

Interview with Wendell Bourne for the Boston Hemophilia Center Oral History Project, A Gift of Experience, by Laura Gray, July 29, 2004.

GRAY: This is Laura Gray. I'm interviewing Wendell Bourne for the oral history project, A Gift of Experience. It is Thursday, July 29th, and let us begin.

BOURNE: Okay, how you doing, Laura?

LG: I'm okay, Wendell. We'll see if we can get this going. So let me start by thanking you, number one, for agreeing to do this, and what I'm interested in, Wendell, is sort of getting an idea of where you grew up. Can you give me a little bit of a sense of where you grew up and who you grew up with?

WB: Well, let me first say that I'm excited to do this, and really, it's an opportunity to do this.

I grew up in Cambridge, Mass, in the Fresh Pond area of Cambridge. Belmont/Fresh Pond area. They called it North Cambridge, just above Harvard Square. I grew up in my first five years in the Central Square area, and then when I was about five years old, we moved to this house on Walden Street in Cambridge.

LG: Who did you grow up with? Who was in your family?

WB: My mom and my dad, and then I had two younger sisters. One about a year and a half younger than me, and another one about three years younger than me. I was born in '48 and my sister Gloria was born in '50 and Jeannette was born in '52.

LG: So that makes you how old today?

WB: I always have to think for a second. I will be fifty-six this year. I'm fifty-five and a half. I'll be fifty-six in December, the 25th of December of this year.

LG: And when did you first find out about hemophilia? Was it you?
Was it someone in your family?

WB: Well, as the story goes, my mom said when I was really young, you know, toddling and starting to walk around the house, they really didn't have any idea. She said that they noticed a couple of little bruises, but it really wasn't something that concerned them at first. It was when I was about eighteen months old. I fell in my explorations around the house and hit my mouth. As she describes, it, I broke that little piece of skin just behind your upper lip and it started to bleed, so naturally, they put ice and pressure on it but it didn't stop and that's what sent them to the hospital. The doctors had some problems stopping the bleeding, too. They ran some tests on the blood and that's when it was discovered.

LG: And had there been anybody else in the family who had had hemophilia?

WB: We cannot trace anyone else in our family, on either side, but particularly on my mom's side, who we can determine had hemophilia. Now, that's not to say that there may not have been, because my mom grew up in South Carolina. Her father and mother owned a hundred and sixty-eight acre farm. He was a farmer and a preacher. There were five girls and two boys in the family. When my grandmother's family and my grandfather's family came together this is a huge amount of people. Of course, they're growing up in the country during the early part of the twentieth century and so if there had been someone else who may have lived a portion of his life and died, no one knew, nor was it determined. Of course, you have to understand that healthcare in

the south for African Americans at that time was probably such that it was not likely for something like that to be caught, discovered and treated in the early 1900s, or the late 1800s. If that might have been when someone in the family, one of my ancestors may have had it; we don't know.

LG: You just don't know.

WB: Don't know.

LG: And none of your cousins? Your mother had no sisters or—

WB: She had. My grandfather was married twice. His first wife died, and then he married a second wife, and my mom was the child of the second wife, along with her two brothers. But no trace there, and her four half-sisters from her mom's first marriage, nothing.

LG: So tell me about your parents a little bit.

WB: Well—

LG: What did they do? What were they like?

WB: Well, as I said, my mom was born in South Carolina. My dad was born here in Boston. In Cambridge, actually. He grew up in Cambridge. His parents came from Barbados sometime at the turn of the century. I tried to do a little genealogical investigation and then got so far and just haven't gotten a chance to get back to it, but from what I can determine, they came in the early part of the 1900s from Barbados, and settled in Cambridge. My dad was an electrician and he worked in the Charlestown Navy Yard in the 1940s during the war, you know, working on the naval ships that were going out of Charlestown to the war. And they met, I think, just after the war because I think my mom came up here—well,

she might have come up actually during the latter days of the war, '45-46.

She came up as a young woman. She had to be in her twenties, I guess looking to get away from the farm. She had relatives here. They were folks from my mom's family in the south that had come up to Boston at various times and had settled here. She had cousins here, aunts, and so on. Some of my grandfather's brothers had come north. So she had family up here, so that's what I guess brought her directly to Boston. Then she and my dad met and married in 1947, and settled in Cambridge.

