

Interview with James Martinowsky (pseudonym) for the Boston Hemophilia Center Oral History Project, A Gift of Experience, by Laura Gray, October 7, 2004.

GRAY: It's October 7th, 2004 and I am sitting with Dr. James Martinowsky, who has kindly agreed to participate in the Boston Hemophilia Center's Oral History Project called The Gift of Experience. May I call you James?

Martinowsky: James' is great.

LG: All right. So, James, thank you, and we are sitting in his office in Boston, Massachusetts, at 1:30 today, Thursday, and James, I'll start by asking you where did you grow up and who did you grow up with?

JM: I was born in Washington Heights, but we moved when I was—

LG: Is that in New York?

JM: Yeah, New York. It's where Manny Ramirez comes from.

LG: And when you say "we"?

JM: We, meaning, my mother, father, and two older brothers. My sister was born in the new house. Well, actually "the house," because we'd been living in an apartment in Washington Heights. We moved to an area of the Bronx, called Pelham Parkway, but that's not quite what other people call Pelham Parkway. It was sort of lower, middle class, we used to call it "working class Mafia," because there was certainly Mafia in the neighborhood, and we had these—

LG: The Italian Mafia?

JM: Italian, yeah. Yeah, in fact the guy across the street, the richest of our neighbors, was murdered. There was no crime in the neighborhood except when the Mafia was involved—and there were a number of stores in our neighborhood that were “fronts.” The neighborhood was actually used for a movie called “True Love,” with Annabella Schiorra. It’s where Spike Lee discovered her and she was actually recently in *The Sopranos*, too. Anyway, she plays a teenage girl in my old neighborhood and is very Italian, you know, seventeen year olds who are going to get married, but they’re not grown up. Anyway, so that was the Italian neighborhood I grew up in, and you lived in attached houses, with common driveways. That was the thing, and there were a few—in addition to the Italian families, there were a few Jewish families and a few Protestant families, although when a Black family was going to move in when I was a teenager, early teenager, there was a petition passed saying that we didn’t want any Blacks living in the neighborhood. My parents were actually very upset about that.

LG: That’s where you really grew up?

JM: Right, because as soon as you could walk or get driven, you went about ten blocks to this neighborhood which really was either called Pelham Parkway or Lydig Avenue, or Allenton Avenue, which was tens of thousands of Jews in six-story apartment buildings, many of them Holocaust survivors or war camp survivors. So that was the “other” neighborhood. The other—from the point of view of my hemophilia, the other thing important about the neighborhood where I was born was that two blocks away, Jacobi Hospital was probably already built, but not able to

accept hemophiliacs. But Albert Einstein College of Medicine was built. The first class started I think in 1955 and we probably moved there in '54. My father had been in the service and on the GI bill he could buy a house. I think they paid, I think it was a twelve thousand dollar, twelve thousand five hundred dollar house in 1940 whatever. I was one year old when we moved.

LG: How old are you and when were you born?

JM: I was born in 1953, so I'm fifty-one.

LG: And what is your diagnosis?

JM: My diagnosis is classical hemophilia, factor VIII.

LG: Hemophilia A?

JM: Hemophilia A, factor VIII deficient, and on some things it will say moderate and some things it will say severe.

LG: You don't know what percent?

JM: Well, it was 3% was what I had been measured at one time, but there are other times when it was lower, and I know it's usually supposed to stay consistent, and my course medically was somewhere in between, also. So it was not exactly clear, but I certainly was—I think moderate is probably fair.

LG: You were the third of four children and you have two older brothers.

JM: Yes.

LG: And do they have hemophilia?

JM: No, there was no family history. There were some suspicions. For example, my maternal grandmother was born in Europe. She was from Galicia. She was a Galitzianna, which is from this area of Austria-Poland or Polish Austria depending on the year. And she

was put on the boat when she was nineteen to come to America and she always denied that there was any connection, but the Eastern Europeans seem to have always denied any connection because they didn't want to be blamed for anything. This was a woman, when she was hospitalized in her seventies, late seventies for a—she had fallen and broken her hip. She said it was—in the emergency room record, it says that she explained that the cause of her breaking her leg was that a woman in the building, seeing that she still had her husband while that woman did not, had given her the evil eye and that's how she fell. So that's her view of medical causality. But she—

LG: Not necessarily scientifically based.

JM: Right, right, and so she didn't really want to be implicated in my hemophilia, but when she was about eighty, she made a slip at a Passover Seder, where she said, according to my uncle, she referred to her brother as the "Elter." There were a number of boys in her family. She was one of there was like eight girls, I think, and one boy who died in a concentration camp. Most of her siblings did, but there was a slip and she referred to him as the "elter." Now, for him to have been the "elter," the older, it meant that there were younger ones and what my uncle, who knows about these things, said what that meant was that there had been male children who had died in childhood. They would say that the boy they referred to as the 'elter' fooled the angel of death, so that the angel of death should think that there were other boys that had already survived. You know, if there other boys, he wouldn't kill this one, too.

LG: He wouldn't be taken if there were others already there.

JM: Right.

LG: So even though he was the only boy—

JM: Boy, there was some suspicion that there was a lot of boys who died quite young or in childbirth and she didn't deny that when he asked her about it.

LG: So that's the only indication that you have that perhaps there might have been a family history.

JM: Right. My mother was tested as a carrier, mostly because my sister, who was born after me, wanted to know and at that point they did it by testing everyone in the family. My grandmother refused to be tested. [chuckles] And since it was my sister, that there was an 85% chance that she wasn't a carrier, that was enough for her. But that was the sort of family history, but there were no other hemophiliacs anywhere. The assumption I grew up with was that I was a mutation—it was a mutation. I used to like to provoke people in the hospital and they would say, "Well, how did you get to be a hemophiliac?" and I'd say, "I'm a mutant," because that had a very complex of meaning to that.

LG: So let me go back a little bit to your family and ask you about your parents.

JM: My father was—his parents were from Russia. He had grown up in the South Bronx when it was Jewish and I would say grew up pretty rough. He was working, barely graduated high school, despite being very bright and was working probably full time, you know, by the time he was twelve or thirteen, in the family business, which was the wholesale fruit and vegetable business,

which is the kind of business where you start at 3:00 in the morning or 4:00 in the morning. You go to the market, business starts to happen. In fact, he would not let any of us go down to the Bronx Terminal Market where he worked growing up because he was afraid that if we went down there, we also would go into the fruit and vegetable business. My brother actually tricked him as he took a summer job, working with the guy next to him. My father comes down to the market and sees my middle brother throwing around grapefruit, but he really felt strongly that that business was a hard life. He was quiet. He used to read like the *Herald Tribune* or the *New York Times* from cover to cover, every word on the weekend. He knew what was going on, and he knew that he was, you know, smart. He was very articulate, but he had very poor self-esteem around all of it.

LG: His lack of education, lack of formal training?

JM: Yeah, in fact, even when I was—it's very painful to me. I remember I was at the Psychoanalytic meetings and I was calling home and I asked my dad "Do you want to meet downtown for lunch or something?" and I said, "How about the Waldorf?" joking around, Waldorf, where they held the meetings. After I told him I was at the Psychoanalytic meetings, he said, "Oh," he said, "don't tell them that your father's a fruit man." So I said, "What do you think their fathers do?" [chuckles] There's a joke in fact, what's the difference between the International Ladies' Garment Workers' Union (ILGWU) and a psychoanalyst, and the answer is one generation. But to him—it was where—how he thought about himself. He was—he had a very difficult relationship with his own

father and the transfer of the business was very upsetting. I found out later—I knew that he had gotten depressed when I was young and I knew that he'd gotten depressed again or seemed depressed around the time I was graduating high school, and I wouldn't find out until much later that he'd actually been in therapy.

LG: That was unusual for that time.

JM: Quite remarkable. Quite remarkable and mostly due to my mother. He had gone to the VA and actually was in this twice a week psychoanalytic psychotherapy in the '50s and then again in the '70s with the same analyst who worked at the VA in the Bronx. I think it was very helpful to my father. In fact, when I told my father that I was going to into psychiatry and not going into medicine, I thought that he would be sort of disappointed about that, and it was at that point that he told me that he did see a psychiatrist and it had been helpful and that no one else knew except my mother. So that was a big deal.

LG: So the family tradition of covering up with secrecy goes through the generations.

JM: Right. Absolutely.

LG: Okay, and your mom, it sounds like she's someone who could confront things?

JM: Yes, well, she has two sides to her and I always joke around with my brother. I'm very close with one of my brothers and it's as if one of her sides is represented by our personalities and the other side by the other two kids. There was a part of her that was—she was very smart and she went to Hunter College. She was a math major and then she dropped out of college to marry my father

when he came back from the service. In fact, even now takes classes, you know. She was really a very good student. Was always a good writer. Would win awards for things and my father attributed, actually, his children doing well academically completely to my mother, which wasn't entirely true, but that certainly mattered to her that we did well at school. She had—she was very devoted to taking care of her children and to taking care of me in particular. She really was a—she was really there for me. On the other hand, she wasn't actually always very assertive in terms of getting the best care for me. It was very hard for her. She was very intimidated by doctors, by medical people. And there were lots of times we waited for hours and hours in the ER and only as I got older I would start to speak up and say, “You know, you got to get somebody down here to get the Factor VIII. You know, to get the cryoprecipitate, or whatever it was.” I think it was also intimidating from a financial point of view, that they couldn't really afford the product and there was insurance—you know, it was paid for by insurance, but it could stop at any time. There was a day when—days of people doing blood drives to try and get enough factor VIII. I didn't really understand that piece of it until much later, when I met some of the older hemophiliacs.

