

Interview with Matthew Vieira for the Boston Hemophilia Center Oral History Project, A Gift of Experience, by Christine Harland, August 12, 2004.

HARLAND: I'm going to start at the beginning, and ask you a little bit about your parents - your family, where you grew up and a description of your family, brothers and sisters and so-forth. Could you help me with that?

VIEIRA: Okay. First of all, let's see. I grew up in East Boston. I have two sisters, no brothers. Just an average American family. Naturally, I'm seventy years old, so we're going back to 1934 when I was born. My father was a longshoreman worker on a truck. My mother was just a housewife and hemophilia carrier, it came from her side of the family, which I don't know too much about. I know—I think it was one of her brothers or someone had it. She was Irish. My father was Portuguese. They didn't know too much about it because we're going back to, you know, '35-40's, which nobody knew too much about it, you know?

CH: That's right.

MV: And just kind of dealt with it, as far as basically don't do anything, you know, in a sense, because you didn't want him to get a bleed or anything like that.

CH: So they were aware that it was a possibility?

MV: Yes, I believe so. Like I say, you know, it was such a long time ago and nobody really probably knew too much about it, but she had a brother, I think. I think it was a brother that had the disease, but I believe they were aware of it. Well, they weren't until I guess we got diagnosed. That's another thing. I had a couple of problems growing up as a kid, cutting my finger and different bleeds and they took me to

a doctor at, it was the old Boston City Hospital.

CH: And how old were you when they took you to Boston City?

MV: I was about six, I think. You know, in that first six years, I mean, different things had happened or something, you know, here and there. I'm not sure if they could figure it out or they thought or what, because I don't think anybody knew too much about it, you know. His name was Dr. Dameshek, I think.

CH: Dr. Dameshek?

MV: Yeah, he was an old-timer and he diagnosed it as, you know, hemophilia. Later on, I don't know if he moved on, but I did see—used to see a doctor there at the hospital, his name was Bigelow, Dr. Fredrick Bigelow. He was another doctor. But then they knew I had it and since they knew I had it, then you know, they basically didn't want me to do too much, like play sports or be very careful. At that time it was a case of when you bled, they more or less just, as you bled, they kind of replaced the blood. They didn't have too many things like factor VIII or anything that we have today or any kind of stuff that would help. It was kind of crude, but that was all they knew about it.

CH: Were you aware of any other patients at that center who were being treated for the same thing?

MV: No.

CH: So you were the only person you knew who had hemophilia. That must have meant that your parents didn't have support. They didn't have other people to talk to.

MV: Yeah—no, I'm sure there were, but back then, yeah, we didn't know of any and as far as support groups go, I don't even know if there was any or anything like that because, like I say, seventy years

ago, it was kind of—I don't want to say hidden. It was a disease that nobody knew much about and people just didn't support or do anything about it, you know?

CH: How much do you remember about being diagnosed and the way your life changed as a result of that?

MV: Well, basically, my life changed in the fact that I just kind of had to be very careful about whatever I did. Of course, my mother and father were very cautious about me not doing anything. Other than that, it was just I tried to lead a normal life, but people didn't—also, it was very—we didn't disclose it to anybody because at that time they used to call them “bleeders.” Hemophilia, I don't know if people even knew what it was then, you know. They'd say a “bleeder.” People thought when you were called a bleeder, you were going to get a cut and something and you'd bleed all over them or something. So it wasn't too public then. I tried to keep it under the table. I mean if it came up and someone had inquired about it, which most people wouldn't, other than doctors or something like that, you know, it was a disease that you kind—it was hidden.

CH: And would you say your parents were over protective?

MV: Over protective.

CH: They were?

MV: Yeah.

CH: Would you say that was true of both your parents?

MV: Yeah, only because of their knowledge that they didn't know much about the disease, which nobody did. So it was like try to keep him in a bubble or something, but—

CH: Did you have much of an extended family at that time?

Grandparents, aunts and uncles?

MV: Yes, my—back then. Yeah, I had cousins and aunts and uncles. They were all living back then.

CH: Then you had a supportive network?

MV: Yeah, but I believe, you know, they were there to help me if I needed it, but they didn't know much about it either. So there wasn't much—

CH: But they all knew?

MV: They all knew, yeah.

CH: But you had a relatively big nuclear family.

MV: Yeah, I had my father's mother and father were living. My mother's parents had died. Her brothers and sisters were gone. My father had sisters and brothers and they were all around. Cousins, yeah, plenty of cousins and stuff, you know.

CH: And had you started school when you were diagnosed?

MV: I started, yeah, at I guess first grade, you know. Basically, you know, five or six, whatever it was back then, you know.

CH: And how did that school experience go?

MV: They didn't—we didn't tell them. Nobody told anybody, but it went okay, other than when I'd get bumps and bruises or cuts. I'd lose time from school and stuff like that.

CH: So basically your peers at school didn't know.

MV: No.

CH: And you managed to keep that—

MV: Hidden from them, yeah.

CH: What about the teachers?

MV: They didn't know.

CH: They didn't know?

MV: No.

CH: Wasn't that a bit risky? If something had happened to you, there was really no one who knew what was going on.

MV: Right.

CH: So you were presumably highly educated about your condition. They educated you so that you would know what to do if something happened.

MV: Well, I knew—I don't know if you'd say highly educated, but I knew basics of it. Back then, though, nobody would disclose anything. As of today, when a child has some kind of a disease, I know they tell teachers or they're supposed to because my daughter is a teacher and my son-in-law is a teacher. My son's a teacher and, you know, things are a lot different. I never disclosed anything to my employers. I mean, I found that if it came up to that point, I was questioned, I would tell them, but it was always fear of your job, losing your job because of that, which they say you can't. Nobody disclosed anything back then because nobody knew much about it, you know. So if it came up, you—if you were confronted with it, you'd have to tell them, but basically you told nobody anything.