Now, my mom, she was a teacher when she left South Carolina. She had taught down there, and I don't think she did any more teaching once she came up here. She worked for a while with a relative doing sewing, as many women did because the men were "off to war," so-to-speak. When she married my dad, she became a homemaker and a house mom, and what have you. So she didn't work anymore in teaching.

LG: When I asked you about the hemophilia initially, you told me that, "Well, my mom told me this. This is what she related to me."

Was she the primary sort of caretaker and manager of the kids and the hemophilia, in particular?

WB: Yes, that's I think both in my memory and I think the fact. My mom and dad broke up when I was ten. They separated and ironically, they never really moved that far from each other. My mom and my sister's and I left the house where we were growing up, a two-family house. The family had lived on the first floor, my mom, dad, my sisters and I. My grandmother, my father's mother,

lived upstairs. My grandfather, my dad's father, had died either before I was born or when I was very young because I never knew him, never remembered him. Didn't know him.

So my mom and sisters and I moved out of that first floor apartment, down the street about a block away to another apartment. That's where we kind of spent our teenage years and so-forth, until we all went away to college and out into the world. My dad continued to live down the street in the house. His mom lived upstairs until she died, and then he had a sister, Lillian, that lived there. She still lives in the house. He has two other sisters, Lucille and Mildred. Aunt Mildred has passed away and Aunt Lucille still lives in Cambridge. My father had one brother, Gordon, who lives in Denver, Colorado and he was career Army. Retired now, but I can remember Uncle Gordon and his wife, Thelma, who's passed, and my cousins Jenny and the late Gordon, Junior, because they'd visit. Uncle Gordon was stationed in Germany and they'd come through to visit.

I had some other cousins, Debbie and Marcia, my Aunt Lucille's children. You asked me about my mom and the management of the hemophilia. She was naturally, from the age of ten, the person that I related to because, for whatever reason, my dad, once they separated, he really never had anything to do with us. It was really by choice, I think, because my mom never really said anything bad about my dad. Whatever the problem was between them, she didn't project it down on us, and he never came by. He never rang the bell and said, "Can I come and get the kids? Take the kids out," or anything. He was around, but we just

didn't—as close as he lived, we never really saw him. He never was really involved.

LG: Before he left, was he involved? Do you remember at all with you or your sisters, or do you have any memories about him talking to you about the hemophilia? Or what was he like? No.

WB: No. My sense is that for whatever reasons, my dad wasn't able to deal with it and that might have been his way of distancing himself from it.

LG: Why do you say that?

WB: Because I don't remember any conversations, encounters, connections with my dad and hemophilia. In the early days when I was really young and they were taking me to the hospital after the discovery, you know, in my first eight-nine years of life, from the time they discovered it until he left, I do remember both of them taking me to the hospital. But most of my memories of in and out of the hospital in later years are just of my mom.

LG: Okay. Tell me about the hospital. What do you remember? Were you there much?

WB: Yeah.

LG: First of all, what level of severity? Do you have Factor-8 deficiency?

WB: Severe, factor VIII.

LG: Severe.

WB: Severe, classical A hemophilia, yeah.

LG: Okay.

WB: Oh, yeah, I remember the hospital very well.

LG: You do?

WB: The Children's Hospital was like a second home.

LG: Really?

WB: Uh-hmm.

LG: Children's Hospital in Boston?

WB: That's right, Children's Hospital in Boston, before they redid it. [laughs] I remember going in the Blackfan Street entrance. Not the big one that's there now, but a side one.

LG: You were saying the hospital was like a second home.

WB: Yes.

LG: And that you remembered.

WB: A second home, and we used to come in the Blackfan Street entrance and the 300 Longwood Avenue entrance was open at that time. It's not open anymore. But, yes, I remember coming into Emergency. We came in so often that a lot of the nurses and aides in there knew who we were, and my name. In fact, my mom knew these folks twenty, thirty years later. There was one woman that worked in there who, when I went in one day as an adult saw me and she recognized me and she asked about my mom. You know, so it was—we spent a lot of time in there. A lot of time.

LG: How much time do you think you spent? I mean, what do you remember?

WB: Well, I think after it was discovered—

LG: And you were young. You were a toddler.