LG: Let me go back, now that the subject of hemophilia has been raised. When did they find out that you had hemophilia?

JM: They found out when I was twenty-two months.

LG: And what happened?

JM: I had at least two other bleeds before then. One of the bleeds was in my gum. I think it was my frenulum or something was torn up,

whatever, but the bleeding wouldn't stop and they actually stopped it by putting in a stitch. So in that sense it didn't seem like I was a severe hemophilia, although I think the doctors told my mother they were suspicious because I always had bruises. Then I had a bleed. I fell in the playpen and had a bleed in my scrotal area that was huge. You know, it was large and very visible. After that got better, they used ice or whatever to treat it, they suggested that I be tested, and I was tested at Columbia Presbyterian by a Dr. Wolf. I only know his name. I still remember it, and apparently he did the testing and said that there was no question that I was a hemophiliac.

LG: What do you mean you still remember it?

JM: I still remember the name, people would say, "Well, how did you know you were a hemophiliac?" "Well, Dr. Wolf did the testing," and that was that, I guess—that meant that it was so.

LG: But you remember that from your mother or father telling you.

JM: I remember it from hearing it, you know, I was a little kid and they would say, "Well, how do you know?"

LG: I see. But you don't remember any of those early, early events?

JM: No, I don't remember them at all.

LG: Now, you mentioned that there were those two events prior to actually being diagnosed. What about the circumcision, was that not an issue?

JM: I had a circumcision and I bled a little longer than some.

LG: But it stopped.

JM: It stopped.

LG: Because that's a classic time, actually, when people are diagnosed.

JM: Right, but it did eventually stop and that's why I said, that note said I was moderate. It would—there were times—and even—you know, I spent, it seems to me, so much of my childhood trying to figure out like when I would bleed and when I wouldn't, because it was so inconsistent. There were times when I could get away doing stuff and other times where like nothing would put me out of action for weeks at a time. So here I got a circumcision or I was bleeding from some cut on my lip, cut, and yet at one point I got hit with an acorn just lightly on my eye and I had the most huge shiner when I started seventh grade. I was going to this new school with a huge shiner, and I felt so bad for my cousin who was throwing the acorn because, you know, it looked like he must have thrown it hard, but he hadn't. He must have just touched a blood vessel and that was it. So it was that kind of unpredictability about, you know, the bleeding.

LG: Tell me who was your primary caretaker in your family?

JM: My mother. My mother—my mother and father had very much a—they had an arrangement. They had an understanding from the time they got married, it seems to be about most everything, including for my—you know, the fact that my mother wanted to keep Kosher. My father wanted to be able to eat Chinese food and they said, "Okay, you have Chinese food on the weekend, we'll have"—you know, they had it all arranged. I think they were big believers in family planning. I know that both me and my sister were accidents. They had actually only wanted two children and maybe they were thinking a third a later on. My mother was really a—she was by training a bookkeeper, is what she became and she

liked the books in order that way. And the idea was that the children were hers to take care of and then my father was to make money and to, you know, and to take care of cars and things like that. The house cleaning, very clear division of labor. In addition, my father really didn't feel, I think very like he had that much to offer as a parent, you know. I think part of that was his profession. Part of that was he didn't get that much from his own. His mother, who I knew, was really a very cold woman. So that was it. So my father would drive me to the hospital, if he was available and he almost never came to visit me in the hospital.

LG: Tell me about what it was like as a little kid or, you know, what you remember about having hemophilia?

JM: To begin my—

LG: Well, first of all, do you remember how it was even explained to you or what you knew about it?

JM: I have one memory. I have a memory of, you know; analysis calls it kind of a screen memory. I have one memory of not being a hemophiliac.

LG: Of not being one?

JM: It was me just being a very happy baby, with like a, just a wonderful, you know, disposition and just like sitting there on the porch. That's my memory of like not being one, and even though I'd been described as having a wonderful disposition when I was a kid, from my point of view, that was the only memory I had. It was actually my first memory. The next memory I have is of them taking—it relates to my sister, and taking—see my diagnosis actually comes just after my sister is born. Right? She's born

about a year and a half after me, and so I have some memories of my sister of their—their moving the crib. I have no other memories of her until I'm like six or so, six or seven, and I realized I didn't want to acknowledge that she was around at all. But the hemophilia part of it, in those days, my mother and I used to refer to them simply as the bad old days.

LG: She used to refer?

JM: We both used to refer to the—to my early experiences with hemophilia, where it never felt like me. It always felt like us, like in the early days, and it always felt like the bad old days.

LG: Why were they referred to as the bad old days?

JM: They were referred to as the bad old days for how much pain was involved, for how much waiting was involved.

LG: Waiting?

JM: Yeah, how much of an ordeal it was to get to the hospital and get treatment. It was a nightmare. It was three busses. Three busses each way. [voice cracks]

LG: How long would that take?

JM: [pause] Take over an hour and it was getting off one—a lot of the injuries were ankle injuries so I'd be limping and it would be getting off and on. And it was very painful and it was very embarrassing. [crying]

LG: What upsets you about thinking about this?

JM: [pause] Embarrassment.

LG: The embarrassment.

JM: I think so. I think that it's interesting because, you know, as a psychiatrist I think that one of the things I discovered as I was in

practice was the importance of shame and embarrassment as a thing that gets people into trouble. But it was very embarrassing. You know, when you're a kid, you know, you want to be able to be tough, and you want to be cool and there was nothing cool about this. Pain is awful, not just because of the physical pain and how untreated that went, but because it removes any ability you have to sort of keep a face on.

LG: Because you can't anymore.

JM: You can't. You can't. You know, the other side of that is that people were very nice. I think that the people recognized that and in general they were very, very nice.

LG: People being the doctors and nurses?

JM: People on busses.

LG: People on busses?

JM: I have—like fundamentally a very positive view of people, individuals and how they react in tough times or with tough situations and I've always felt that way, particularly about New Yorkers. They want—you know, I joke around about this like if someone drops down in the street in New York, everyone says no one will do anything, but my experience is that everyone will do something. People will run over, try and help. As soon as the person's okay, they take off. Right? They don't want to be involved, but my experience is that they care and that was my personal experience growing up.

LG: How did that manifest?

JM: Well, they helped you out or they'd start talking with you. They'd try and distract you from the pain.

LG: Really?

JM: People were very nice, yeah. That was the other-

LG: It was always you and your mother?

JM: Yes. Yes, and it was the—it was the main resentment I had towards my father growing up, would focus around his uninvolvedness with it. Now, in truth he was uninvolved with my siblings, as well, but my rage at him, my anger at him was that he wasn't there around my illness.

LG: He wasn't present, he was in the business a lot of the time, but emotionally did you feel he wasn't present?

JM: I think it was very painful for him. I think he couldn't face it. I think it was not a problem related just to me. He was scared of the doctors and hospitals. There were a few exceptions that I remember—when he drove me, he would carry me to the car and carry me out of the car. I remember that. You know, things were so complicated. You know, there was also some relief in not having to talk to him about it. The other men involved, my uncles, they would—a couple who I was close with—

LG: Uncles on your mother's or father's side?

JM: Both. Both on my mother's side. My mother's brother and especially my mother were very close to her sister. They were really like best friends, her younger sister and her husband. They were both engineers, and they were right out there. They used to just blame me. They used to say, "How could you be doing this to your mother?"

LG: They would berate you?

JM: No, they would blame me. They would blame me, [unclear] in the sense of, you know, like they would understand like why I'd gone out to play football or why I'd gone out to run and think, "You know, how can you do that?" you know, and they would just like yell at me.

LG: Oh, if you got a bleed, you mean.

JM: Right, if I got a bleed. Right, right. They would blame me.

LG: So it was your fault for causing such trouble in this household to your mother.

JM: That's right. But, you know, I—you know, when I got older I'd say—I remember I had a confrontation with my Uncle Leo, the one—and you know, I real—you know, I told him that, you know, you know, enjoyed him coming to visit me, but he could do away with this blaming business. He—did, too, but they were both, I thought genuinely well meaning, you know. They cared.

LG: What was your mother's attitude toward your having hemophilia?

JM: Well, I think she felt terrible about it. I think that she struggled with blaming herself for it.

LG: Why do you think that? Did she ever talk about it with you?

JM: There was one time—there was one occasion where I was in extreme pain and I was crying.

LG: How old were you, do you know?

JM: Must have been about eleven or twelve by then. I remember hopping, going to the hospital and we were sort of getting ready to go. In other ways it was not unusual, unusually bad one, as these things went. I wouldn't go to the hospital unless I was to that point, anyway, so it was—

LG: Unless it had gotten so excruciatingly painful.

JM: And, you know, a lot—some of that was some of the whole set up, the way it was but that was how I knew it was time to go is I couldn't take the pain anymore. So for whatever reason, she must have been—I think the problem was I hadn't had a bleed in a while and she said, "It's all my fault," and even though I think I must have known that she thought that at times, and she started to cry and berate herself in one way and I just went off. I started yelling at her that she could never ever say that.

LG: Really? Because?

JM: Because it was my problem, not hers. [voice is cracking] And it meant that I couldn't ask her for the help I needed, she was busy blaming herself. It felt like I would just be adding to her ordeal.

