

Interview with Roy Arruda for the Boston Hemophilia Center Oral History Project, A Gift of Experience, by Christine Harland, August 23, 2004.

HARLAND: I'm going to start at the beginning and ask you a little bit about where you were born and the circumstances under which you were born.

ARRUDA: Okay.

CH: I think you were born in the Azores.

RA: Correct.

CH: A Portuguese Island, and how many people were there in your family?

RA: There were five people.

CH: Five children?

RA: Five all together. Two parents, a sister and a brother. I'm the oldest.

CH: And what year were you born?

RA: I was born in 1960. October 9, 1960 is my date of birth.

CH: Tell me a little bit about your father, what he did.

RA: In the Azores he graduated from a technical school and he worked as an engineering technician. He worked for a company that manufactured soap, cooking oils and animal feed.

CH: And your mother worked?

RA: No, she didn't. She stayed home.

CH: You went to school in the Azores?

RA: I did.

CH: Until what grade?

RA: Fourth grade, and then at that time I was pretty sick with my hemophilia and we came to this country.

CH: When were you diagnosed?

RA: With hemophilia? When I was six months old, I fell off the baby carriage and cut my lip and my parents couldn't stop the bleeding. They took me to the doctor and that's when he diagnosed that I had hemophilia A (factor VIII).

CH: Was there a family history?

RA: Not that we know of.

CH: So this was a complete surprise?

RA: Yes.

CH: And presumably they didn't have many resources for dealing with it.

RA: Correct. As a matter of fact, the doctor that diagnosed my disease, Dr. DeLima, a Portuguese doctor, said it would probably be best to let me die if I developed a major bleed, just let me go because there wasn't much he could do for the disease. Because he knew the disease. He was familiar with it, but resources were not there, especially on the island.

CH: And your parents brought you home and they certainly weren't going to do that. What did they do? How did they go about dealing with the news?

RA: Okay, well, they kept researching things out. They kept doing whatever was best for me. They kept learning as much as they could about the disease. Yes, so they learned as much as they could about hemophilia and what to do and what not to do and all they could do is give me blood transfusions. We had three adults on the island that we knew, friends—so we knew that those three individuals had the same blood type that I had. So when I developed a major bleed in my joints or the major muscles in the body, my parents would take me into the

hospital and we would take along one of the so-called friends to donate blood, and then their blood would go into my veins, and that's how we would control the bleeding.

CH: So there were only three people on the island whom you could identify who had your blood type?

RA: Yeah. That doesn't mean there weren't others, but—

CH: Those were the only three you could find.

RA: And who were willing to help out.

CH: And I assume that the medical system wasn't wildly sophisticated.

RA: No, it wasn't.

CH: It was basic.

RA: Very basic stuff. I mean we had to bring our own blood donor because the hospital, the doctor did not recognize this as a 911 type of emergency. A lot of the bleeds we just took care of at home. I just stayed home away from school and suffered the pain.

CH: You stayed at home, stayed in bed.

RA: Yup.

CH: What were your parent's educational levels?

RA: Well, my father graduated from technical school. And my mother third grade, which is the equivalent of a completed grammar school in this country.

CH: So they were very proactive in terms of helping you, for all of you coping with this?

RA: Uh-huh.

CH: Were your brother and your sister older than you?

RA: No, they're younger than me.

CH: Did your brother have hemophilia?

RA: Yeah, he did. He died, 1995.

CH: He did?

RA: He died nine years ago from complications with HIV and Hepatitis C.

CH: So it's been a long, sad walk for your family, hasn't it?

RA: Yes.

CH: What about school? You were six months old when you were diagnosed. Did you start school in the Azores?

RA: Yes, I did. I completed four years of grammar school. I flunked two years because I was spending more time at home babysitting bleeds than I did in school and I couldn't keep up with the work. But I managed to survive four years. I didn't graduate because we came to this country in '72.

CH: I know you were very young, but did you feel part of school or did you feel isolated because you weren't there a lot of the time?

RA: Yes, I was always different. It was always, "Don't do that, you're going to get hurt. Stay away from the swings," or "Stay away from the soccer field," or what have you. So, in school, I was always the guy in the corner or the guy that didn't participate in sports I think because I was afraid that I would get hurt or the teachers were afraid I would get hurt.

CH: The teachers knew about your condition?

RA: Yeah.

CH: And the pupils?

RA: Most, yeah.

CH: And were people understanding of it?

RA: Some. Others weren't because they just didn't understand it, so they were afraid it was contagious. They would stay away from me.

So it was a mixture.

CH: And that compounded your isolation, of course.

RA: Yeah, it did.

CH: They were hard years.

RA: Yeah. You know, my parents always encouraged me to play and be active, with my cousins and my neighbors, but school was different. In school I had to stay put, you know.

CH: So your parents were not over protective? They did encourage you as far as possible.

RA: Yeah.

CH: To participate.

RA: Yeah. Yeah, playing in the yard, soccer with my brother.

CH: Did you have a big extended family, grandparents, aunts and uncles?

RA: We all lived in the same neighborhood, same village.

CH: And they were all supportive, presumably.

RA: Yes.

CH: So you had a network.

RA: Yes, a family network.

CH: Which was very important, I would assume.

RA: Yes.

CH: And took care of some of the loneliness, at least.

RA: Yeah, yeah, it helped out.

CH: And your father made what must have been a huge decision for him, the decision to come here. Tell me about that decision.

RA: It was more my mother's decision.

CH: Was it?

RA: Yeah, he was kind of hesitant to come because it was a big

move and we had a house there, jobs. I mean we had everything, really. My parents knew that there were two countries that they could go. One was Russia, which had factor products, and the other was the US. In 1972, you didn't want to go Russia—well, we didn't want to go to Russia. So my parents decided that my mother and me would go to the United States and be treated. Although we understood quite a bit about hemophilia, we didn't know there was no cure for it. We thought there was a cure.

CH: I see. You were looking for a cure.

RA: We were looking for a cure. So my mother and I came to the U.S. We stayed with my uncle and aunt and we went to Boston, Boston Children's Hospital. We met with the people up there, the hematologist and the orthopedic surgeon. Back in those days, your primary care physician was an orthopedic surgeon, not a hematologist. Dr. Manson.

CH: Dr. Manson?

RA: Manson, yes. He's no longer there. He may be doing consulting. So we met with him and he informed us there was no cure, but I could live a fairly normal life with the factor products, with cryoprecipitate, back in those days. So now we came home, back to my uncle's house in Fall River, Mass. We felt depressed because there was no cure. We didn't go back to the Azores. My mother said, "Well, I'm staying here. I'm not going anywhere."

CH: That's what your mother said?

RA: Yeah.

CH: So she did not go back to Dr. Manson?

RA: No, we did not go back to the Azores.

CH: Oh, I see.

RA: We stayed in this country and we decided that, okay, this is the best for me. It would be a good thing for my parents, for my father and my brother to come to the United States and reestablish the family here and start from scratch. After four months, six months living with my uncle and aunt, my brother came over to the States. He also had hemophilia, but he wasn't as severe as I was at the beginning. I mean he played and he never got a bleed. I was the one having more bleeds than not having bleeds. So he came over to the States by himself and moved in with us in my uncle's house. It was a small apartment: two families, three people. So we were kind of squishing out each other, so then we decided, okay, it's time to call dad over. So dad comes over. He sold the house there, the car, some land—not all the land. We kept some land because we weren't sure what was going to happen. He came over. We found an apartment. My father got a job and then we started from scratch again.

CH: When was your brother diagnosed? You were diagnosed in 1960.

RA: To be honest with you, I don't know.

CH: When was he born?

RA: He was born in '64, so I don't know if it was diagnosed when he was born because they already knew there was hemophilia in the family or if it was later. I don't know the answer.

CH: Where do you think your mother did her research on hemophilia? There wasn't the Internet, of course.

RA: Talking to the doctor and the nurses there. Particularly the doctor, because he was a smart guy. The government paid for him to go to medical school and he went to Portugal, the mainland. A lot of the people there also traveled to the US for training or other places in

Europe, England or Spain. So he had access to a lot of information that he would feed to my mother and father. So that's how they got the education about hemophilia.

CH: Did you get to know any other people with hemophilia in the Azores?

RA: No.

CH: So you remained isolated?

RA: My brother and I were it, that we knew of.

CH: So your father came up to the States and your sister, presumably.

RA: My sister was born in the States.

CH: Oh?

RA: She was born in '75.

CH: I see. Where did your father get a job?

RA: He worked at a boat yard, working assembly, engines or doing something on boats, and he didn't know much about boats. You also have to remember he didn't speak English so he had to get a job wherever they would take him.

CH: Just out of interest, was that very difficult? Did it take him a while to find a job or did he find one quite easily?

RA: It wasn't too bad. We had a good connection of people here through my uncles and aunts who knew others, so it wasn't too bad to get a job. It wasn't a great job, but something to help pay the bills. He didn't make a lot of money.

CH: And did it give him health insurance?

RA: Yes.

CH: Which was crucial.

RA: Which was crucial, but that's another nightmare because every

chance the insurance got to refuse payment, it would, as far as blood products. Cryoprecipitate, I don't remember the price for it. It wasn't cheap. A stay in the hospital, I'd average three days every other week, this continued for a year or so. That's expensive.

CH: That is very expensive.

RA: It's very expensive.

CH: Did your mother speak English at all?

RA: None of us did. I didn't either.

CH: How did you communicate when you first went to see Dr. Manson? Did they have a translator?

RA: We had a friend who spoke both languages and we used to take her with us. We also didn't drive. My father drove in the Azores, but we didn't have a car here and to have a license, you had to go to driving school, you know, start from scratch. They wouldn't transfer the license. So she would drive us to Boston, or her husband would because he worked in construction and a lot of times he worked in Boston. We would leave at 7:00 in the morning for a 2:00 p.m. appointment; spend all day in Children's Hospital. They've got a nice garden. I don't know if you're familiar with Children's Hospital.

CH: No.

RA: They have a little garden with little fountains and we'd just sit there and eat lunch. Breakfast and lunch and wait for the appointment at two. Those were the days.

CH: There were a lot of barriers. You had a lot of things to overcome.

RA: Yeah.