WB: Yeah, and you know, I guess I remember probably starting at age, about maybe four or five.

LG: That young.

WB: When I started going, because I was going in for a lot of things—my biggest, my focus joint, if you will, was my left knee. That's the joint that gave me the most trouble. So I remember going in for knee bleeds, sometimes ankle bleeds. I'd swell up very fast, and see, there was no—there was no home medication at all, so when I was getting a bleed, it was a case of, you know, I banged it or whatever I did to it, and it would start to bleed and it would swell up very fast and it would get painful very fast, and then mom had to get me to the hospital. Or mom and dad when I was younger. It was in the car and it was driving down to the hospital and so-forth. Oftentimes, by the time I got there, it was like killing. It was big, you know, orange size, you know, as a little kid. I remember one of the treatments they used to have for that was an aspiration. I remember getting my knee aspirated a number, number of times. They would aspirate the fluid off of it. At the same time, the treatment at the time was fresh frozen blood plasma.

Fresh frozen blood plasma. They matched my type. My type is B+. We would be in the emergency room for hours, as several of the plastic bags, thawed out plastic bags of fresh frozen blood plasma, were dripped in at a safe rate, so as not to cause reactions and things like that. I had a few "hive" reactions when I was little to some of this material. But then, you know, once you got it in, you had to then wait for it to start for the bleeding to recede and you have to keep a five-year-old quiet. The other process was to put a splint on it. So I had lots of casts, particularly casts that were cut in half and with straps on them, so you could

take them off as the swelling went down. So my leg was in casts for a long time. I was on crutches a lot for that and other joints and other things. Anything I whacked or banged or whatever sent me in.

Sometimes it resulted in a couple of days up on the ward, as they watched it and nursed it back to health. Then they'd take me home and I had some periods where I had home schooling because I was recuperating from a bleed or something. So the home school thing, you know, was something my mom dealt with, you know, talking to teachers, talking to principals, getting my work sent home. I did a lot of my school work at home. As I got older I went to school on crutches in times. It was well enough to go back to school, I would end up going on crutches and there's that whole, you know, kids get out of your way and kind of giving you all this, "Can we help?" and so forth and so, I got known as the—I guess in kind of vernacular terms—the sickly boy that was always on crutches.

At the same time, I don't remember it dampening my spirit or my sense of adventure or my wanting to do different things. My mom always encouraged me to do different things and arranged different things for me short of organized sports. Naturally I couldn't play any sports in school. I was excused from gym a lot of the time. I don't remember a real active physical education experience in school because if I was relatively healthy, they were afraid that something would happen to me. So I wasn't even tried out for anything. I would sometimes go to gym class. I remember seeing the other kids playing. If I was on crutches or whatever, I

didn't even have to go down to gym. I stayed in the room and read a book or did something else.

But at the same time, my mom got me involved in Cub Scouts and church activities. We were very involved in our church. Still are. She sent me, as I got older into my adolescent years, off to Camp Caravan. I don't know if it still exists. It was in South Royalston, Massachusetts. It was a camp for kids with disabilities and different kinds of things, everything from polio to anything. We had kids with—gosh, I'm blanking. Kids who have epilepsy. All kinds of things. So you had kids in wheelchairs, kids on crutches, kids with braces, kids who looked normal, but had other things going on.

LG: What was that like for you?

WB: Oh, that was a ball.

LG: It was a ball?

WB: I had such a good time at Camp Caravan.

LG: So you weren't put off by kids who have problems different from your own?

WB: No, not at all. No. No, I wasn't put off by kids who had problems. I wasn't put off by kids who didn't have any problems. I'm the quintessential extrovert in terms of people and wanting to be around and then getting involved and stuff. So Camp Caravan was a great experience to me. I remember going to Camp Caravan on crutches and in wheelchairs and going to Camp Caravan and being able to walk around, over a period of I don't know how many years, but whatever I guess the maximum number of years until you were too old to go, which had to be at least three seasons,

maybe more. I even was elected Mayor of Camp Caravan one year. I had my first little girlfriend. She gave me a kiss in the woods. [chuckles] So it was like, these are things that you don't forget.

LG: Uh-huh. Absolutely.