LG: It meant that you couldn't ask her for help if you had to struggle with her own issues.

JM: With her guilt. Not that I didn't have my own, right. So that was—yeah, that was—and—

LG: Did you have a lot of 'you can't' in your upbringing? You know, "Don't do this. Don't do that. Be careful," or what was their attitude?

JM: "Be careful" was all the time. My pediatrician was a very interesting guy, a very important guy. His name was Julian Shorr and he was brilliant. He was a pediatric hematologist who was at Montifore and then at Jacobi when it opened up and he was head of the blood bank. His wife was administrative director of it. He later murdered his wife and I wrote to him in jail, but he developed the blood banking system in Vietnam. He was a full professor of

medicine. He'd gone to—in later years he'd gone down to the medical school in Virginia that they had just opened to be one of the founding professors and that's where he murdered his wife, who I knew well. She was actually the person who taught me how to give myself an injection, and I can understand why he murdered her, but [laughs] that's another story. But that was his story. He cared about my psychological well being and trying to preserve some semblance of a sense of self—and he really wanted me to have sort of a sense of self and to learn about taking risks.

LG: And what?

JM: Learn about taking risks.

LG: What do you mean? What's the connection between learning how to take risks and maintaining some sense of self and self-esteem?

JM: Well, he had seen, I think, what I had also seen was hemophiliacs who had become so passive, who had become so fearful of getting hurt that they really stopped taking chances. So I was really very aligned with him about that. Unfortunately, as my mother would say, he didn't have to suffer the pain afterwards. So he encouraged me to—exercise as much as I could, to do as much sports as I could, to take some reasonable risks. He encouraged something she felt uncomfortable, with which was using steroids after a bleed to try and reduce the arthritic—the arthritic changes that were starting to happen. He really made an effort to improve the process of getting transfused. He made it something that could happen in the Emergency Room without being admitted. He gave me lots more control of it. He encouraged me to come in before it got too bad. He would make contacts with people in the

Emergency Room. If they screwed up, they would sort of have to answer to him, if they kept me waiting a really long time. I mean, a lot of times it didn't quite work that way, but there was at least a sense that you weren't without a voice in that situation. And things definitely improved. So he was—I'm not sure when exactly I started to see him important. He had a partner whom I didn't feel the same way about, but I liked him.

LG: So it sounds like he was a major influence on you, as far as saying, "It's okay. Try it." It wasn't all about, "Do everything you can to avoid a bleed."

JM: Yes, that's right and he—yeah, was about—you know, he represented my taking charge of my illness.

LG: Even as a little kid?

JM: It started—well, yeah. Yeah, he was—this is actually very interesting. He used to speak with me, not with my mother, you know.

LG: He'd direct his conversation to you.

JM: Right, you know, I'm a child psychiatrist so I joke around that, you know, the secret to being a psychiatrist is you talk to children like their adults and adults like they're children and you do just fine, and he used to talk with me that way, from a very early age because my mother was pretty, you know—you know, she would always speak for me if she was given the choice. You know, she was always the expert, but he would just, you know—and he would ask her to leave sometimes to talk to me, and he came to my Bar Mitzvah. I was just thinking about that recently. That he came to the service, just for a short while, but I remember him showing

up, which I was very, very happy about. This was very important for me and it was important to my mother, also. I knew that. I knew that—

LG: In what way?

JM: I knew that he was the—she really appreciated him and, you know, saw him as, you know, in a way, you know, in that situation he was the father that my father wasn't. He was there and he wasn't—he wasn't disrespectful to her at all, but he would push her away and make it clear that this was my illness and my decisions. He was very—and in my history, when I was—there was a period of time between the ages of fifteen and twenty-three where I didn't have a physician. When I was fifteen, I left the hospital, against medical advice and I didn't return to a hospital. I would go pick up Factor VIII and treat myself until I was twenty-three and it was he who sort of allowed that to happen.

LG: Why did you leave against his medical advice? What happened?

JM: So I was fifteen. I knew what the bleed was about. I had been trying to dive and I had belly whopped and I had started a bleed internally and I came pretty close to dying. My crit was very low. I think it was like twelve or something when they measured it in the ER and as I sort of lost, you know, consciousness I heard them say that they didn't know whether I was going to make it. So they were pumping blood into me. I had let it go way too far, partly because I felt guilty about how I had caused—you know, how it had happened and I'd been out with some friends trying to learn how to dive. I let it go on for like a week of bleeding. Anyway, I got better and every time I got better, they would do a

sigmoidoscopy to try and find the source of the bleeding, which was quite unpleasant, and it would start bleeding again. There was a guy named Michael Cohen—Michael Cohen? Was the head of the adolescent medicine division at Montifore who was really an incredible asshole. I knew him later on, as a medical student as well because I went to medical school at the same place I was a patient. Oh, it was kind of interesting. But the—so he had decided either I had Crohn’s disease or ulcerative colitis and hemophilia and he wanted to prove that. So finally I said, “No, every time I start to heal, you do this and I start to bleed again,” and he said, “We have to find out because it’s life threatening,” and I said, “I’m signing out,” and they talked to my mother and I said, “mom, you’ve got to let me sign out.”

LG: Because you were still a minor at that time.

JM: I was still a minor.

LG: She could have fought you on that.

JM: Yeah, and she said, “Okay, I won’t fight. If you want to leave, when do you want to leave?” But by the time I was fifteen already, I was like, you know—you know, I was angry and also quite—I would have gone to the mat about things, so—and also I knew a lot by then. I mean, I had become my own little expert on this illness and on medical things related to it.

LG: In that you knew your body or you had studied it or both?

JM: Well, I learned about it the way—I mean, I knew my body, but I went to that—but I went about it the way I went about a lot of things which was to learn everything about it. So I knew more

about the clotting cascade than anybody did. I read every textbook and I went to the library.

LG: So that's one of the ways you coped was to learn about it.

JM: One of the ways I coped, yeah. And it took me a while to realize why they kept doing this, what they were doing to do here because they really weren't being straight with us about it, and I overheard a conversation that Cohen was having with one of the people and I realized why I wasn't—being listened to. And the other thing that happened—the other thing that made that admission different than any other admission was that two of my close friends visited me at the hospital. They visited me, so that I wasn't—so shut off. They had like a pool table there and we were playing and I was talking to them. So it was not the regressive experience that other hospitalizations were. You know, my buddies came and we were hanging out there and so I had choices all of a sudden about whether I was going to stay. That's the way it felt to me, at least. All other hospitalizations always felt very regressive.

LG: What do you mean by regressive?

JM: Regressive. You felt like a kid. You know, they're asking you for urine. You're being fed. You're being taken care of. You know, as a psychiatry resident, I used to always be very upset because they would do consults at the hospital and they always said the patients were borderline, but I knew that everyone's a borderline when they're in the hospital long enough, because you regress. You start thinking, "Those are the good nurses. Those are the bad ones." You know, everyone gets split into good and bad and you don't have really the—you don't have any arms and legs. You

can't get up and do stuff for yourself. I mean, I think that's changed somewhat more than it was.

LG: What was it like when you were in the hospital?

JM: Yeah, when I was in the hospital, you couldn't do anything without asking. You know, it was like a really big deal. Like you had an IV in you and I always had an IV in me because they were always going to be giving me more Factor or more plasma or whatever it was.

LG: Do you remember your treatments through the years?

JM: Yeah. They started out with—I remember the plasma.

LG: What do you remember about the plasma?

JM: You know what I remember? I remember screaming whenever I saw a needle. I remember that they used to—I had terrible veins and I remember they used to have me scream so that they could—so that my jugular would pop so they could give me my plasma through my jugular vein.

LG: They used to ask you to scream?

JM: Yeah, and I liked that.

[end of Side A, Tape 1]

LG: The nurses used to have you scream so your access was better in your neck?

JM: Neck, yeah. There were times—access was a very big problem for me as a kid, and it was one of the reasons why I—I mean why I was reluctant to go to the hospital and there were times where I get sent home because they couldn't get a needle into me.

LG: So you couldn't get any sort of treatment?

JM: Right. So then right. So I'd go to the hospital and they'd stick me like sixteen times and you know, the joke was that I was like a pin cushion and it hurt. Your threshold for pain, you know, goes down and down and by the tenth needle or so, the tenth time they're sticking you, you have like no reserve at all to the needle and so it was just really agonizing, and then if they didn't get it at all and had to send you home, you know, you just had another day of that once, you know, you know—and there used to be—

LG: And you would only go to the hospital when the pain was excruciating.

JM: Right.

LG: What was it like for you when they “had to send you home”?

JM: Well, I would just—well, by the time they sent me home, I must say, I would have—you know, after a few needles, I was ready to go home. I was ready to bear another few nights of pain, whatever the joint was, and not got stuck because when you got into when you got stuck over and over again, would be frustrated doctors, who then would have to call their attending to come in, who were very frustrated about coming in, and you'd get like lots of people enraged at you, you know, which—[laughs]—which added to it. And I used to end up feeling just terrible about the whole thing and they were frustrated and they would, you know—the more character disordered ones would blame me for wiggling or blame me for screaming or blame, you know, blame me for moving once the vein was in. In fact, anytime anybody got blood return, I froze. I was like so happy and I was like thanking them and praising them for the rest of the time that they were around, and would look for

them the next time I was in the hospital, hoped that they would be the ones that would be drawing, you know, putting a line in.

LG: And once they got the line in, what would happen to you then?

