

Interview with Robert Massie by Laura Gray for the Boston Hemophilia Oral History Project, October 21, 2004.

GRAY: It is November 21, 2004.

MASSIE: October.

LG: [chuckles] It is October 21, 2004. Thank you. And my name is Laura Gray and I'm sitting here with Mr. Robert Massie in Somerville, Massachusetts. And we are—he has just agreed to do an oral history for the gift of experience for the Boston Hemophilia Center. So I want to say thank you.

RM: You're welcome.

LG: If you could just tell me what your birth date is, how old you are and what your diagnosis is for this account before we start.

RM: I was born on August 17, 1956. I'm 48 years old. My diagnosis was when I was about six months old; I have severe classical hemophilia. Factor VVV hemophilia.

LG: Great, thank you. Now, Bob, tell me, where did you grow up and who did you grow up with?

RM: I was born in New York Hospital, New York City. I have two parents, Suzanne and Robert Massie. I was the oldest child in my family. For the first year or so of my life we lived in an apartment that I don't remember. But we moved when I was quite small, maybe 18 months old or two years old, to a very little house at 136 Northampton Drive in White Plains, New York. It was a tiny Cape house with two small bedrooms and living room and dining room. And that's where I lived until I was seven. I had a sister who was

born 20 months after me. So the two of us grew up there together with our two parents.

LG: And her name was—

RM: Susanna.

LG: Susanna. And your parents, what are their names?

RM: Robert and Suzanne.

LG: Mm-hmm, and tell me a little bit about them.

RM: My mother was born and raised—well, she was born, I believe, in the New York area but she was raised in Philadelphia. Her father and mother were Swiss citizens and my grandfather was a diplomat with the Swiss consular and diplomatic service. And he spent most of his career in the United States in various responsibilities with the Swiss delegation. And he ended up as Swiss Consul General in Philadelphia. So—and he, his wife—his name was Maurice Rohrbach—R-o-h-r-b-a-c-h. And his wife, Suzanne, was a woman with an extraordinary background who had spent time in Russia and many other places and married my grandfather and had three children—three daughters, my mother, who's the oldest, and two sisters, Simone and Jeannine. My grandmother was primarily a housewife. They spoke French at home. When it was discovered that I had hemophilia, my grandfather and grandmother traced back, because in Switzerland they keep quite good records. I was told in any case that they traced back for several generations and couldn't find anyone who had died of any unusual bleeding-related illness. My aunts, Simone and Jeanine, both have children. Each has sons. And they did not have hemophilia. So I don't know that Jeanine and Simone have ever been tested themselves, whether they're carriers.

But both of my sisters, it turns out, are carriers. And my sister, Susanna, has had two sons, one of whom has hemophilia. His name is Ian Thomas. His younger brother, named Mason Thomas does not have hemophilia, my sister, Elizabeth, who's—was born later when I was eight years old—has a daughter named Violet and is expecting a baby boy, and they have established that that boy does not have hemophilia. So anyway, that's the overall genetic history. So my mother grew up in Philadelphia and went to high school there and then eventually went to Vassar. And my father came from a family that had been in the United States for a long time, originally from Virginia and then through various steps made it to Kentucky. My father's father died when my father was only 14 or 15 months old, leaving him and his brother, who was born practically the same time that his father died, and my grandmother. My father grew up in the South, first in Kentucky and then in Nashville. And eventually he graduated from high school in Nashville and got a scholarship to go to Yale. As I remember him telling me this story, he was driven to the edge of town by his parents and he hitched to New Haven to go to Yale at the age of 17.

LG: Why did he hitch? Why didn't they drive him?

RM: They had at that point three other sons and they didn't have the time or the money. This was during—in the immediate aftermath of World War II. It was in 1946 and I think that it was just too far. But I don't know. Maybe he took the bus but I remember him telling me that he hitched. So he arrived.

LG: He was on his own.

RM: He was on his own from the time he was 17. And he went to college and he—and he worked his way through college, graduated in 1950 and won a Rhode's Scholarship, which was a very big deal, and gave him the opportunity to go to Europe where he had never been. And he was at Oxford and he went to Paris on a trip with the Oxford Debating Team. And my mother during this same period had taken a junior year abroad from college and gone to Paris. And so she went to hear this debating team and she met my father, she had expected to see French students and English students. And in the midst of all this was this young American student and so that's how they met. My father was in the Navy for four years before they finally married. And—and then I was born shortly after he left the Navy. And he became a writer. Both my parents became writers. And they started off as journalists.

LG: They were both journalists.

RM: They were both journalists. They worked, not in newspapers but in magazines, which is a little different rhythm. My mother worked for "Time Life Books" and "Life Magazine" and a number of other publications. And my father wrote for "Colliers," which—that doesn't exist anymore—for "Newsweek," for the "Saturday Evening Post," for another magazine that got off the ground and then folded. So they were both writers. And then they eventually made a transition to writing books. But that didn't take place 'til I was 11 or 12. So mostly they were living as writers, which is a challenging profession [chuckles] to make a living, but they did it very well.

LG: Challenging in what way?

RM: Well, simply, that you weren't paid unless what you wrote got published, at least under certain arrangements that my father had. At one point he was on salary. But he was—later, he was paid according to what he wrote. And so, you know, you had to, first of all, identify good topics and then get a good story. And then you had to hope that the editor actually ran it. Both of my parents, but particularly my father, sometimes had to travel in order to cover various big things. He actually was down at Ole Miss during the integration of Ole Miss. And he went to Africa. He was a major magazine writer and so he went where the stories took him. But he—but he also—as he gradually made the transition to writing books, he was also around a lot. And so one of the things that I remember about my childhood, which I think was quite fortunate, is that my parents were—and particularly my father—were around more than those of most of my friends. And I've, I think, grown up with that model that dads are around a lot. And I've been able to do a fair amount of that myself, so that's—that's part of my childhood.

LG: So growing up then it sounds that your parents were home, but for your father traveling periodically when you were younger.

RM: That's right.

LG: Now, tell me about the hemophilia. What was the story you were told about when you found out that you had it, or do you remember that?

RM: Like many people, most of what I know about my early childhood is from stories that I've been told. So I gather that there were questions fairly early on. The story that I grew up hearing most often was that my—

LG: And who told you this story?

RM: My mother or father. But was that my uncle, my father's younger brother, came over and was playing with me when I was five months old or something like that. After he left—you know, he'd been tossing me around—we'd been having a good time—and after he left I had a couple of bruises and that struck my parents as odd. And I think they then sought medical guidance on what this might be. And that led to a series of tests that eventually led to the diagnosis when I was about six months old. And that's about really all I remember. I would imagine that my experience is similar to others. Because it's something you're born with, there's no point at which you suddenly go, "Oh, my goodness! That's what I have!" It's just part of who you are and what happens as you achieve gradually deepening understanding of what it is. And then also, I think that you come to understand with some surprise that this isn't the way other people are living. So you—discovering that, first of all—that there are these set of circumstances and conditions and then you learn more about them. And then you learn that other people don't have them. And then you have to cope with that gap between what you're experiencing and what other people think or experience and so forth. And that was—that was always a challenge in my childhood.

LG: What do you remember about that, actually?

RM: My wife, Anne and I have talked about this quite a bit, when I look back on my childhood I seem to have a rather selective memory, because what I remember are mostly very good things. And I have lots of normal childhood memories of doing things with my parents or playing with my sister, watching television programs or going away in the summer. And those things are very, very vivid. I didn't really

start to have joint problems until I was about three or four, and really not seriously until I was five, so I think there was a period when I was very small where my parents had to cope with bruising and things like that but not with joint bleeding. But when I was about four or five years old, one quite vivid memory that, in retrospect, definitely takes [chuckles] on certain meaning, was in nursery school when I was four years old and I can remember being able to run, which is something I lost in the ensuing years. I had a terrible bleeding, which I don't remember what caused it, but terrible bleeding in my left knee when I was about five—four-and-a-half, five. And it incapacitated me for many weeks. And my leg bent up, as joints do, and my muscle atrophied. And I was never really able to walk properly again. Eventually the only way they could get me back to walking was to put me in a leg brace on my left leg. And then shortly afterwards I had similar difficulties with my right leg. So I wore a left leg brace from the time I was 5 until I was 12. And—

LG: All the time?

RM: All—well, other than sleeping. I mean, whenever I—

LG: But only during your waking hours?

RM: Yeah, as soon as I got up I put it on. And yeah, that I could show you. I kept them.

LG: You kept your braces?

RM: I have a couple of them downstairs. I didn't keep all of them but I kept two or three, partly because they were so much a part of my childhood, it just didn't feel right to throw them away.

LG: What was the brace like?

RM: Well, it was designed to transfer weight off of the joint and so it was—and, well, I don't remember the earliest ones but the slightly later ones were beautifully handmade structures made by a brace maker in New York. They had sort of two aluminum metal bars running on the outside and the inside of the leg with leather straps that strapped you in on one or two places on your shin and one or two places on your thigh. And then there was a kneepad where you covered that. These braces were made of aluminum in order to be lighter, although they were fairly heavy. And they also could bend when you sat down, which was an important piece. They had a locking mechanism where when you stood up you could slide—just under your pants you could slide a small, metal square over a joint on the side of it, which then secured the whole leg. And so this was a natural reflex that I did for many years. I'd stand up, you know, which was a challenge in itself, but I'd stand up and then I'd lock my braces and then I could walk. And then when I sat down I could unlock them, which meant I could sit in a car, or I could sit in the theater, or I could do things that, you know, you need to be able to bend your legs to do.

LG: But when you walked, you didn't bend your leg?

RM: No, I walked, you know, like sticks, a stiff-legged person. The way you walk when you have stiff legs is, since it's hard to advance your leg directly over your foot, you tend to swing it out. So you have a sort of gait where the left leg would swing out slightly and then the right leg swings out slightly, because you can't just pass straight over your foot. And—

LG: And you were literally in this brace then for seven years.

RM: On the right side, I don't remember exactly but I think it was five years. So that was a long—that was the hard part of my childhood. I mean, although again, you know, I have to say that I was never really focused on that. I still feel sorrow even though I don't really remember it, but when I think about it what I feel sorrow about, is that process of actually losing the ability to walk as a child. So you go from a place where you could run—I have that single memory of being able to run and then being in bed for a long period of time. And then when you get out of bed you just can't walk again. And—and then, conversely, because this is an important piece of this story, regaining the ability to walk later when I was 12, 13, 14 and then, you know, to advance all the way [chuckles] to now. I mean, now I can walk and I have—I've had two knee replacements. And, you know, even in the last six weeks I've made a great advance, which is that I've been able to get back on a bicycle. I used to ride a little bit but after the knee replacements I couldn't ride. But my wife is a designer and an architect, and we were talking about what exactly was it that kept me from riding a bike. And we realized that it was the length of the cranks that attached to the pedals. And so I found an adjustable crank where you could make it shorter, because if your legs couldn't turn, and then I bought a recumbent bicycle so you're lower to the ground and don't have to hop down. The recumbent actually has three wheels. It's a sort of tricycle so that I don't have to worry that much about being sure footed on either leg. And as a result of that I've been able to do incredible amount of bicycling in the last six to eight weeks. And I almost never go out without thinking what an incredible miracle it is that somebody who could not walk is now out

there biking around on his two steel knees and feel great. My legs don't hurt and I'm zipping up and down. And so that's a pretty profound experience when you look at it in the whole context of my life. But going back to my childhood, one thing I should mention is that I think people with hemophilia, or any chronic illness, or really any identifying feature that makes them different have to cope with this experience of you present yourself to a new group—new group of children, new group of adults or any setting. You have to be mindful and you have to, in some sense—manage isn't the right word—you have to negotiate the reaction that they have to you. So having braces was—was disturbing to other children in the short term.

LG: What do you remember? Why do you describe it as disturbing?