CH: Tell me about the earliest you can remember about the care system and what the doctors were like and how you felt about what was happening to you physically. Was it really disturbing? Did you have a lot of shots and transfusions?

MV: When you say the care system, you mean—

CH: Oh, the hospital and the doctors.

MV: Well, my first experience—basically, my first experiences were at the City Hospital in Boston, and it was for cuts and stuff that I had, and extraction of teeth and stuff like that. The knowledge was as good as they could do then. Most resident doctors or anybody else

knew nothing about the disease. I mean, when they would come in to see me, they would look at me and I don't know if they expected to see a basket case or what, but you know, they would say—they'd look at the chart once and they'd say, "This is Matthew," and then—I mean, I know what they were looking at, you know. I mean, they knew nothing about it and they would ask me the same questions over and over again, you know, like, you know, "Who had it? When did you know you had it?" Kind of the questions which sometimes were a pain in the neck, but I knew why they were asking because none of them knew anything about it. The care was the best I guess they had. Then later on we moved on to New England Medical Center with Peter Levine in Boston.

CH: How old would you have been when you made that move?

MV: That was—oh, actually when I was in my thirties or forties because we had gone to Boston City. I moved on to him and then he moved on to Worcester, so we went out to Worcester with him. Of course, when I was thirty, that would be what, the '60s or so? There was a little more knowledge of the disease, but still not a great, great amount of it, you know. And since I've moved back to Worcester back into Boston to the Brigham and Women's, and of course now there's a lot more knowledge.

CH: It's much easier, isn't it?

MV: Yeah, it's—I mean, people today if you say you're a hemophiliac, they know what you are because they see it on the news. They read it in the paper. They know it's a bleeding disease. Some of them don't know how it's treated and stuff like that, but it is treated much better now because these kids have all kinds of factors and stuff that they can live almost a normal life, which basically I couldn't at

the time. You know, I had to be very, very careful because it was just a matter of trying to treat the blood as it—you know, there were different variations. There was cryo's they had at one time and stuff. It's a lot easier now.

CH: Were you taught to transfuse? Were your parents taught to transfuse?

MV: Ah, no. No.

CH: So whenever you had an incident, you needed to go into Boston City?

MV: Yes, because there was no—there was nothing to transfuse at the time. I mean, it was just up until they got the factor VIII and stuff, all the things were basically done at a hospital or whatever, you know, because nobody knew about self-infusion or anything like that, you know.

CH: In those early years, how often would you say you found yourself going to the hospital?

MV: In a rough—oh, it's such a long time ago. Quite often. I mean, I would say quite often in my earliest years up until maybe the thirties or so or the forties. Say thirties or forties. I guess I got a little smarter and more cautious. Most of my problems growing up were trying to play sports and, you know, doing stupid things. Also, a lot of times I may not have to go into a treatment center. I might hurt an ankle or a knee or something, and I would just have to stay home for a couple of weeks or something and elevate it and put ice on it and stuff like that, because there wasn't anything else. At the time you couldn't infuse. I mean, now if you bump something, you're supposed to infuse and you know, rest it a little bit, but also you can be active on it. Back then it was just get off your feet, put ice on it, elevate it, stuff like that.

CH: How would you say overall it affected your school experience? Did you feel that you could really participate or did you feel different somehow? Do you feel you missed some of your school experience?

MV: Not so much in the school experience itself because I never was that type of person who wanted to participate in a lot of things. As far as sports, yeah, I couldn't get involved with any sports or anything because I would have to disclose my problems and this and that. Naturally, at that time I'm sure they would have said no, period, you know. But as far as my general education and stuff, I don't think it impaired me any.

CH: As we do when we're growing up, did you formulate ideas about what you wanted to do? Did you think ahead and think about your profession and start to develop your life?

MV: Not really, no. No, I mean I just felt I was going to go to grade school and high school. I had no intentions of going onto college. Maybe a—at one time I felt I might want to go to like a technical school or something, become a photographer. At one time I was hooked up with photography and there was a Wentworth Institute in Boston I thought I might go. Get into something like that, but no, that was just something, if it happened, it happened, and it didn't. I just went on and took what came along, you know.

CH: What about economically? Did it affect your family economically, all of the hospital visits and doctors? I understand that in the '30s it was very different, but was that a point of strain at all?

MV: I don't think so. I really forget if my father and mother had hospitalization insurance or anything. They probably did, but I don't recall them ever complaining about it or anything. We might have been getting free care, too, or something, I don't know.



CH: It was very different then and of course, Boston City may well have been free.

MV: Yeah.

CH: And your sisters were older than you are?

MV: One's older and one's younger.

CH: Well, you were diagnosed at age six, so I wondered if that affected your parents' decision to have children?

MV: Well, my oldest sister, she can't have children and she's a couple of years older than me now, so there's no chance. She never had any. My younger sister has a son—I don't think it really affected her. There's no problem with him or nothing. I don't think it affected them basically.

CH: But what about your parents? Do you think that affected their decision to have more children?

MV: I don't really know, but I don't think so. I think the three of us was plenty, I think.

CH: Right.

MV: Well, no, but you know, if like I was born in '34. My sister was born in '32. My other sister was '38. So let's see, '38, my parents, you know, they were in their thirties I guess by then or something. I don't think, you know, they were planning on any more children because basically I—you know, they had one girl, one boy and one girl. So I don't really think it affected them, you know.

CH: May I ask what their religious affiliation was?

MV: Catholic.

CH: And you are also, of course, Catholic.

MV: Yeah, Catholic but actually I go to a Greater Grace Church now. I'm not too involved with Catholic Church right now. I'm with

a Born Again Christian group.