JM: I would sit perfectly still and I would wait for hours for drops. The drops were slower because, you know, it was a lot of volume and they were always very worried about whether your body could take the volume. So you would watch the plasma go in, you know, this yellow fluid drop by drop and then sometimes it would be in so long that the vein would clog or you'd move or something and it would dislodge and you'd go, "Oh, no, they're going to have to do it again," and you'd pray, or it would start to burn and the term that was used—it probably still is—infiltration. They said infiltrated. Now, I don't know whether you use that word in war terminology, like they infiltrated Vietnam. We're infiltrating. Oh, no. So, yeah, and you'd see it swell up around the site because oftentimes, you know, you would basically bleed around the site and they'd have to find another one. It would be a time, though, a sort of blessed time where enough—you'd watch it drip in and there'd be a moment, almost like a moment when the pain would stop. It's pounding, horrible pain and it would just stop and you knew that it was the beginning of the end of that bleed. Even if you didn't get anymore, you probably formed a clot and the healing had started.

LG: So you could actually feel that?

JM: I could feel it and it was like a little—see, because I knew—I would feel the same thing sometimes when I would stop on my own. You know, it was like whenever the pressure stopped, and the clot held the pain stopped. The pressure on the nerves in the

joint was always linked to the pain. The stopping of pain was always for me linked with healing. It meant that a clot had formed and that if I just kept totally still, I'd be okay.

LG: How much were you in the hospital growing up as a kid?

JM: A lot. A lot.

LG: What's a lot?

JM: I would say maybe a quarter of the time between when I was diagnosed and when I was fifteen, a quarter of the time.

LG: How long would you be in the hospital for?

JM: Like hepatitis B, I was there for two or three weeks. Every tooth that came out, just about. When I lost a baby tooth, there were huge clots that went down to the floor. They'd just keep growing. I'd wake up in pools of blood, and even though those weren't really life threatening, they just wouldn't stop. I'd hold the gum down for hours and hours, I'd press them, but then I'd need a shot for that, a transfusion for that. So there was just a lot and they always kept you overnight in those days, two or three days. I remember I had a tooth pulled. I remember a lot of dental stuff now because I'm having some dental work done and it's so easy now. I remember I had a tooth pulled when I was like ten years old. Hepatitis, they thought it was somehow related to that. Ten or eleven. I was at Mt. Sinai. For some reason the dentists were at Mt. Sinai and I was there for like three weeks. I remember being in a room, everyone in the room was all these boys having circumcisions at age twelve or thirteen. They were all walking around in agony. [laughs] I thought things could be worse. I could be one of those guys. And they were also—there was this

whole—I was there enough that there was this whole other life I felt like I lived. Like I knew the nurses. I knew Jacobi. I knew the kids who came back and forth. I knew all the routines there. I was like a regular customer, and most of the kids there were from really poor, you know—really my exposure to Black kids and kids from, you know, the ghetto and kids from broken families and kids on welfare, you know, kids who had been in fights. Kids who were going to die. Kids in these incredible orthopedic apparatuses they had then. You know, they'd like—be family. And so there was a whole world, other world that was so different than mine. You know, the world at my elementary school and such. By junior high school there was a different population. I'm sorry. There were tough kids that were in junior high school "T cars," but in my elementary school, you know, people might have had Holocaust backgrounds and be working class, but they weren't like the kids I'd see in the hospital.

LG: Would you make friends with these kids? Was it a positive or a negative experience?

JM: Yeah, it was pretty positive.

LG: Really?

JM: Yeah, it was pretty positive. I felt like, you know, pain, illness levels the playing field.

LG: It really levels the playing field.

JM: Yeah, it was very—everyone's the same. I used to like to play a lot of cards. You always would have card games and my mother was really good at this stuff because she really—I think my mother liked people and I think she—in those days, she really was—she

very much believed in everyone being equal and, you know, she became prejudiced in her older years in ways, but in those days not at all. In fact, she'd actually been a—she'd been a math major and a Negro history minor at Hunter College. So she was really—cared greatly about Civil Rights movement and things like that.

LG: Were you on your own a lot in the hospital? How did that work with three other kids at home?

JM: Yeah, I was left alone. I had to be left alone a lot, but she was really religious about coming to see me every night and I was pretty good about letting go. I mean, I didn't—you know, I sort of understood my relationship with my mother before. I think that my mother—my mother and I liked each other and that we were a good match. That we enjoyed each other's humor and some of it was probably what we went through together, but I think that we were good company. So I think we were lucky that way. We enjoyed each other's minds and can talk.—I've always had close older women friends in my life and attribute that partly to that relationship.

LG: It sounds like you experienced an enormous amount of pain. What is your relationship to pain today?

JM: Well, I did think the pain was a big part of it and was—there was a tremendous amount of ignorance. I think there still is today about treating pain, but I used to like hallucinate, I was in so much pain. I used to do everything. I used to try and hypnotize myself that, you know—try to hypnotize myself that my arm didn't—that I didn't have an arm. I didn't have an arm, I said over and over again, and then I didn't feel my arm and I got panicked. It was really bad,

and they wouldn't let me take—aspirin and that would make you bleed and sometimes I would sneak an aspirin because it did help a little with the pain. I used to ice things. And I often felt that people didn't understand how much pain I was in and what it was like to wait with pain. What happens is I would get to the hospital and—when the pain was too much, I'd go to the hospital and by then I knew I had given up and the pain would just break on through and I would really be overwhelmed. I also used to do—

LG: What do you mean you had given up?

JM: You know, if I could hold and deal with the pain, then eventually it would stop bleeding, right. And then when I decided to go the hospital, I had given up that strategy and then the pain would be overwhelming.

LG: And at that point you wanted treatment.

JM: Yeah, then I'd want treatment right away, and of course, right away was not—what else to say about pain? The—of course, when I got older, you know, there'd be less of the acute pain and more of a chronic pain from all the arthritis and all the joint injuries and trying to sort out what—you know, what the bleeding pain was from what the arthritic pain was could be very difficult. Excuse me. I remember I once had some MMPI or some test that someone was doing and, you know, it showed that like I had tremendous denial about serious pain and no tolerance at all for minor pain and I think there's a certain truth to that. You know, that when the pain is severe like, okay, this is familiar territory; I can grin and bear this if I have to, and minor pains make me very uneasy and I want to treat them and get rid of them. But there's a

level at which if you have a certain amount of pain, it doesn't really matter. It breaks through. I remember—we were talking about this in my analysis a lot. It was one of the—the reason I went into psychoanalysis at all was because this whole area was something that I needed a place to talk about, without burdening anyone. And I think it wasn't obvious to everybody, the people around me, how much these things troubled me. So that my analysis didn't change—

LG: What troubled you?

JM: The issues related to my hemophilia, my childhood, but it was the reason I went. It was like every time I'd try and think about it, it would just be like a screen went up. I couldn't see anything, and one of the things that the pain did which was cruelest was that it really made me see things about myself that I could have better waited a long time to see. Things like—I mean, [unclear] play these like mind games, like what would I do to get rid of this pain? And you start wishing awful things on people. So you find out that, you know, the truth of it is that who knows what we would do to get rid of this kind of pain, but I knew what I would have done, or at least what I thought I would have done when I was just a kid. I'd say, well, would I let this friend die? It was a horrible thing. So I needed to talk about that and I think that you could say that there was guilt. There was self-criticism adding to it. There was the anxiety and the fear. There was the separation, but you know, the pure pain alone was enough to do it to me. It was really bad and I don't wish it on anybody and whenever I see somebody in that kind of pain, like see somebody with a absolutely devastating

headache, a migraine, I think that, an unrelenting migraine had some of this feel to it. But I think that pain should be treated first, and do whatever else afterwards.

LG: Were you visibly disabled a good amount of time, crutches, in casts?

JM: I had a brace when I was in 6th grade, and that was awful, also. I didn't like that. A huge brace on my left leg. It was supposed to protect my ankle and I had these metal plates in my shoes and they would squeak, you know. So, yeah, that was a drag. I was very social as a kid. I had lots of good friends. I was very fortunate that way. I had a pretty, smart girlfriend in third grade and I recently saw her. She was so nice and she was like this great person. It was just a pleasure to see her. I saw her at a reunion—you know, she'd heard about HIV and she was thinking about, you know, me and how I was, and was so glad to see me. You know, it was just very nice. There were a whole bunch of other friends I had, even in elementary school. One that I was friends with into adulthood. Then in the 7th grade that I started with the black eye, I met my very best friends, including my best friend. He I met when I actually kicked him with the brace. He let a door close on me.

LG: He what?

JM: He let a door close on me and so I just kicked him and I forgot that I was wearing it, so he got like a big cut on his—and so, yeah, it was—I mean I limped and I hid it a lot. I didn't tell people too much about it.

LG: Did kids ask?

JM: A little bit. Not that much. You know, I think that people knew about it and they—I didn't know what to say. My behavior was not consistent. I used to wrestle with people. I really insisted on being treated like the other kids.

LG: Did your mother ever talk to anybody at the school?

JM: Yeah, she used to—well, she used to—actually, I would ban her from doing that, you know? I would ban her from telling people. Or interfering in any way at all. I absolutely wanted to be normal. Was more than willing to have a bleed and end up in the hospital, than be humiliated, what I thought was humiliated. You know, times I was absent from school, lots of kids knew, and where I had bruises. So kids knew, or I was limping, but there were also times where I was fine and that way it was just sort of like normal. Really, outside of tackle football, there wasn't a sport that I didn't try playing for a period of time.