WB: So, that was great. My mother always allowed me to experience things, but at the same time she was very protective. If you went into our home back then sharp corners would have had taped little pads taped on them. Sharp objects or anything I could have bumped myself on would have been pushed aside and she was very conscious about it, even today. Even today. [laughs] I'd be in my own house and I walk by something and I tap against something, Mom would say "You okay?" She still asks—"Hit yourself?" "Yeah, mom, it's okay." She'd say, "You better put some ice on that."

LG: Really?

WB: So—

LG: What's that like, even today?

WB: Well, sometimes it's a little bit of a pain, but I understand from where she came and where she's coming from.

LG: So her attitude was what toward the hemophilia? What was it like growing up with your mom as your caretaker? How did her attitude affect you, do you think?

WB: I think her attitude was, "We've got this issue. We want to err on the side of caution, but at the same time, I don't want this to become a psychological impediment or crutch to my son about what he can or cannot do." Certainly in the realm of physical

activity there are limitations, but beyond that, anything is possible. So she was then and continues to be—as my wife and I are—advocates. Number one advocates of education in the family, and she pushed all of us to do well in school. She was a very active participant in the school community, you know, in PTA and all that. She was a den mother of the Cub Scouts and all of that, and she always told all of us we could do or be anything we wanted to be.

And so I think that part is what stuck with me and stuck with my sisters in that we all went to school, graduated high school and went to college and, you know, embarked on careers and families of our own and so-forth. Then we have instilled those same things in our kids and have seen them, so far, thank God, do the same thing. You know, all of our kids have done the same thing.

LG: So what I'm hearing is, as you were growing up, you were in a lot of pain a lot of the time and your life was disrupted periodically with crutches, or wheelchairs, or hospitalizations. Were you a depressed kid? Did it upset you? Did you resent it? What did you make of this? Was it a big part of your life?

WB: I guess I eventually said, "Well, this is just me," and it's kind of like—it's kind of like my birthday. Now you're saying, "What are you talking about?" Well, I was born on Christmas, so people always ask me, "You must get gyped. I mean, you get one present and you don't have a birthday." And I would say, "Well, I guess. I don't know." My mom would give me two presents and other people in the family would say Happy Birthday and then Merry Christmas. But, I said, "I never had a birthday any other

time, so how the heck would I know what it was like to have a birthday other than that?” So that was me. That’s when my birthday was. That’s the way it’s always been and so I guess I treated the hemophilia the same way. This was part of me.

I didn’t see it as something that had to go away—keep me from doing what I wanted to do, except I was a diehard basketball fan from the old days of the Celtics. Bob Cousy, Bill Russell days and I would have loved to have played ball. I didn’t. I couldn’t play any kind of organized sports. Did I go down the park when I felt good and play playground ball with the kids whenever I got a chance? Yeah. Did I get whacked around and hurt and have to come home and take medicine? Yeah, but I kind of tried to learn my limits. Sometimes I just couldn’t resist it. I’d get in there, and street ball is nothing to play around with. You’re going to get an elbow, you’re going to get whacked down. You’re going to fall. I did all of that stuff.

I remember I rode a bike. Even with some limitations in the range of motion in my left knee because of all of the problems, I rode a bike. I used to have to take my left foot off the pedal when it reached the top, put it back on. So watching me ride a bike must have been really funny because it was over, and off, and then on, and then off. But I could whip that racing bike around the block. I remember taking a terrible spill on Concord Avenue and it was a good thing a car wasn’t coming behind me. Bent the handle bars. Went home, a scratch on my face and my mother said, “What happened?” “Well, I fell off my bike.” I had to take some factor. I don’t remember whether we had home treatment or not. I think we

did because I would have had to go in to the hospital for something like that. [phone rings]

Home treatment—I think I was an adult and out of the house before that began. My mom never did home infusion. She knows I home treat now, but she doesn't remember that in her experience with hemophilia at all. That's something I think began after I went away to college and I was doing these things more on my own. But anyway, I tried these things, but I knew I'd never be a professional athlete, and I never aspired to do that—I'd never be able to play professional football or anything like that. Although, I was playing football in my own front yard when I broke my leg at age twelve. I was in the seventh grade, and it wasn't by getting tackled. It was my mom calling us for dinner. I was in the front yard with two or three other friends, a little yard. The yard couldn't have been much more bigger than this room. I had to climb over a mound of snow or ice to come in the house. Slipped on it and fell and forced my leg beyond the range of motion and broke my femur at age twelve. Probably the worst injury I've ever had.