CH: Looking back, apart from nonparticipation in sports and so forth, was there anything you wish had been different?

MV: Yeah, you don't mean—naturally, I wish I didn't have the disease.

CH: Of course. But given the disease—

MV: Yes. I wish—I wish they had known more about it, but you know, it's such a long time ago. Yeah, I wouldn't want people to be over protective and also I wish we knew more about the disease at the time, or they had stuff that they have today, medicines they have today. But that's something that will have to be in my next life or something like that.

CH: What was the first medical innovation in terms of hemophilia research that really impacted you?

MV: Let's see. Well, I guess the cryo's were—the cryo's, you know, when they had cryoprecipitate that was sort of a step up, but I guess the best thing that happened in the whole thing was learning to get factor VIII and self-infusion and stuff like that. The idea that we could have operations and things, if we needed them, with no problems or anything, you know. You know, I guess basically that because prior to that, any—they really never thought about operations or anything like that because of the amount of blood involved and stuff like that and everything. But once that came along, they do them—

CH: And how old were you when factor VIII came along?

MV: Gee, factors must have been about the '80s, I guess. I'd say roughly in the '80s. '70s or '80s.

CH: When you were in your fifties.

MV: Yes, and that was a big factor about the time of the people getting HIV, the viruses and everything because most of the stuff then was tainted and everything, you know, at the time. Fortunately, I never got AIDS. I had hepatitis C, but I went on a program about two years ago and got cured with that. But I've never had AIDS. I was one of the lucky ones. That was—so it was back around, it was '75, '70s, '80s when factor came out, which was a great, great, great thing for everybody because you could infuse yourself. I didn't because I didn't learn to infuse. It's only about—it's not even ten years ago, but my wife used to always infuse me, you know. But it was there for your people to use. That was the biggest innovation, you know.

CH: That must have been quite a day.

MV: Yeah, because you didn't have to no longer go to, you know, a medical center or a hospital. You'd call them up and you'd tell them you had a bleed this or that, and they'd tell you, well, you know, infuse because we'd send to the different places and get our [unclear] get our stuff, which I store downstairs. We have our needles and syringes and she'd infuse me or I'd infuse myself. Now I infuse myself and maybe take it easy for a day or so and then keep in touch with them. You didn't have to keep running back and forth like before.

CH: Do you remember when news about the tainted blood began to emerge?

MV: Yeah. Naturally, I was a little worried about it. I don't think I was too worried about it because I never—I was one of those people that never infused, probably when I should have. That's why I have—I have a bad knee and a bad ankle from constant bleeds in them and stuff, you know, and it's killed the cartilages and stuff like that. If I

was to come back in life, my next life, I'll know enough to infuse. That was one of the things they always used to tell me, "When in doubt, infuse," which I never did. They were saying, you know, if you've got a little pain or a twinge, infuse.

CH: They said that even in the early stages?

MV: Even in the early stages, always infuse because it's not going to hurt. When you could infuse, I should say. When it was blood that we got, you'd have to go to the hospital or something like that, and have them give it to you.

CH: Right.

MV: But the reason they were saying that was because it's not going to hurt you. You can infuse all you want and it won't harm you. It's just going to go in and make your blood healthier, you know. So infuse. You know, doesn't matter. I never got to that point. I'm better now today, but a lot of these things I have are injuries that are going to be there. They can't help them any, you know.

CH: Do you think some of that probably had to do with the fact that to get a transfusion, you had to literally go to the hospital?

MV: Yes, and also I think some of what I was thinking of at the time was insurance and what do you call it? You know, how much insurance you have, like two million or whatever it is. What's the word I'm thinking of?

CH: Health insurance?

MV: What's it—your cap.

CH: The cap. Oh, I see.

MV: I was always thinking of, you know, that I'm going to use up my cap or something, which I could never use up in a million years because, you know, if you've got a million dollars, I mean. These

young kids today, yes, because if they start at a smaller age, like say at five to ten years old, by the time they reach my age, they might have gone over their cap and they would have to recap or get new insurance. I would never have gone over my cap at the time. I never will now. So it's got to do with insurance and it's got to do with going back and forth to the hospital, you know.

CH: You said you'd elevate your leg, stay home from school for a couple of weeks.

MV: Yeah, I'd be out of school periodically here and there, you know. Constantly, you know. Naturally, when I went back, they'd say, "What happened?" I'd say, "Oh, I bruised my leg," or something like that. I would never say I got a bleed in my leg or something, you know. You know, you got your way through out of stuff like that, but you know, it's probably one of the reasons—you know, and then like I say, I never did infuse that much, but all you needed was one. I just happened to be lucky enough not to get it.

There was one time that Dr. Levine called and said—excuse me—that they had received a notice or something that there was a bad batch of Factor 8 or something like that, and fortunately I didn't have that batch, anyways. I didn't get it or something, so there was no problem. But other than that, I never really thought about it, and then after say the middle '80s and everything when they went to the heat treated and supposedly today there's no problem with any of it, you know.

CH: That was just roulette, wasn't it?

MV: Basically, yeah. Uh-huh.

CH: In that little period, that window of time.

MV: Yeah, but an awful lot of people, you know, got AIDS and stuff

like that. And, you know, I guess it's something that basically could have been dealt with better. I mean, I don't know. They claim that the drug companies knew about a lot of this. Whether they did or not—they might have. I mean, I know drug companies make an awful lot of money. You know, I mean just with general medicines today, prescriptions and stuff are unbelievable. Whether they knew and didn't want to do anything about it, who's to say? It's all politics, I guess.

CH: Did you follow it very closely?