CH: Your mother sounds a very determined woman. Is this true?

RA: Yes, she is. A little more than my father. My father might say,

"Well, let's think about it." My mother says, "No, let's go. Go."

CH: Aren't you lucky she's that way?

RA: Yeah.

CH: Going back for a minute to the doctor, whose name I forget.

The Portuguese doctor.

RA: It slipped my tongue.

CH: It doesn't matter.

RA: Okay. His name was Dr. DeLima.

CH: Within the limited resources he had, would you say that he did all he could? Did you feel that that early treatment was all right?

RA: See, I was twelve years old or younger. I mean, it's kind of hard to say. Yes and no. I mean, I would think he would have been able to provide blood from the blood supply from the hospital and help us out, but he said, "This is not considered an emergency situation. It's not a life and death situation," but it was.

CH: It was, indeed.

RA: "You need to bring your own blood supply." Really. So here comes this guy—

CH: Walking in your blood supply.

RA: Yeah. So he would go in one room and I would go in another room, sit there. I'm still bleeding because what are you going to do? There's nothing you can do. Put an ace bandage on it, that's about it. And then he's donating the blood to the bag and then they have to do whatever they need to do for the blood, and then I would get the transfusion. So I would stay overnight, sometimes a couple days and come home still bleeding because one dose, one unit of blood, is not going to stop it right away. It's just going to go in the vein and come out the hole, in a way. But, yeah, I think he could have done a little

more. I'm not sure he could provide us with factor concentrates. They're so expensive, insurance would never go for it. But it's there now.

CH: And the health system in the Azores was nationalized.

RA: It was a nationalized health system, but I don't think they would have paid for the cost of the factor concentrates or the cryoprecipitate. It was just too expensive. Right now it's different. Right now they do have the stuff there.

CH: Is there much hemophilia in the Azores now?

RA: I don't know about the islands. I know there was a chapter in Lisbon, which is the capital of Portugal. There was a hemophilia chapter there. As far as how many hemophiliacs are there, I don't know. I know there are some and there might be some old ones, hemophiliacs who are infected with HIV and AIDS. So, you know, they've been around for awhile.

CH: Tell me about the nature of your treatment up here with Dr. Manson, both practically and emotionally. Were they very supportive and did they help you begin to put a life together?

RA: They provided me with a second life, really. Really, I mean I almost owe my life to them, you know, to the people in Boston and I mean everybody. Social workers, nurses, everybody, even the secretaries. They're wonderful up there. It doesn't matter who. I mean, there are so many people to name, but I just mention Dr. Manson because he was the first contact there that I remember. But, yes, he told us about the disease in more detail. He told us that I could live a normal life, whatever I wanted to do. Maybe I would never be a football player or a hockey player, but that's life. He offered to help, which he did. There were support services through the social work

department. Yeah, they helped out a lot.

CH: And they got you on your feet.

RA: Yeah. They also kind of guided us to different organizations, if we needed help. We were reluctant to ask them for public assistance, but at one time we agreed, just for a little while, but we didn't last long because, as I said, we wanted to be independent. We wanted to be self-sufficient. We don't need the government to help.

CH: Was that a family decision, that you did not want to be on the social welfare system?

RA: Yes.

CH: Are your parents religious? Are they Catholic?

RA: Yes.

CH: And is the faith a strong aspect of your life?

RA: Yeah.

CH: And would you say that helped them?

RA: Well, it helped me, for sure.

CH: It helped you?

RA: Big time. I think it helped them. I can't speak for them, but I think it helped them. But it helped me. Religion is a big thing in my life.

CH: You found an apartment or a house?

RA: It was an apartment in Fall River. So we got all four people living there. My sister wasn't around yet.

CH: And how was your brother at this point?

RA: He was in school.

CH: Was he going also to Children's Hospital?

RA: For checkups. He was never hospitalized for bleeds. He was doing good. He never took any medication at that time. He ended up

taking medication later in life.

CH: So he was really sailing along.

RA: Yeah, he was doing good.

CH: And your father went to work. Did you go to school?

RA: Yes, I did. I went to grammar school.

CH: Tell me about that experience.

RA: I went to school in Fall River. It caters toward the Portuguese community, so the teachers teach English and they also speak Portuguese. So it's like a bilingual program, so they kind of guide you along. Spent about two years on a full-fledged bilingual program to learn English. I didn't know anything. And at the same time while you're in that program, they kind of introduce you to the math and sciences, just so you don't fall back. It took two years. As I said, every two weeks, I was in the hospital two or three days. Then you'd get out of the hospital, a few more days at home and then go to school and then you're lost because you don't have a clue what they did for the past week or so. So I actually took three years to be comfortable with the language. To learn to speak, write, and communicate.

CH: And were you out of school less often once you got here, or were you still having problems?

RA: It was about the same. It was about the same, two or three days every couple weeks. So it was about the same as over there. But things improved. They ended up putting me in a regular class in sixth grade. I was the oldest person in sixth grade, but I was able to keep up with the work. I started taking the factor VIII concentrates. No more freeze-dried, I mean cryoprecipitate, because you can't take that home. You've got to go up to Boston or to a hospital to take it. But they came out with the home treatment program with the freeze dried

stuff, keep it in the fridge and you do your own infusions, back in the '70s, mid '70s, late '70s. So I was placed in that program and I was going to the local emergency room to get the factor every other day, even if I didn't need it. So that was great. No more going to Boston to be hospitalized and all that stuff. So I was going to school full-time. Completed a few months in sixth grade because they put me in sixth grade towards the end of the year. From there I went to eighth grade, graduated grammar school. Missed a few days of school just for checkups or what have you. No major bleeds after the home infusion program.

CH: Once you were doing the factor VIII prophylactically —

RA: It was great.

CH: Then your life evened out.

RA: Yes.

CH: And what about the people at school here, were they understanding? Did you have any difficulties?

RA: The teachers were extremely over protective. This was a Catholic school so the nuns drove me nuts. [laughs] Excuse me, but they did. I couldn't do anything and it was driving me nuts because I wanted to do things. They wouldn't even allow me to go on a field trip. I'd say, "Oh, come on." But I used to fight back left and right. I used to tell my parents, "Oh, she won't let me go on a field trip," and they would call and talk to them and stuff. Most of the time I went. Sometimes they just said, "No, no, he's not going. We can't take responsibility." As far as kids were concerned, I can only remember one person that didn't want to be around me because she thought that she would come down with the hemophilia. But the rest of the time it was all right.

CH: So your school experience became much more normal for you?

RA: Yeah.

CH: Did you enjoy it?

RA: I liked school. I liked school.

CH: You began to enjoy it. Did you do well?

RA: Grammar school wasn't bad. I had to fight. I had to fight to keep up with the work and so-forth, but I did okay. I don't remember all the grades I got in grammar school. I remember more high school and college, but I did okay.

CH: And you were generally feeling pretty well?

RA: Yes.

CH: And your brother was fine?

RA: Yeah.

CH: Did your family settle down well here? Did they like it here?

RA: Yeah, we did. We liked it. It was different, but it was definitely the land of plenty, of opportunities. It was up to you. If you want to do something, it's out there. So there's a lot more opportunities here than there. I never went back, so—

CH: You've never been back?

RA: Never been back.

CH: What about your father? Is your father still living?

RA: Yes.

CH: And does he go back?

RA: Yes, both my parents have gone back two or three times. I haven't.

CH: Because they have or had parents there themselves.

RA: No, my father's father died when I was little, so both my grandfathers died before I was one year old, so I don't remember my

grandfathers. So my father's mother died when I was six or seven and my mother's mother, she's still alive. She lives in Canada with her other sister. She's ninety-five years old.

CH: Were you beginning at this point to have thoughts about what you want to do with your life? Were you developing goals?

RA: Absolutely. Absolutely. I was determined to continue on through school and to work with jet engines. That was my dream. I wanted to work with planes. I wanted to work with jets. I just wanted to do something with jets and that's what I did. I went to school. I went through high school, after I graduated from grammar school. I went to Bishop Connolly High School in Fall River. First year was very difficult. It's a private school. They just dump you with information and I wasn't ready for it, so the first year I almost flunked out, to be honest with you. But I was determined that I would overcome this and I did. I did. I managed to graduate high school with a B+ average. Freshman year, the first quarter—actually the first half of freshman year was rough, but things started to improve. Second year I was on the honor roll. Junior and senior grades dropped a little bit, but that's okay. I still managed to graduate with a 3.3 average or a 3.4 average, I forget.

CH: That's a real achievement.

RA: Yeah. I was determined to continue because I wanted to go to college. So you can't go to college if you don't have a high school degree or diploma.

CH: And presumably your parents were very much for your continuing on to college?

RA: Yes. See, one of the problems I was faced with was I couldn't come home and ask my parents for help with schoolwork. I was the

oldest in school. My parents didn't know how to read English. I mean, if you can't read, you can't do math. You can't do science. You can't do history. You can't do English. You can't do grammar. You can't do spelling. You can't do anything. So I had to depend on myself to teach myself how to do things, and a lot of times I used a tape recorder to record the questions and play it back—this is how I studied.

CH: For class?

RA: To record the questions. No, at home. To record the questions and then play it back and then I would answer the questions myself. It's a time consuming process, but it worked.

CH: So you found that if you heard the questions asked of you, it was easier. Did you have any mentors, people who helped you? Maybe someone special in school?

RA: In school, yeah, there were a few people. I'm not the type of person that likes a lot of people, you know. So I had one or two friends.

CH: Do you think that's a result of your early experience, when you were isolated a fair amount home?

RA: I don't know. I'm not sure. My mother—my parents, I should say, always told me that as a baby I was always more comfortable being alone than being with others. You know, when we went out to visit people, what I would do is cry. When they got home, I was fine. So maybe it was in my genes. My brother was totally different. He couldn't be home for more than ten seconds. He just had to be around people. The more people, the happier he was. My sister, too.

CH: You're more independent?

RA: Yes, I think so.

CH: And you really made your own way through high school?

RA: I did. I did.

CH: And where did the urge to work on jet engines come from?

RA: It's a childhood dream. I just wanted to build things or design things or fly or something. I wanted to do something with jets.