RM: Well, I remember, for example, in kindergarten, and first grade and second grade, you know, you're trying to fit in. And there were a lot of things I couldn't do. Leaving aside for a minute misunderstandings and anxieties that people had about hemophilia, there were certain sports I couldn't do. There were certain activities that, again, leaving aside whether I was allowed to do them or not, I—there were some things I just couldn't do with the braces. And so—so, for example, there was a gender issue when I was in maybe second or third grade. During recess most boys ran out and played kickball or ran around and did stuff. And a lot of girls played jacks. That was in my—you know, in early 1960s in—in Westchester County, New York. Girls played jacks. So I couldn't go out and run around with the boys, although occasionally I sort of did. But, you know, and I couldn't keep up with two steel braces. But I was a boy so I couldn't really play jacks. But finally, I decided, "Screw that. I want to learn to play

jacks.” And so I did learn to play jacks and I got very good at jacks. And as a result, the girls were quite accepting of that. And the boys also—you know, after the sort of initial shock of, how does this piece fit in, I ended up getting along very well. But one of the, I think, very deep traits that I have developed, and I don’t know how other men with hemophilia have dealt, but that I understand in order to survive or in order to flourish I, because of just natural human reactions—I have to in a sense convey reassurance to the person I meet. And this is something inherited. I think I still do it and I think it’s led to some—actually, some interesting aspects of how I’ve lived my life. But I’m used to conveying a sense of reassurance and confidence to people. Although I may have these things, you don’t have to worry about me; I’m okay. And I’m—it’s—you know, it’s going to be all right and we can be friends and so forth, and sort of crossing that barrier. Now, one reason that I bring this up is because I’ve lived my whole life as an activist, somebody who’s been very interested in social justice issues, basic problems of fairness in our society and a range of activities. And I’ve asked myself many times why. I am a privileged white male from the Northeast whose parents went to good colleges—on scholarships—but on to good colleges. And yet, I have this burning passion for—for making the world a better place, and which I’ve lived out now my whole adult career and can trace easily into my childhood. And one of the things that I believe is that—that I have this sort of almost dual identity that I have—yes, I am a privileged white man. And yet, I grew up in this place where I was immediately categorized and judged on the basis of nothing that I had any control over and nothing that really mattered. So issues like

discrimination, exclusion, all of those issues at a political level, a social level and a spiritual level I feel very deeply. I feel very deeply about them and I feel very deeply for people who've experienced them. And so that is—and I think that comes directly out of my experience as a child and knowing what it's like to be rejected, knowing what it's like to have to have enough self-confidence to reintroduce yourself repeatedly to a group, and then knowing that, you know, eventually one can win acceptance and transcend that. But that—but it's sad that human beings have this reflex to be scared of people who are different, and that they apply it to all different kinds of differences. And I think that one of the things we have to learn as human beings, and one thing that I hope I've conveyed to my children as a parent is that is something we have to train out of ourselves if we're going to live in a fair and peaceful world.

LG: Where do you think you got this skill or this capacity to transcend that initial difference, tension, rejection?

RM: That's a good question. I don't know. I will say that I seem to have been an extrovert right from the beginning. I loved to talk. I was always very interested in people. My parents and adults who knew me when I was a child still remember with a certain element of humor my belief that I could and should inject myself into any conversation and hold forth on any topic, or query anybody about anything. You know, "Tell me about this." I was a very, very curious child and I think I have remained a very curious man. I'm interested in almost everything. And my career, which has been a little odd in that I've had several different professions. [chuckles] But for me, it's always been part of the same desire to know and understand the world. And

that curiosity really drove a lot of things. I think my parents deserve great credit because they—my mother’s attitude particularly, but my father’s also was, “This is a very hard thing. You are faced with a tremendous challenge and we’re going to help you as much as we can. But you need to keep in mind that you are a good person. You have tremendous value and whatever you run into is—it’s not going to stop ultimately who you become. It’s not going to—you know, it’s going to be”—they didn’t sugarcoat it and say, “This is—oh, don’t worry and”—nor did they try and make everything work perfectly for me. But they gave me a tremendous boost of confidence. When I would be in bed for long periods of time they were both very generous in their time and energy. And even when their own sense of what the future was going to be like was much more uncertain, they presented me with a sense of hope, a sense of energy. And they also really helped feed the life of the mind. I mean, you know, we were living in this little house and basically the only access I had to the outside world when I was in bed was television, which I watched a fair amount of, but also books and then whatever they could bring home. I sometimes wonder what would have happened to me if I’d had access to the Internet when I was a child, because I was just hungry to know things, advancing a little bit. I mean, when I was 10, 11, 12 years old I’d sometimes miss, you know, as many as a hundred days of school. And I would be at home and I would read everything that arrived in the mail. If the “TV Guide” came,—I’d read “TV Guide” cover to cover. The Sears Roebuck catalog, I could have told you the price of any tent or any shotgun, even though I didn’t own either one of those things. But, you know, I was—and I read magazines and I

read whatever books I could pull off the walls. And I just was—and I think my parents encouraged that as a way of, “You can bridge this gap.”

LG: You can bridge this gap. Explain that to me a little better.

RM: Part of your question, or part of the—what you raised at the beginning is how things have changed. Well, I don’t really know but my sense is that now our institutions are in a broad sense more willing to accommodate people who have differences. And when I was growing up institutions didn’t really have room for people with differences, they had rules and occasionally those rules were adjusted, but mostly not. So—so I missed a lot of school. There wasn’t—I mean, I went to public school and when I got better I went back to school and tried to fit back in to where the curriculum was and where the kids were and so forth. And I think—I mean, this is a little tangent but, you know, one thing is that when you live with hemophilia you are constantly facing disappointment. And coping with disappointment is very hard as a child.

LG: What kind of disappointment?

RM: Well, I’ll give you some examples. But I do feel for—that it’s a series of very hard blows and not everyone can survive them. I mean, I’ve known people with hemophilia who’ve—for whom this has been more than they can take. And I understand that. But, I mean, you know, the—so to lose your ability to walk is terribly disappointing. But more frequently, the problem is—I mean, more regular experience is that you want to go on the school field trip and that’s on Friday. And through Monday and Tuesday, Wednesday you hear all the kids getting prepared for that and you’re excited for that. And

then on Thursday you have an ankle bleeding or a knee bleeding and you can't go. And so they all go off on the school trip and then you hear about what a great trip it was on—when you get back to school the following Wednesday. But there's no making that up. You can't suddenly say, "Let's all get together and go back on the field trip. And those—those kinds of experiences were very, very frequent. I mean, from as little to, you know, I—tomorrow morning I want to go outside and play in the leaves because it's autumn or out in the snow because it's winter. And then you get up and you can't.

LG: Did you resent your hemophilia because of that? How does a kid cope with that?

RM: Well, resentment—resentment isn't quite the right word.

LG: Okay. How did you feel about your hemophilia?

RM: I never put it that way because I think I felt—and I don't know whether this is a strength or weakness or what. But I never could distinguish between my experience in life as a human being as something different from my experience in life as a human being with hemophilia. So I couldn't—maybe this is a lack of imagination—but I couldn't really imagine what it would be like to not have this.

LG: So you didn't really feel it was a separate entity from yourself.

RM: No.

RM: Maybe I at some level didn't want to go down that road, because if you start to go down that road then you can start to think a lot of things that are very painful and difficult. Maybe I just instinctively thought, 'I can't go there.' But I never did go there. I mean, I always felt—and again, this has shaped my spiritual understandings later, you know, as—I mean, as I went into the ministry and did many other—

many other things, but that somehow the key to living a joyful and happy life is not to wish that you were somebody else. I mean, even—yes, it's true that if we were—if we had all started out as somebody else, we would be somebody else. But that seems like a—that's like the joke about economists on an island who are faced with the task of opening a can of food that's floated ashore. And they say, "Well, assume a can opener." I mean, if you—yes, if you start with sufficient assumptions about something else, it doesn't really advance you at all. So I—I think the challenge that we face—that I faced and that everybody faces is to live the life we've actually got and not to spend our time preoccupied with fantasies about lives that we could have lived. And that's true not just, you know, like, I wish I were born somewhere else or born—but also, once we've made mistakes, once we've made choices in life, you can always go back and try to replay that tape and say, "Well, I wish." Well that's not productive either. I mean, there has to be some way to accept where you are and then move from that point. So I don't know whether that's realism or whether that's—I don't know what it is. But that's the way—that's the way I dealt with it. Now, that's not to say that it didn't hurt me. I mean, it did hurt me, these disappointments, particularly being such a gregarious child and being very interested in everything. So a chance to go out with friends and discover something new and have that cut short—very hard. And that happened many, many, many times. I mean, in different forms. You know, we—we rehearsed and rehearsed and rehearsed for a nursery school play. And on the last day right before it I had an ankle bleeding and I could not be in the nursery school play. I remember my father carrying me and sitting

me next to the play so that I could sing the songs with the others that I'd learned with the other kids. And, you know, my heart ached. I wanted to be up there and doing the things I'd learned to do and I couldn't do that. So—and that's been—you know, those are kind of—that's a set of hard experiences that I have had all my life, and even up until now. I mean, one of—I mean, the great challenge that I faced in the last two years is that after—you know, with some sort of giving you a snapshot of the end of the story—but after having gone through all of this and dealt with HIV and hemophilia and so forth, and then lucky enough to get an extraordinary job where I was managing running a national coalition of environmental groups and institutional investors, and had a great staff and lots of national and international obligations. I was the chairman of an international new organization that we started with the U.N. I was going to all kinds of places and really having an impact in ways that I could never have really imagined even—even a few years before and learning from it. You know, I went to Brazil; went to Japan; went to India and—and then suddenly I find that my hepatitis C has advanced so far that I really have serious liver cirrhosis. And one of the things that—one of the first sets of disappointments was that in—I was supposed to go and give a set of speeches at a huge international gathering called The World's Summit on Sustainable Development, which was to take place in Johannesburg, where I've been. And I have great love for South Africa and I wrote a book on South Africa. And I was looking forward to—this was the culmination of several years of work and I—so it kind of represented the coming together of many different pieces of my life. And I get to go back to South Africa and see all of my

friends and speak about these topics that I've been working on and so forth, and then I couldn't go. I couldn't go because I was still recovering from my knee surgery, which—and I didn't seem to be recovering very well. And then we realized that one of the reasons I wasn't recovering very well is because I had such serious liver problems. And so I couldn't go to that and then I couldn't go to a great many other things. And then I actually had to step down from my job. I realized in one very painful period in January of 2003 that if I took any more steps to—this organization was called CERES—C-E-R-E-S—and that every step I took to benefit CERES, support CERES, lead it, raise money for it, was a step against my health. And any step that I took for my health would increase the risk for CERES because it was—this was a very tricky time for us for a lot of reasons that had to do actually with our success. But we had spun off a key portion of our organization and we had to rebuild. And I at that point should have been on airplanes talking to people all over the country. And in fact, I couldn't go anywhere. And so letting go of that and coming back and sitting here in Somerville and deciding that part of my life is over, and now I'm in a new part of my life. And how do I make sense of that? How do I make sense of it in terms of—you know, it's a—with a loss of salary and a loss—and again, you know, a gregarious person who likes to be out talking to people, I'm home all the time now. But there's some happy sides to that. One of the things is that people come see me [chuckles] which is very nice. I also have used the Internet the way I would have used it as a child. And I—I am learning—and I am reading and learning about the—so it's kind of like a sabbatical, which I had wanted. [chuckles] I just didn't quite

want it in this form. But anyway, that's just an example of, this is an absolutely consistent challenge to me all the way through my life.

But—and here's a—here's a broader theme. I mean, I think everybody who goes through a hard experience, whether it's a medical experience or experience of discrimination or whatever, or unhappy family life, and abusive—I think everybody has to come to terms with, “All right, this is what's happened to me.” And they have to decide, “Because it's happened to me, I can't understand anybody else because—and they can't understand me, because this is a unique set of experiences. And only I've experienced it and I've suffered in some unique way.” In other words, it can become a very isolating experience. Or it can become a kind of bridge. And this theme of bridge, which you've already—you've picked up—it can be a bridge so that, whereas I had my unique set of experiences, it becomes a window into a lot of other people's experiences, and put mine in context.

LG: In what way does it put it in context?