MV: Not as—not that close. I mean, I, know you, kept a little bit here, a little bit there and what I heard through the groups and the Hemophiliac. I guess probably because I wasn't infected with it, maybe that, said to myself, "Well, I feel awful bad for everybody, but it's not my problem," you know, "Or it's not me."

CH: It's not you, right.

MV: Which wasn't probably right, but—

CH: Well, you have your own concerns to deal with.

MV: Well, I think it's like a lot of things. Even today, we find that in these groups and everything we go along with, a lot of the young mothers and everybody, nobody gets too involved with anything until it affects them personally, you know. You know, like I guess everything in life, you don't get involved until it affects you personally, you know.

CH: I think that's true. Tell me about the groups. When did you start participating in groups?

MV: I believe we got involved with the New England Hemophilia about—oh, it's got to be twenty years ago or so maybe, twenty-five. You know, through going to New England Medical Center and

finding out that there was a Hemophilia Association and stuff like that. There is—I don't know if you're familiar with them. They had their office in Dedham there, or—we go out to Dedham and we volunteer a lot because I'm retired now and my wife works part time. We'll go out and help them do mailings or stuff, you know, clerical work. Or they even come here, bring the mailings here and we do them here, you know. We're pretty much involved with them when they have any kind of events or anything, we kind of try to help them with other people and stuff. So it's been about, I'd say twenty-five years ago, which would have been what? About the '80s or something?

CH: Did you join groups where you talked with other people who had hemophilia?

MV: My wife went to a bunch of teas and stuff like that and we used to all, any seminar or anything that they had, you know, and if people asked questions, we'd try to help them. But as far as actual joining, I don't think there was any like membership or joining. It was just, you know, they had different things going on and you would attend or you wouldn't attend.

CH: But not support groups where you'd go and sit with other men and talk about your experiences and so-forth?

MV: They had a few. They had a few and if they were there and we were available, we'd go and talk to them, you know.

CH: So you graduated from high school.

MV: Uh-hmm.

CH: And then what did you do?

MV: Let's see. I went to Newman Preparatory School in Boston for about six months or so and then for some reason I just left. I just went

on to work. I think most of my early jobs were just doing clerical work or shipping and receiving and stuff like that. Then eventually I got into truck driving and I drove a truck for like forty or forty-five years, you know, for different outfits and stuff.

CH: Long distance?

MV: No, just within the state, you know. All within New England states.

CH: You did not reveal your hemophilia?

MV: Not to anybody, no.

CH: Did it ever pose an issue for you in your work life?

MV: No. I mean, I did have to, like I say, take time off here and there, but I always managed to, you know, say this happened, that happened, whatever. But, no, it never came to a problem where I actually got a bleed or a cut or anything right there at work, or anything like that, that I was involved with that. I might have bruised a leg or something and I kind of limped through the day and then came home, or something like that, but I never got any serious wounds or cuts or accidents that I had to deal with right on the job.

CH: As you say, you probably become very canny about how to take care of yourself.

MV: Yeah, you kind of—I guess you learn to deal with situations and things and you learn to, you know, kind of get through things. You know, like I remember one time someone said, “Don’t say you have hemophilia. Just say you have a factor VIII deficiency,” you know, which sounds a little better. It means the same thing, but when you tell someone that, it kind of stumps them and they don’t ask any more questions. They don’t really know what it is, I don’t think, but it suffices them, anyways. If you said to them, “I have hemophilia,” you



know, which is a factor VIII deficiency or a factor IX, I mean, all kinds of whistles would go off and they'd start asking questions, you know.

CH: That's a very interesting thing because it's true.

MV: Yeah, that's all it is, is a factor. I'm not lying. It's a factor VIII deficiency. It's just I'm using my terminology, rather than saying what it actually is, you know.

CH: Were there questions surrounding your choice to get married and have children?

MV: Not really. There might have been a minor, but not really, you know. It wasn't a big issue.

CH: Was that something your parents talked about with you or again, was there so little information that basically you just found your way.

MV: There was so little information, and I think my mother had—I don't know if it was my mother or father. One of them—my mother I think passed away. My father was still living I think when—but—yeah, no, it was never—never really entered the issue. I don't know if it was that big a factor at that time. I think it's a lot more today than—like my daughter is a carrier and she had a child, it happens to be a girl. There was an issue of, you know, whether it would be a boy and be a—there could be a fifty percent chance he would be a hemophiliac, fifty he wasn't, you know. They chose, you know, to find out if it was a boy or a girl. It was a girl. If it was a boy I don't know if they just would have, you know, went along with it or what, but—I think it's more today than it was in my era because I've been married thirty-five years or so, you know.

CH: Did the doctors talk to you about the implications of getting

married and having children?

MV: No.

CH: They never brought it up?

MV: Not in a big issue. They might have brought up the fact that there is that possibility, you know, but I don't think that in my—going back, let's see, 19—let's say forty years. Would be what? '62, back around the '60s or so, I don't think it was as big as it was today. They might have said, you know, "Possibly when you get married, there could be this or that," but it wasn't a real big, I don't think, issue.

CH: It wasn't something you struggled with?

MV: No, no.

CH: And you met Eleanor when you were how old?

MV: Oh, well, I was in my thirties, I guess. Actually, I was married twice. My first wife, who I had a son by, that's my older grandchildren. That was back about '60, '61 or '2 somewhere back then, and there was really no big issue with that. And then I remarried again in '68 to Eleanor and I was—well, at that—let's see. '62 I would have been thirty-four or twenty-eight or so, and then another—I was in my thirties when I married Eleanor, so there was no real big issue. Because maybe we didn't know that much about it, too, you know. It was just after we got married and stuff that we started to get more interested with Eleanor. With more interested with Peter Levine and with New England Hemophilia Association to find out more about my disease. Prior to that, I was just kind of like, "Well, I have it," and just forget about it. It's there, it's there, but she was interested and she more or less encouraged me to learn more about it and deal with it better, you know, because it was going to be—whatever we had children and stuff like that, it was going to affect everybody, you

know.