I went through the whole rehabilitation process for that, but apparently at that age and stage of my life the injury affected the growth of my leg. They called it the "growth plate" in your femur and as I grew larger and taller my leg didn't. So as a result, I had to wear a lift on my left shoe. When people asked me "What happened to your leg," I'd say, "Old sports injury." [laughs] I mean, because I was playing (yard) football, but sometimes I didn't get into it. In fact, I never got into a long conversation, even

as I went through school or with employers, about my physical condition. In some cases—in most cases I never even mentioned it unless it was necessary. I never said it was anything else other than what it was, but only when it came up or if I felt that the person I was talking with needed to know. But I never put it out there at the very beginning in any situation, in any of the jobs that I've ever had.

There have been some situations where, if I had a hospitalization or something where I was going to be out for a long time and folks needed to know what it was, I would, naturally, say. But I've always kind of kept it in the back, although it was very much a part of me, but it was never something that, other than common sense, directed what I could or couldn't do. I mean, I don't bungee jump, but I've done some pretty—I consider them adventurous things over my life and career.

For example, a ropes course when I was teaching. I did the zip line from twenty feet up in a tree. But when I did something like that, I would look—I would make sure that physically I was able to kind of handle what was on the other end. If it was something that involved a soft landing where you had to do a deep knee flex, I could see I couldn't do that because I couldn't do a deep knee squat from probably age nine because of that limitation in my knee. But when I looked at the zip line, it required you climb up in the tree, sit on a platform, connect the harness and slide down this rope and at the end, you're hanging on the rope and the spotters catch you and then you ease yourself down. I said, "I

can handle that.” So after twenty minutes sitting frozen in the tree going, “What am I doing up here?” I did it!

LG: So it’s interesting, as you said. I’m going to repeat back to you what you said to me is, “You know, while it played a huge part in my life, I never really let it define me or get in my way.”

WB: Right.

LG: What do you make of that?

WB: I think that was my mom.

LG: You do?

WB: I think it was her and the experiences she tried to expose me to when I was growing up. I had a Big Brother, you know from the Big Brothers Association. She got me one when I was twelve or thirteen years old, who took me out and took me places and he happened to be a graduate student at MIT at the time, so he took me all up in the labs that he was working in. I don’t even know what he was doing now, but it was just cool being up in the lab. Things like that and the fact that I spent a lot of time enjoying school.

LG: How did the kids treat you in school?

WB: Fine. You know, it was—

LG: No teasing. No taunting. No—

WB: No, I don’t remember any teasing or taunting.

LG: Really?

WB: In fact, it was probably just the opposite. It was more kind of special treatment and pampering and that kind of thing, which I don’t know, may have had an adverse affect on me. I don’t know.

But, you know, it was not—there wasn't taunting or anything like that. Uh-uh, no.

LG: So what was the hardest thing, do you think, about dealing with the hemophilia? Was it the pain? How did you deal with the pain as a kid.

WB: Pain was—the pain was—I remember the pain. Pain was, that was the hardest. But I think the pain kind of made me stronger in some respects, because in some cases there was nothing I could do. Most cases there was nothing I could do about it. I had to either live through this pain or I don't know what. So I would find different ways of getting through it, mostly by telling myself, "It can't last forever. It's going to get better. It's going to get better." [chuckles] And eventually it did. I mean, I don't even know what you give a five year old for pain. Or a six year old or a ten year old, or a fourteen, fifteen year old. I just remember pain in all kinds of parts of my body. Probably mostly my knees, though. Mostly that knee. That was the thing that was the most painful. I had other target joints, too. I have elbows that today won't straighten all the way out. I have a shoulder that gives me a little trouble now and then. I have an ankle that I wear a plastic orthotic brace on, rather than getting it fused. I chose to wear the brace because of the ankle. It's not painful, but these are just things that I've gotten used to.

It's the pain and I think arthritic joint damage that resulted from that, that causes certain limitations. Like I can't ride a bike. Now as an adult I don't even try. I have some difficulty going up

and down stairs and I had to get a knee and a hip replacement about eight years ago at age 40-something.

LG: How is it for you as an adult to be dealing with all this?