RM: Well, to give you an example, I could be sitting here thinking, ‘Oh, my goodness. I—all of these great things I used to do and instead, I'm sitting here and I'm not doing so many great things.’ But the way I think about, for example, I was in Amsterdam about eight or nine months ago and I visited Anne Frank's house. And I saw—and I just reread her diary—and I saw this—the room where she sat and wrote everyday for more than two years. And I thought about what it would be like to be a young girl under these unbelievably trying conditions with the threat of death hanging around, you know, you at all moments, and trying to grow as a human being under these—you

know, being crammed in there not only with her family but with other people and living under this fear. And I thought, ‘I’m living in a comfortable house with the ability to go anywhere with people who care about me.’ You know, this is—this—I mean, and—and—and so I was moved by that, very deeply moved. The story of South Africa—there are many, many examples of people going through unbelievable things and emerged not just all right but with a great—I mean, Nelson Mandela spent 10,000 days in prison—27 years in prison. Nineteen years in the same cell. And I’m sitting at home with fine foods and access to the Internet and no restrictions—no real restrictions on me of any significance. And so I guess that’s what I mean. It allows me to bridge and say, “Well, yeah, certain things I’m going through are tough but not really that tough.” And this isn’t just me sugarcoating, this is really an insight that allows me to experience a great deal. Once you’ve gone through the kind of sorrow of a disappointment, but then you find all kinds of new touchstones for joy, and for peace, and for inner calm and for being able to give, not just to be the recipient but actually to give. So—but that all has its root in both the great love and generosity that I experienced as a child from people around me and the difficulties that I—

LG: Well, I think what you’re talking about is that you haven’t gone to a place where you feel victimized. You know, of a sort of “poor me” stance, that there have been times that you felt badly, of course, and have experienced a disappointment but haven’t settled in this “life is awful.”

RM: No, and I—it’s interesting to bring that up. I understand at some level how people could reach a point where they feel so battered that they

feel like victims. But I have a very deep feeling that one should do everything possible in one's power to move back to a position of agency and action, because to remain, even if you—I mean, if you get thrown into the experience of victim it's a terrible thing. I'm certainly not blaming people who feel that way. And yet, it should be our—individually and collectively we should be helping people to move out of that stance, which is a paralyzing stance which allows you ultimately only misery and only passiveness. And so, yeah, I think that's a very deep part of me that—that I—there are areas in my life where I had no control and where bad things, or sad or painful things happened to me. But what was key for me is to define and move forward in areas where I could grow and change and feel happy. And so, yeah, that's a big part of who I am.

LG: Let me ask you something just about physical pain now.

RM: Yeah.

LG: Tell me about your experience around physical pain.

RM: Well—well, that's hard to talk about.

LG: If it's too hard we don't need to talk about it.

RM: Well, it's interesting because now with the perspective of an adult I can recognize that I went through some—and many, many experiences of truly awful pain. I mean, not just discomfort, not just being in pain but really of agony. And I do block those things out to some degree. I can—I can kind of approach them. You know, I can approach the hazy edges of the memory but I—it's very hard for me to go back in. I think that part of my mental equipment is that once I survived those things I wanted to delete them essentially. I could remember them but it seemed no purpose in hanging onto it. But I

had many terrible joint bleedings and the pain of joint bleeding is like torture. Your joints become, you know, all the metaphors for terrible pain. It's like they are being broken in slow motion, like they're being burned. The pressure of a joint—bleeding joint is—is particularly terrible because you have this sense of this massive, enormous force growing inside you—inside your joint. And—

[end of side 1, tape 1]

LG: Okay. We were just talking about physical pain.

RM: Well, you know, so—and they—they—I was never someone who could really take—first of all, people didn't treat pain as well as they do now. And secondly, I had bad reactions to pain medication in this. So when I was given codeine, for example, it would tend to intensify my pain. And I would get, rather than sleepy and dull—I would be—it's a characteristic of my metabolism, I would get heightened. And also, I was a child so they were reluctant to give things that might be habit-forming or things like that. So—and there weren't—just weren't very many things available at that time. So for me the main treatment for pain was ice. You know, you would—but sometimes, you know, it's hard to get enough ice on some joints. The pressure of having any ice on a swollen knee was agonizing in itself. I mean, there were times when my knees hurt so much I couldn't bear the weight of a sheet. My mother had to construct a—it so that I could have blankets or stay warm, but she'd construct it so that the—there was actually—it arced over my legs so that they wouldn't touch because I—it was terrible. You know, to put your—a bleeding ankle that is inflamed and in—in terrible pain into a bucket of ice is a hard thing to do, because although, if you succeeded in keeping it there it

can numb the joint and cut it down, it intensifies the pain to put it in there. So, you know, it was a—it was a very, very hard thing. And I, well into my—you know, at least well into being a teenager, you know, I would have incidents that—where I would be up all night, up several nights. I feel lucky in the sense that it didn't kill me because it's a—or kill my mind because—and I do have a strange recognition now that I did not have as a child that these were far more horrendous even than I recognized at the time. For me, it was just something you survived, you get through. You try to forget about it. And so anyway—

LG: Do you remember how you did cope with all that pain as a kid?

RM: Well, when you're in the middle of it it is like being in a burning building and you are not doing a lot of reflection. You're just trying to—to not actually intensify—walk into an even more fiery place. So you are just reflexively looking for a way to alleviate, whether it's through movement or through anything—any, you know—distraction was one of the things that worked. And, you know, so having people talk to me, although that didn't always work very well. But—or television sometimes or a movie. We didn't have—we didn't have VCRs then or anything like that so it was kind of potluck. And my parents. My parents, you know, had the courage to stay with me through many of those things and talk to me and kind of try to get my mind off of it. That's—that's really the only—the only method. When it abates—I mean, I do remember there's kind of a pattern for bleeding. And so the first part of it is this dawning recognition that something is wrong. It's very subtle at first. I used to call it having a “feeling”, and it's just as though the joint were slightly—not tingly,

but just that you had an unhealthy awareness of the joint. And it was so that you'd be walking around and suddenly you'd find yourself thinking, 'This knee is—something—just something not quite right.' And then there'd be a period of the onset of pain itself and, you know, sort of discomfort. And that was usually the period—and I'll tell you, one of the things that's critical about that period is going from this vague feeling to the decision, "I'm now entering into a problem." That's a very hard thing to recognize. You have to sort of—and sometimes it was an issue of pride, like I may have been—I remember one occasion when I was very active. And my father said, "Be careful." And I said, "I'll be all right." And then I had a bleeding and I didn't want to admit it because he'd been right. I even once, and this—I'm sort of ashamed to say this—but I even once had a bleeding after a very active and very fun day. Then my knee started bleeding in the middle of the night. And I woke up and I didn't want to tell my parents, so I strapped my leg into a brace and I went to school with a full bleeding knee. I mean, in—and then waited about two hours [chuckles] until I could call my parents and tell them, "Oh, oh. I have a bleeding knee." It was a total farce. And my parents were not judgmental. They didn't say, "Oh, I told you so," or anything like that. But it was still in me, like, I didn't want to admit that there was a connection between this. But anyway though, so you'd have the—then you'd have to alert—in my childhood, you had to alert my parents. They would have to call the doctor. The doctor would have to come over. During that whole period the thing would be getting worse and worse and worse. Now, if you were unlucky, which is unfortunately—then this chart—I mean, the graph would just go right

through the roof. And you would then be entering a crisis period where I think running around a burning house is about the—you know, trying to figure out, is there any exit? And the answer would be no for a long time. Then whenever the period—however long it takes, you know—a few hours, a day, whatever it took—you'd come down and the crisis is sort of over. You're now—you know, the bleeding has stopped or—and then you'd come into the fact that you're now—sort of like coming over a mountain. And now you're at this enormous long plateau and desert, which you now have to cross because the knee or ankle or whatever could take weeks sometimes to go down. And so, you know, here you were doing all these activities and then you have this bleeding. And then you have to come through that and then you have to readjust, and that can happen again. I tell you, I had diaries from when I was—1967 and 1968 when I was 11 and 12. And I reread them recently and one of the things that is heartbreaking to read is that I'm so chipper in these writings. You know, "Oh, I've learned this and I did this today. And I'm really looking forward to going back to school." And then the next entry is, "Well, I had an elbow bleeding, knee bleeding and couldn't go back to school," in this one. So then I filled several pages of—you know, several days of, "Well, I did this or did that. I had pizza for lunch. I'm waiting." And then I'd get—my hope get right back up. I'm going to go back and then, wham. And this happens, you know, in the course of one year maybe 50 times. So that experience of—and then—then you have to manage your recovery, which is long, slow, boring, confining and isolating, and then gradually reenter, and then, well, you know, often as not go right back through the whole thing

two weeks later. And then sometimes you got in and I had a real problem with this that a single joint would continue—would bleed and sort of heal and then bleed again, and then sort of heal and then bleed again. And in all the time with every one of those bleedings each bleeding during its reabsorption period was destroying my joint. So, you know, eating away at the joint so that it work and my muscles would atrophy. So after each bleeding I was going back into—I was getting bigger but my joint was getting more corroded and my muscles were getting weaker. So it was a very, very hard spiral to stop. But anyway, I—you know, I have—I'm mindful that if we're going to fit the rest of my life into 45 minutes—

LG: It's okay. [laughter]

RM: But maybe I'm talking too much about this but, no, I—I—I mean, I think the thing that's important is that I came through all of this. I grew up. My bleeding stabilized. Prophylaxis came along and self-infusion came along. And I—we moved to Europe. And one thing I want to say for this tape, because it's a very important thing—we moved to France when I was 12. We went there for a year so that we could learn French because my mother—and because my father published his first book and it had done much better than anyone had expected. So we had a little financial room and we went to France. And I was covered for all of my factor products, which were freeze dried factor and so forth. I was covered as a foreign resident. I was not a French citizen. I had no claim on the French national health insurance. And I believe that I owe my ability to walk to the fact that I received French factor VIII for four years as a—as part of simply living in France. And when I compare that to the United States,

which, you know, 56 years after Harry Truman tried to put in place national health insurance—the only country in the world that does not make health care available to its citizens—it’s absolutely shocking. And we’re in a period now, which I hope will soon fade, where people are very critical of France. I don’t share that view and particularly regarding this, because they managed as a nation to have a system that not only provided for the people who were French citizens but could provide for people like me. And that’s an example of how my own experience has translated into some very deep political convictions. I know that the way health insurance works in the United States is it gives the best coverage at the lowest cost to the people who least need it, and that in fact is designed to exclude people who actually need medical care. And I think that’s disgraceful. So—but that comes out of my experience as—as a child and then observing how other people are—are punished and have this terrible added burden applied to them. They’re already coping with enormous amount, and then on top of that they’re threatened with denial of care or with bankruptcy as a cost of trying to live through something over which they have no control. And that’s in a country that normally commends itself for its compassion and good judgment. It’s absolutely shocking. And so I like to make that point whenever I have the opportunity in the hope that someday the United States will set a different course.

LG: Tell me about your relationship with the health care environment, with doctors, with nurses, with hospitals, with people you came into contact with.

RM: Well, I have to say that one-on-one I have benefited from a great many very serious, very compassionate doctors and nurses. And I

have many, many stories about—and, you know, particularly when I was a boy and—was a local pediatrician. Well, when I was a very young boy a pediatrician named Mario Bisordi, who had hemophilia himself, and took care of me. And then later Dr. Lee Engel in Westchester County, who would get up in the middle of the night and put on his clothes and a tie and get into his big, eight-cylinder car and drive over and give me a shot at three o'clock in the morning, get back in and drive over and then, you know, go to his practice the next day. And that happened many, many, many, many times and Lee was always a wonderful, generous man. And his partner, Dr. Herb Newman, also did that. And Dr. Margaret Hilgartner, a great—a great—an incredible leader in the field out of New York Hospital. So that's the overarching thing. As I said earlier, a lot of institutions had very bad rules. And so I experienced many of the bad sides of this. You know, being taken into medical treatments as a child and my parents being denied access to me, not only during the treatment but even afterwards. Being set in places where—you know, being sort of victimized by rules like that—because I had hemophilia they had to call the hematology resident to do the infusion. This is when I still had to go to the hospital rather than the pediatric resident, so the hematology resident, who was a perfectly decent human being, but had no experience getting into a child's veins. And they wouldn't call the pediatric resident until the hematology resident had tried two or three times to sink a needle into me. And they often failed. And they didn't feel any better about it than I did. [chuckles] But that was the system. And so one of the things I'm very proud of—well, let me just mention that when I started having—for a long period in my adult life

I didn't have to go back to the hospital. And when I started going back I was nervous about it because of these experiences. And my wife reassured me. She said, "You know, Bob. Things have changed and, you know, people are more responsive now." And I've definitely found that to be true. And what I'm proud of is that my parents' decision to go ahead and write a book about my experiences, our experiences as a family, I learned in the aftermath that that book was—for a period of 10 or 15 years was very widely used in nursing schools. And I got letters and even now I occasionally still get letters from people who talk about what impact it had. So, you know, there—it is possible to learn. And people—and I do think our systems now—while I'm sure there are many lapses, but just in general there's a responsiveness. But part of that's also that I'm a much smarter and more engaged and, you know, as an adult, more commanding patient. I—you know, it may be that for young families coming through coping for—with hemophilia, a sudden appearance of hemophilia and it—I'm sure it's still very hard. When I think about what did doctors and nurses do for me, I think my parents were more angry and bitter than I was, because I'm just very aware of the care I actually got. I think they're more aware of what they had to do to get it, of the occasions when I was denied it. I didn't tend to be aware of those things.