CH: You told your first wife, but it was not a big issue for her?

MV: Yeah, not a real big issue.

CH: And she wasn't proactive in the sense that she didn't pursue it or want to know more about it?

MV: No. No.

CH: You had your son.

MV: Uh-hmm.

CH: And was he tested?

MV: I don't really even know if he was. I think he has a—as of now, I mean, that we just know. He has a mild case of Von Willebrand's Disease, but he doesn't have hemophilia. His daughters have—he has two girls and a boy. They have a mild case of Von Willebrand's, which has nothing to do with me. We went through this, you know. Some hemophiliacs have both, hemophilia and—I only have the hemophilia. It always came up naturally that, you know, it's my fault because, you know, they had that, but it isn't. We diagnosed this with my people in Worcester and everybody and it's a genetic disease or something that has nothing to do with me. They have it, and they got it from either my wife's side or her, the mother's side or whatever it is, you know, or something like that.

CH: When it came up, when they discovered they had Von Willebrand's, did you feel that they were disturbed with you?

MV: Not disturbed, but I think like anything, they might have—you know, someone was trying to put the blame on someone. You know, saying—not in a real vicious way, but you know, they did kind of say, you know, it's Mattie's fault, or something like that, you know. But not in a vicious way, you know.

CH: That's our nature, isn't it?

MV: Yeah, but now they realize that it had nothing to do with me.

CH: And presumably your son was fully informed when he married?

MV: Yes. Yeah, uh-hmm.

CH: So he knew.

MV: Yeah.

CH: Then you remarried and Eleanor was much more proactive.

MV: Right.

CH: She wanted to know more about it. When you told her that you had hemophilia, she presumably accepted that?

MV: Yeah, uh-hmm.

CH: Was there discussion around whether to have children?

MV: No, I don't think so. No, I don't think so.

CH: You just decided to go ahead?

MV: Well, I think also because we didn't know that much about it at the time, too. It was because of our, you know, not knowing, ignorance of the knowledge and stuff like that.

CH: Ignorance was bliss.

MV: Yeah, like they say ignorance, you know, of knowledge in specific things is bliss, you know. I think we didn't really understand or know too much then, so we went ahead. Then we found out. We kind of got more educated on what's what, you know?

CH: Were you surprised at some of the things you learned?

MV: Ah, yeah. Yeah, because, you know, I just kind of knew the basics. But, you know, basically it was we got more interested in it because, like I say, I had the disease and now I was trying to find out more about it. You know, there's certain things still about the disease that I don't know and, you know, I'm at that point I guess in my life

where I probably know as much as I'll ever know or want to know and I can handle it and everything. Maybe the younger children today want to know more about it, but then again, I don't know if they really do because of the way they're able to handle it a lot better than I was with all the new things out there and stuff like that. And then hopefully, I don't think it will ever happen in my age, but they're talking about, you know, gene therapy where some day it may not be there, you know. But hopefully it won't, you know.

CH: Hopefully it won't. It will be one of the things people used to have.

MV: Yeah, and then they'll say, "Well, you know, forget about it," because they've cured it, and then another disease will come along, you know. But it will help someone, you know.

CH: Do you counsel or talk to young people? Have you ever worked with them one-on-one?

MV: No, I—only if I go to a meeting or something, like a tea. Well, teas were my wife, but only if they have some kind of a different—people have groups or New England Hemophilia might have different seminars and things like that. I'd go to them and I'll talk to them, you know, if they would like me to, or if someone asks me a question. I don't usually get up and be a public speaker. The hardest part I find is trying to convince these young kids or young people today about like basically like what I went through, from having nothing to where they are today. You know, it's like me saying—you know, it's like me saying, you know, "You don't know how hard it was when I was a kid growing up. I mean, we didn't have television and we didn't have this," and stuff like that. You know, they don't want to hear that stuff. You know, I mean, all they want to do is know what's going on today

and I stay, “You guys are so lucky to have this here.” I think they still resent the fact that they have the disease, which that will never come about, but it’s a lot easier to handle today than it was when I was a kid. I try to help them as much as I can, you know.

CH: And it’s a lot safer.

MV: Yes. Yeah, uh-hmm.

CH: How has it affected your overall health? You say that you have pains in your joints.

MV: My overall health? I think I’m fairly healthy, you know, other than my—I have a bad left ankle, a bad knee. The right ankle is pretty good. My other joints are basically—my general health, I think I have really no problem. I mean, as far as, you know, I see a regular pediatrician. I go to see my hemophilia doctor. I was in the trucking business for like forty-five years. I mean, I don’t get too many colds that I find. Last time I was hospitalized, I can’t remember. I’ve gotten more careful, I guess, as I went along, but my general health is in pretty good condition. I have high blood pressure, but I take a pill for that. I take vitamins. I try to exercise. I try to keep my weight down.

CH: Presumably you never had to have surgery as a child?

MV: The only surgery I ever had as a child was extraction of teeth, and that was a holocaust because—

CH: I’ll bet. How old were you when that first occurred?

MV: Oh, I would say back in my teens or something like that, you know, which would have been in the ‘40s or so, you know.

CH: Can you describe that experience? How did you handle it?

MV: Well, what they would do is basically, first of all, back then I guess my parents never sent to the dentist that often or something. I

guess we weren't dentist freaks or anything, which a lot of people weren't. Today we are. I mean, I go to the dentist all the time and everything. You know, every six months and everything, and naturally my teeth decayed or whatever and stuff like that, and I had to have some teeth extracted. I don't know, it was like—well, back then they would probably only take a couple of teeth at a time, too, because they were very leery about doing it and then they only would take so many out, you know, because they didn't want to get involved.