CH: And at this stage, your hemophilia really wasn't proving to be a barrier to your dreams.

RA: Not through high school. I was determined to live with the disease and just put it on the back burner and control my own life, not let the disease control my life.

CH: Did you have residual pain from the early bleeds?

RA: Oh, absolutely. Sure.

CH: In your joints?

RA: Yeah, my left knee was—it was history. That was what caused us to come to the States. I was hopping on one leg.

CH: I see. So that was—

RA: Eleven years old.

CH: That was really what drove your mother to take that drastic step, because you were deteriorating?

RA: Yes.

CH: Your joints were deteriorating.

RA: Yeah, big time. Big time.

CH: Here we are at the end of high school, and what happens?

RA: This was, well, '80-81 and we got the fiasco with the HIV stuff and that was—well, they didn't call it HIV. They just used to call it—I forget what they called it, but it was drug addict/homosexual disease. That's the way it was presented to everybody on television and the newspaper and so-forth.

CH: What year did you graduate from high school?

RA: It was '81.

CH: Tell me about the sequence of events with the transfusions and the news about the HIV. Tell me your story if you would?

RA: Sure. My first contact was—they didn't call it HIV then. It was in the '90s I think when they came up with the HIV acronym. The information I got initially was from the paper and television and then secondary information was from Boston Children's Hospital. My brother and I, most of the time, had appointments together. This was a check up every six months or every three months. Sometimes every three months, sometimes six months. We went in together. We sat down. At that time, in the 1980s, they were already switching back to—switching to a hematologist as the primary care physician. They were moving away from the orthopedic surgeon, which I suppose makes sense.

CH: Was this a general trend or specific to your family? Was it a general trend that hemophiliacs were no longer going to orthopedists, that they were going to hematologists.

RA: That was just the way the Boston Hemophilia Center was set up. They were doing those changes. I was just kind of going along with it, you know. He would come in, still maybe about once a year, the orthopedic surgeon, but the hematologist—I don't know the names. I mean, people moved. Every six months or so there was someone new. The doctor sat down and he told us, you know, your blood count because all they had was CD4 counts. They didn't have HIV viral load tests or geno testing and all that stuff. They said, "Your blood count is going down," and I'm sitting there going, "Yeah, but I don't do drugs." "Well, but you know, it's the same

thing with men who are homosexuals.” I said, “Well, doc, I don’t do that either.” He said, “Well—”

CH: Is that how they put it to you?

RA: Yeah, that’s the way it was presented to us. It used to drive me nuts. You’re sitting there saying, “Oh, man, another type of—”

CH: So there was an implication that it was your fault, that you were doing something.

RA: Yeah, because the way it was presented to us, my brother and I, was that it’s a homosexual problem and an IV drug user’s problem.

Okay, so I don’t do either one of them and you’re telling me that my blood count is dropping. What happened? He said, “Well, we don’t know what’s going on. Maybe it’s in the blood. We just think—we don’t know what’s going on.” But we suspected it had to be the blood because all my life I was brought up with taking blood, either whole blood, blood derivatives or what have you. I mean, if you do a little research with factor VIII, factor VIII is my deficiency. It takes like sixty thousand people or so to make one batch of factor VIII. So you know whatever diseases are out there, I would end up getting.

So he kept insisting that, “Are you sure you never did drugs?” I said, “Yes.” “Okay, then we’ll just have to monitor your blood. Just live a normal life, make sure you eat well, you exercise and do the best you can.”

CH: Were you feeling anxious at this point?

RA: Oh, yeah. At first it didn’t bother me. I told myself not to worry about it.

CH: This was before you knew. You were just anxious.

RA: Yeah, but they were drilling through my head, “Your blood counts are dropping,” so my brother and I would come home and just

cry our guts out. That's how we dealt with it for about a year. I'm still going to school full time. I was a senior in high school. I'm one of the original—I'm a lucky person, I guess. There's no other way to look at it. Still alive, and I'm still doing well. So I suppose there must be some positive in every negative situation.

CH: And with all that you were still getting a three-point-something average in school?

RA: I did well. Towards the end of school I did well. I managed to do well, considering what, you know, and then looking forward to college and looking at different colleges and doing the applications and what have you, and working part time.

CH: Were you beginning to hear more about it in the newspapers?

RA: Absolutely. As things went on, I kept grabbing every piece of paper I could find and again, ninety-nine percent of the information I got was that it involved homosexuals or IV drug addicts. I said, "Where's my hemophilia here? How did I get this stuff, you know?" That used to tick me off, but as time progressed, then it was pretty obvious that I got it from blood products. Most likely I didn't get it while I was living in the Azores. Most likely I got it through the factor VIII concentrate here. Every time I stick my arm with a needle, I'm actually sticking it sixty-thousand times, so eventually I will be exposed to all those diseases that people may have.

CH: Do you remember the occasion when the doctor finally said to you that the blood transfusions were probably where it had happened to you, or did he ever say that?

RA: They did say it, I just don't remember the—they did say it, that most likely it was through blood products, factor VIII.

CH: So finally they stopped saying that you were a drug addict or a

homosexual and they were saying, "It's probably this."

RA: Yes.

CH: Do you remember, as I'm sure you do, the first time someone said to you, "You have a problem, you are—"

RA: HIV positive?

CH: Yeah.

RA: Yeah, when the test first came out. You probably know more about this than I do. I don't remember the year, but it was—I don't want to be guessing because I just don't remember the year, but whatever year that test came out, the HIV test, yeah. I was in Boston and they did the test on me and my brother and they said, "It's HIV positive." We said, "Oh, well."

CH: And your life did another turn.

RA: Well, it was official, yeah.

CH: But you knew in your heart, didn't you?

RA: Yeah, we knew it was—I mean all those tests they did with the CD-4 counts, all the lab work and they were constantly saying, "You know, your blood count is dropping." It was dropping. I think a normal CD-4 count for anybody is like fifteen, seventeen hundred, and every time we went up there, it would drop two hundred, another two hundred, another hundred. So we knew there was a problem somewhere along the line. The same thing happened with people that were IV drug addicts, that are IV drug users, or people that are in a homosexual lifestyle who get this disease.

CH: How did your parents cope with all this news, this new information?

RA: For the longest time they said, "Oh, it will get better. Someone will come up with a cure, or a pill or with a shot or something."

Something will get done.” I mean, we were just like—I mean, we didn’t look sick, my brother and I. “So it will be okay.” But we didn’t know any hemophiliacs that were really sick at that time.

CH: You didn’t?

RA: Did not. Did not. Not until many years later that we finally saw that some hemophiliacs died, and we said, “You know, this is not good.”

CH: So there was no connection through the hospital or anything with other hemophiliacs who were suffering the same fate?

RA: Not in the beginning. Not in the beginning. Ryan White, I’m not sure when he jumped in the picture. He was another hemophiliac who—well, you know Ryan White. His mother did a lot of work and his family. He did all sorts of things to open up the possibility, you know, that hemophiliacs are being infected with HIV through blood products and not necessarily as IV addicted. They were not necessarily IV drug users or homosexuals or what have you. So him and a bunch of other people started coming out and said, “You know, we’ve got this disease and we’re not doing any stuff, so it’s got to be other problems.” As years went on, it was pretty obvious that it was through the blood products that I got infected.

CH: What were the doctors and hospitals doing to help you? Here’s this big new news, two in your family. Did they kind of drop you? Did they not want to talk about it?

RA: No. No, no, no. They were very supportive, Boston. They would encourage me to continue to live a good life, as far as good nutrition and exercise. If I was sexually active, you know, not to pass on the disease to someone. Use the proper protection. They would drill that into your head every time that you went up there. I suppose

that's part of being a medical person. I was meeting with a social worker. As far as my parents, well, they had their own help through their own doctors. Their doctors offered to help them. They didn't want it, you know, been doing okay.

CH: But your parents did not want that help?

RA: Did not want it. Not through Boston, through their own doctors, local. They said, "No, we'll be fine." I suppose our family, we kind of support each other, so when we have a problem, we just talk it over and resolve it within the family. We didn't go out of the family, out of mom, dad, brother, and sister, particularly with HIV stuff because we didn't want other people to know about it. It took me a long time to kind of go to school and not tell people in school that I had hemophilia because I wanted to put an end to it after grammar school, which I did. In high school, I didn't want anyone to know about it.

CH: Is it fair to say that you decided that when you went on into high school you were not going to be a "man with hemophilia."

RA: I'd just be a man, period.

CH: Just a man.

RA: Because I didn't want to deal with people telling me not to play this, not to do that or "Gee, is that contagious?" I didn't want to deal with it. I went to high school and college and I didn't want to deal with the politics, all that stuff. So we definitely never told anyone about the HIV stuff. We just kept to ourselves.

CH: Did you deal with it as a family through your faith?

RA: Yes, among ourselves. We didn't talk to no priests, nothing. We didn't want to make it a public issue, so we just kept it within the family. Mother, father, sister and brother. Well, my sister was young

still.

CH: Aunts and uncles?

RA: No, absolutely not.

CH: You didn't? You were very discrete. Are you glad you did it that way?

RA: Not really.

CH: Why? Did it cut off support?

RA: Yeah.

CH: Why would you do it differently this time?

RA: It was too stressful, trying to analyze your words before you speak. There's things that you can't—you don't want to give the person an impression that, "Gee, this guy's sick." Oh, man, it's pretty stressful.

CH: You were living a lie, really.

RA: Yeah. Yeah, you're walking around with a false face or a façade. It's tough. Very difficult. Very difficult because when people—I would notice many times in school people would be talking about people with HIV and AIDS, they were making fun of it. They were saying, "Oh, they're a drug addict. Oh, they're homosexual," or whatever, and I'd be, "Oh, man." Armpits are soaked with sweat, dripping all over the place and I was like kind of like going along with it, but in a way I was not. I would say to myself, "God damn it," excuse my language, but "That's not true. Just look at it as a disease. Don't look at it as a lifestyle," you know.

CH: Would you say those things to people? Would you try to correct them?

RA: No, absolutely not. I would only say it to myself—quietly.

CH: You just stayed out of it.

