want to let people know you have it because it's going to cause all types of problems. So it was like, do you tell them or don't you tell them? So told the parents first and then it was like, okay, "Should I tell the sisters or not?" And it was like, "Okay, got to tell them—they are my sisters, so let them know."

LG: And what about your wife, did she know?

CD: Yeah, because when I tested positive, they wanted to get a test on her and seeing my daughter was just born at the time, they wanted to test on her, just to make sure.

LG: Did it affect your family's or your wife's feeling about medicine?

CD: No.

LG: How did your caregivers treat you at that time? How did you feel about them?

CD: Oh, I feel fine. Never had a problem with my caregivers. They would always tell me what was there available to me, but I used to fight—one of the doctors, I used to always fight with him and say, “No, I don’t want this now. No, I don’t want this right now.” Then he said, “Well, this is what we recommend,” and I said, “No.” Finally, they got me cornered one time and they says, “What will it take for you to go on treatment?” I says, “Either the viral load’s got to go higher or my T-Cells got to go lower, and if you give me those numbers, then it gives me something to go with,” and my T-Cell dropped below the 200, so that’s when I said, “Okay, we’ll treat.”

LG: Did you ever want to meet other people with hemophilia?

CD: Never—never phased me.

LG: Did you ever wonder, “Does anybody else have this?”

CD: Oh, I know there’s a lot of people who have it, but—right now I have a nephew who has it. I never see him, but he has it. But he’s being treated on an every-other-day basis, so he won’t have the problems that I’ve had.

LG: What’s that like?

CD: I’m glad for him, because he won’t have the joint problems that I had. He may still develop joint problems, but they won’t be as severe.

LG: So when you think about kids being born with hemophilia today, what do you think about it?

CD: They have a much better chance of living more normal because if the Center pushes it, they'll get them on the prophylactic care and that makes a big difference in what happens with the kid.

LG: Would you have any advice for a kid dealing with hemophilia today?

CD: Not too much because it's something that you learn to live with. No matter what you get—it don't matter whether it's hemophilia or whether it was diabetes—you get it. Eventually, you've got to either accept it, or you're not going to. Most people who have something that's wrong with them from the beginning, they end up accepting it and they just don't let it really bother them because it's part of their lifestyle. So getting advice, there's not much—it's just mainly keep the joints healthy. That's the biggest thing.

LG: What about to the mothers and fathers? Would you have any suggestions for them as to how they would raise their kids or talk about it with their kids?

CD: Not—there's really nothing you could really tell because parenting isn't something that can be taught. It's something that you learn on a day-to-day basis.

LG: Was there anything do you think that your father and mother offered you that helped you cope better or worse with this? Anything that really helped or hindered your coming to terms with it?

CD: No. They were just there for me. Anytime I needed them, they were always there.

LG: That's what you remember.

CD: That's what I remember. The bad times, after awhile just become another day. It's the good times you hold onto. And that's basically what family comes down to. It's not the bad times. Yeah, you're going to have them, but the bad times sort of get pushed in the background. It's the good times you always remember.

LG: Did having hemophilia and all these diseases affect you financially?

CD: Yeah, a bit.

LG: In what way?

CD: Well, when I turned twenty-one because like the last few years before I got out of high school, the state was helping my dad. He shouldn't have been paying the bills because up to a certain point he was paying all the medical bills. Every time the bills came in, he just paid them, no question. Finally, somebody came in and said, "You shouldn't have to do that." So the state ended up picking up the tab until I turned twenty-one and then the day I turned twenty-one, they just said, "You're on your own."

LG: So what happened?

CD: Well, I still had to get treatment. So if I needed treatment, I came in, got what I needed. Then the bills would come in and one time they ended up sending me out to Social Security to try getting aid for them. So I had to fill out all the paperwork there and they said, "Well, we can't help you, so go to Welfare." Went to Welfare, filled out all types of paperwork there. They said, "Well, we can't help you. Go back to Social Security." This went for a couple of months. Finally, I sat down with one of them. I says, "You can't

help me. Why?” They says, “Well, you’re making two dollars a month too much. At the time, I was two dollars over the limit. So they says, “Take the bill, put it in the barrel.” I says, “What does that prove?” They says, “It will eventually go to a collection agency.” Then he says, “Once it goes to a collection agency, then you got to go back to the hospital and say, ‘Hey, I can’t pay’ and the hospital would end up taking care of it.” So I had to do that four or five times, right after I got married. The collection agency would start sending me letters and I just ignored them.