CH: Right.

MV: What they would do would be they would put you in the hospital and you would—

CH: Because of the hemophilia?

MV: Yeah, and they would give you pints of blood, the whole blood. You know, you'd have to—you'd either have to have people come in and donate blood for you or they'd take it from the blood bank and then they would replenish it or stuff like that. They would fill you up with blood. How many pints I don't know, before the surgery. Then they would do the surgery with the one or two teeth, whatever it was, and then they used—I thought they used to—they would pack it with a thing, I think they called it an oxycell or something like that, which was supposed to be some kind of a coagulant or something. They would put like a mouth—they would take an impression of your teeth, almost like what people wear today as a mouthpiece, almost, you know. Close your mouth, they would strap your head with gauze bandages so you couldn't open your jaws.

CH: And they put this device over the place where the tooth had been?

MV: Well, where they—when they pulled the tooth out, they would

then put the oxycell on the gum, I guess the hole in the gum to try to stop it from bleeding, put the rubber thing over it or something. You know, you'd bite down and they'd strap your head with gauze so you really couldn't open your jaw. Then I'd have to eat liquids for about two weeks or so, you know, all kinds of frappes and things or whatever they had at the time. You weren't supposed to move your mouth at all. I was in bed. You know, you weren't supposed to—too much activity or nothing, you know. They would check the thing every, I don't know how many days in all. Naturally, it would just ooze and ooze. At first it would bleed so much and then it would bleed, clot and then as the clot would come off, it would bleed more. Eventually it would heal, over maybe a couple of weeks or so, you know. It was a terrible process, but it was all they knew, you know. There was a lousy taste in your mouth. There was all kinds of problems with fungus and everything there, and you'd lose weight and everything, naturally, because you weren't eating and stuff, you know.

CH: So having a tooth out was a big deal.

MV: It was almost like no such thing, but it had to be done, I guess, so they did it. Today it's a lot different. I mean, I had a tooth out a couple of—I don't know if it was ten years ago or not. I infused with my Factor. I went to the dentist. Oh, I had a tooth out and then I also had gum surgery or something a couple of years ago or so. Same thing, you just infused before you went. The tooth extracted, I went to the office. It was in Worcester and I went there. He took it out.

There was no bandages, no oxycell, no nothing like that. Just came home. I was taking a pill—I can't think of the name of it now. It's a coagulant, too, plus my infusion for the next few days. Went back to work the next day, you know. But the surgery, I was retired at the



time with the surgery here a couple years ago. He did my gums, or whatever it was or something, you know, the impacted or whatever he had. I infused and went back to see him in a few days, and, you know, it oozed a little bit for a couple of days or something. Kept on infusing for like the week or whatever it was, and no problem whatsoever, you know.

CH: What a difference.

MV: It's come a long way. It's almost like you having a tooth out.

CH: Yes.

MV: A little bit more cautious, but basically about the same. So you can go to a dentist and have it extracted. Of course, the basic thing is don't let the teeth get that bad and stuff, you know. But, yeah, when I was a kid, it was terrible. I think I had it done twice because I think they had to do one part and then they had to come back and do a couple of other teeth. But it was—

CH: They did this with gas, did they, in those days?

MV: I don't know if they would have—

CH: They didn't have Novocain.

MV: I don't think they wanted to stick needles in you, anyway.

CH: No.

MV: Now, like if I go, I haven't had any—too many fillings for a while, but they do use Novocain. They stick you. Usually when I go to the dentist now, I usually infuse myself before I go and if there is any problem when I come back, which there hasn't been, I would infuse myself again. But, yeah, any kind of operation was a holocaust back then. I mean, whether it was an appendix. Fortunately, I never had an appendix. Never had surgery, other than that there. I mean today I could go—I could go and do anything. I mean, any kind of

surgery and, you know, they have day units and everything and they follow everything up, you know.

CH: What about injections, the normal childhood injections that you have. Were they an issue?

MV: I don't really know. I think I was so young that I don't really know, you know. Today, let's see, I haven't—excuse me. I really haven't had any injections, other than—I don't get the flu shot because I never really get too many flues, so I figured leave well enough alone. I don't know if that's a problem because that's an intramuscular thing or something.

CH: I didn't know about smallpox, but that's actually just under the skin.

MV: Yeah, that's such a long time ago. When I did have the hepatitis, I had to inject into my stomach here in the soft tissue, but that needle was so small and everything that it was no problem. When you infuse, you infuse into the vein, you know, so it's a little bit different. Yeah, I guess there's always a fear of needles, but I mean they draw blood from me and stuff like that, you know, but I really never have any problem with it, you know.

CH: Tell me about finding that you had hepatitis and what happened in that process.

MV: Well, I guess I must have contracted it from the, not the factor, but from blood transfusions that I had over a period of years, or something like that. I don't know if it really—how it affected me growing up or nothing. It was just laying in my system dormant there, but their thing was that it could lay there for the rest of my life, it could erupt sometime and it could affect my life. I was aware of it, but I guess I was—I was saying basically, "It's there. What's it going

to do?" you know. I mean, their concern was that I guess if it erupted—

[end of Side A, Tape 1]

MV: --when they were doing my hemophilia clinics or anything, you know, it would always come up and they knew it was there and they'd more or less say, "It's there and it's Matthew's"—"He's living with it," or something like that. When I—it was just when I changed doctors a few years back to Brigham and Women's, because we figured all these years I've been going out to Worcester, which isn't on the other side of the earth, but it's a little further away, you know.

CH: It's a ways.