RA: I just stayed out of it. Too emotional. I couldn't. I couldn't. No, I couldn't. There was no way. I didn't want anyone to suspect that I was one of them. Maybe different circumstances. Well, absolutely different circumstances. Different lifestyle, but still the same disease.

CH: Did you tell your parents when you had difficult times like that or did you keep that to yourself, too?

RA: No, I kept it to myself. I kept it to myself.

CH: Did you tell your brother?

RA: I wouldn't tell my parents that this happened in school with HIV and AIDS. I just kept my mouth shut. I would tell them that "We just need to keep this to ourselves. We don't want to be open about it. There is a prejudice out there, and we need to get on with life. I mean, we don't want to come home and find the house burned down because the neighbors don't want us there." Over there in Fall River. We lived in an apartment. So we kept it to ourselves. Even my brother, for the longest time.

CH: And how did that affect the dynamics in the family? Did it bring you very close or were there times when that was just too much to be dealing with in a very small group of very involved people?

RA: As far as dynamics, what do you mean?

CH: Well, that's a lot of stress to spread over a very small group of people, and everyone, I would think, including your mother and your father, everyone has personal concerns and approaches it differently. So if you don't have outside resources, you have to do all of that work within a very small group. I wondered whether that proved to be very stressful within your family or were you just very, very close and worked that out?

RA: We were very close. We worked it out among each other. We did—I suppose we did have some help with the medical people, obviously, Boston knew about my situation. My blood situation, my parents' situation. We were meeting with social workers, my brother and I and my parents would meet with their doctors. They never saw a social worker. I mean, the doctor would offer help if they needed it. They declined. So we would work it out at home. If we were too stressed by it, we'd just sit back and cry our guts out for, I don't know. For whatever time it took us to get rid of the stress. Then we went out and did whatever we needed to do. So that was our way with dealing with the stress and depression and anxiety and all those psychological stuff that one can come down with.

CH: Fortunately, it sounds as though you were a demonstrative family.

RA: Yeah, I suppose that's a good way to put it.

CH: That's important.

RA: Yes.

[end of Side A, Tape 1]

RA: Looking back, being 2004 and looking back, I wish we had done it different. I wish we were more open, more open about it especially in my situation. I wish I could have been able to talk to people during my high school years, so I could get the public to accept the fact that this is a disease and kind of help out that way.

CH: About the HIV?

RA: Yeah, yeah, and maybe also with hemophilia because it kind of goes together, hemophilia, you know, in a way they go hand-in-hand.

So looking back, I wish I had done it. I don't dwell on it. I don't feel sorry for my decisions, but I think it would have been in a way easier.

CH: It would have taken a lot of courage.

RA: It would. It would because there was a lot of prejudice. We would have lots of education and—well, it took us many years to make it a public issue. So.

CH: You would have had a very hard time.

RA: Probably. It's hard to say, but probably I would have.

CH: It's hard to remember how frightened people were.

RA: I mean, there were people that had their houses burned down. There were people that lost jobs.

CH: In Fall River?

RA: No, not Fall River. There were—well, my brother lost his job when the company found out about it. Not through him, through others. It kind of leaked out. There was a fellow fourteen years old in Swansea, not far from here, and their parents took the kids from high school, from junior high, because they didn't want their daughters and their sons to be in the same classroom with him. So all this is local stuff. You know, the high school kids, junior high school. My brother—you can't get any more local than that.

CH: Let's talk a little bit about your brother during this period because his story went a very different route than yours.

RA: Yeah.

CH: So he's HIV positive, and what did he go on to do?

RA: He graduated college. He graduated Southeastern Massachusetts University. Same place that I went to, with a degree in mechanical engineering. He went to work for a company that did parts for the missiles, Tomahawk and a bunch of other missiles.

Local, in Rhode Island, Newport. But he had a girlfriend. She knew about it, and somehow it leaked to the company that he was HIV positive.

CH: How do you think that happened?

RA: It's not clear. I mean, I'm not sure if it was through her. You would keep it quiet, but once in awhile you would kind of, have ideas or kind of leak out a little bit that you had the disease, and you just wanted to live a normal life and so-forth. He was a go-getter. He wanted to be like everybody. He wanted to be normal. He wanted to be able to talk comfortably about everything and so-forth. He had to be around people. He couldn't be alone. Totally different than I am. So somehow the company found out about his HIV status and pretty much after that he lost the job.

CH: Can you remember the day that he came home and told you all that he'd been through?

RA: He was laid off. That's the way the company did it—because you can't—legally you can't fire someone for being sick. Well, he wasn't sick. He just had this disease in his system. But he was laid off and he was all upset. I remember him walking out as we tried to talk about it. We lived here.

CH: In this house?

RA: Yeah, he walked in and said he was laid off, and I said, "Gee, why?" Well, he didn't want to tell me. He suspected that someone knew about his disease. He found out later that they did know about his disease.

CH: How did he find out that they knew?

RA: I'm not sure about that. I'm not sure if it was friends that told him that the people at work knew about it, or some employees called

him. I don't know. There was one thing that it would—well, actually, I probably know the answer because they would write nasty messages and leave them on his desk. So that kind of dictates that they knew that he had it. They would smear red stuff or whatever it was on his coffee cups or tissues and put it in his desk or something. So they would—they had little things they would do to him. So it was obvious they knew about it. Now, I'm not sure who were the colleagues.

CH: He must have been devastated.

RA: Yeah. Yeah, he was in rough shape. That was his first job after college and it was his last one because he got too depressed and he got pretty sick.

CH: And his girlfriend?

RA: They ended up splitting. She couldn't deal with the stress or vice-versa and that was the end of it.

CH: A lot of loss.

RA: Yeah.

CH: And what happened to him then? He began to decline?

RA: He still had a few friends, about three or four friends who would come and visit, but he began to decline very rapidly with the HIV and Hepatitis. Particularly with the Hepatitis. He just couldn't kick that. He wasn't an alcoholic, but he did drink a glass of wine or a glass of beer. Back in those days doctors would say a glass of wine, glass of beer is okay. Now, no alcohol whatsoever.

CH: With Hepatitis?

RA: With Hepatitis-C. I don't know if it's true of all Hepatitis, but particularly Hepatitis-C. So, did that have something to do with it? I don't know. I still say it had to be depression, laid off from a job, lost

a girlfriend. He tried to get another job, couldn't find one.

CH: When he couldn't find a job, was that a result of the HIV?

RA: I don't know. I mean—

CH: Was he starting to tell people he had it? No, no. To the best of my knowledge he did not—I never heard that guy tell another person about his HIV status. So it's still not clear to me how his employer found out about it.

CH: Or communicated it. Were the jobs he was applying for jobs he should have got?

RA: I think so.

CH: So something was going on.

RA: Something was going on. As far as did they know about it? I don't know. Maybe. Maybe.

CH: He started to sink into depression?

RA: Yeah, and he was—he was a patient at Rhode Island Hemophilia Center at this time. Somehow, I don't know what happened between Boston and him. He didn't like them, so he transferred his care to the Rhode Island Hospital Hemophilia Center. They do have a center up there in Providence. So he was getting his care there for his hemophilia, HIV stuff and also he ended up getting some psychological help through a psychiatrist and he was taking medication for the depression.

CH: How long did he live after life began to fall apart for him?

RA: He died—he was thirty-one years old when he died. He died in '95. Let's see, '92 or '93 was when he lost his job.

CH: So three years.

RA: I would say '92, so three years.

CH: And he lived at home?

RA: Yeah, he lived—yeah.

CH: And what were those times like for the family?

RA: Eh, it was a mess.

CH: It must have been a mess.

RA: But I don't think, even though we kind of looked to each other for help, we didn't do a good job at that time.

CH: In what way?

RA: Didn't do a good job, I think, looking back because we were too busy arguing or yelling. It was just a mess. We just didn't know what to do with him. We were just overwhelmed. We were just way overwhelmed with stuff, you know, because here he's going. He's so sick. He's telling everybody he's dying and everybody else is saying, "Oh, you're not dying. You're fine. You're fine. You're fine." Oh, man, talk about a reality check we need here. This is like looking back.

CH: Was it your parents who were into denial or—

RA: We were, all of us.

CH: All of you?

RA: All of us.

CH: So you were not accepting that either?

RA: I wasn't either. No, all of us. We didn't.

CH: You weren't listening to him?

RA: Reality check didn't kick in until he was in Rhode Island Hospital dying. Then I said, "Oh, yeah. This is it."

CH: I guess that's what I meant by the earlier question. There's a point at which the family can only absorb so much with all the stuff going on. That put it over the edge.

RA: I think so.

CH: Did your parents deal with it the same way or did you find they dealt with it a different way?

RA: Well—

CH: And did it bring them closer or not?

RA: I don't think it changed. I don't think it changed a bit. It didn't change a bit. They were getting along just the way they always got along. It didn't change a bit. We would always have arguments, or they would have arguments, but they would work out. But my mother's sixty-nine years old. My father's seventy-three. They can't live without each other. You know, like I always say, "Mom, dad, you bitch and moan, but you're always together. That's good. Keep it up." [laughs]

CH: Well, sometimes it can be very destructive when you have that sort of issue.

RA: Yes. Yeah, yeah.

CH: Such a situation can be very divisive.

RA: Yes.

CH: Your brother, whose name I don't know?

RA: Joe.

CH: Joe. Joe went into the hospital.

RA: He was at home. He was pretty sick, but he kept, you know, he was doing okay. He took a shower. He went to bed and then he said, "I'm not feeling good." I checked his temp. His temp was outrageous, so I took him to the hospital in Providence and my parents followed because that was the deal. "Okay, I'll take him over there and then you can follow." So we went over there and based on blood cultures they determined he was septic. He had everything in his blood. So he was going through liver failure and then the kidneys

started failing. Then he went into a coma. Well, at first it was induced because they needed to put him on a respirator. He managed to get a little better in ICU. They did some exploratory surgery to look at the liver, see what's going on because they weren't sure what was going on, you know, as far as why did he have so many bugs. They thought, okay, maybe there's something leaking in his digestive system. There's a little leak in there and it's spraying all these bugs in his abdomen. So they did some exploratory surgery. He had some cirrhosis of the liver. It was pretty obvious because he was pretty pale and jaundiced. They couldn't find anything except for the cirrhosis, so they sewed him back together, you know, continued antibiotics and he did get a little better. He went from ICU from here to about ICU down here. Still in ICU, but they have different levels or grades. He did come out of the coma. He talked, not very—how can I say?