WB: It doesn't bother me. I guess I'm thankful, first, to be able.

Secondly, that my limitations aren't as bad as they could be, and I've learned to kind of adapt and to deal with them. I can walk. I can go up and down stairs. I can drive. I spent several years with a cane before the operation. I can't walk too long without some discomfort, feeling it later. But then I hear other fifty-something year olds say the same thing!

LG: With hemophilia?

WB: No, without.

LG: Oh, I see.

WB: You know what I mean? So I'm saying well part of this would have happened, anyhow, perhaps because, you just get older and your joints start creaking and whatever. So maybe my pain is a little bit more; and my endurance is a little less than others who don't have the artificial joints or the joint damage in other places. But I learned to live with it. Even though I have a standing order for Tylenol, I don't take much—I hate taking it. The only thing I'll take painkillers for is a headache. I can't stand headaches. Beyond that, I'd rather feel the discomfort and then feel my body get better. I don't like pain medicine, unless it's post surgery or something like that. But not just for, "Oh, my knee's bothering me. I've got aches and pains, I'll take some Tylenol." Because I want to feel how bad it gets and then I want to feel it getting better.

LG: Do you think having lived through so many years of pain, you're relationship with pain is different than other people then?

WB: Yes, probably. Sometimes it's just kind of something's always there. Some little pain's always there, and sometimes I'll be walking around doing something and think, "Boy, phew, I feel really good. I don't feel a thing." I guess one of the things it does is it puts you in real close relationship with your body. You know how it feels and what it tells you, and I think I know it pretty well. I can usually tell when something's coming on. I can tell probably within the first ten minutes what's going to turn into a bleed, what's going to get worse to the point where "If I don't take some Factor now, this is going to be a problem. It's going to last several days or longer. Or be very painful." Most times, I can jump on something real quick.

Sometimes it will occur in a situation where I won't be home for hours, and I have to delay treatment a little bit longer than I want. One thing I noticed as an adult is I'm more prophylactic about things. I've kind of learned what sets things off, what kinds of activities set things off, so I will often opt to take some Factor before I do that, or immediately following doing it. Even when I haven't felt anything yet, I know time, after time, after time, if I don't, it's going to result in something.

Example, yard work. Example, travel. I'll usually take some factor before I travel because walking through airports carrying your luggage, going up and down plane things or whatever, I always naturally take it with me. If I've had a heavy day of going to the museum and doing other kinds of things, I find

that infusing works to keep me kind of on an even plain. Rather than fighting an episode, it keeps it from occurring or from getting bad.

LG: What do you remember about your nurses and doctors and healthcare providers? What was their attitude towards you?

WB: I think I had some of the best nurses and doctors in the world at Children's Hospital and at the Brigham and Women's, through the hematology departments—what eventually became the Hemophilia Center. It wasn't the center then, it was the Hematology Department of the Children's Hospital under Dr. Sherwin Keyv that I remember most of my early years.

LG: And being an inpatient, what was that like? Was it okay? Could your mother visit?

WB: Oh, yeah, she stayed. She came whenever she wanted to and would stay as long as she wanted.

LG: Really? Even when you were a little kid?

WB: Yes. My recollection is that there were some times when she may have even stayed—before the Children's Inn—probably long into the night, if not overnight.

LG: Did your sisters have any relationship with the hemophilia? Were they jealous? Did they feel left out?

WB: No, I don't think they felt left out. I think they were very much a part of it. I think they were protective and helpful. Sometimes I think I was maybe treated too much with kid gloves. Sometimes I think it was a little bit much.

LG: You felt that?

WB: Yeah, I think so. But I think it was just their way of dealing with it.

LG: What was the biggest treatment impact that affected your life?

WB: In what respect?

LG: With the development of the treatment of hemophilia, what impacted the quality of life the most?

WB: Well, I think there were a couple of advances that made a big difference.

LG: Like what?

WB: One was the advent of cryoprecipitate.

LG: Why did that make a difference?

WB: Because when cryoprecipitate came out, even though it was a frozen blood product, it significantly increased the potency and reduced the amount of medicine that had to be taken. So that you could get it faster. You could thaw it out and administer it much faster than—I remember, huge, must have been 250-300 cc bags of orange juice colored plasma dripping in over three hours, four hours when I was a kid. Now you had this little thin bag of kind of clear liquid and now I'm bigger and I'm older now, but that's all that was needed to have the same affect. That was one.