MV: And you know, they said, "Well, there's awful good doctors here in Boston that you can go see," you know, and geographically it's closer. I'm getting older and my wife's getting older and so we decided to come here. When we first came here, I already went through like three doctors. The first one was Dr. Ewenstein and he left. Then Dr. Marks, he left and I was saying, "Is it me or, you know, should I go back to Worcester?" [laughs] Now we've been with this nurse practitioner, Elyse Mandell I think is her name. I don't see her that often. Like it's like about twice a year, you know, and because they're right there in Boston, I can call them and stuff like that, if I have a problem, which I don't have many problems. You know, I can't remember the last time I infused. I mean, people will say, "When was the last time you infused?" I don't infuse every day. I only infuse when I think I've got a bump or a bruise," you know, and I try not to get those, you know. But anyways, when I—it's just when I went to Brigham and Women's, they sent me to see a gynecology—not gynecology, that's—

CH: That's ladies'.

MV: Ladies. What's the—gastro—

CH: Gastroenterologist?

MV: Ologist, yeah, right. They have to do with I guess the kidneys and stuff like that and everything.

CH: That's right.

MV: Right, and they knew, you know, I had it. I guess they were running—at the time they had been running surveys and stuff about people with hepatitis C and they were trying to cure people with this particular drug. Happens to be interferon. Mine was peg-interferon, which is a drug that takes, a medicine that takes care of leukemia.

Same medicine, but it works like in different ways. And they sent me to see the doctor and his name was Grace, Dr. Norman Grace, and he said, you know, that there was a possibility that they could cure it. There was no guarantee of anything. He told me the side affects. There's a lot of side affects from the drug. Basically, it kind of zaps all your strength out. You lose your appetite. You lose weight.

CH: Like chemotherapy?

MV: Sort of, yeah. You feel fatigued.

CH: Nauseous?

MV: Sometimes. My biggest problems was I lost weight. I lost about thirty-five to forty pounds. My appetite was suppressed. I didn't feel like eating. I was very tired. I'd come up a flight of stairs from the basement and I'd be huffing and puffing and a couple of times I felt like I had the flu or something like that, but basically the most of it. Some people experience different affects and stuff. I went on the—so anyways, their idea was that it could erupt. It could not erupt. They said—here I was, I think I was about sixty-eight at the

time and I was saying to them, “Why do you want to put me on this and cure me for this? I’m probably going to die in ten years or so anyways,” and they said, “Well, that’s not the way to look at it.” They said that you could—“You might live to be a hundred, if we can cure this,” or whatever it is, you know.

CH: Why did you think you were going to die in ten years?

MV: Well, always say people to that. Why fool around with a seventy year old men when you can get a seven year old kid and help him. I mean, my life is pretty well—I feel, pretty well, you know, gone. I mean, but it’s not true really. I just kind of joke about that. I could live to be a hundred, but I usually say, “I’m seventy. How much longer am I going to live?” you know. I was just kind of being a wise guy, something like that, you know. But anyways, they said, “If you want to try.” So I said, “I’ll go on it,” so I went oh the program for about forty-eight weeks I think it was.

CH: And how old were you when you did that?

MV: Sixty-eight.

CH: Retired?

MV: Yes, and that’s another thing. Basically, to go on this program you’d have to either be retired or take some time off from work or school because it does exhaust you, in a sense. So I only infused once a week, usually on Sundays, and it was only a minimal, oh, a minimal amount. It was called peg-interferon, which is the same as with leukemia.

CH: Forty-eight weeks.

MV: Pills. I took some pills. I think it was Ribavirin or something like that. It took like five a day: two in the morning, three at night, or three in the morning and two at night, something like that. After

about—they check you like after you infuse for once a week for forty-eight weeks, but after I think it's like the first week or two, you have to go in and see them and then after that, it's like every second week and then every third or fourth week. As you get more into the program, it's less and less, but they watch you very closely the very first three months of the program. Basically, they want to see if there's any changes in your blood and everything and also if the side effects are causing any problems with you. In my case, after like three months they couldn't even find the virus anymore and the side effects weren't that great. I was dealing with them, you know, and then after six months they still couldn't find any virus, and I still had the side effects. I was losing more and more weight, you know, because I went from like about two hundred down to about one sixty. They were concerned after about six months about the weight. They didn't want me to lose anymore weight, you know, because they wanted me to stay like around one sixty. Actually, they put me on a program with this Ensure and stuff like that, you know, to put—I'd drink that and everything, but I might have minimized it. It helped a little bit, but I don't really know. But I didn't lose any more weight over the next six months, but even after six months they couldn't find the virus. Everything was going fine. I said, "I'll struggle with the virus." I mean, the side affects. After nine months it was the same thing, no virus, no nothing. "Can you handle the side affects?" At one time they thought possibly they would take me off the program, but then they said "If we've already gone nine months, you know, if we don't go to the extra three months and it does come back, they might say 'Well, gee, we went all this way for nothing. We should have stayed.'" So what they did was they cut my medicine down a

little bit for the next three months, the last three months of the system. It never showed up. It never came back. I gained about ten pounds or so after I got off the program. I've been off it now for a year and a half to two years or something like that, and they can never find the virus. I've had my blood checked, you know, periodically from different doctors. Still can't find it. I don't feel has tired, and I put some weigh on back, but I don't want to put it all back on, and stuff like that. So in my case it worked out good for me, you know.

CH: It did, didn't it?

MV: Yeah, basically. Maybe I'll live to be a hundred.

CH: Did you have a health policy through your retirement plan that paid for this?