CH: Coherently?

RA: Coherent, but he did manage to say a few words. He had a few bites to eat, some Jell-O and famous hospital food. Jell-O and freeze pops and then there was a little hope. The nurses said, "Gee, maybe he's going to pull through," but deep down I said, "I don't think so. This is it." But my parents were still saying, "No, he'll be okay. Look, he's getting better." I remember coming home and telling them, "Be careful. He's not good. He's not doing good at all, just be careful." And we came home that evening. I think it was Friday and then Saturday we got a call from a doctor that they had to put him back on the respirator. He wasn't doing well. So we went back up there and there he is again on the respirator just lying there. Things were going bad. His kidneys were completely shutting down. He didn't want a lot of medical treatment. You know, he was a DNR, do

not resuscitate. He was on a respirator but not full. Not at a hundred percent. It was like—I forget what the percentage was. So I was his medical agent. Of course, I didn't want to do it. I said, "No, talk to one of your friends or something," and then he just looked at me and said, "Why? Why don't you want to do it?" I said, "Okay, fine, I'll do it."

CH: Maybe easier than it would have been, say, for your mother?

RA: I think so. I don't think she would have been able to make the decisions I had to make. I had to meet with the doctor, his doctor, and I told him that he wanted to be a DNR, do not resuscitate. He didn't want to be on the machines for life support and I had issues as far as why did he put him on a respirator and the doctor said, "Well, that's comfort level only. That's not set at a hundred percent." I said, "Okay, fine. Just keep him comfortable and we'll just take it from there." He said, "That's fine," but even the doctor told me that he didn't think he would make it, and I'm trying to feed my parents this information. They didn't want to listen at the time. They were in big time denial. I did tell my sister. She just accepted it. She cried.

CH: What was happening for your sister during this time? She's younger and her life's going on.

RA: Yeah. Well, she was in college. This was in '95, so she was in college already. UMass, Amherst. My brother was in the hospital, Rhode Island Hospital. I was home. I was here. I wasn't working. That's another story here. This is a complicated situation. You sure you want to do this? [laughs]

CH: Tell me about that.

RA: We could be here all day and all night.

CH: That's all right. Tell me about that.

RA: So my brother's in the hospital, she's in college and I'm home trying to make sense of all this stuff and so-forth. Just to finish this part, we got a call at ten o'clock at night. The doctor called us. "You need to come down, he's having heart palpitations." I said, "Okay, fine." My whole family were around him when he died. So that was in May of '95. That was the end of it, all right?

We came home and that was it. That was like, in a way, it was like the icing on the cake for me because I said, "There's no way in the world"—[voice is cracking] [unclear]. And I don't want to cry today, but—[takes a drink]. Phew, okay. There was no way in the world that I was going to look the other way and stick my head in the sand.

CH: There was no way you were going to stick your head in the sand, after that?

RA: Yeah. Yeah, "I'm not sure what I'm going to do yet, but I'm not going to ignore it. I'm going to figure out a way to get together, myself and to tell people about the stresses, about different ways to be exposed to HIV or AIDS, and the way it was, as I was growing up, the way you the public treated us, and so forth." That was like the icing on the cake.

CH: Your brother's death pushed you into that decision?

RA: Exactly.

CH: You were already feeling that way because you said you really weren't very happy hiding.

RA: Yes, it's too much. I mean, it's just too much. I said, "The wheels are turning. There's nothing to stop me now," and everybody would say, "Slow down, Roy. Slow down. You're doing too much." I said, "No, I'm not. I'm not done. Just the beginning. You haven't

seen nothing yet."

I came home. I sat at my desk and I just wrote my life story. I just wrote and wrote and wrote and wrote. Then I typed it in the computer. I wanted to check my spelling mistakes, tons of spelling mistakes. I put together my life story from the beginning in the Azores, coming to the States and being treated, going to school, but mostly I concentrated on when I was working and the different stories I would listen or hear from people.

Hey, come on in. It's your husband.

CH: What did you do with your life story.

RA: I wrote my life story and I told the people up in Rhode Island Hospital that I would present this to whoever wanted to listen and they were my so-called guinea pigs, the people from Rhode Island hospital. Social workers and nurses. So I presented the story there on World AIDS Day, December 1st, 1995. So my brother died in May of '95 and December 1st, 1995 is when I presented my story to them. Then it wasn't too bad. I got a little choked up towards halfway through it, but I did okay under the circumstances.

CH: How did your parents feel about this? Were they still very reticent for you to be out there?

RA: They didn't find out about it until it was done, as far as the write up. Then I told them I was going to speak.

CH: And did they try to persuade you not to?

RA: They weren't happy at first. Then they said, "Okay, fine. I wish you wouldn't do it, but you want to do it? Go ahead." That was their statement to me. So I said, "I need to do this. There's no way in the world. I can't just bury my head in the sand anymore. People need to know the truth," and that was the end of it. So I did that. I did

that and after that I came back here, took a little break and then I went to Fall River and I spoke at the Fall River City Hall. I mean, there was everybody there. Anybody that wanted to come in, could come in, and I spoke there. That went very well. I didn't get stuck on that one. That was okay.

I spoke there and people were just coming up. They were like, "Wow, I didn't know it was that bad." I said, "Well, yeah, that bad." At that time I was working part time at a group home, the group home where I'm working now, for people with advanced HIV that are homeless. So I wanted to do that, too. So I called them up and I said, "Are you looking for volunteers?" because I was disabled for a while before I had the knee surgery. I'm jumping all over the place here, but I was disabled about a year, a year and a half, and it's kind of hard to go back to the workforce when you're disabled because then companies don't want you. They say, "What's wrong with this guy? He doesn't even work." So I decided to find out where this group home was, and I knew about it. I just didn't know where it was located. I knew it was part of St. Anne's Hospital. So I called them and I told them to transfer me to the group home for people with HIV and AIDS. I requested an application to be a volunteer there and I did that for a while. The director at the time asked me, "What do you want from us?" I said, "I want a job." She said, "Okay, in the future maybe we'll do that." I guess I must have done a good job as a volunteer because they hired me. It was part time and I was going around presenting my story and I did a bunch of them. I did it to local high schools. I did it in Boston, to the medical people there at the Educational Symposium. I went all over the place, and I did that, oh, for five years. After five years, I said, "That's it. I think people have

heard enough. Now they don't need to hear this," and I took the whole speech, the story, and I burned it. Took the ashes and said, "No more." Now what I've done is if I hear something that's not very nice, I will approach him/her personally and talk to him, if I feel that someone needs to be more educated about hemophilia and HIV and AIDS.

CH: What happened to you in the workplace? Did you have any difficulties?

RA: After I graduated grammar school, I was determined to keep hemophilia to myself, okay. I didn't want to deal with little kids not being allowed to hang around me. So in high school, no one knew about my hemophilia, and after I graduated from high school, for sure I wasn't going to tell them about my HIV status, either, or my hemophilia. That was done. That was a done issue. I went to college. I graduated from college. I graduated in four years. I went on to mechanical engineering technology and remember I was telling you I wanted to work with jets? And I did. I wanted to work with GE Aircraft Engines and I was able to get a job with them. I applied with a cover letter and resume, and they turned me down. I said, "Well, that's all right, I will work for them," and I did. They came down to my school, SMU, Southeastern Massachusetts University—now it's called UMass, Dartmouth. They came down to my school. I met with the recruiter and I told him, "Why did you turn me down? I qualify for your job that you have available."

CH: You went down and confronted them.

RA: I did, because I wanted to work for them. That was it. I didn't want to work for anybody else. They said, "Who are you?" and I told them who I was. They said, "Okay, fine. Well, stop by tomorrow and

we can discuss it," and I did. I went to the interview and I sat down and we talked about a position and the rest is history. They hired me. So I went to work for them. Of course, they didn't know anything about my hemophilia or HIV stuff. I worked for them as a field service rep in their jet engine division. GE Aircraft Engines make—they also make jet engines. They just don't make light bulbs and refrigerators and washing machines. I worked out of the plant out in Lynn, Massachusetts, but I was out in the field. I was all over the country. I was at Myrtle Beach Air Force Base. I was at Kelly Air Force Base in San Antonio, Texas. I was in Mesa, Arizona. There was a McDonnell Douglas plant out there that we had a contract with. I was at Lemoore Naval Air Station, California, and a bunch of other places.

CH: Did you enjoy it?

RA: Very much so.

CH: It was all you had wanted to do.

RA: It was what I wanted to do. I wanted to get a job working with jets, with jet engines, making a lot of money and travel and it was everything. I mean, this is what I got. This is what I asked for and I got it, you know. I worked for them for four and a half years. After four and a half years it started to get very difficult to carry on a conversation about HIV/AIDS and not reveal my situation, which I did not. You had all these people talking about different diseases out there and about their background and so-forth. I thought, "Oh, man." This was before the '95 situation, though. My brother was still working and so-forth, and so I've got to return home. So I was at Kelly Air Force Base. That's where I was stationed and I called my manager and I told him I was thinking of leaving the company. He

practically had a nervous breakdown. He said, "No." I wanted to do something different. I wanted to move back to Massachusetts, and I want to do something different. I'm not sure what, but somehow I had enough of this. I don't want to do this no more.

CH: And they couldn't quite understand that?

RA: Correct, I kept telling my manager I needed to return to Massachusetts. That is all I told him. But I wanted to do something with people that were real sick that nobody wants to do anything with them. They don't want to help them. They just kind of push them aside. Leave them alone. That's what I wanted to do—help people that are pushed aside.

CH: Was the move a positive thing, something that you wanted to do, or do you think the stronger influence was the atmosphere around you, the prejudice, or a mix?

RA: It was a combination. I think it was a mix. It was the voices in the background, the prejudice stuff. It was not being able to be frank and honest with people. Not being able to open up a newspaper or turn the television on and say, "Why is this going on? What is this stuff? Why do you have to burn the guy's house down because he's got this disease?" or what. So it was a combination of things. I actually told my parents, "Okay, what I'll do is I'll take a week off from work. Go on a vacation," and I did. I drove from San Antonio to Flagstaff, Arizona. One of my hobbies is mountain climbing. I went to Flagstaff, Arizona and I hiked the Grand Canyon. Spent a whole week in that hole. Loved it. Came back.