LG: Mm-hmm. You weren't aware of what your parents had to grapple with so much.

RM: Not really until much later. Because—and in fact, reading this book that they wrote was a great revelation to me. And—and then re-reading it when I was myself a parent, that was probably the most

revelatory moment because I suddenly discovered, “Oh, my God! How would I feel if this was happening to my son, Sam, or my son, John, or my daughter, Kate?” And I realized I have no idea whether I would react with the kind of strength and tenacity that my parents felt. So reading—it’s interesting—reading that as—you know, as a man in my 30s when I really had small children taught me more about my parents than I thought I could learn. Because I’d grown up with them, I thought I knew all about them. And no, I learned a lot of new things. So—I think my mother still bears sadness and anger about the way that she and I—the way we were treated.

LG: In what respect do you think?

RM: Well, I just think that she remembers the—what we would now, I think, all see as more heartless institutional or personal acts. And my mother is a great lioness of support and my father, in a slighter quieter way, also absolutely. And that—and that’s a story in itself, how growing up with such engaged parents, we were able to make separate lives and so forth. And that, you know—because having such incredibly supportive parents can be a trap [chuckles] in itself. But—but I think we negotiated that really, really well, partly because my parents—and I—this is sort of a funny flip side, but my parents, and especially my mother, always—it was always clear that she had a lot of other things she wanted to do too. [chuckles] She had a lot of other interests. My mother became very interested in Russia, became an international expert and historian on Russia. And so she was a person who wasn’t sitting there saying, you know, “You’re my whole life.” She was saying, “You are absolutely central to me, you and your sister, or sisters,” when I had two. “And I can’t wait for the

moment when you have your independence, which we're all working for, and they have their—and I can do more of the things that I'm interested in.” And I never really felt caught between—and I was always kind of relieved in a way that my mother and father, but especially, I think, my mother, had this whole set of aspirations and desires and interests, because I thought, “Thank God. That means it's not all on me.” [chuckles] And I think that's another way in which in some ways I'm fortunate because I do know that—of some mothers of boys with hemophilia who become so intensely shaped by this experience. It's very hard for them to make a transition and I sympathize with that.

LG: And actually, you're also alluding to not only them making a transition but also the parent making the transition.

RM: Yeah, actually, that's what I was most referring to is the letting go of the child, but also the child having to—you know. Yeah, absolutely, because if you build up all that incredible structure of support and commitment so that you can get through it, well, then what happens when you have to separate? And, you know, we had some bumpy parts. I can remember really having some very ferocious arguments with my mother when I was about 16. But they didn't last very long. Today, I have very, very deep admiration for both of them.

LG: Tell me about the treatment changes that you experienced. You've talked a lot about really having almost no treatment but for ice and just tolerating what was going on.

RM: Well, when I was—when I was very young, I mean the only treatment was fresh-frozen plasma. And so that was hard to obtain, hard to preserve. The amount of factor VIII in a bag of fresh frozen plasma, a

large bag was very small. And so—and you couldn't give that much to a little child. So it was—it was pretty primitive. I'll tell one story just to set this in context. When I was about four or five we went up to Smith College where my aunt was in college. And I don't remember—my father was giving a talk or she was graduating, or some reason we had to drive up to Smith. And that day before we left, I was pushed against a doorknob by a classmate in nursery school. You know, I just fell back against it. And I got a bruise on my back and the bruise got worse as we drove north. And it got worse and worse and worse. And then in the middle of the night it was—it was huge. I had this enormous bruise that was starting to—I don't know—involve my ribs or my spine, a lot of things. And I couldn't—I couldn't move and I—so they took me to the hospital. And, of course, this hospital in Northampton or wherever it was—they didn't have any fresh frozen plasma. And they didn't have any way of getting any anytime soon. And I—and so the decision they made was my father lay down and gave whole blood. One of the very vivid memories of my childhood is my big, strong daddy lying down, and then drawing blood out of him, and then giving it to me. And—and then, you know, that was—that was the only treatment that was available. Then cryoprecipitate came along when I was—I don't really remember—maybe eight or ten—seven, eight. And that was better because you could—you could mix more bags and have more factor VIII. But it still—you know, you still had to keep it frozen and you still had to do all kinds of things to—so whenever we went anywhere we had to go with dry ice and it was a production.

LG: Did you do it at home or did you go to the hospital?

RM: Well, in the early period I—I did it at—excuse me, at the hospital. And that was a huge production in itself. I—you know, having to go to the hospital every time. As they became frequent, as the cryoprecipitate became a little more commonly used, and as we found these great doctors, Dr. Bisordi, Dr. Engel, Dr. Newman, who would come to the house to do it, we began doing it that way. And so that's how we did it through, I would guess, from a period of five until I was about 12. When I was 12, two things happened that were of extraordinary—that had extraordinary impact. One was that I was taught to self-infuse. This was in 1968. Right, I was about—about 12 years old. I still remember the nurse who taught me was a woman named Elaine Sergis, who was the nurse practitioner at New York Hospital. And, you know, she taught me how to—how to hit a vein and how to do that. And for a number of years that followed then—she also taught my father. So sometimes my father would do it; sometimes I would do it under his supervision. And we kind of went back and forth but gradually, I gained the ability to do it. And we—when we went to Paris my father often did the shots for me. So we did parental infusion. And then secondly, the factor VIII concentrates began to appear. And—and those made an enormous difference because, not only were they much more powerful, although looking back on some of my shot records, you know, I was giving very low doses. We were, I think, under-infusing because it was rare and hard to get, unbelievably expensive, as it still is. But—but the key piece there for me and as—when I became an adolescent was that they did not have to be—you know, kept under—that they could be kept cool rather than frozen. And that opened up an absolutely enormous vista

for me to do things on my own, because I could take my bottles of factor. And then eventually they learned that they could be kept at room temperature and they would be okay for—and so that meant that, instead of being tethered to a hospital or tethered to a large [chuckles] heavy-duty freezer, I could pack a backpack quite literally and go. I lived in France until 1972. I came back, graduated from high school in 1973. And then I took a year off because I'd gotten sort of ahead of myself. And during that year off I went and worked in the United States Senate. I worked for Senator Scoop Jackson. I worked in the Senate Investigation Subcommittee where I worked with people with whom I no longer share the—many of—many common views, people like Richard Perle and Elliot Abrams and all the people who have become very well known neo-conservatives. But I learned a great deal from Senator Jackson, who was an amazing guy. But I could do all of this and then I started traveling to Europe, and then by myself and, you know, doing—I was able to do shots on camping trips, in the bathroom of an airborne 747. You know, all kinds of things that enabled me. Just at the moment of adolescence when your life is expanding anyway, my ability to manage hemophilia improved in a way that allowed me this freedom. And then I also was regaining my ability to walk steadily. And so, you know, it kind of was an explosion from this childhood in a very—which was in a very different era—to adulthood. And that period really went all the way through 1982 or 1983. I got—I went to college. I went to divinity school. I took a year off and worked for Ralph Nader, which was something I was very proud of until recently. But—and I was ordained in the Episcopal Church in 1982 and was married in

November of 1982 to my first wife, Dana Robert, who was is a religious historian and an incredibly talented woman. And we were married and I went to work as an assistant at Grace Church in New York City, assistant minister. I was one of the staff of five in this enormous, beautiful miniature gothic cathedral and a chaplain at the K through 8 school. And we were living and Dana was working on her doctoral dissertation for a Ph.D. from Yale in American religious history. And that's where we were living and that—so the period from becoming a teenager—you know, let's say in '72, '73 to getting married in '82—that was a period of enormous freedom for me. And then in '84 was when I found out I had HIV. And, although—do you want me to talk about that?

LG: I do. Tell me about that.

RM: Well—

LG: Before you found out, did you start hearing—what was your awareness?

RM: Well, the first—I guess—I was living in New York City. And I guess in about—and I don't remember the dates exactly. But in about '82 or '83 there started to be some concerns about what I think was originally called GRID, which was “gay-related immune disease.” And then for a while it was referred to by the—what they were calling the virus, which was HTLV3. And then eventually, rather late, it began being referred to as AIDS, which I remember thinking was a very odd choice of terms. For one thing, the idea of aid is supposed to be a positive thing, and AIDS being such a dangerous—and also, there was an [chuckles]—there was a dietary supplement—a diet—a diet thing that you could take that would help you, you know,

suppress your appetite called Aids. And I thought—I remember thinking, ‘Boy, that—that—that brand name is doomed if they’ [laughs]—it was advertised on TV. You know, “Do you feel overweight? Take Aids.” [laughter] It sounds funny now but it was the—so I began hearing about this a little bit.

LG: Now, you were married at this time when you first heard—

RM: I was married at the time.

LG: Working in New York.

RM: Working in New York and I began hearing about this. And—and one thing that’s really important to state is I didn’t have any reason to be particularly fearful for a couple of reasons. One is that I knew I had been exposed to blood-borne viruses before—various kinds of hepatitis and they had not had any clinical impact on me as far as I could tell. Now, now, years later, the hepatitis C but, you know, maybe I had gotten sick briefly. But I felt fine. And so I thought, ‘Okay, I’m not going to panic about this. I mean, I’ve gotten through—you know, things have been okay. They don’t know very much about it,’ and so forth. And then the other thing is that there was some reason to believe that the process of freeze-drying factor VIII might disrupt or attenuate a virus, particularly a virus that seemed to be so fragile that it had to be blood-borne. So there was a sense that, well, we’ll see whether this has any impact on the hemophiliac population or on anybody who receives blood products. And there was really a lot of uncertainty about that for much longer than people remember. And there was occasionally some discussion of, “Well, maybe we should cut back on factor treatment because we don’t know.” But the idea—you know, having been through what I’ve

described to you—the idea of going back to cryoprecipitate or going back to fresh frozen plasma because there might be some problem didn't seem like a great idea. I know from subsequent events that this—the potential that I might have contracted HIV was much more on the mind of my first wife, Dana, and that she worried about this with gradually increasing intensity. And I should just say now our marriage ended in the early '90s. And, you know, I think this is a major reason. I mean, I know it is. She and I are—have remained quite close. She lives a few blocks from here. We co-parent our children and we've had the chance with the distance of time to recognize some of this burden. But I really wasn't aware, and I fault myself in some ways for not being more aware, because I was operating in this, “Well, we don't have any bad news and, you know, so far, so good,” where she was operating on this, “Oh, my goodness! This is a cloud on the horizon that's getting closer and closer.” In 1984 I discovered—when they had the antibody test I discovered that I was HIV positive. And I can—I remember very clearly the day—this was before they had any counseling or anything like that, or—you know, I think most people recognize now that there needs to be some structure around people getting this news. But I went for my annual checkup or my semi-annual checkup in New York Hospital where they would run a battery of tests on me, and check all my joints and basically say, “How are you doing?” And I'd say, “I'm okay.” And they'd say, “Well, you know, you're doing pretty well compared to a lot of folks,” and then would always give me some advice like this. Like, “Well, just keep it up and don't—you know, just keep it up but just don't do too much but keep going.” You know, sort of like,

“Thanks, that’s”—but people were very nice and I was glad to get checked from head to toe. And then I remember going into Margaret’s office. She was always very good about asking me to step in and talking to her. And then, as sort of an afterthought she said, “Oh, do you want to know your—about this HIV score?” or whatever it was called. And I said, “Sure.” And so she—I remember her getting two books out. One was the list of, you know, my name and my—whatever my subject number was, and then going to another book and looking at the subject number and the result. And she said, “Oh, well, you’re positive.” And I did not have any strong reaction. I didn’t know what it meant. It might not mean anything. I mean, if I had been told this a year or two years later I might have been much more shocked. But I basically went, “Oh?” And she sort of went, “Oh.” And we thought, ‘Well, let’s keep an eye on this.’ And I walked out and I really have to say I didn’t give it that much thought. I thought, ‘All right. Well, one more thing to keep an eye on.’ When I told Dana, I think she was more shocked. But either she didn’t show it or I didn’t pick up on it. But so—so anyway, that’s how—and now, I do remember in 1985 or 1986—I think it was in ’85—there was almost a panic nationally about AIDS. People were really becoming aware of it. I think we had a delayed reaction in this country because, for one among many reasons, President Reagan refused to talk about it. And though he was—became president in 1981, I don’t think he talked about it until the mid-’80s. And this created this sort of sense that it was a secret illness and a dangerous illness. And I remember once being in a supermarket. And I don’t remember exactly where I was. I—may have already moved to Boston in 1984, and looking

down the aisle and seeing the checkout counter where they had the magazines. And from 40 feet away I could see the cover of “Life” magazine, which said in huge red letters—I mean, you know, six-inch letters, “AIDS” and then the subtitle was, “Now No One is Safe.” And that—and I suddenly thought, ‘Oh-oh. Maybe there’s going to be—maybe I’m in real trouble. I don’t know what’s going to happen.’ There was a sense that maybe—and, you know, people were talking about that, like, maybe they’re going to find an island and move all the people with HIV out there. I just had no idea what the reaction was going to be. And there was this sudden sense that maybe this was going to be a very, very serious thing. Now, I should mention that also during this period Dana and I were trying to decide what to do about having children. We’d been married since 1982. We’d decided not to have children right away, just because she was finishing her doctorate. And then this came up. And so we spent about a year in counseling with a person who’s a social worker or a psychologist who also specialized in HIV, was actually out of the Fenway Community Health Center in Boston, which did a lot of work with gay people at the time. And we sat and we talked—

LG: So you were in Boston by this time.