LG: Really?

JM: Yeah. And might not do. I was really—I was really pretty crazy about it. I ran. I was fast runner until my ankles really got, you know, were getting more damaged. My mother used to scream, and she used to scream out the door. Some of my best friends will joke about it.

LG: She used to scream what?

JM: At me to come back, I was going to get hurt, and then she started screaming at them. "Don't go with him, Sheldon. Don't go. Don't play. He's going to be hurt, it's going to be your fault." Sheldon will be at my son's Bar Mitzvah in about a month. My mother will be there. She's now in her eighties and she'll joke about it.

LG: You were pretty much left to do what you wanted to do?

JM: Yeah. Well, yeah, I was. When I was home, my mother had four kids within six or seven years of age to care for and she could not be watching me that closely, and that was a blessing.

LG: That was a blessing?

JM: Yeah, for me. I think so. I mean if I got really damaged more than I had, it wouldn't have been such a blessing, but from my point of view it was a blessing. She would say to me sometimes—how did she put it? She said “There are some things I'd rather not know,” or something like that. She said that a few times where I was clearly going to be doing risky things and she clearly couldn't give permission to do them. And so we had sort of an understanding that, you know, I was going to do some things that she wouldn't want me to do, that she would say no to, but that I would think was the best thing. I think she trusted my judgment. I think she knew. We had this discussion many times where I would say to her, “You know, I know how awful it is when I get hurt, but I know what the consequence are, you know, and I'll be bearing it, not you.” You know, primarily.

LG: So let me make those decisions.

JM: Yeah, yeah. So that was it[laughs]. I had a couple of friends, this kid David who used to be scared to come into the house at times. My mother would project that these guys were leading me into dangerous behaviors.

LG: Would your friends ever try to protect you?

JM: See, again, if they said to me, you know, “This is dangerous. You shouldn't do it,” you know, I would say that if they ever said

anything like to me again, you know, they were going to end up playing by themselves. I just—I didn't want that relationship with friends. If I wanted someone to take care of me, my mother was happy to, you know, but I would like climb a fence or something. I wasn't that risqué. I wasn't that big a risk taker.

LG: So you in fact did put some limits on yourself?

JM: Oh, yeah, I had a lot of limits. Oh, yeah. Yeah, I mean I didn't like what happened either, but I made choices. For example, I tried really hard at tennis. I cared about tennis, even though tennis resulted in a lot of injuries. But you know, I played—I played touch football. Not tackle but touch football. I loved football.

LG: When you were a little kid in elementary school, were you allowed to do sports in school?

JM: No, I didn't do gym.

LG: So you were kept out of that.

JM: Yeah. For a while, yeah, and that was noticeable. Gym and that was even before—gym was really not a big deal then. Everyone wanted to get out of gym. It was really—yeah, I mean, people were simply envious of me because all they did was get yelled at. I always played sports with the kids at recess. We played stickball. We played King-Queen.

LG: And the teachers weren't worried about that?

JM: Teachers were—you know, the teachers in my elementary school were really pretty ignorant. They really didn't know what was going on, with a couple of exceptions and in fact, one of them was—my first grade teacher, who was very bright and a very fine teacher. We used to joke around, if she couldn't teach you to read,

you were really in trouble. Like you'd never learn to read, and she spent hours with these very, very slow or very dyslexic kids after school teaching them to read. She met my brother on the subway some years ago and asked about me. So when we meet people from the past—you know, there were three boys who were within close ages in my family and they'll all say, "And how's James?" and when he told her that I was a physician, right there on the subway, she started to cry. So, there was a belief by some of the people who knew what was going on that they thought that I wasn't going to make it.

LG: That you weren't going to live?

JM: Yeah, that I wasn't going to live.

LG: Did you ever worry about that?

JM: Well, I had read in my readings that many hemophiliacs died by the time—by puberty. So I knew that those were somewhat outdated, but it was really quite frightening, yeah. The thing that from my reading I had been led to worry about was head injuries. Whenever I banged my head or something, I'd be very worried and wouldn't know what to even look for, really. Seemed like would affect the very agency that would be used to look for what was wrong, and I wouldn't be able to tell anyone because I didn't want them to worry about it and be checking on me every hour or whatever. So, yeah, I had a lot of denial about that stuff and tried not to think about it and basically just blocked it. I knew about it, but I just sort of—

LG: How did you progress in school with having so much absenteeism?

JM: I was a really good student.

LG: Were there expectations of you to be a good student by your family, despite your hemophilia?

JM: Yeah, because I cared about it. To be, you know, being a good student was—I wanted to be in the physical realm normal, average in every way not noticeably different. In academics I wanted to be the best and I thought that would be good for a whole variety of reasons. I was very smart. I used to tell my friends I was much smarter as a kid than I am as an adult. I really was—I really had an incredible memory. It runs in my family, actually on my father's side, but just really a photographic memory, but it was like even now sometimes—even by medical school I saw that sometimes I could sit in a lecture and I could repeat it back to you, everything that was said for forty-five minutes. So that was a sort of gift that made school very much easier for me. I missed, for example, in the second grade I missed over a hundred days of school and I remember they had me come in at the end of the year to take a test. Now, I heard that two girls had been skipped from second grade right to fourth grade. I thought, oh, this must be the test. So they had me write a story. In fact, they had me do this composition in order to see whether I should even go into third grade or be left back, but I thought I was going to skip—even with how much school I had missed.

LG: So there was never a lowering of expectations, certainly not from within, but from others around. “Oh, he's in pain. Oh, he's got hemophilia, let's not expect much”

JM: No. No, I wouldn't allow that and it was important for me to keep up with schoolwork when I was out. I was happy to get the

homework and do it. I never felt overwhelmed by school. It was normal to do it and when I went back to school, I'd be where everyone else was. Of course, you've got to remember, the elementary school that I went to, I mean, there weren't a lot of bright kids there. [laughs]

LG: Oh, really?

JM: No, this working class Mafia community did not—there were a few bright kids, but there were lots of kids who didn't graduate high school, who went to that school. The brighter ones went to Catholic school.

LG: I see. So, there weren't a lot of bright kids.

JM: Bright kids, yeah, like there weren't a lot of bright kids there.

LG: I see. I thought you said White kids.

JM: No, they were all White kids. There were very few Blacks, but there weren't a lot of bright kids. Then when I went to junior high school, it was a little more mixed. It was only when I went to high school where my brothers had gone as well, that I met, a lot of really smart kids who were much smarter than I was.

LG: What about your brothers and sisters; what was their relationship with your hemophilia?

JM: Yeah, I didn't pay much attention to that until I got older, I must say.

LG: You didn't feel much when you were growing up?

JM: Oh, I think I felt a lot, but I wasn't really—was really sort of, you know, not quite conscious. I had felt very uncomfortable if in any way outside of my hemophilia I got any more than they did, so that when, for example, you know, when I had my Bar Mitzvah my

father had started making more money and the option was to have a bigger party. You know, I was very reluctant to do that, to have more money spent on me. When we went to college—my brothers went to City College, and I had an opportunity to go to Colombia and I went and spoke with them about it.

LG: With?

JM: My brothers and actually decided not to go because I didn't want my parents spending more money. So I had a sense that—

LG: That you had gotten enough.

JM: Yeah, unbalanced as it was, but I think the person that suffered most. I think my sister got hit very hard by it. She was a year and a half younger. She was special because she was a girl, but I think that she really got less and I think it was very hard for her to ask for more of my mother's attention, given what was happening. I think that she's doing all right. It's not like anyone is in trouble. I think my oldest brother probably would have been the way he was anyway. He's—he's sort of unrelated in some ways and for example, he never asked me—you know, even when he knew about HIV, he never asked me whether I had it, whether I was at risk for it. Nothing. We'd have phone conversations and I finally said, well, I'm going to bring it up that I was worried about that issue, you know, about whether I was going to get it or all that stuff, and he never asked me about it again, even though we had other phone conversations. So his way of dealing with it was not dealing with it. My brother Jay I'm very close with and I was sort of surprised that Jay didn't actually become like an Emergency Room physician because there were a couple of times where he

really helped out. He's great in emergencies. People will call him up. That was the good thing he got out of it. He always had a very difficult relationship with my mother and I think that was mostly about all the attention that I got. But he's such a good guy and he actually is the main caretaker for her, as it turns out, because he lives nearest her, and he and I are quite close. So I think it did affect him and I think he didn't have the confidence he would have had otherwise. I think he's a really brilliant guy and he's a legal aide lawyer. He is moved up in legal aide, but he's had opportunities to really do other kinds of things and I think he doesn't take the risks that he could have, should have. I think that detracted. I'd like to think that when there are things like this in families, if it doesn't break the family, it makes them stronger, and there's some data to support that, I guess. I remember when I worked at Spaulding Hospital I reviewed the literature and the literature on illness in families and I think there are ways in which my family is fair and strong about things, and where my mother was seen as somebody who could be counted on, where my father, in his way, always, you know, stood by you. People master things. You know, people get through tough times.

LG: So somehow everybody got enough.

JM: Right. Now, you know, from their point of view, my outcome is a great outcome. You know, I've done well. I'm been a very lucky guy, you know, I didn't get HIV, you know, and all the other things that could have gone wrong. I've lived a charmed life, given, you know, how unlucky it was to have hemophilia, I'm an incredibly lucky guy. So, you know, if it hadn't turned out that

way, well, maybe it would have had a different meaning to the family and to me. I still have a kind of magical thinking about, you know, when, you know, bad things happen that, you know, it will be OK. You know, I've been a high risk before and I'll duck this bullet, too, you know.