CH: By yourself?

RA: By myself. By myself. I'm a solo. So came back and the feeling was still there. I said, "I need to go. I need to get out of here,"

and that was that. I approached my manager and I told him that I was leaving. He couldn't believe it. He was laughing, because they all liked me and they didn't want me to go, obviously. So he calls his boss, so my boss's boss is calling me. Said, "I want to meet with you," so we did. He met with me and he said, "Why are you leaving? What's your problem? Are you sick? Is there a family issue?" I said, "No, everything's fine. I just need to go. I need to pursue another career, something else." "What are you going to do?" "I don't know yet. I don't have a job. I'm just going to leave." "Where are you going to go?" I said, "I'm going to move to Massachusetts. I'm going to stay with my parents and then we'll see what happens." "Well, you're sure? You want a different job here?" He went on and on. I said, "No, I'm all set. Thank you very much for the job. I don't have a problem with co-workers. Everything's fine." "Okay, fine. We'll move you back to Massachusetts." So they did that. Came back here and I'm just starting to figure out "What am I going to do here?" So I'm sending out resumes asking for engineering positions, but I really don't want it. I'm still sending these things out, cover letters and resumes, all that stuff. This was back in 1990. In the 1990's the job market in Massachusetts was nada. I mean, people who graduated college had nothing. They couldn't find anything.

I ended up working part time like local minimum wage stuff. Just get me out of the house, keep me busy. Nothing special and my knee kept bothering me. My left knee. Still the same knee from childhood, and it kept bothering me. It kept bothering me and I said, "This is it. I've had enough of it." Boston didn't want to operate on it because they still couldn't figure out, "What's this guy doing? He's got hemophilia. He's got this bad knee. He also has this other

disease, this HIV stuff that we don't know much about it. His blood counts are dropping." At least that's the way I perceived it. I mean, "Do we fix his knee or what?"

CH: They didn't know. They were afraid.

RA: They were afraid to do anything. So I kept asking, kept asking. I said—Dr. Bruce Ewenstein at the time. I said, "Doc, do something. I mean, you've done knee replacements on other hemophiliacs," which I had a friend who was a hemophiliac who had his knee replaced. And I said, "Why can't you do it on me?" He said, "Well, come back in a few months." That lasted for almost five years.

CH: And that was because of the HIV?

RA: Well, they never said that, but that's my own—

CH: That's your guess.

RA: That's my own thinking. I kept working part time jobs and so forth and just said, "Oh, this stinks," and "I don't want this," you know. The knee was getting pretty bad and I just made a decision, "That's it. I'm going to go on disability. Maybe it will put some pressure on the medical people to do something," and I went on disability. I was disabled for about a year, a year and a half. I did it on my own—after I filled out the paperwork, I called them up and said, "By the way, the Social Security Department is going to call you because I signed up for disability." "You did what?" I said, "Yeah, well, you guys won't do anything, so I might as well do something." So I don't know if that put any pressure on the people in Boston, but I like to think that it did because after that they did agree to do my knee. I'll never forget, Dr. Ewenstein came up to me and said, "You know something? I can't sleep at night because of you."

CH: That's interesting.

RA: "I can't sleep at night because of you," he said. "Well, that's good. At least you're thinking. So let's get with the program and let's fix my knee because I need to go back to work." They said, "What are you going to do? Are you going to go back to engineering?" I said, "I don't think so." "What are you going to do?" "I don't know yet, but I will get back to work, I promise you, and I will be working forty hours a week at least." So we had the surgery and as a matter of fact, we had the surgery the same month that my brother died in May of '95. So that's another stressful thing.

CH: How long were you in hospital?

RA: I was in the hospital ten days.

CH: And then rehabilitation?

RA: Rehabilitation for six weeks. Yeah, I had a PT come over my house. I said, "I don't want to deal with nobody out there. Just come over the house." But while I was in the hospital, it was another icing on the cake because there were two people per room. Okay? So there was another fellow there who had leg surgery. I had leg surgery, too. So we were both on the same machine. I forgot what it's called.

CH: A machine that pulls your leg?

RA: Yeah, bends it.

CH: Exercises the leg.

RA: PCM or CPM, Continuous Progressive Motion. Something along those lines. He had the same machine. I had the same machine. Now, nurses would come in and ask me, "Okay, what kind of diseases do you have?" I would tell them, "Okay, I'm a hemophiliac, HIV, Hepatitis, damaged joints."

CH: You told him?

RA: No, not him. The nurses, and they'd write all this stuff down.

Of course, they've got the drape closed, but that doesn't protect much of anything. You know, he could hear everything, so my roommate heard it. So after that, when his wife arrived, he had her mark down his machine because, "Oh, he's got the disease." That's the way he referred to it.

CH: You heard him?

RA: Oh, yeah. I could hear him. He told his wife that, "Oh, he's got the disease." I thought, "Oh, shucks, here we go again." Then he had her mark down—I don't know what she did to the machine, to make sure that it didn't get swapped because they were identical, both machines and I said, "Oh, man. This sucks." So I went to sleep. Couldn't sleep much that night. Actually, I cried alone. Nurses would come, "Everything's fine." The next day I said, "Oh, this is it. I've got to do something." So this was in May. My story wasn't presented until December 1, '95. This was in May of '95, so I suppose kind of started there. Well, the first thing was my brother's death. I was determined to do something. I wasn't going to let him just die in vain, that was the other thing. He died May 5th. The surgery was on May 10th or 11th. May 10th because he was buried on the 9th, so it was the day after he was buried. Everything was scheduled. I said, "Well, if I need to be home, then I'll just cancel the surgery, postpone it, whatever." So basically he died. The 9th he was buried. Ten was the surgery and then sometime that same week this guy tells me, no, he doesn't want to be in the same room with me because of my HIV status.

CH: He told you he didn't want to be in the same room?

RA: Well, he told his family. He had his family—he had his wife relocate the crutches. That machine—I can't think of it. That machine

there to move the leg and so-forth, put it on his side of the bed. Didn't want it being next to me and so-forth. But anyway, the next day the hospital Chaplin came in. I can't remember her name. I wish I remembered her name because I wanted to go to her and say, "Thank you for coming in that day," but I can't remember her name. She came in and she started talking. She actually was studying to be a Bishop. She wasn't Catholic. I forgot what religion she was.

CH: Episcopal, probably.

RA: I don't know, all I know was that she was studying to be a Bishop of whatever religion she was involved with and she was pretty stressed out because she had just finished an exam of some type. I said, "I'm also stressed out here myself," so I guess we were both in the same situation. And I said, "Here's my chance now," and he's lying there. He's all by himself. I said, "You know, something?" and we started talking and talking and I just told her, I said, "You know, it's not so bad living with the diseases that I have: hemophilia, HIV, Hepatitis, arthritis. That's not bad. What's worse is dealing with the public and the way the public perceives you, and the way they see you, and the way they treat you." Of course, I'm saying this nice and loud because I want him to hear, and he's looking the other way pretending to be sleeping. She started crying. I said, "What are you crying for? I don't want you to cry." She didn't have a clue because I didn't tell her my roommate didn't want to be in the same room with me. I didn't tell her that. So I just went on and on and on and on. I couldn't keep my mouth shut. We just talked for a little while and then she left. He was discharged either that day or the next day and when he was discharged—no, I'm sorry. Let me back up. His wife came in that day and she asked me—she went to him first and there

was some talk and I didn't know what they were talking about, but she came up to me and said, "Do you need anything?" I said, "No, I'm okay, thank you." Then when he was discharged, he came up to me and said, "Good luck." So I said, "Thank you." So I said, "Okay, my work is done. This is what I need to do."

CH: He came up to you?

RA: Yeah, he came up to me and said, "Good luck." He didn't shake my hand. That's good. Words are fine. So—

CH: What was your feeling during this time—how did you feel about him? Did you feel angry or just hurt? Frustrated? Did you take it personally?

RA: "D", all the above.

CH: All the above.

RA: I felt frustrated because I said, "Now, how can people still be like this in 1995, after all the information that's out there." You're not going to get this disease from shaking my hand. Why couldn't he come up to me and ask questions, if he didn't know much about it.

CH: He didn't talk it over with you.

RA: Or call the nurses. They were just there. Just walk out of the room, and it's right there, the nurse's nation. If you're familiar with Brigham and Women's Hospital. It's a cloverleaf. Each nurse's station's got enough nurses there. It's not like they're over worked. Well, they don't like to hear that.

CH: No, we won't say that.

RA: But, no, I was frustrated. I was angry. It was just a bunch of things going through my head.

CH: You had had it.

RA: I had it, you know. Between my brother's death, between this

guy doing this and all the chit chat at work and when I would go out to eat with my coworkers from GE and they were making fun of people with HIV. They would said, "They were homosexuals. They were drug addicts." I'm thinking, "Well, I'm not a homosexual. I'm not a drug addict. I have the same disease, so what gives here?" I didn't say that. Just kept to myself.

CH: What about the nurses, for example, who were treating your brother or treating you when you had your surgery? Did you feel anything from them, anxiety?

RA: Very little. Some of them were kind of hesitant. They were kind of, "Here you go. Here's the water for your pills," but not very many. I said, "Okay, that's fine. I'll live with it." At least they came in and gave me my pills. For pain. I never took anything for the HIV and I haven't. I won't take it. But, yeah, when he said, "Take care of yourself," when he was discharged, it was just like a little thing in my head, like "This is it. This is what I need to do. I need to go out there and educate the public. I need to work with people with HIV. That's my calling. That's my future. That's my next career, and that's what I have to do." How—

CH: That was a turning point for you?