RM: Well, we moved to—what happened is Dana finished her Ph.D. I had done two years in the ministry and I was thinking about doing a doctorate myself. And through a whole series of things we ended up, and really, almost miraculously, after considering many options, Dana was offered a job teaching at Boston University as a lecturer and then assistant professor. And I was admitted to Harvard Business School in the doctoral program with a full scholarship. I was always

interested in these economic and justice issues. And I'd done the work for Nader and I was thinking—and I'd been admitted to Yale Management School but decided not to go in order to get married and be in actual practicing ministry for awhile. And then—but—and now was sort of time to go back. And Dana had finished her degree so now I was going to do my degree. So we moved to Boston in the summer of 1984. And then we started talking about whether to have children then. So we went through a very, very long process. And I'm sure—you know, it would be interesting to talk to her a little bit now about how she did. But, I mean, I thought we were painstakingly thorough in trying to review all of the emotional issues, the medical issues, the spiritual issues. You know, everything we could think of we put it out on the table. And we basically decided that—and I don't know—you know, who knows if—but we basically decided that I was very—I was apparently completely healthy. We didn't know much about the transition and what we knew, it seemed like it was a small risk, and that if I were to get sick or worse, that the risk would probably go up. So maybe we should try. And there were no really—I mean, the only other advice that we were getting was, "Well, just wait." But we had waited for a number of years already, so the idea that we would wait, you know, for maybe five more years didn't really seem—that was—that was one option versus maybe just trying. And so we thought, 'Well, we'll try for a very limited period.' And Dana got pregnant extremely quickly. And so we thought, 'Whew!' You know? And we went through the whole pregnancy and Sam was born. And people listening to this story will appreciate that shortly before Sam was born Dana got back a blood test, which suggested that

she might, in fact, be a carrier for hemophilia. So we suddenly [chuckles] had a possibility that maybe we were going to have a child with hemophilia. These were antigen tests and ratio tests and not anything like what we have now. But that just—so suddenly that—there was this odd possibility that maybe I'd married a carrier with hemophilia. And so—so there was a lot of turmoil, just, you know, finger crossing and who knows when—and then Sam was born. And Dana was fine, no trace of HIV. Sam was fine, no hemophilia. And I just thought, 'Thank you, God.' And I thought, 'Well, maybe that's all we'll do.' And so anyway, that's how we—how we ended—and I was—and you can see that, coming through these various things, and if it worked out all right, I was just like, "Whew, that's enough. I'm fine. I'm happy and thank you." And the—the decision to have John was sort of an impulse that really Dana said, "I'd like to have another child." And I said, "We have to go back through this whole discussion process." And she said, "No, I don't want to go back through it. I just want to have a child, like, right now." And she did [chuckles], which was—but the sad part of this story is that, despite the courage or whatever that we showed—she showed, it continued to gnaw at her and her sense that my life was going to definitely be foreshortened was part of, I think, what was very, very hard for her. And then it ended. It wore away and led to the end of our marriage. If I had to pick of all the things that I've been through, that was probably the hardest thing in my whole life, not joint bleeding or—but having that terrible sorrow of losing a wife and having a family be torn apart. We were able to build a system that healed a lot of things but, boy, that was—that's the number one most awful thing I ever went

through. But I—anyway, on the positive side, we had these two beautiful boys. And I was—finished my degree, pastoring a little church. Dana was teaching and growing in her field and I was doing a lot of childcare. I like to think it was almost equal but it may not have been. But I did all the cooking, for example. And I loved spending time with children. I really, really love children. [chuckles]

End of Interview #1

Interview #2 with Robert Massie, December 9, 2004

GRAY: This is Laura Gray and it is Friday, November 20th. And I'm sitting for the second time, almost exactly a month later, with Bob Massie in Somerville. And we had left off—this is tape 2, side 1. And we had left off last month about the effects of the HIV crisis and Bob getting infected with the HIV infection. And he had just finished telling me how losing his first marriage was one of the toughest things in his life. So, Bob, thank you for this second sitting. And what I wanted to ask you is if there's any more reflections you want to make in this time period of the '80s as to how you think this HIV infection and news affected you? I've heard personally. You may have other things to say, and please do.

MASSIE: Okay. Well, I think that there is a theme that runs through my life. I believe I talked about it to some degree in the first tape. One challenge, I think, for any person with a chronic illness, and particularly with hemophilia and then particularly with HIV, is to judge, is to sense how much these phenomena that overtake you are going to affect your relationship with other people. In the case of

hemophilia, I had to work with all of the challenges and prejudices and anxieties that other people felt towards people with chronic illness, and particularly with braces. And then when HIV came along, and I told the story about the “Life” magazine cover last time, seeing it in the supermarket from very far away. And it was about the time that people were really understanding the range of the epidemic. And it said in huge letters—red letters—I remember I could read it from 30 feet away—it said, “AIDS.” And then the subtitle was, “Now, no one is safe.”

LG: How did that affect you?

Tape on/off

LG: Our last sitting was interrupted. So now Bob and I are sitting together. It’s December 9th in the morning. And we’re going to continue where we had left off. What are your thoughts, Bob, about how HIV has changed you or affected you politically. And let’s start there. You were saying you were in Star Market and saw this magazine.

RM: Yeah. Well, I mean, I think that my reaction to seeing the magazine was that I began to wonder whether I would have to start concealing my HIV status from people.

LG: Because it frightened you?

RM: Because of other people’s fear and discrimination and so forth. I—really wasn’t sure where this was going to go. I—

LG: Had you ever had to conceal anything before?

RM: Not really. I think I’d always taken the point of view that hemophilia was ultimately not a frightening illness, that most of the things people were frightened about were not true. And so it was a question of

explaining that you weren't going to bleed to death from a cut or something was going—so that once people's familiarity rose, their anxiety dropped. And you would be more inclined to be accepted. But HIV had this—these extremely emotional and panic-inducing qualities. I mean, it touched so many things. It was a blood-borne illness; it was sexually transmitted. At the time it was viewed as inevitably fatal. So it carried with it a lot of the sort—it touched many of the most sensitive areas in people's mental and emotional makeup.

LG: What about your mental and emotional makeup?

RM: Well, for me, I had—and I don't know whether this was a form of denial or what, but I, as I think mentioned earlier—I had a bit of a wait and see approach, because I had been told, and I forget whether I related this story before, but I had just learned about my HIV status simply by going in for an annual checkup at New York Hospital where a set of blood tests were drawn and other things were done, and saw the orthopedist. And I went back, I guess a few weeks later, and saw Dr. Margaret Hilgartner, who had been my caregiver since I was six or seven years old, and here I was 28 when I found out about this. Yeah, so I'd known her a long time. And I remember her saying, "Well, you know about this virus," which I think at the time wasn't even called HIV; it was called HTLV3. And it was just another peculiar virus that may or may not have been related to the cause of what was also called at that time "gay-related immune disease" or GRID. And people were just piecing together, I guess, in '82, '83 that these were all linked and just coming up with an antibody test. And I remember Margaret saying, "Well, you know, we've run all these tests. Your liver functions are a little elevated," which I heard every

time, which was a sign that my liver was deteriorating from hepatitis, we now know. But—and I said, “Yeah, I’d like to know.” So she looked up—she took out one book and looked up my code name, my code number. And then she took out another book and looked up that number for the results. And she said, “Oh, well. You’re positive.” Years later there was a huge superstructure formed to help people cope with the news that they were positive and they wouldn’t give you the results on the phone. You had to come in. You had to meet with someone. None of that existed when I learned my status and I remember leaving and thinking, ‘Well, okay, you know, another bit of news.’ But I was not shocked. I certainly don’t think that the caregivers failed, because what was known at the time—we just didn’t know very much. And I suppose later when AIDS hysteria intensified, then I might have liked to have had some greater contacts and discussion when I got the news. But at the time nobody really knew anything. So I remember walking out. I was still living in New York City at the time. I went back and told my first wife, Dana, and although she didn’t show it, I think this had a much more frightening impact on her than I was aware of, than I think anybody was really aware of, perhaps even she was aware of.

LG: All right. And you actually talked at length about how you felt. This had affected your marriage and it ultimately destroyed that first marriage.

RM: We were married in ’82 and when this emerged in ’84, one of the first significant questions -my first wife was finishing her Ph.D.- when we would try to have children. We were in our 20s so it didn’t seem like an enormous rush. But on the other hand—and Dana was about to

start teaching after she finished her Ph.D. By '85, '86 we had moved to Boston and we'd been married for four years, moving into five years, and we were starting to wonder, what did this mean? So we ended up enrolling in a weekly counseling session at the Fenway Community Health Center here in Boston, which was a sort of unusual situation. I think we were one of a very few straight couples who were in there. The whole thing was geared towards—I guess, primarily gay men—but gay and lesbian people. And here we were, this, you know, heterosexual couple coming in and talking about having children. But I don't remember the name of our counselor but he clearly specialized in working on gay relationships. But he was very helpful to us, I thought at the time. And we talked out a great many things and then we decided to try to have children on the assumption that I seemed very healthy. We still didn't know what the probability was that HIV really would have any impact on hemophilia. I mean this was before people with hemophilia started dying of HIV. There was also the challenge that if we were to wait I would get sick and my infectivity would go up and, therefore, pose more of a danger to Dana and so forth. So we decided to try and get pregnant for a short time and we had no idea whether getting pregnant would require multiple months or whether it was something that would unfold fairly quickly. And I think that in my son, Sam's case, I think Dana got pregnant the second month. And, of course, we were very targeted when we were trying to get pregnant because we'd long before committed to safe sex. And so this was a question of sort of some isolated incidents to see what would happen. Looking back on this 20 years later, it's easy to say maybe we were just being

completely foolish. At the time, we thought we were really working through all the issues and making an informed judgment and a judgment that felt that we were taking into account as many of the unknowns as we could, and that on balance it seemed like something that was not such a great risk.

LG: You never really then blamed the physicians. You never were in the situation where you ever wondered, ‘Should I be treating myself? Shouldn’t I be treating myself?’ Did you get encouragement or discouragement from your doctor?

RM: There’s a very interesting twist to all of this, which I’ll just mention briefly and perhaps we can come back to it. I don’t believe I mentioned it before. Between high school and college I took a year off because I graduated a year early from high school. And I went and spent six or seven months working for Senator Henry M. Jackson of Washington. Did I tell you about this?

LG: I think so but go ahead.