LG: What do you remember about the treatment changes of hemophilia?

JM: It was like a miracle. It was like, there was always talk about there'd be some cure, some, you know, it was always five years off or three years off, whatever.

LG: Even when you were growing up, there was talk about this?

JM: Yes, there was. Yeah, and we knew about, very early on about Alan Johnson's work. I think that was his name, at NYU. There was this concentrate that was being worked on that eventually would end up not being the one chosen, in a very kind of ugly story about how these things got decided by money and not by what was the best product. There's this book, *Journey*, that came out that documents some of that, but we knew about that. There were also periodically fads, like there was one that said honey cured hemophilia and I would get a huge spoonful of honey every morning for months. And to this day, I can't—even stand a little bit of honey or I'm very nauseous.

LG: What other home treatments?

JM: Peanuts. I ate a pound of peanuts every day for a while.

LG: Because peanuts were thought to be good?

JM: Yeah. I had found this letter that my mother had written to the scientist who'd written about peanuts and my mother had written

her and said, “Is it true that peanuts really help with clotting?” and she said in the reply, that no, it turns out that it doesn’t, or whatever. But peanuts, I still love them, and I still sort of think they help me. So there were those kinds of things, and then there was—you know, there was always hope for some kind of concentrate and something you could take by mouth, a pill. We’d give money and we’d get involved with the National Hemophilia Foundation, but not in a huge personal way. My mother thought that it was—I think she couldn’t handle it partly, but I also think that she thought it wasn’t good for me to be around a lot of hemophiliacs.

LG: Because?

JM: Because I was going to be normal. You know, she didn’t want me to sort of see myself that way. She would always say, “Oh, they’re a lot worse than you are,” and some of them were. The ones that had knee problems all were very crippled. I didn’t meet hemophiliacs, get to know them well, other hemophiliacs, until I was in college. I had a high titer of antibodies to hepatitis B, and I would donate my blood. They’d pay me money and I would donate two pints. Plasmapheresis, it was called. They were actually using it, I think, in that Willowbrook Study where they tried to vaccinate children. That study ended up being very controversial. That was when I met them. There were about five or six other hemophiliacs, all older than me, and the stories they had to tell. It was like group therapy. We were all, lying there for two hours, having—

LG: While you were all giving your blood?

JM: Yeah.

LG: I see. So that's how you met them.

JM: And we would talk about our experiences.

LG: What was that like?

JM: These guys were amazing. They were so hardboiled. They were so—I just used to leave in shock. It was eye opening. They had had such fucking hard lives. They had seen stuff. They had—you know, stuff that was just unbelievable. Most of them had periods of time when they were junkies. They had fought for their lives with blood banks. Most of them were getting blood products as payment. They hoarded blood products because they were so frightened of going without, returning to the days when it was hell for them to get it. And blood banks would have blood products and because they didn't have money, they couldn't get it. They had a whole different view I'd never faced. I never faced that. They were so crippled by their illness. Oh, it was just devastating and it was devastating to talk to them, and they knew each other. Some of them knew each other from different ways. And some of them had come out the other side. I remember there was one guy, this guy Bill Adams, he may have been the most crippled of them. He must have seen that my eyes were bulging out of my head at what I was hearing. I had been so over protected compared to them.

LG: You had been?

JM: I had been so over protected.

LG: Really?

JM: Compared to them? Oh, yeah. Like I had my mom there the whole time. These people were like ten years older or so—and I

understood that my experience was transitional. That as hard as my experience had been, it was nothing compared to these guys. It really explained things to me. In the same way that kids ten years younger than me, those that didn't, you know, get HIV, they had a whole different experience than I had. There was this one guy Bill Adams, I mentioned. He asked if he could talk to me and we chatted. He talked about how these guys had had hard lives and I shouldn't take it, you know, to heart. That that wasn't going to be my experience and that some people had found a way around and I talked to him about his life and he said that he had gotten married and he was very happy. Then he talked about this miracle that had happened. That he had had a son, and he was so frightened that he would have a daughter, that she'd be a carrier and pass on what he had, but they had this son and what a blessing it was and how it sort of changed him. So it was very moving. That was a very important experience—and it went on for about a year on and off, that group.

LG: What I don't understand is, just because they were older, ten years older, why was their experience so much different than yours?

JM: Oh, why? Because the whole blood bank system, I think, hadn't been set up like it is now and they didn't have hematologists to go to the ER and get them blood. You know, they were—people just didn't know what they were doing, and the blood banking system was based on, you know, you had to pay for it. They had to like beg people, getting people to replace the blood that they were using, the plasma that they were using. There was this replacement system and they couldn't get people to do it after a

while. They'd be begging everybody they knew. They were angry.

LG: Because they just couldn't get treatment?

JM: Yeah.

LG: Whereas you felt you could. There was a mother advocating for you, a family and also a doctor by that time.

JM: And then my father had health insurance. Which was a huge issue, right, and we also felt like there was, you know, that they wouldn't turn you away in the Emergency Room and eventually you would get something at the City Hospital.

LG: I was asking about the advances in hemophilia.

JM: Right. Oh, the advances were—so, they went from plasma, which took forever and then I had fibrinogen, which was definitely an improvement. You ended up getting it a lot faster. There was a lot less volume. So that was good and then they had cryoprecipitate, which I actually used to go into the blood bank and make myself. I had volunteered to learn how to make it.

LG: Really?

JM: Yes, because I lived near the hospital and my doctor ran the blood bank, I asked, "Can I work here and make it and learn all about it?" They would give me lessons. They would teach me about, you know, all the clotting factors and all the tests. I also worked for a while, let's say—they let me work as a lab technician. I would test the blood for antibodies, and did A, B and did blood typing. I did all that and, was taught a lot during high school.

LG: Now, were you already interested in medicine by this time?

JM: Yeah, I couldn't imagine anything else.

LG: You couldn't?

JM: I really couldn't. For me—you know, medicine was both, answers. I was going to help everybody, but it was also going to make me no longer helpless when I got sick.

[end of Side B, Tape 1]

LG: It sounds as if having hemophilia had a direct impact on what direction you took professionally.

JM: Yeah.

LG: You were just saying that you were going to go into medicine because you wanted to feel as if you had some control.

JM: Yeah. You know, I mean, there's no question that it had a specific wish to somehow be involved in curing hemophilia, but certainly also in making sure that other people got treated differently than I did as a patient.

LG: Tell me about that.

JM: You know, I felt—I felt like the medical system stunk. You know, I felt like it was really patient unfriendly. I thought that it wasn't set up to provide efficient care. I thought that it was all about waiting. I waited in clinics for hours and hours all the time. You know, I hear now about Children's, the waiting there. I read an article about it. I'm outraged that these doctors think that that's acceptable waiting. You know, I was waiting in pain, but not always. I had these follow up checkups. That's where I was when President Kennedy was assassinated. I was waiting in a hospital clinic four hours to see, you know, a doctor who was, you know, just going to say, "Oh, your arm is better. You can go home now," you know, or, "You don't have to come back for another three

months.” That stuff seemed to me incredibly wasteful and disrespectful towards patients and I don’t think that’s changed that much. It’s changed a lot but not that much. Still a lot of waiting, but that that would be built into the system at Children’s Hospital today. I don’t get it. You know, I would hire another doctor or train more. And there were lots of other things, like not getting pain medication, which became, you know, a matter that troubled me a lot. The fact that the people that I would deal with often knew so little about kids. I was doing lots of things that were done routinely that were totally unacceptable. Like every time I came in, I would have to give a urine sample and they would harass me for hours and hours to pee in this little cup. You know, for a kid that was like, like hard to do, you know, and it became like this obsessional thing with these old ladies running after me to pee in a cup. It was usually some elderly nurse’s aid. There were lots of crazy things like that that didn’t make any sense. I used to rock when I was a kid, back and forth, a soothing activity and it also helped with pain. I rocked to the rhythm of the pain. It relaxed me a little bit. I remember one time when I was a little kid they—more than once, but one time I remember they tied me down because I was rocking. They were afraid I was going to hurt myself. That kind of stuff that—you know, there was a lot of that. Just reminded me of what my—if I had been asked years ago of what my worst memory was of being sick, it would be babies crying because I was always—when I was a little kid, they would always put me in with the babies. I was two or three or four or five, and all I remember is babies crying all the time while I was in

the hospital. It was like this nightmarish sort of thing, crying babies in the hospital. Anyway, but you asked me about something else. I lost track. I'm sorry.

LG: We're going to go back again to the advances in hemophilia treatment.

JM: So then the biggest advance, of course was cryo. I could make it myself. I was even doing cryo at home in college and before because I would just put it all together. I'd have these little frozen bags in my refrigerator and I'd give myself cryo by myself. That was the period between about fifteen or twenty-three when I was treating myself. A lot of it was with cryo. I would go in and I would make it, and I would just sign it out. So that took an hour, or an hour and a half. I mean, now I can give myself a shot in ten or fifteen minutes. So that's better, that hasn't changed my life. What changed my life more was being able to travel with factor VIII concentrate. That was very cool. That was real freedom and I went I went to Europe by myself, just with factor VIII.

LG: And you could never imagine doing that before?