RA: How, I don't know yet. I still don't know. I knew about Hope House. That's the place I work for. I knew about it. I knew when it opened because they made a little story for the television. I just happened to turn the TV on and there it is. I said, "Hmm, interesting. We'll keep that in the back of my head for future reference," and then I came home from the hospital. I'm doing my physical therapy stuff and I say and I say why not work on my story, "my personal story." This is in May of '95. The story wasn't presented until December of

'95, and I'm typing away on the computer and so-forth. I did the speech, presented my story to the staff at Rhode Island Hospital in the morning. In the afternoon at the Fall River City Hall during World AIDS day. Sometime in November of '95 I called Hope House. I called St. Anne's Hospital. They transferred me to Hope House because I didn't know where they were located, and I asked the secretary for an application to be a volunteer there. I didn't ask for a job. She mailed it to me. I mailed it back to her. Never heard from them for, I don't know, two or three weeks. I called them up again. I said, "Is there a problem?" They said, "Oh, no, we'll get back to you." A day later she was calling me for an interview because you have to go on an interview. I went in. I met with the director and the clinical social worker and I believe there was also a nurse there at that time. They interviewed me. That's when she asked me, "What do you expect from us?" I said, "Well, I expect a job," because I wasn't working at the time. I was disabled, you know, but my knee was fixed so I'm ready to work. I'm ready to go. So she said, "Okay." So I ended up working as a volunteer there. I would go in and sometimes cook dinner for everybody or take them out to the doctor's or do odd things around the house there. It's a group home and they've got ten beds for people who were intermediate to end stage and technically they're supposed to be homeless. Well, homeless means the family don't want you. That's what the homeless definition is. Most of them don't live in the street. Only one that I've met that actually was picked up from the street.

CH: But they really don't have anywhere to go.

RA: Right, and then they offered a part time job. I said, "Okay, I like this." Then a full time job. I got a little frustrated. I left for

months. I felt guilty as heck and I went back. They rehired me. So I'm on my second tour. If I leave, I'll leave to retire. And I continued with the speeches, like I said, for five years. Started in '95. 2000, that was the end of it.

CH: You had done that part of it.

RA: Yeah, I—

CH: When you do this work now, do you feel you are really where you belong?

RA: Yeah.

CH: It feels right to you?

RA: Yeah. It's sometimes frustrating because you're not dealing with just the HIV stuff. Most of the people there are IV drug users, and they're not just a person that would use IV drugs today and not tomorrow. Now, they are heavy-duty IV drug users. They come from families that also used drugs. Once in awhile we get someone that had a homosexual lifestyle. Not to many, but yeah, we do get those, also. That's fine. Just come in and I will treat you as a human being. Doesn't mean I will support your lifestyle—

CH: You can do that no matter what they're presenting.

RA: Yes. Yeah, that's something I had to reprogram my head because, you know, being a Catholic, you're not supposed to be a homosexual because it's against the Catholic religion. You're not supposed to do drugs either, but I just look at them and say, "Well, they're human beings. So let's help the person as a human being and if they decide to do this or do that, well, I don't have control over that."

CH: Which is what you wanted people to do for you, treat you like a human being.

RA: Yes. Yeah, I mean treat the disease and forget about habits or what have you.

CH: Being a man of faith, do you feel some of these things were destiny for you? Things like turning it on and seeing Hope House or that Chaplain who came in and the man in the room.

RA: I think so.

CH: Do you feel a passage?

RA: I think so. If you look back, I mean, obviously when you're in that spot you don't think about it. You say, "Hmm, interesting," but then nine years. I looked at the calendar, 2004, nine years later you're looking back and you say, "Wow, no one ever asked me that question, but yeah." First of all the presentation on Channel 6, on television.

I'll never forget that.

CH: The presentation?

RA: Of Hope House.

CH: Oh, yes.

RA: When it opened, I just happened to turn it on and there it is. Toby Shea, who was the original director, and then the Chaplin, which I can't remember her name, in the hospital. My brother's death, we can't forget that. Listening to people's small talk when I went out to work or out to eat. So, yeah, looking back you say, "Gee, you know, I suppose it was a big influence," [unclear].

CH: Little turning points.

RA: Yeah, little hints. But I like working with people that are sick.

CH: You like working with people?

RA: Who are sick, sick. Really sick.

CH: You do?

RA: Yeah, I mean—

CH: Is that because you feel you have a lot to give to them?

RA: I suppose I have understanding and compassion, you know, which a lot of them I don't think get it from their family. They should, but they don't. Most of them, they die there, no one shows up. If we're not there to help them through it—

CH: Does the fact that you are around death so much, does that bother you?

RA: No, not a bit. I mean, there was one fellow who died last Thursday. He died. I was there. I didn't think he was going to die that day, my shift. I work from three to eleven. I'm not working today, so don't panic. It's ten of three or five of. No, I took the day off. And he died that Thursday night and this particular fellow had a very supportive sister. So the sister was there.

[end of Side B, Tape 1]

CH: To deal with people in those situations is really a privilege. You're really sharing something, almost the most personal moment you can share.

RA: Right. When I left Hope House, okay, I went to pursue other things. I went to work as an EMT and that didn't work out because number one, I hated the job and number two, I was getting too many bleeds, you know, carrying people. I couldn't handle it. My disease didn't allow it, the hemophilia. Then I went to Hospice Outreach as a CNA, Certified Nurse Assistant. I liked that, but it was at people's houses and it was like three jobs in one. It was the driving, the social work part of it working with families and then taking care of the patient. But I felt so guilty, I needed to go back and I called. I knew

the boss there, the present manager there and I knew his boss. So it was kind—it kind of helps to know people in a higher level. So I called Paul Quinn, who was the Vice President of the hospital and said, “Gee, I need to get back there.” “I’m sorry, but human resources told me they were full, you know.” “I felt guilty as heck leaving the place.” “Yeah, but they will really have a difficult time taking you back because of the things you told them.” “Well, they asked me how I felt and I told the truth.”

CH: The things you told them being about yourself?

RA: No, no, about the way the place was being run. I didn’t think they were doing a very good job and I told them. “You guys aren’t doing a very good job. Here’s why,” and I told him, “You can do this, this, this.” Well, they didn’t want to hear it. Well, don’t ask me the question, if you don’t want to hear it. I told Paul Quinn, who is the boss of my boss now. I said, “It’s an honor and it’s a pleasure to take care of someone who is dying,” you know, and that’s the way I look at it. I mean, I don’t want to sound like I’m Dr. Kevorkian. I mean, I don’t pass out pills to make people die because I don’t do those things. You know, people die in their own time. You know, there’s people there that I go to work and I say, “Gee, I don’t think this person will make it,” and the person’s still telling me what to do. So we don’t know these things. When it’s your time to go, then it’s your time to go.

But does it make me depressed to see someone dying? Not really. Do I worry about it? Yeah, I wish there was no death, but it’s part of life. If you’re born, you’re going to die. That’s the way it is, and as far as is it good to see people die, in a way for me? Yes, because I know I did a good job. I know I made that person

comfortable. I know I passed out the pills. I know I was—I made the person comfortable.

CH: Do you find that what you're doing now makes you feel more peaceful with what happened to you and to your brother?

RA: I know right now I'm very relaxed and I feel this is where I belong. Sometimes I get so frustrated with the politics at the house that I tell my boss, "That's it. I'm looking for another job. I've had enough of the people at this place. I can't take it anymore." Not because seeing the people die. Oh, no, the politics. But he looks me in the eye and says, "Well, I'll miss you," and a week later, "Oh, forget it." By now he's probably saying, "Yeah, yeah, yeah, yeah, just like the little girl who cried wolf, the way it sounds. I don't believe you no more," you know. But absolutely. Would I stay there forever, I don't know. I don't know.

CH: Does it matter?

RA: If I stay there forever, that's great. If I don't, then so be it.

CH: You'll move on to something else.

RA: But I don't think I will ever do anything that doesn't involve somehow helping others that are unfortunate and that need help of some type or another.

CH: During all this time, did you participate in the class action suit against the medical companies?

RA: A little bit. People were on my back to get more involved with it and I would tell them, "I'm not in the business of using my diseases to make money." That's the way I felt.

CH: Did you have no sense of wanting to have some retribution for what happened to Joe?

RA: I didn't want anything to do with it. I didn't want any money

coming in this house that was, I call it dirty money. I didn't want any of that stuff. I said, "I don't want it. You keep the money," but I was under a lot of pressure and I did fill out the paperwork. I did collect the two hundred thousand because there were two different lawsuits. One through the company and one through the government.

CH: You did collect that.

RA: I did but obviously Joe didn't get any money because he was already dead. My family collected the money that was awarded to Joe. I did, but I also made a promise and I kept my promise, I didn't want to get involved with the dirty money. That's what I called it, and it's still dirty money. I don't condemn people that took the money and used for themselves. That's your decision. I'm not going to put you down for it, but I could not live with myself if I kept that money, and I'll tell you what I did with it. The first hundred thousand I divided in ten thousand increments and I donated to ten different organizations. [voice is cracking]

CH: And were they HIV related?

RA: No, they were different organizations. Ten different organizations. I don't want to mention who they were. They were organizations that provided assistance to people that needed help. I wanted to educate, also, those organizations because some of them were hotheaded about HIV and AIDS. I included with each check for \$10,000 a poem that I wrote, and in front of the card I drew a red ribbon.

[Roy recites the poem]

Imagine!

Imagine—if you saw!
Imagine—if you knew!
Imagine—if you grew!
Imagine—if you lived!
Imagine—if you respected!
Imagine! Imagine!! Imagine!!
Let the world—imagine!

—RBA 1995

And I said, “Here you go.” Just walked in. They didn’t know who I was.

And with the other hundred thousand that came to me, I forgot when I got it. I started—that one I’ll tell you what I did with it. I called the people up in Boston. I told them that I wanted to start an endowment for people with hemophilia, factor VIII or factor IX deficient, and I wanted the people of Boston Hemophilia Center to be the folks in charge of this endowment and I would provide the hundred thousand dollars for it to get it going. They almost had a heart attack. [laughs] I don’t think they believed me because Dr. Bruce Ewenstein—he’s no longer there. He left. He left Boston. He went to do some other things. He met with me and he said, “Are you sure you want to do this? Are you sure your family don’t need it?” I said, “Yes, I’m sure. The bills are paid at home and we don’t need it.” CH: Were your parents in accord with that decision?

RA: Yeah, they were.

CH: Did they get money for Joe?