MV: Yeah, we tried to get, you know, the company, the drug companies to do it, but we couldn't get that. Fortunately, at the time I only had to pay I think it was fifteen dollars for the peg-interferon and fifteen dollars for the Ribivirin, which I used to get like a month's supply at a time. So it was costing me about thirty dollars a month, roughly. That was a big issue. If I couldn't get my prescription, my people to pay for it, I wasn't going to go on it, unless I could get them to pay for it, a grant or something because the medicine itself is very expensive. I think it's like, something like. I don't know if it's twelve hundred dollars just for the one shipment of four peg-interferon and another twelve or even more. It's probably about three thousand dollars or more per month, you know, but it only cost me thirty and naturally I was able to claim that on my taxes and things. So it wasn't a big problem, but, yeah, cost was a factor.

CH: Oh, it would be a factor.

MV: Yeah.

CH: That's a huge amount of money.

MV: Definitely, yeah.

CH: And for something that isn't affecting you in an overt way.

MV: Right, yeah. Uh-hmm.

CH: Is there any doctor in all of this experience that really stands out for you, a nurse, or somebody who really made a difference for you?

MV: You mean that kind of helped me along the way and everything?

CH: Yeah, not only physically, but emotionally.

MV: As a kid growing up, yeah. Dr. Bigelow, he was very, very helpful, very knowledgeable. I mean, I can picture the guy. He's a tall, thin English man, blonde hair and everything. He was very knowledgeable at the time because I'm going back a lot of years, you know. He helped my mother and father, which they knew nothing about it, and he tried to help us about and where it came from and everything, stuff like that. Then, of course, as we went along, I believe just recently there's this—in Brigham and Women's Hospital there was this nurse, Helen Mahoney West was—she was very, very helpful and she—I had known her for years. I'd seen her at a lot of functions and things and she was kind of always, you know, not begging me to come to Brigham, but she was always saying, "You probably should think about it. There are very good doctors." But she was very helpful in anything we needed. I wasn't even a patient of hers and I could call her and she would give me knowledge and information and anything I wanted. Since—she's also left, since I went to Brigham Women's, but that was only because it was a point in her life where she moved on to different things. But she had been with Brigham for the longest time. She was very helpful and Dr.



Bigelow was very helpful. You know, I mean, the doctors I have now are good, but they kind of—kind of stood out in my life, you know?

CH: Yes,

MV: Not that anybody was bad.

CH: Oh, no. I'm looking for the people who went the extra mile with you.

MV: I think they went the extra mile.

CH: And Dr. Bigelow, you would have seen him at what age?

MV: Oh, back about, let's see, '40, '50. Around the '50s, I guess.

Yeah, he was after Dr. Dameshek. I'm not sure what happened to Dr. Dameshek. He was the one who diagnosed me, and I don't know why we moved onto Dr. Bigelow, but it would be back about the '50s, I guess. Yeah.

CH: Do you think it took a real toll on your mother?

MV: I don't think so. I mean, I'm sure she was concerned, you know, but I don't—no, I don't think it stressed her out that much. I think she didn't know that much about it, too, other than she wanted me to be—don't do anything. Just be very, very careful about everything, you know.

CH: I think there's a modern day attitude that it isn't fair, and I don't feel that you ever felt that way. It was something that happened. You dealt with it.

MV: You mean?

CH: You were talking about how differently some of the young people approach it today, and quite rightly you say, "Well, it is much easier."

MV: Yeah. Well, no. Yeah, I think it was case of back then they didn't know much about it and they kind of just accepted that it was

there and, you know, they just said, “Don’t do anything like this.”

Today I think the mothers and fathers, a lot of them know about it when they’re going in. They know that someone in their family had hemophilia and the girl’s going to be a carrier, in that sense. Some don’t. There are these people that come up and they say, “We’ve got no history or nothing. I don’t know this involves, how it gets it.” They’re a little more shocked, naturally, because they don’t know anything about it, but people that know their brothers or someone had it and there might be a possibility.

CH: It’s a possibility.

MV: They kind of—they deal with it. It is still a shock, too, because they’re hoping, you know, when they have a child that they’re not going to have a hemophiliac boy or something like that, but it’s a little easier to deal with, knowing that it was a possibility and that there are medicines and things today that they can lead normal, basic lives, in a sense, you know, and there is help out there for them. You know, not all of them look for it or get it. A lot of them still, I think, feel that, you know, “Well, why me? I mean, it was a possibility, but I have a child now.” They’re a little resentful, but—

CH: You never were?

MV: Yeah, I guess basically in life, to this day, I say, “Gee, I wish I never had hemophilia.” You know, there’s a lot of sports things. Basically, a lot of things I probably wanted to do, but I didn’t, and I’m probably a little resentful that I got a bad knee and a bad ankle, but that’s not—that’s not their fault. That’s my fault because I didn’t, you know, infuse myself or take care of myself when I was younger. So I guess I have to, say, slap myself for that, but as far as—you know, naturally, I mean, nobody wants to have a disease, you know, but

everybody has something.

CH: But you dealt with it.

MV: Yeah. I mean, I dealt with it more as I got older because I guess you get smarter, you know. Just like anything, I mean, you should get a little smarter as you get older. Kids that don't have the disease do things today they shouldn't do, and later on in life they say, "Gee, I did this. I did that. You know, what a jerk I was," you know.

CH: As a child, did you dread the transfusions? Did you dread the hospital part? No child likes needles.

MV: Yeah, I guess I really didn't like to be stuck with needles and I didn't particularly like transfusions and stuff like that, but I dealt with.

CH: Even then, when you look at the needles they used.

MV: Yeah, they were bigger.

CH: So it was not a nice experience.

MV: No, it wasn't. I mean, today I don't particularly like needles either, you know. Someone always said—I guess somewhere along the line, someone said, when they're going to take blood or anything, stick you with a needle, turn your head so you don't see it because when you're watching it, you know exactly when—

[recording ends here, but obviously the interview continued]