RM: Well, the key point of this is that I became—and this is in 1972—’73, really, and in the spring of ’74, I became very interested in what I saw as a deeply flawed system through which American blood companies were operating. American pharmaceuticals were collecting plasma products from impoverished, financially desperate people in the U.S. and from—and overseas, from Nicaragua and other places like that. And they were importing this, knowing that there was a high degree of viral contamination. They were importing and pooling this plasma and so I began to look into this. And with Senator Jackson’s support, we actually launched a small investigation of the Permanent Subcommittee on Investigations in the U.S. Senate, which we ran for

over a year. And we sent out letters asking about the issue of viral contamination to the major drug companies. And—because the way in which it had an immediate impact is that the drug companies were making this concentrated product and then they were trying to market it overseas. One of the primary issues was hepatitis. Whereas most American hemophiliacs had already been exposed to hepatitis A and B, many people in England, many boys, had not. So they were becoming quite sick with hepatitis as the result of receiving American products, which the American firms were promoting as superior to British products. And they were not superior, except in maybe some very small technical ways, and they were making people sick. And this—so I raised the issue and even got into—this is what's quite fascinating in retrospect—why the pharmaceutical companies were not committing to heat treatment in order to increase the safety of the blood supply. And we got back some answers, you know, because this all came out on U.S. Senate stationary and with Senator Jackson's signature on it. We got back a wide range of material but the gist of it was, you know, a lot of explanations and excuses. But the biggest—around viral protection was the yield issue. You know, that if you heat-treated factor VIII, then the yield would go down and, therefore, the price would go up. And so, we heard from the companies, "We can't do that and we're not inclined to do that and there's no reason to do that," and so forth. In 1975 and '76 when I was in college I went back. We actually continued this investigation with the thought that it might become a full set of hearings. There's some irony here. I worked directly for an attorney who later became famous for other things, Elliot Abrams, who went on to become a big official in the

Reagan Administration and so forth. But at the time he was a Democrat and I was assigned to him and we worked on this issue together. 1976, this was still dragging on but two things happened. Scoop Jackson said, "I want to have these hearings. I really am disturbed by what we're learning." But he was running for president and basically he said, "Well, if I become president I'll be able to do a lot more about this. And if I'm not president, we'll come back and revisit this." And then, simultaneously, the senator from Illinois, Charles Percy at that time, received information and pressure from the companies based in Illinois, which included Baxter, in which they said, "It's totally inappropriate for a biased young man with hemophilia to be involved in this investigation." And so Senator Percy, who I otherwise admired, went to the Minority Counsel of the Senate Investigation Subcommittee. The minority counsel called me into his office without any warning and basically delivered my first experience in hardball politics. I was only seventeen years old. He said, "We are willing to consider moving forward with this investigation with Senator Jackson. And we are willing to even consider issuing subpoenas for it, but only on one condition, which is that you personally recuse yourself and withdraw from any connection to this, because, you know, Senator Percy (i.e., his major corporate constituents) feel that you shouldn't be involved in this." Well, this was a battle that I couldn't fight or really win. I went back and told the general counsel and told the senator and he was really, really pissed. But—but, you know, presidential politics and life intervened.

LG: So how did you feel then when this whole thing blew up and the companies were ultimately sued and had to settle?

RM: Well, I—I mean, you asked me how this affected me politically. I mean, we have a horrendous system in the United States, both in terms of the creation and in the distribution of health care. We have wonderful science going on and wonderful care for those who can afford it. But one of the things we have is that much of the research, for example, that led to the commercialization of factor VIII was done under government funding in North Carolina and other places. When that government funding demonstrated that this was a viable way to approach the concentration of factor VIII, —and I don't remember all the details of this—those contracts and licenses were acquired by firms who then made just an extraordinary amount of money. Back then I ran some calculations; revenue and probability projections. This was long before I went to college, let alone business school. I ran some calculations on what was the likely volume of, you know, how many AHF units per year were being produced by the U.S. industry total. And, you know, you could figure that out by figuring out roughly what the U.S. population was and—I mean, hemophilia population, roughly what their treatment dosage was. And so you could get a sense of the total thing. And then you'd multiply that by what they're charging per AHF unit and it was hundreds of millions of dollars. And then you ask, "Well, what are their operating costs and then what's the margin?" And, you know, it was—even under the most conservative estimates, they're making tens—at that time, tens of millions, and very quickly, hundreds of millions of dollars. And when you have a product that—where you have essentially a captive population, there's no elasticity of demand around whether you need factor 8 or not. You have a group of people who are forced to seek

and obtain this product through whatever means they can. Then you can charge whatever you want. And, you know, to carry it one step further, there's even a disincentive to create advancements because this is such—I mean, and what I later learned in business school, this is such an unbelievable “cash cow”. It throws off so much cash that allows you to do other kinds of research and pay your shareholders a lot more money. One thing I learned is that there's always a bias against safety, because people want to move a product out and they don't want to hear bad news. And, now, I don't want to cast aspersions on everybody in the entire U.S. medical system, and I know there are some people who care a lot about this and have learned from their mistakes. But I think there's no question that, in this instance and in other instances that followed, commerce overwhelmed science and did end up exposing a great many people, including me. I mean, to put not too fine a point on it, if in response to the hepatitis concerns that were already well established in the mid-1970s, the pharmaceutical companies had decided to pursue a system of viral inactivation or heat treatment, there would have been no HIV catastrophe for the hemophilia community. And that speaks for itself.

LG: How do you make peace with something like this, or do you?

RM: Well, it depends on what you mean by make peace. Some—I mean, one decision that I made, which not everyone agreed with, but which is I think a response to your question, is that I did not turn this into the great crusade of my young life. When Journey—my parents' book, Journey came out, I was asked to come and speak. And I enjoyed very much doing that. I spoke 30, 40 different places around the country. And it gave me a chance to see America and to meet

hemophiliac communities, and to see what was going on and to speak to—and I was appointed to the American Blood Commission, which was a sort of quasi-public group looking at blood supply issues. And I was really the young hothead on that committee. But that was kind of as far as I wanted to go. I thought about obtaining a medical degree and going on. But I thought, ‘You know, I didn’t choose to have hemophilia and I don’t necessarily want to spend my entire life with this as my frame of reference.’

LG: So many people ended up so angry and so devastated by this event. What about you?

RM: I don’t know the answer, why didn’t I? I think I understand that anger and that—and I don’t want in any way to condemn it. I understand it and I know people have suffered a great deal. And I think many of the things that were happening were just beyond outrageous. They were—so I think for me it was a question of feeling that there were also other things that were outrageous in the world, and there were other injustices that needed addressing, and that I wanted to have a bigger frame on the whole thing. And for me, you know, I’ve been involved as an activist for my entire life on a wide range of issues that sequentially have now allowed me to do quite a few things. But they’re all rooted in this experience of hemophilia and I still feel a great bond. I understand—well, let me try to reframe this. I feel I was very fortunate to have extremely intelligent and aggressive parents in coping with this system. And they were, you know, to use a football analogy—they were great blockers who allowed me to pass through what otherwise would have just been, you know, crushing circumstances. And—and I was—but I was very aware, like what

would happen to someone if they didn't have this level of devotion, resources. My parents really had no money. People tend to think—I've learned over the last few years that people believe that if you're a writer and you sell a book you're instantly rich. My father wrote books that took a very, very long time to write for which he was not paid that much. So it was a living but it was certainly not wealth. But they both had gone to Ivy League, or Ivy League-equivalent schools on scholarships. And they had—they were very smart and they used this on my behalf. And—

LG: And how did that lend to your feeling that your political activism was rooted in your hemophilia?

RM: Well, for one thing, I realized that—that—that your success in life, your access to basic forms of care, and here's where I generalize that, whether it's a good doctor or a good home, or even a good job should not be determined by your connections, and that, unless we have a system that is powerfully committed to inclusion and to equity, you are going to end up with a system that distributes benefits according to connections and not according to need or according to fairness. It is a constant struggle in America which image of life is going to predominate. Is it the one where there's a basic sense of justice and basic sense of inclusion and fairness, where people who are not to blame for the things that have happened to them are given access to the resources to survive and to succeed? Or whether it's just really going to be a lottery, that whoever you—wherever you were born and whatever happens to you—you know, some people have crushing things and are simply wiped out. And other people are born to privilege and never have to think about a second thing. The America

that I know and that I love and that I think people admire is the first one, not the second. The second is just a, you know, paper mache version of aristocracy. So—

LG: Justice plays an enormous theme in your life then.

RM: Absolutely. But also, so does grace, which I—you know, from a spiritual standpoint, I mean—

LG: Tell me about that.

RM: But before I do that, there's something I've been meaning to tell you—

LG: Okay.

RM: —which goes back to this thing and where I think there's a positive thing to be—that needs to be said. In the mid-'80s, around the time of the panic around AIDS and the scandalous silence by the president—

LG: President Reagan.

RM: —President Reagan—there was an eruption of fear and people began to tout ideas that were really frightening in their content. I mean, quarantine. People were beginning to suggest that maybe we should find an island off the coast of the—you know, somewhere off of the Atlantic Coast. You know, one of the Carolina islands or something and just put everybody with HIV there. And, you know, having—since America has gone through things like Japanese internment camps and so forth, these ideas were starting to gain currency. And at one point my father got into a ferocious battle with William F. Buckley, who was a classmate or class or two ahead of him at Yale, and who my father basically liked, although didn't agree with his political views. But Buckley wrote a column, which in his typical manner was both serious and sort of tongue in cheek, where he was

suggesting, and he clearly—if the idea had taken off, I think he would have been happy to endorse it, but where he was basically suggesting that people with HIV should be tattooed in order to warn their sexual partners that they were in danger. My father publicly wrote a letter to Buckley, and my father, who's normally a very reasonable man; when he gets angry, he is not. And he basically said, you know, something pretty basic, like, "If anybody tries to tattoo my son or anybody else, I'm going to come over there and tattoo your forehead, you know, with "bigot" or something like that." This produced a back in forth in the—I don't know whether it was in the "New York Times" or where for a while. And it took a number of years for my father and Buckley to get over it. And then they eventually got old enough and rediscovered their friendship. But that—that debate was happening just below the surface. Reagan's silence countenanced in a sense some of that, even though many of the people who were affected were friends of his, or alleged friends of his, this sense of horror about, and the sense that it was a gay plague and God's judgement on—so forth. So America, its—and its constituent communities—but America as a whole had a very important decision to make here, which is whether the response to this was going to be one of fear, isolation, interment, tattooing. And who knows where that would have led? To lynching? And there were enough currents of that going on. Or was it going to be a reaction of acceptance, compassion, engagement and so forth? And I think if you look at the 1980s that's part of the huge battle, was for the soul of the United States and for pockets of the United States, what our approach was going to be to this. I think that one of the things that needs to be highlighted is that the response of the churches,

and particularly the mainstream churches—you know, traditional, but also others—was a little—at first a little tentatively, but then absolutely firmly on the side of compassion. And that movement by the churches, early, and in some sense aggressively, to say, “We will countenance no other response, no other moral response by this nation,” damped down what was otherwise this accelerating community of anxiety and, you know, incipient cruelty. I mean, that’s what was bubbling up.

LG: So this is what you’re speaking to, what good came out of this.

RM: America, I think, made the right choice. And I think the forces of hatred, homophobia, of—of, you know, the people who predicted that this would—that this was a plague brought on by an alien group who need to be isolated and punished—that argument—that framing of it failed, and failed in the broad sense—I mean, sadly, for individual people there were still pockets of bigotry and brutality that continued. And I think we can carry that right up to Matthew Shepherd’s death. And the White family—Ryan White’s family was treated absolutely horribly. I believe his home was burned down. So it’s not something where we want to say we—that America escaped completely. But the weight of decision and public judgment—and I think the public leaders, the actors and actresses, the other public leaders who stepped forward and were willing to identify with people with HIV really helped there. But anyway, all of these things contribute to my emerging [chuckles] political and spiritual views, because that was a moment in time where America could have become something truly horrible and chose not to be, chose to be compassionate. The other thing I want—just want to mention very briefly is that I got a—I had

grown up my whole life with gay friends of the family, because my parents, particularly my mother, very, very—was very involved in the arts. And so I knew lots of gay people and I sort of always knew that they were gay. I never really thought about it very much. But this all brought sort of homosexuality into much higher relief as something to think about. I was also as a pastor at that time. And one thing I will say is that I was awestruck by the love, patience, compassion, commitment demonstrated by many members of the gay community towards other people with HIV. And something that I think—if I'd had any prejudices—I don't know what—but about, you know, about was homosexuality something that could induce a full and rich and committed set of relationships, those completely evaporated as I watched, you know, gay men, particularly, give of themselves to other people through the most painful of circumstances and with—with a strength that I think any human being would be—would be proud and touched to see. I mean, this comes up later, you know, like in movies like “Philadelphia,” where we see these issues are kind of played out. But I—that movie, I think, came out in the early '90s. I saw that behavior well before then. So anyway, I—that's—so already by the time that, you know, I—let's see, I turned 30 in 1986. You know, these issues were all very, very—very, very vivid for me. Now, I should mention that in 1986 I had come—already come to Boston to pursue a doctorate at Harvard Business School, having been a minister and still serving as a minister in a little church near here, and part of my conviction, and this was at the—you know, 1984, '85 was when Reagan was reelected. Reagan was reelected and it was really believed that the market could solve all problems. And so I took on

endless debates in the Harvard Business School MBA program, because I had to do the first year of the MBA on this question. And I remember in one, I think, probably overly melodramatic moment when we were talking about the ability of supply and demand to solve all problems, I remember whipping out my factor VIII out of my briefcase and saying, “Take a good look at this.” You know, “Let’s talk about the cost structure of this. Let’s talk about what people have to do if they can or can’t pay for this.” And it was one of those situations where it was so overwhelming that people just cringed. [chuckles] Nobody would talk to me for a day or two. It’s like, “Oh, man. We don’t want to get into all that stuff.”