JM: That just felt great. I couldn't imagine that kind of freedom. I was walking along the street, I remember, in Denmark where they had these poles, like one-way signs, and they were placed right in the middle of the street. I was looking around and I walked straight into one, and I hit my head really hard. So that was the sort of situation where I would give myself a shot. And I walked into what was some kind of sauna and, you know, just took out the stuff and gave myself a shot. I still remember like some of the people there saying, "Oh, American junkie," you know, because I was

giving myself a needle but, you know, within ten minutes I was out of there and that was great. So that made a really big difference. It also made me feel, and this is important, too, that maybe I would have children. Whether the illness was now such that I could say it would just be a bother to have this problem, but it wouldn't be a reason, you know, not to have children. I had no question that given the choice, someone shouldn't have a child who went through what I went through. You know, you have it, okay, you live with it. You make the best of it, but you don't do that on purpose and by the time the factor VIII concentrate came out, to me it was, you know, it was more at a level of being a bother. Little was I to know about HIV, but that's the way I saw it. So it meant that I could be thinking about what I really wanted, which was to have a family.

LG: How did hemophilia affect your love life?

JM: Well, I was very social through junior high school and then at high school, I really withdrew and again, a lot of that had to do with high school and the lack of social stuff that was going on there. It was really not a hot bed of dating.

LG: What wasn't?

JM: The life and people were really pretty. Then, I went to college and lived at home. I did some dating, but I wasn't really very sexually active until I got to medical school, and I think I was really, really anxious about that. So yeah, I think it did affect me, and then once I felt comfortable, then I had a number of different relationships, sexual relationships. There were some women that I slept with just once, but that was certainly nothing that I would do without a lot of

thought and preparation in my own mind about it. That was also before I knew about hepatitis C, which I have and before I started worrying about HIV. When the HIV came out, I was obviously very troubled, not only about having it, but also about what it would mean in terms of sexual activity. What it would mean to tell somebody, ugh! So during part of that time, when I was just beginning to worry about it, I was actually dating a hematologist, so that was convenient. [laughs] At least I didn't have to explain to her what the risks were that we were dealing with. I'm laughing about it. Well, this is not funny at all.

LG: So how did it affect you at that point? Did you get tested?

JM: Here's the story. In the early '80s, I was still in medical school, being treated by the director of the blood bank there, and he was my sort of hematologist, so-to-speak, although I wouldn't really see him very often. At the time the HIV concern arose, I asked if I could have a heat treated factor VIII and he said that it was—hadn't worked for hepatitis C, although in fact it does I guess a little bit. He said—he said that it would make it cost twice as much money to do it. I said, "Since you've given me some reason to think that it might work," and he said there was nothing to worry about because the blood supply was not affected. I felt very, very angry at the way he dealt with it and the way he dealt with it in sort of an ongoing way. I later received a letter from him that he had given up his clinical practice, but I think that he was pretty outrageous and when I asked about risk factors, sexually and all that, you know, he said, "It ain't happening."

LG: So you asked for the heat-treated and he pooh-poohed that request.

JM: Yup.

LG: You were concerned that the blood supply was unsafe.

JM: Right. I had gone to see Peter Levine once before for a consultation and I respected him a great deal and I thought highly of the idea of a comprehensive hemophilia center. He had done it right and I really had a lot of respect for him and was very disappointed because he also felt that it wasn't in the blood supply. In his case, I think he just couldn't accept it. I think he loved a lot of his patients and I think he just couldn't accept that they were all going to be infected. That's my take on that. I don't remember how I got to see Bob Handin, but I must have asked somebody for who at the Brigham can I see, and I spoke with Bob about it, and I liked Bob. I mean, I thought that he understood. He didn't ask me too many questions about why I wanted to change. Oh, so what was the order of things? See, because it matters how I remember the order. I saw Dr. Jerry Groopman a few times, who was really incredibly mensche. I mean, you know, most of the guys that have his sort of rep end up being these writers, you know, most of them are very narcissistic, but not Groopman—he's the real thing. I saw him before he was very well known and I thought he was just an incredibly thoughtful, caring guy. The kind of doctor that when I became a doctor, was the kind of person I wanted to be. And I spoke to him, and he actually had my girlfriend at the time come in and talked with both of us, which was his suggestion, talk to her about what the risks were. At that point, you know, I was HIV concerned. I was HIV negative. Huge relief, but not completely out of the water, in terms of retesting and things like that. And he

talked to us about risk factors in terms of using condoms and things like that. And it seemed to be quite important that it be the physician talking. That was the girlfriend after the hematologist. So Jerry was very helpful and I can't remember whether I went directly to him. Isn't that funny.

LG: So at this period, you didn't know if you had it or didn't have it?

JM: Yeah, there was a period when I didn't know whether I had it or didn't have it.

LG: And people were talking to you in case you might? Was that what was going on?

JM: No, no one was talking to me in case I might, because no one knew I was a hemophiliac, very much.

LG: Not your girlfriend, either.

JM: My girlfriend knew, right. Of course, my girlfriend knew, but many people in my life didn't. Only my close friends knew until—

LG: But I mean your doctors at that time or what you were thinking at that time, when Dr. Groopman brought you in. Why did he bring you in to talk to you?

JM: No, I went to see him. I wanted to talk to him about getting tested and to talk with him about the risk. Oh, yeah, I saw him to be tested and it was pretty freaky going there because his waiting room was completely filled with people who had active AIDS and you know, so it was very troubling. In fact, I had—had shoulder surgery in, was it '81 or '80? And I put it off because I had gotten worried about HIV being in the blood supply. I was taking a lot of narcotics because I had a lot of pain. I needed an anterior

dislocation repair and kept bleeding into this shoulder, but was anxious about having the surgery because of how much factor VIII would be required. So I finally went ahead and had the surgery and got tons and tons of factor VIII over weeks, during the period of time when the factor VIII was most infected. So I had a lot of reasons to be worried that I would have it and so I was quite relieved when I found out that I didn't. But during that period of time, it was possible to still have a certain amount of denial because there were still people saying that, one, it's not in the blood supply and two there were still people saying, that maybe hemophiliacs, like with hepatitis B, will have antibody to it and will not get the severe form of it. So I used that to reinforce my denial, and I truly am of the belief that, you know, there are some things that, as long as you're doing the medical things you have to do to find out the information and taking the precautions you have to take, that sometimes it's great to be able to just not think about it. Not live it until you have to, until you know the answer. I think it's very much that attitude. My wife doesn't get it. We'll argue about it sometimes, you know.

LG: Argue about?

JM: About worrying in advance about things. Long before you know. You know, as a psychiatrist it sort of runs against what you want to espouse, you discourage people from denying things, but you know, the ability to split things off that way for me has allowed me to live my life. You know, it did in fact—there was a period where I held off dating, I didn't date at all until the thing got resolved. See, I know what happened. I wasn't dating. Saw Groopman and

when I saw him, I started dating somebody. Then he met with us. I had him meet with the two of us to talk to us about it. That's how I did it.

LG: About the possibility of HIV?

JM: Yeah. No, and yeah, about the—that I didn't have it and what precautions to use just in case—I was still giving myself shots and the supply might not be so pure. That kind of thing. Because I didn't have recombinant DNA then. I wasn't using the recombinant DNA, but was just using the heat-treated at that point.

LG: I don't think it was available yet.

JM: Yeah.

LG: When you got married, had you already resolved in your mind, once the Factor was available, that it was okay to have kids?

JM: Right. Well, I never worried about it so much for me, but for my child. So it would be two generations, the way I saw it. So if I had a daughter, she'd have to worry about it for her children. That would be twenty-five years and I thought—you know, I felt strongly that that wouldn't have been a problem. My wife actually was very relieved that we had a son and not a daughter. She didn't feel great about the idea of having a daughter who was a carrier. You know, but it was something we discussed.

LG: Kids who are being born today with hemophilia and parents who are, you know, just hearing of the diagnosis, do you have any advice for them?

JM: I don't. I think it's almost a different disease, it seems to me, than what I had. I think these—hopefully now with the recombinant DNA, the risks are near zero, in terms of the horrible things like

HIV, but I think that it's like a different disease and it's great to think about that. I don't—you know, I had a friend who died recently of multiple medical ailments that she had. She was actually an important person for me, in terms of being both a doctor and having a history of being a patient, which has always been a struggle for me. You know, we both believed very strongly that suffering is ultimately not good for the soul. You know, that you learn things from having been through a lot, but the price is much greater psychologically than whatever you gain. So I think that it's just great that people—I assume that these kids very rarely have the kind of pain that we had, or if they have joint problems, they have some joint problems, but not the crippling. My joints look like—my body looks pretty normal, but if you see x-rays of my body, my joints, I don't have elbow or ankle joints. There's no synovium there at all. It's bone against bone. You know, I think it's just a whole different thing and I think it's great that people won't have to go through that. I think that if I was five years older, I have very little doubt that I would be crippled, that I would be in a wheelchair. You know, of my group, of the ones I knew and I got to know, I was like the luckiest of them just about and I wore the braces, but you know, I've been ambulatory. I've considered actually getting ankle—having my ankles fused, right, a couple of times and actually this new drug Celebrex has actually been the best thing that's happened to my hemophilia in years. Because it's really enabled me to walk long distances again, but I think that hemophiliacs today have probably a very different experience. I think the most important thing is not to—is to remember the

psychological affects of these illnesses. The reason I became a psychiatrist and switched over my idea of being a hematologist was because in medical school, once I saw a doctor again and you know, sort of accepted my role as both patient and doctor, it became very clear to me that the primary damage that had been done was psychological, more than physical at that point.