LG: Because you didn’t have insurance at the time?

CD: Didn’t have any insurance. So ended up going back to the hospitals and say, “I can’t pay it,” and the hospitals would fill out the paperwork and it would be gone. Then get treated again, start all over again. So five years after I got married it was that. It wasn’t that I didn’t have insurance. Back then they had clauses in the insurance that they didn’t have to cover you if you had pre-existing conditions until so many years, or so many months. So you had to make do.

LG: Was that stressful?

CD: A bit, but just got to the point where “Okay, I can’t have money because if I have money, they’re going to take it anyway.” So basically, I got no money. They can’t take what I don’t have.

LG: Did that affect what kind of work you could do or what kind of promotions you could get?

CD: Once I got into the job force, it’s pretty much what I went into. I went into the electronics field and I’ve been there for twenty-five years. Actually been in electronics for twenty-six years.

LG: Did you go to college to get into electronics or did you go right out of high school?

CD: Actually, not right out of high school because out of high school I had gone to college for one year and then I couldn't get the courses I wanted because I was going after math and science to become a teacher and I just happened to be in the wrong school to get that. So after one year, I didn't go back the second year. I had other jobs, like worked in warehouses. Worked for myself for a couple of months, just because it's what I wanted to do, but I ended up finally go into electronics and been doing that. The second place I got into electronics, that was Wang Labs at the time, and they were willing to teach people. So I went to school for nine months and got a certificate saying I could be a technician and I've done that ever since.

LG: Did you ever worry about not being hired due to your health?

CD: Oh, I got jobs that I knew why they didn't hire me. I had one job, I went out, I got the job. They hired me, called me up an hour later and says, "Oh, we can't hire you." But you don't have anything that hired you fired you and they fired you at the same time. You couldn't really do anything, so it was like, "Okay." In other words, you know what the reason was, because they ended up reading your medical history.

LG: But Wang went ahead and hired you?

CD: Yeah, they hired me.

LG: Did you ever worry about disclosing the hemophilia?

CD: Nah, that never phased me. If they asked, I put it down on the paper.

LG: And you never lost anything from letting people know you have hemophilia?

CD: No.

LG: That was never an issue.

CD: No.

LG: How about with the HIV?

CD: HIV, that was pretty much not really told to everybody. Only select people.

LG: Do you have any advice for your caregivers—for your social workers or your nurses as to what is helpful for people like you who have been through such a rich and complicated medical history?

CD: Well, just keep doing what they have to do. They're caregivers. I've been in the hospital a couple of times since I've been an adult, actually. One time it was for bilateral knee replacements. Another time it was for bilateral hip replacements. I was in because I got kidney stones from one of the medications they gave me for HIV. They all do fine.

LG: Is there any attitude that you've picked up that's been either helpful or not?

CD: No, because most of the time all the caregivers I've had, they've all been excellent.

LG: You have no memories of things when you left feeling, "That wasn't good."

CD: No.

LG: Or "That was particularly helpful."

CD: Like when I had my hips done, they were just about ready to send me home after a week. I had one hip that started bleeding out and one of the nurses happened to come in and I told her. She stayed there with me the whole time until they got me up back into surgery to take care of it all. So caregivers, they were always right there.

LG: Do you think hemophilia has affected you in a positive way?

CD: Probably just makes you stronger.

LG: In what way?

CD: Eh, because you're always having to cope with something. In other words, nothing's just black and white. It's, "Okay, if you do this, you're going to have this consequence. If you do this, you're going to have this consequence." So with the hemophilia, you know what your consequences are. You know what's going to happen, and if you basically push it, you're going to end up with a blood and you're going to suffer for it for a few days.

LG: So how does that make you stronger?

CD: You realized things—everybody's got limits. It's you can't do everything you want to do. Nobody can. Everybody's got a limit and you've just got to find out what your limits are and you try getting to them without actually causing problems. And sometimes that's tough because there's something you want to do, and you're going to try it. You may pay for it. [laughs]

LG: Do you think it's important for your to find your own limit?