RA: They did. We used it for other things. They did, you know, but they did that themselves.

CH: But they were all right with your decisions?

RA: Yup. So right now we have an endowment in Boston. It's called the Hemophilia Family Endowment Fund and anybody can donate to it, if you so chose. They cannot ever touch the principal. That's the way I wrote up the policy for it, but they could use the interest that accumulates and they have. They have used the interest to help out other people with hemophilia, you know. Laura knows about it and she helps with the dispensing of the monies and the nurse out there and the doctor.

CH: Did you feel anything at all towards the medical establishment that had been responsible? Did you feel anger towards the people?

RA: Yes, I still do.

CH: You do?

RA: All of my life. Well, since I was a baby, that Dr. DeLima. He told my parents—I was just a little baby, so I didn't know at the time, but he had told my parents that "It would be easier to let him die," and that was just because of my hemophilia. Being born in the Azores, there wasn't much you could do. So, you know, here's a doc telling my parents I should die, and then during the process of fixing my hemophilia, I get two other diseases, the hepatitis and the HIV stuff and I said, "Gee, what is the medical people doing to me?" So, yeah, when doctors approach me and say, "Well, you need to do this, this and that," I'm like "Let me get back to you." I have to go to the library and research it out with books. I'm not a fan of the Internet. I

like to do things—you know, give me advice. Give me feedback. Give me opinions, but I need to do my own decisions, after I consult with the books.

CH: Would that be one of your pieces of advice to people going into medical situations?

RA: Well, I always tell people, listen to what people tell you and then follow your gut instinct. If you're not comfortable with it, then don't do it because you're just going to be depressed and then being depressed, you're going to be sick and then you're going to be wondering, "Gee, was it the medication that made me sick or was it depression that made me sick?" Well, I believe that you can fight a lot of things with psychological and mind power. I believe in mind power, you know. I really do. I mean, I'm still here. I'm forty-three years old. I've been living with this hemophilia for forty-three years and HIV and hepatitis at least twenty-four years. We didn't have a test to confirm it. All we could go by was the blood count, the CD-4 count. There was no HIV viral load stuff test. I'm asymptomatic. I've had three operations, you know. Recovered very well. There's no difference than the next guy who's perfectly healthy. So I consider myself to be in good health.

CH: Wasn't it lucky your parents listened to their gut reaction?

RA: Yeah.

CH: Rather than just go off and let you die.

RA: Yeah, otherwise I would have been dead.

CH: I am going to ask you about—obviously, it's impacted your life hugely. What about relationships for yourself?

RA: I knew that was coming somehow.

CH: You did?

RA: I knew that was coming. I said—

CH: If you don't want to answer, that's fine.

RA: That's fine. That's fine. I don't have a problem. It was a hard decision, but it was something that I never wanted to get involved with it. I always somehow put it on the back burner. There were plenty of girls and young ladies and woman that would die to go out with me in a split second. I just found excuses to call it quits.

CH: Was that even before you had HIV? Was that a hemophilia related decision?

RA: It was hemophilia, and deep down I just somehow in my head, I said, "Okay, well, okay, I don't want to end up with a bunch of kids with this disease and I don't want to see them go through the pain that I've gone through over the years." Now it's just not true. Now we have all sorts of factor concentrates, but I just didn't want to do it. Then when the HIV came along, I said, "That's it. No. Nothing. I don't want to be responsible for passing this disease to some girl or some lady. I just don't want it." I would tell this to Laura, too. We would sit down and discuss it. "No, I'm not doing it." "Yeah, but you shouldn't be scared, da, da, da." "I'm not doing it, Laura. I don't want it." I couldn't live with myself if I got married and accidentally passed the disease to the wife. She said, "Yeah, but there's other ways you could," because I want to have kids. Yeah, I wanted to have, you know, kids and so-forth. "Oh, there's other ways to do it. We've got all these medical tests"—procedures, not tests—"that we can do. We do have couples here who the father is HIV positive and they have a kid and they're doing fine. You just have to work with this," and so-forth. I said, "I don't want to deal with it."

CH: You just don't want to.

RA: I don't want to, right. Last time I saw her, she's still on my back, "Do you have a girlfriend?" "No, I don't have a girlfriend." Says, "What are you waiting for?" "When I retire." So I told her, "I'll keep the doors open." "Thank you."

CH: Are you used to that now?

RA: I think so.

CH: Or is it something that makes you sad most of the time?

RA: It doesn't make me sad. Not at all. No. I don't mind being single. I'm very independent. I work. I have a bunch of hobbies. I suppose if I meet someone who we just got along, good personality, maybe I'll—I don't know, maybe a relationship will develop and we'll end up husband and wife. I don't know. I'll keep the door open.

CH: That's destiny.

RA: That's the last phrase I told Laura, "I'll keep the door open."

CH: Again, that's destiny.

RA: So what happens. We'll see what happens. I mean, I am not going to go to single bars and do that thing, because that's not my thing. If I meet someone while working or outside somewhere, then so be it.

CH: You also need somebody very mature and very special.

RA: This is pretty stressful. I mean, I look back at my friends who are hemophiliacs and HIV and hepatitis who got married. A good number of them ended in divorce. They married, but it didn't last.

CH: But it didn't last.

RA: Didn't last because they say, "Oh, my wife couldn't take the stress," what have you. I don't know. So it didn't last. I mean, looking at all those things, you say, "Well, do I want another stressful

chapter in my life? I'm doing okay this way, let me just stick with this situation and we'll see what happens."

CH: Yes, you can see what happens. Would you say overall that you're pleased with your life at the moment? Are you pleased with what you do?

RA: Overall, I think so. To be honest with you, I wouldn't change a thing in my life. I like the way things are going.

CH: Obviously it would be nice to change the big things that went wrong.

RA: Yeah, but maybe I wouldn't be doing what I'm doing now and I like to say or to think that I'm helping a lot of people.

CH: Yes, you are.

RA: So, directly and indirectly.

CH: That's correct.

RA: I figure if I help you, then you're going to go out and talk to somebody else and then, okay, you're spreading my news and even helping me.

CH: And how are your parents doing?

RA: They're doing good.

CH: Good.

RA: They're doing good. They should be home in an hour or so.

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

RA: [sighs]

CH: Anything?

RA: A final thought, like I say, I want to thank the people in Boston for giving me a chance with the left knee operation and with all my medical care. With the support they gave me. It's a wonderful organization and I hope they stay around for a long time.

CH: Do you ever think about going back to where you were born and seeing it, or does that feel very remote?

RA: I don't want to go back there.

CH: You don't?

RA: No. I'm the type of person that when something's complete, the book's closed, I don't want to go back. Just leave it that way.

CH: So you don't look backwards?

RA: No.

CH: You're not a person of regret?

RA: Not really. Not really. Sometimes I say, "Gee, I wish I had known that. No, no, forget it." I don't want to dwell on it.

CH: Do you talk very often to other men with hemophilia? Do you participate with them?

RA: Yeah.

CH: In groups and so-forth?

RA: Yeah, groups. Groups. I've done that. For the longest time I wasn't very supportive of groups. I just didn't like them. I like better the one-to-one situation, but yeah, I got involved with Committee of Ten Thousand. I don't know if you've ever heard of them?

CH: Yes, I have.

RA: For a while, but I kind of dropped out of the group. For the longest time, actually, for three or four years now. But, yeah, I've got involved with them, the older generation, the older hemophiliacs.

There's still a few of us around. A good number have died and once in awhile I get a call, "Oh, so and so died." I used to go to funerals, but somehow, I said, "Oh, man, I don't want to see another one." So for the last two or three, I didn't go. They were the closest friends of mine. I said, "Oh, man." Now there's only one close friend that's

still kicking around. So it's like, oh, well.

CH: Do you find yourself thinking about the younger men and how much easier they have it?

RA: They have everything made for them. I got involved with NEHA, the New England Hemophilia Association. I went to camp and most of them were young kids there and they would ask me some questions, but I just somehow I didn't feel that that's what I wanted to do, educate the younger hemophiliacs. I couldn't connect.

CH: It's almost another world, isn't it?

RA: Yeah. I'm not sure how to—what to do because they've got everything made. I would tell them, "Gee, you're got everything made. You've got factor. I didn't have all that stuff." "Yeah, yeah, yeah, yeah, yeah." They're too busy playing soccer or football or going swimming, so I don't know how to connect with the young kids. I don't even know if that's necessary, to tell them the way I was. Why? He's all set. They're all set. Why?

CH: I don't think it is necessary.

RA: I don't know. I mean, people are—what's her name? The director of NEHA? I can't think of her name? She used to be a social worker at Boston Hemophilia Center. I can't think of her name right now, but anyway, she said, "Oh, we'd love to have you here as a counselor, and so-forth." I said, "Yeah, yeah, I'll go next year." I did go one year to camp. I just showed up for that year, that was it. They were so happy to see me, but I just don't fit in somehow. I just don't know how to connect with the young kids. I don't see any need. She thinks there was a need. "Well, they should know. They should know how you lived and so-forth." I said, "Why?"

CH: They don't want to know.

RA: Look at them. It's too depressing. They're more interested in playing soccer. That's fine with me. I'm not angry with the kids. I'm not going to make a five or six year old sit down and listen to my story. For what? If they want to listen, fine. If they ask questions, I'll give them the answers and so-forth, but otherwise, that was it. Most of the groups I was involved with, people my age, were trying to figure out what to do with girlfriends and so-forth. You know, how to have a girlfriend and how to have a relationship and not have to—and not have her run out as soon as she finds out about your diseases. You've got to be honest. You've got to tell her. I mean, you don't want to just keep it to yourself because I don't believe in that. If you're going to have a decent and healthy relationship, you've got to be honest, both ways.

CH: Did you ever tell someone you cared for about your situation and have them leave?

RA: Not really. I never got to that point because as soon as I found I was too friendly, too caring or too close, I kind of, "Oh, well, time to go." I left. That was the end of it. But anyways, that's just it. I kept walking out. I'm not going to start thinking, "What if?" No, no, you get a headache and half with this and then you use half a bottle of Tylenol.

CH: Thank you very much.

RA: You're welcome. I don't know if I talked too much.

CH: You didn't. Not at all.

End of Interview