LG: But it brought the whole emotional and real piece of individual’s lives into focus.

RM: Well, and that’s something that I feel very strongly that we are called to do. I mean that—that the way most people—I mean, politically and spiritually, the way people address most problems initially is through denial, segregation, avoidance. You know, the resolution of cognitive dissonance so that the unpleasant thing disappears. That is a—that is an understandable response but it is the immature response. It is the response that we permit of children or of teenagers because it’s all too much. But adults are expected to have open eyes and to be able to accept the idea that not everything in the world lines up perfectly with what their ideas of how things ought to be. And so that ability to be—to be able to see and not to have—not to interpret—not to take some overarching system and say, “Well, that’s going to explain or obscure all problems that I encounter.” One of the reasons I’ve been so public about my circumstances is because I feel I have a duty to help people

make the transition from a superficial assessment to a more mature assessment of what's going on, even as they have a duty to help me do it on other issues. So, yeah, and in a sense you can see that that leads me into ministry and into political life and into writing. But what's important for me to say is that when I got into the pulpit I—you know, I never started a sermon saying, "I have hemophilia and, therefore, I can pronounce to you." When I wrote my 800-page book on South Africa, I don't think I ever mentioned that I had this. But my understanding of what can happen when one part of a human community decides that it has to be afraid of and control another community because of their appearance, or because of something they might do to them over the long run, and the grotesque self-justifications that can flow from that that are then accepted by others as real, when in fact they are—they are nothing but—nothing but excuses and tyranny. My experiences fueled all of my research and my awareness that that—that those things are not far away from us. I mean, even taking things like what happened in the Second World War in the treatment of Jews in—by the Nazis, one of the things that's always sort of horrified me is our sense that, "Gee, that was an incredibly awful, terrible thing, but it was such an isolated thing. Those Nazis were really bad and it was a special situation." And of course it was a special situation in its uniqueness and its vastness. But the notion that those Germans or those situations are somehow held in time and can be walled off from all other people and all other experience, that's dangerous. The truer reality for me is that we're all about two steps away from doing that again. And it is only by being very vigilant in our compassion that we avoid sliding right back down

that track, as we almost did with HIV and as I fear we're doing now on a whole range of other things.

LG: Bob, tell me about grace. What does that mean to you?

RM: Well, I wish I could give you a short answer about that. It is a way of being that has touched me very greatly and forms one of the guiding questions and principles of my life. And so I don't think that I will ever understand it completely. But what it means is that we tend to live in a world in which we react to each other through complicated systems of approval. And the more you respond and do the things that we approve of, the more we like you. And the less you do, the more we dislike you. And all of our lives are built on this, conditionality, school is built on this and job performances are built on this. And social hierarchies are built on this and politics is built on this. And so it's a sense that your value as a human being and your capacity to love and be loved is determined by a measurement against some outside standard, and often multiple outside standards, including your relationship to the eternal and to the Creator God, and to the universe that we live in. What's interesting is how many people who have quite profound religious feelings and training still feel this too. Most people think of basic Christianity in these terms: if you're a good person you'll go to heaven and if you're a bad person you won't. And if you're a good person then good things will happen to you. And then if you look around at all the people bad things are happening to, you must think, 'Well, they must have done something wrong.' And that's very explicit in the Bible and particularly in the book of Job where all these terrible things happen to Job. And his friends come around and they imagine they're trying to help him by pushing him to

wrack his brains to identify exactly what it was he did wrong that led to all of this punishment.

LG: Did you go through that, having gotten all these chronic illnesses?

RM: Well, I think I was exposed from a very early age to something, I think, about as close to unconditional love as you can get in this life from other people. My parents had lots of challenges in front of them and I, as an adult, certainly see some of the limitations that they had in themselves to cope with and in each other, but they loved me unquestioningly. Their support for me was so overwhelming that in the moments that I was the most exposed or in pain or in danger I never doubted them. In the many things that I had to fear, the one thing I didn't have to fear was the withdrawal of their love. And I think that set up a core set of convictions about the power of love and about my own self-worth, which—which gave me—which was an essential ingredient. You know, these are in some sense mysterious, but which was an essential ingredient in everything I was able to do and be afterwards and—

LG: Was this a core piece of your spirituality? Does this tie into it at all?

RM: Absolutely. In fact—

LG: Tell me what you mean.

RM: Well, as I mentioned briefly, there's kind of a popular shorthand for what religion means, and particularly for various forms of Christianity meaning, which is "do good, get reward; do bad, get punished." The core idea that really captured me, that I'd always kind of sensed, but really, in my view is at the heart of a Christian gospel and I think is also part of many other traditions, but for me as a Christian it's absolutely at the heart of my faith—is the idea that ultimately our

relationship with God has nothing to do with our performance. It has to do with simply God's desire to love God's created beings, God's children. And there are many passages in the New Testament which basically—and also many passages in the gospels, in the life of Jesus, in Jesus' own words where the emphasis is on love over and above and without regard to performance. I'm thinking of doing some writing about this at some point. A simple example is the parable of the Good Samaritan. Jesus is asked, "What are the greatest commandments?" He asks the person, "Well, what do you think?" And that person says, "To love the Lord your God with all your heart and soul and mind and strength, and to love your neighbor as yourself." Jesus says, "That's right." The person then, as it says in the Scripture, "seeking to justify himself" says, "Oh, yeah. Okay. But who's my neighbor? Exactly who does this apply to?" And then Jesus tells this story about a man beaten and left by the side of the road and then three people who go by. The first one is a priest—that is, someone who one would expect would recognize—this is all told in the Jewish context—would recognize this person and would stop and not let—go on. Next is a Levite. This is a person who also would be understood to have special duties to fulfill the laws of compassion. The third person to go by is a Samaritan with whom there were fundamental religious disputes. Samaritans deny the authority of the temple, thought you should worship God somewhere else.

[end of side 1, tape 1]

RM: So what's so interesting about this is that Jesus does not ever actually lecture this guy. His interchanges consist primarily of these questions, so at the end of the story Jesus asks, "Who proved neighbor to the man by the side of the road?" And the person who was inquiring says, "The one who showed him mercy." And Jesus says, "Go and do likewise." The point is that the lawyer was looking for some definitional mechanism, which would allow him to apply his compassion to one group but not to another. And yet, in constructing this story the way he did, the lawyer himself concludes that the boundaries of compassion are limitless. Another story, which I won't go through the whole thing of, but is the prodigal son, where if there were ever a person who deserves to be punished in some sense, it's this young man who goes and takes half of his father's inheritance and completely squanders it on wine and women and comes back. And even he recognizes that he has completely blown it and his aspiration is to be hired as a servant, at least to get a job as a servant since he knows that he's no longer qualified to be honored as a son. And he, instead, is received as a long lost this son and they kill the fatted calf and they have a great party. One of the pieces I love about that story most is that it doesn't end there. It's not just about the nice father welcoming his son back, the other son, the older son has been very dutiful, comes back in and hears the party, and says, "What is going on?" He calls the servant out and says, "What's going on?" He says, "Oh, great news! Your brother's back after all these years and your father's killed the fatted calf." And the older brother makes his father come out to see him. [chuckles] And he says, "This jerk took half your money, went and spent it and now you're having a party." And

it actually says in scripture in a way which—one of the things I love about—he says, “You’re giving him a party, which you never did for me and my friends.” [laughs] “And it’s not fair.” And the father’s response is, “You have always been with me. Everything that I have is yours. Of course I love you. But our brother—your brother was lost and now he’s found. He was dead and now he’s alive.”

So what I take away from that is—and one of the key dynamics in that story is that the person who’s having the biggest problem with forgiveness is the older brother, who feels that the structure of correctness should dominate. You know, it’s like, “Yeah, he’s been dead. We didn’t know where he was. But what’s important is that he shouldn’t get a party, not that he’s back. That’s one of the things that has affected me tremendously. I feel we are constantly being drawn into these systems that make us disproportionately small and fascinated with how much better we are than somebody else. These systems deny to us the community of compassion in which we recognize that in our failure and weakness, which is universal, we are able to love and care for each other instead of being preoccupied with, “I’m a little bit better than you. I have a little bit more stuff than you and God’s going to like me better because I’ve been—you know, I’ve been a better student of life and I’ve got more gold stars.” I mean, that’s just—that’s antithetical to what Jesus is trying to describe. And so that—and what is it that disrupts and heals this passion, this obsession with hierarchy is grace. It’s the idea that, ultimately, we are all recipients of and deserving of an unbounded love that is not tied to what we manage to do and that will not be withdrawn if we through

our humanity end up doing something absurd and stupid, which is what humans do constantly.

LG: Do you think having hemophilia—it sounds like the unconditional love that you spoke so poignantly about had a huge effect on your life. But also, what about these challenges of having hemophilia since you've been a child, pain since you've been a child? We've talked a lot about how hard that was in many ways. Do you have any sense that there were good things that came out of these challenges?

RM: Well, let me—it's funny. I thought your question was going in a slightly different direction. So let me answer the question I thought you were going to ask and then I'll—

LG: Okay, and what was the question you thought I was going to ask?

RM: Well, the question I thought you were going to ask is, how—you know, what is this feeling of grace somehow tied to—or in some sense, how could it be tied to, since you have been the unwilling recipient of so much difficulty? And I think that I am very, very keenly aware on a daily basis of how, yes, I have some troubles. But relative to many people who have lived through the eons of human generations or living now—I mean, I am [chuckles] fortunate. You know, I am a great creature of comfort and privilege. I was in India a number of years ago and I was taking a taxi from the airport to the hotel where I was going to be chair of a big set of meetings. We stopped at a red light at one point. And I noticed a little girl, a very small little girl, maybe three years old—four years old, sitting in the gutter and, you know, obviously completely destitute. And what really was a bolt through my heart was that she had another little girl who was smaller, two years old, maybe 18 months old with her head

in her lap. And she was stroking the hair of this girl who was trying to sleep with the cars zooming by and so forth. And I thought—you know, and that’s a particularly vivid and disturbing image. But I could tell you thousands of things that I have observed. When I used to not be able to walk and my highest aspiration of my whole life was that I would be able to walk again, and now I can walk. And [chuckles] I don’t want to be one of these people who say, “Well, thank you. And now that I’ve got the highest aspiration of my whole life, now I have a new list of highest aspirations of my whole life.” Well, of course you do. That’s what human beings do. You know, say, “Thanks very much,” and move on. But even as I move on, I need to remember [chuckles] that I got the highest aspiration in my life. And that’s true also when I look at my children, when I look at the educational opportunities I’ve had, you know, just on and on and on. So that’s the question I thought you were going to ask. I don’t condemn people who feel terribly burdened by what has happened to them. I mean, it’s an understandable human response. I think that as long as people remain in that place where they’re focused on all that has been taken away from them, this image in their head of the way life should have been and they’ve been denied that, and that that source—is a source of pain and anger, frustration and so forth, and basically defined as an injustice that can only be rectified. I think you are putting yourself in a position where you can never be happy. And so I understand how people find themselves in that place. I have certainly been there sometimes but I think spiritual growth is about moving away from these pictures in our head about what we deserve, what we’ve earned, what we ought to have and what is fair, which is

what governs most of our thinking, into what we actually have, what is happening right in front of us, and all of these things that we take for granted but then that are unbelievable gifts. Not just unbelievable gifts and opportunities to start with to the ability to draw a breath and live [chuckles] is an unbelievable gift.