CD: Yeah. Because I remember when I worked for myself for a summer, I had taken a job and I'd given a person a timeframe that I could do it in, and my dad just looked at me and he says, "You

can't do it in that amount of time," and I says, "Why not?" He says, "Too big of a job. You're biting off more than you can chew." I says, "No, I said I could do it." So to prove to him, I had to do it in that amount of time. It should have been a two-day project, but I did it in one day like I told the person.

LG: You had more determination.

CD: Yeah, if you're told you can't do something, you get, "Watch me. I'll do it." I still have that same drive because if somebody challenges me to something, I will try to meet the challenge.

LG: It's interesting because what many parents struggle with today is how protective they should be. Do you have any thoughts about that?

CD: Not really because the rules I had when I was a kid, until I was sixteen, you had to be in the house like ten o'clock. Okay, ten o'clock. Okay, that's fine. During the summer, it was summer it was 10:00 during the week. During the school time, it was probably 8:00, but that was just rules of the house. And as I got my license, the rules changed because it was "When does your license expire?" At sixteen, it expires at 1:00, so you know what time you have to be in the house by. So you're challenged once in awhile, but most of the time, I always abided. If they said 1:00, it was 1:00.

LG: What about "Don't climb. Don't run. Don't this. Don't that. You might get a bleed."

CD: Well, back then, that's what would happen. Today most of the kids who are getting it, they're probably being on prophylactic care, so they're being treated every other day so that they don't

have that. They'll still get bleeds, but their bleeds are much milder because they're keeping a level of factor in their system. He gets his bleeds, but they're not as severe as probably what my bleeds would have been.

LG: So you're going to get bleeds no matter what.

CD: You're going to still get bleeds. It's just the severity of the bleeds, because if you're being treated every other day, you're going to get a bleed, but the bleed may only last a couple of hours and probably once you start treating it, you're pretty much all set. Whereas, if you're older like I am, and you're not on every-other-day program, you get a bleed, the bleed may last two days or three days. So it's the severity becomes the issue.

LG: When I told you I wanted to interview you for this, did you have any thoughts about what you wanted to say?

CD: No thoughts on that. Actually, when you first approached me, I said no.

LG: Right.

CD: And you talked to me that day and I agreed because you said it could probably be a benefit on the people further down the road.

LG: So that's what changed your mind.

CD: That's what did it.

LG: Is there anything that I haven't asked you today that you think might be useful, or just something, some experience you had that I didn't somehow tap into?

CD: No. Pretty much got it all. Like I said, biggest thing is I find that you got to live one day at a time. You can't try living down the road. You got to live what's happening now. Because you never

know what's going to come up tomorrow. That's the hardest thing.

LG: What's the hardest?

CD: Living one day at a time because most people want to live, "Oh, this is what I'm going to do down here." Most of the time you can't really look at that because you have problems. You never know if one of the problems is going to flair up or whether it's going to be fine. So you basically get up in the morning, "Okay, I can do this today." Fine, you do it. If you can't do it, "Oh, I can't do it today." So it's a day-to-day basis thing.

LG: So you're saying that otherwise you're just setting yourself up for total frustration.

CD: Yeah.

LG: Because you never know what's going to happen.

CD: You don't know what's coming down. If you take one day at a time, you can deal with one day. You can't deal with weeks at a time.

LG: Or the 'what-ifs,' you mean.

CD: The what-ifs. You deal with the what-ifs when we get there.

LG: I see. Can you do that actually?

CD: Pretty much. Pretty much because like right now, my HIV meds, they may be changing them again.

LG: Has this changed your perspective on dying or living or your philosophy of life?

CD: No. Like I says, one day at a time. And some days it's not a day at a time, it's an hour at a time, you know. Some days you have

bad days. You go an hour at a time and you get through it and you say, "Okay, I made it through that far. Go a little further."

LG: So just deal with what's in front of you.

CD: Just deal with what you're dealing with right away. Don't try dealing with something that hasn't got there yet. And basically, that's what I keep telling my kids. You know, deal with what you're dealing with. Don't try dealing with something that isn't a problem yet. You know, it's—don't worry about it. You can't stop something that's going to happen further down the road because you don't know what's going to happen. Because if we did, we'd avoid it and we don't know what to avoid.

LG: Well, Cliff, I want to thank you very much for doing this and it's just been a pleasure.

CD: No problem. Okay.

End of Interview