LG: More than your joints?

JM: Yeah, yeah. That there were ways in which I was just not—I was just crippled. In fact, the decision to be a psychiatrist, also, that was what I felt I would have wanted to do, if I hadn't had hemophilia. Maybe it would have been psychology or social work, instead of psychiatry, but it would have been about people and learning what makes them tick. But at the same time, the damage that the illness did to me was more psychological.

LG: If you had advice for parents around raising a child with hemophilia today, as far as trying to maintain their psychological health, would you have any thoughts to give a mother or father today?

JM: Be active instead of passive in things, in choices. Make a lot of choices. Make mistakes.

LG: Make mistakes?

JM: Yeah, not be criticized too much for making mistakes. Hard to do as a parent, very hard to do. Usually someone else says it's okay that your child makes a mistake, but I think—

LG: Parents are so often fearful that their child is going to have joint damage.

JM: Yeah, yeah, but there's other kinds of damage. There was a kid—I won't mention his name—whenever I had trouble—two quick stories now about this issue because it was so crucial in my development, in my thinking about these things. There was a kid I really liked named Francis and our families were a little bit friendly. He was the one kid I knew from the National Hemophilia Foundation, and I saw—he was a couple years older than me and real nice, sweet kid, and I saw him get more and more passive and basically not be able to move far from his mother. I thought—I was always saying to myself, I didn't want to end up like Francis. You know, that's a terrible loss. He's never going to leave home. And the other story I want to relate is once, I was in my orthopedist's office, who prescribed the braces. Brilliant doctor. I don't know if you ever heard of him before, but he used to fix the legs of ballet stars. People would come from all over. You'd have the ballet stars on the one hand, who had liked strained an ankle, and then you'd have this hemophilia population that he treated with braces and other kinds of things that he made. So you'd meet these hemophiliacs there and there was this guy, and he was—he had a really bad injury, knee injury or something and we were talking about how that happened and he said, "Well, playing football," or something like that, and I said, "Playing football? You're out of your mind." He said, "But it was a dare," and I said—and he said, "Because you know you're a hemophiliac." He said, "You know"—he said, "You know, other kids I wouldn't say, but you're hemophiliac," he said, "You have to take a dare sometimes." So it was—and he said it was worth it. He doesn't

regret it at all. Someone dared him to play and he had to play.

There was something about maintaining the macho thing on the one hand and yet it's also a kind of healthy denial, I think that you need some of, or else, you know, you can really get caught up in fears upon fears and end up being very, very crippled that way.

LG: You had mentioned a good deal about Bar Mitzvahs and your Jewish faith in this discussion. Did faith play a role in your life?

JM: I'm laughing. I'm not going to get away with any of my—yes, it did. It did. Yeah, it really did actually.

LG: In what way? Are you surprised by that question?

JM: I am. Actually, I'm very impressed. All the questions you've asked me have all been things that have stood out, actually, as things that I do connect with my illness. So when I think—there are things that are different. For example, I think that I believe in God more than anyone, except for my mother, and it's one of these things that I sort of take for granted. It sort of relates to my magical thinking. I feel like, yes, there is a God. Why? Because I've gotten through, right. That's the proof. I have this personal faith that there is a God, and you know, since I was raised Jewish, I assume he's, you know, might as well be that God, you know. But there's a sense that there is a meaning and I haven't survived for no reason at all, and all this stuff, which is very much a belief of mine. When I was thirteen and fourteen, at the time of my Bar Mitzvah, I became—although my family was—my father wasn't that religious and my mother was, you know, sort of conservative. I became more religious and I actually wore a yamulke and studied and became Kosher and thought very seriously about becoming

Orthodox and continuing that. I think that some of that was out of my tremendous anxiety, which had shifted from my health to sexuality and other things. Then the anti-war movement broke out when I was about fifteen or so, fifteen or sixteen, and the Rabbis who I was sort of looking to, were all pro Vietnam War. They were—they felt that Lyndon Johnson was a big supporter of Israel and that we should support him in the war and to me that was tremendous betrayal. So I dropped my yamulke and took off for Washington DC for marches. [laughs] There's a movement that was very important, too, in my sort of like rebellious period and my feeling like I had to have a voice and I had to be active and I had to make changes and all that stuff. But what has stayed is a kind of—a belief in God, a distrust of organized religion, including my own, but I think that runs pretty deep. When people have a very deep faith or when they're very spiritual, I'm very comfortable with that. It's sort of like that's okay. I get it and I don't pathologize it.

LG: Has any good come from having hemophilia?

JM: Well, I think it helps me in my work. I think I understand some kinds of suffering that I think if you haven't had some personal experience with, and some crazy kind of thinking and fearfulness and all kinds of things, that I might not otherwise be so personally familiar with. I think I can get to that faster sometimes with people. I some of these people realize that I get it.

LG: Your capacity to empathize.

JM: Right, but I'm not sure how much that—and I think I'm a good listener, but I'm not sure how much that extends to my family.

You'll have to ask them about it. I think it does help me in my work, and I think it does keep me honest.

LG: In what way?

JM: I think it's important to know when you're lucky.

LG: Now, despite all that you've been through, you still consider yourself lucky?

JM: Well, one really bad thing happened that—yeah, I consider myself incredibly lucky because my adult life is all about dodging bullets. You know, my childhood is all about close calls and doing all that with close calls, but yeah, I think I'm very, very lucky.

LG: That's a wonderful place to end. I wonder, though, did I not touch upon something that you think is important, that you'd like to include?

JM: I wonder about one thing for myself. I wonder how—and it relates to what you're doing here, which is asking me about my experience. I wonder a lot how this experience gets passed on to my son.

LG: Do you have one son?

JM: Yes, and I wonder at times whether I say too much and other times whether I say too little about it.

LG: About hemophilia?

JM: Yeah.

LG: So you talk with him about it.

JM: Yeah, yeah, he's seen me give myself shots. But—so, I like the idea that there's this record. Maybe he'll want to know more. Maybe he won't. I'm not sure what.

LG: You know, one person said to me, “It’s been interesting to be a man.” He’s a little bit older, not much, “to be a man”—he’s got quite a bunch of joint involvement and health issues going on. He said, “It’s been an interesting experience looking at a healthy son.”

JM: Oh, yeah.

LG: A jock, basically, and just how other it has been for him.

JM: Yeah, he’s right. [chuckles] It’s amazing.

LG: Do you have that experience.

JM: Yeah, it’s wonderful. You know, both there’s this fear like he’ll get hurt, but then there’s also like his arm goes all the way out. Or, he can swing that bat! Oh, it’s great. It’s hard when I have to pull back and say, “Wait a second,” you know, “just because you couldn’t doesn’t mean he has to play ball or he has to do any of these things,” but it is. It’s amazing, and that’s what I think that guy Bill Adams was trying to say, too, that it’s like a very special thing to have a healthy son. Yeah. It’s really—but, you know, I could easily see how, you know, my son might want to do more to make up for or to please me without saying it, but he’s good. He seems to have a mind of his own, at least.

LG: It doesn’t sound like you missed a whole lot, either. That you let yourself do a whole lot of things, too.

JM: Yeah, yeah.

LG: I mean in the sense of in your spirit.

JM: Yeah, well.

LG: I’m going to say thank you.

JM: Thank you.

ADDENDUM: JAMES SENT THIS ADDITION TO HIS HISTORY

JM: You asked about my experience applying to schools and I think it is important to note that when I applied to medical school in 1974, even after factor VIII concentrate had been available and the medical situation for hemophiliacs had change dramatically, that it still was not easy. For example, University of California at San Francisco, one of my first choices, withdrew an offer to interview me and requested a letter from my hematologist. Dr. Kochens, the division chief of hematology, and my covering physician, wrote a beautiful, supportive letter to them, but they rejected me despite this. Harvard Medical School, offered me an interview, probably because of the rarity of a hemophiliac physician. Unfortunately my interview with a Harvard internist went awry when he suggested that my hemophilia would limit my choice of specialties. For example, he told me I could never consider psychiatry, because a psychotic patient might strike me. I replied that I could probably give myself an infusion in plenty of time, since there is usually a delay in the onset of bleeding. I also explained that my approach, thus far successful, was to try not to let my illness limit me any more than was absolutely necessary. He replied that my denial was of concern to him and that he had known and treated many hemophiliacs so he knew what he was talking about.

Fortunately, I had already been accepted into a number of medical schools. In fact, I was on the waiting list at Duke, a school that none from my college had ever been interview at, primarily because of a computer glitch that amusingly had placed me as a star on the my school's varsity football team. (the school

never even had a football team) But the interviewer and I got along very well after a good laugh.

In the end, I went to another medical school. My father had had a myocardial infarction and I had flown home from Israel to be with him panicked that he would die before we had a decent relationship. I decided to stay nearby and indeed it was important and a good decision because our relationship felt so much better. It was however, a very difficult place for me to learn and begin to practice medicine. I worked on some of the same wards and clinics and with some of the same staff who had cared and not cared for me as a child/patient. Often, they had no idea and it was very freaky when it would come out. In the end, I think I only made it through all the posttraumatic stress symptoms (insomnia, nightmares, flashbacks, and brief moment of dissociation) by promising myself that as soon as I graduated, I would get into psychotherapy.

End of Interview