LG: What I was trying to get at before is people perceive hardships sometimes as just that, just hardship.

RM: Yeah.

LG: And my question, I guess, is, do you feel anything positive can come out of hardship?

RM: I think I do. I don't say that lightly. I know that some people say, "Oh, you know, I'm stronger for the experience." That's certainly not a reason ever to wish anything on anyone. But I think that going through hard things ideally, and in many cases, can make you more compassionate because you understand the suffering of others. You know, one—

LG: Do you feel it's made you more compassionate?

RM: Oh, there's no question about it. You know, I sometimes think, 'What kind of person would I have been if I hadn't had hemophilia? Some things probably would have been very much the same, the energy and enthusiasm and curiosity and so forth. But I think the arrogance would have been much greater. That's not to say I'm without arrogance now. But, you know, the image I have in my head is, you know, I might have wanted to become a fighter pilot and an astronaut and a hotshot, you know. And, you know, that would have been fun to go zooming around and be a tough guy and so forth. But—and—but, you know, what I realized, that I so easily could have

been a straight, white, privileged male in the dominant country of its era in some position of great authority and wealth, and that I could have achieved all of those things. And my predominant response to them could have been, “I did it. Why couldn’t anybody else?”

And one of the mysteries that the Bible talks about quite a lot is, how is it that good fortune produces hardness of heart? It doesn’t always but, you know, you would think that the more good things happen to people, the more they would be humble and generous. In fact, when you look out very often, the more good things happen to people, the more judgmental they are of people to whom bad things have happened, and the more tightly they control what they have. Now, that’s a response that’s kind of mysterious to me. Now, in political terms, and when I was running for office I would say, and still believe this and if I ever go back out into more public debate—I would say, I mean, “I think it is totally unacceptable to have a system in which not only do we have widespread poverty and disease, but that we blame the poverty on the poor and we blame the suffering and the disability on the diseased, as though we still have this early Biblical mentality that, if you are having so much trouble, it must be because of something you did wrong. Now, of course people make mistakes and can intensify their own problems. And I absolutely, as I think I’ve made clear, believe that one needs to mobilize one’s own sense of responsibility and agency and move out of victimhood and into strength. But one of the ways you do that is by—that people give you resources and affirm that you can do it. But we live in a culture now which basically says, “If you’re sick it’s your own damn problem,

probably your own fault. And if you're poor and you stay poor, it's because you're not working hard enough." And I find that backward, offensive, statistically and morally wrong.

LG: Let me move this more around hemophilia, because what you're saying is when things happen it's important to mobilize. If you were to speak to a family who just found out they had a child with hemophilia, what advice would you have for them, if any, or if your daughter one day down the road had a child with hemophilia? What would you say to them?

RM: Well, I think—actually learned this morning about someone who's a member of our congregation who has just discovered—this is kind of a distant connection, but through the—that a grandchild of theirs has hemophilia. My pastor was asking me what I thought about that. I think in the first instance when you're talking to a family who's experiencing that, the first piece is to help them grieve, because we go through life by building up these elaborate senses of what the future is going to be like and how we're going to get there and how we deserve that to—I mean, as I say, my wife and I used the term of “pictures in the head.” And losing the pictures in the head is—and the sense of the narrative of your life—my life began here and then here, and I get married and I have children. My children are going to grow up in such and such a way. And losing the thread of that narrative is very painful. In fact, one Catholic writer defines that as the essence of suffering. Pain is one thing but suffering is the loss of a narrative that gives your life meaning. And he applies that, I think, very effectively to talk about people who have—are trying to recover from war-torn situations where their entire life structure has been eliminated and

they have to try to reconstruct some order and some image of the future that's radically different from what they original had.

So I think the first thing is helping people, you know, step through the sorrow about that whatever it was that they imagined may not happen. That's also a part of growing up. The second piece is many more things—but you're not going to lose everything. I mean, many of the things that right now you may think are going to be gone for good are in fact probably still going to be able to be—to happen. I mean, and then you start able to—you start being able to say things like, “And the care is so much better,” and, you know, “A child can achieve autonomy.” And, you know, so the things that one longs for in a child, which is sort of to free the child from suffering, and to enable that child to grow into a full and happy and sort of free individual, those are all still possible for both the child and for you as a parent. Then sort of getting past that—so you don't have to—you're not giving up everything. Many, many things that can happen will happen. And then the third thing I would say is—or do is really focus on the—this cushion of unconditional love. And that—that, the greatest tool that you can give to a child—I think any child but especially one who's coping with a chronic illness and potentially facing lots of added-on judgments and trials by—from others is the sense that, you know, you're in there for them no matter what and that if—and that doesn't mean you have to be perfect or that you have to always be, you know, loving. You can be strong and you can provide guidance on proper behavior and discipline when necessary. But the core idea is that we don't love you any less because of what you're

going through. And there's nothing that you can do that's going to break that bond. I think if—you know, if parents can internalize that—if they can hear that, then I guess the final thing is being willing, and so many parents are, so it's really unnecessary advice in many cases—but just being willing to mobilize the resources that are out there, and to recognize that one is not lost in some isolation, but there's a community of people who have the experience, who have resources who are willing to help you out, and that—and that the only thing really that will deny you access to that is your own decision to remain isolated. But if you remain frightened and withdrawn, then you are cutting off the ability of so many others to provide you with what you need. So I think isolation is a danger in all kinds of issues of suffering. As a pastor, I've seen that in many, many, many different settings. I mean, including, you know, just come through difficult challenge with this senior friend who lives across the street. But I think that's what I would say, although I would really wait to be invited to say something [chuckles] because I think lots of free advice offered without invitation isn't always the best thing.

LG: Bob, we've really covered many of the subjects that I wanted to cover today. Is there something that I haven't asked you that you want to include in this oral history?

RM: I think there may be two things that come to mind. One is that for all of this talk about acceptance and so forth, this was—and I've alluded to it before—it was a great trial when I was divorced because what essentially happened—I mean, to boil it all down—is that the person that I trusted to love me unconditionally and forever—my expectation, picture in my head—suddenly announced that she didn't. And not

only did she not love me but she didn't even like me very much, and that for her own well-being I needed to leave her life. That experience was far more destructive than any of the physical suffering that I had because, in line with what we were talking about, I had a narrative, a story about my life that included fidelity to my wife, who I admired and loved, who was different from what I was but not in ways that I thought were anything but interesting. And then suddenly that was entirely shattered. And I think there was a real question in my mind for awhile, as to whether I could make sense of all that and find love again. I did and I have an incredible wife, Anne, who had been a friend of mine before and had not married. And Anne is—understands me better. And I think I have achieved a level of peace and safety in my relationship to her that exceeded anything I had with Dana. So I guess I raise this because I think that, as a word of hope to—because I don't think—no matter how hard we work, I don't think we can guarantee that our human relationships are all going to work out. And people marry for a lot of reasons. And people, you know, agree to get married for a lot of reasons. And, you know, not all of those things survive the—all the different demands. In our case, the appearance of HIV just put so much new stress on what perhaps wasn't the strongest relationship anyway. I think that my experience was of a kind of a death but followed by a kind of resurrection into a new life of love and comfort and mutual support. The second thing I want to say is that you haven't asked me very much about having children—I mean about being a father.

LG: Let me ask you about that then.

RM: Well, I would just say that I love being a father. I don't pretend to understand how my children have internalized or made sense of all of the medical problems that I face. I mean, in one sense, I'm candid about them and they're part of our daily life. They've seen me have shots. They know when I have a bandage on my arm—they know this. You know, we sat down and talked to them about hepatitis and my daughter—the way my daughter, Kate, who's six, raises this is that she has divided her life in—her engagement with me into things that she can do with me now, and things that she will be able to do with me after my operation. She likes to roughhouse and—

LG: Your operation, meaning—

RM: Meaning a liver transplant. We—but we've said, you know, I'm going to get this big operation at some point and then I should be healthier. And—and so Kate has sort of classified—and that's helpful for her because, you know, she realizes, "Okay, certain things I can't do but we hope that I will be able to do—most of these have to do with energy. I just have so little energy. I don't know what kind of parenting lessons my sons will have taken away. Of course, you worry when you've gone through divorce that that's a very dangerous thing to be leaving them with. But Dana and I have managed to live a few blocks apart from each other and continue to parent the children together. And I think that's worked out so I think Anne has played a role in all of that. And so I think that worked out far better than my early fears. But thinking about being a parent—I mean, one of the ways we actually joke about this, my son, John, is incredibly into sports. And, of course, I have virtually no experience playing sports. But we tease about this. The little fiction we have going is that I in

fact was a great sports hero, that I won the Heisman Trophy, that I was, you know, drafted for the NBA and I had to pick between that and my stellar baseball career. So John will say things [chuckles] like—we'll be watching the Celtics and he said—you know, some old player—and he'll say, "Oh, you must remember him from your days, Dad." And I said, "Yes, I taught him everything he knows." And, you know, we joke about that and it's quite funny as a running joke, both of us imagining me as a running back or as a shortstop or things like that. It's fun for me to think about it; it's fun for him to think about it. And we both know that's there a sort of little wry sadness in it but it's also—means that we can embrace it. And there's a third thing that I just want to mention, which is that right now, even as we're talking, I'm going through a most amazing experience—one of the most amazing experiences of my life, because for me to have a new life, restored energy and, you know—and [chuckles] possibly literally curing my hemophilia, I need to go through a liver transplant from a living donor. And for many months, we've been talking about this and a few months ago we sent out a letter to a close circle of family members and a few friends. And we were disappointed to find out that the most likely candidates, who are three cousins of mine, big, strapping young men in their 30s—early 30s, who—when my aunt heard about this she said, "Oh, one of my sons will do it." And every one of them said, "Oh, we'll do it. We'll just draw straws." Well, they're all the wrong blood type. So that was disappointing. But just in the last 10 days or so, we released a new version of this letter to the members of our church. And I'm just awestruck that seven or eight of them have stepped forward and said, "We want to be tested. We want

to be”—I haven’t even sent it to my friends through my environmental work, my former students, my wider circle of college friends. I mean from just this one community, we have seven or eight people who are going to go meet with the doctor. And from that pool, perhaps, will emerge a donor and so, you know, I think about this a lot in spiritual terms. One of the things is Jesus says—phrased in the old—the old King James way is, “Greater love hath no man than this that a man would lay down his life for a friend.” That’s rather male language, but the central idea that somebody would lay their life down, or put it at risk on behalf of someone else, is an act of generosity and grace that is incredible. And I may end up being the recipient of that, sometime even in the next year, and then may be able to go on—you know, the pictures in my head are a little fuzzy right now as to what the future represents. But I may be able to go on to new things—unimaginable things right now. And so how do you take—when you start with that you were the recipient of this great love and support from your parents, imperfect beings, though they were—that you’ve been a recipient through your whole life of the best that a medical system could offer, even though sometimes you had to yank it out of them, that I have been graced with many things that many otherwise healthy people have not had the chance to have, for whatever reason. You know, for three children and, you know, an interesting career. And now, I have survived HIV for reasons that are absolutely also unclear. I have had HIV for 26 years. For more than half my life—I’m only 48- and I’m still here drawing breath and enjoying my life. And now you add to that that somebody may give up a portion of their own liver in order to give me an extended life and

to free me permanently from hemophilia. That's just an amazing story. And what kind of life should flow from that? It seems to me somehow a life of great rejoicing and great generosity. I don't know how exactly—and a life—and a—and a—you know, if I had the time and energy to move forward, what I would want to be able to do is give people hope, because what we live in is a world where people try to steal or crush each other's hope all the time, and to suggest that whatever world we're in is the world we're going to be trapped in, or one that's worse. And for me, even through all of these difficult things, I have had this opportunity to go into worlds that are better. And I think we can do that as a community too. And the other thing is, even if I—even if this all ends, you know, not really that well—I mean, let's say I don't get a transplant, or I get it and it doesn't work, I'm not—I'm really not at all afraid of the future because, you know, I just feel my life has been so unbelievably rich, even with all the challenges, right up and through now. None of that can be taken away. It's all part of who I am and what I've been able to do and who I've been able to love and care about and so that's all—that's all been completed. It exists already in its fullness. So we're talking about adding to that.

LG: Thank you.

RM: Thank you.

End of Interview #2