The next was the coming of the antihemophilic factor, the reconstituted Hemophil-M and it had a couple of variations. That and the home infusion. That was the biggest because then that made the access to the medicine almost immediate. Within twenty minutes to a half hour, you're infusing. You don't have to go the hospital, at least to begin treatment. Because going to the hospital was, you go in, you get registered, the doctor comes to see you.

They leave the room, they come back in, and meanwhile, once they started the IV the pain went away. That got better over time because, as I said, we were well-known, so we didn't have to start from square one every time you came in, but there still was travel time. Getting in there. Painful moving, and all that.

So now, you get something at home and that just kind of revolutionized the whole treatment. I think also the ability to get on top of things earlier and minimize, or at least to mitigate some of the damage that is often done in joint bleeds.

LG: What was it like when someone said, "Try this," for the first time.

WB: It's interesting. I guess in some respects I was probably one of the best subjects that the Hemophilia Center had for a while with different things. When I got old enough and able to make decisions for myself, I always asked a lot of questions, as you probably know from my visits to the Hemo Center, but I was willing to move to the next level or to try something a little different, if my questions had been answered to a level of satisfaction. I know that at various points, because of various treatments and things that have happened, I had developed, I think it was Hepatitis B antibodies, something like that. It was something that my blood was producing that was good. It was not adversely affecting me, and they needed it for treatment of other people or for research they were doing. So I was donating blood on a periodic basis for that.

When the next generation of medicine came along, I wouldn't necessarily always go right to it. Sometimes I'd wait awhile, but I would always ask questions. I would always want to

know how it was coming. I still get the newsletter for the NHF and so I'd read what was being said about it.

LG: Why wouldn't you go for things right away, if they seemed new and better?

WB: Well, sometimes I did, but sometimes if what I was doing was working, it was like, "If it ain't broke, don't fix it." It took me awhile to go from human monoclonal to the total—

LG: Recombinant.

WB: Recombinant. Because I think I was comfortable that—
[end of Side A, Tape 1]

WB: And as I was saying, sometimes I just felt comfortable with the way it was and it took me a while, for example, to change from the recombinant human—I mean the human factor to the recombinant, because I was kind of comfortable that it was safe. Although, clearly there was a period of time in the '70s when it wasn't. You know, something wasn't safe, vis-à-vis the number of hemophiliacs that contracted AIDS or HIV.

LG: What do you remember of that time?

WB: You know, I think I was kind of oblivious to the possibility because I was thinking, certainly as I think most of us were, that the factor we were taking was safe. That it had gone through all the kinds of medical things it had to go through, and so I wasn't really concerned about it. I was following along, like everybody else, on the news, certainly in the late '70s, early '80s when the AIDS thing broke. The focus started on the West Coast and then all the different iterations of kind of fear and discrimination that

was associated with it was in the gay community. So I wasn't even thinking about it.

LG: In relation to you.

WB: In relation to me, even though we were taking the blood products and I'm looking at these things coming in white boxes from medical pharmaceutical companies and not even thinking about it. Then when it became apparent that this had come into the hemophilia community in the amount that it had—

LG: How did it become apparent? How do you remember even getting that?

WB: I think my recollection is coming in for a hemophilia periodic check out and then being told that it was a concern and being asked to take the test. In fact, it was in conjunction with—it was actually in conjunction with the birth of one of our kids. I think it might have been my son, Cheo, eighteen years ago. That would have been about right. Middle '80s. He was born mid '80s, or it actually could have been Noni, his sister, who was born three years before him in '83. So it might have been more her, but it was in conjunction with one of the pregnancies. It came at the same time and so then it was like, "Whoa," because there were issues around naturally the health and safety of my wife, Margo, the child, myself. When they said, "Well, this is something we're asking everybody to do, to get tested to see where it's going." So I mean that was—that was probably one of the scariest times.

LG: Did you test positive?

WB: No, I didn't. It was like I was just totally convinced that was just God's grace that had to do with my situation. Not that those who

did test positive were any less deserving of the grace of God, but I just think it just was—I don't know. It's like I have no idea why it didn't happen, and I don't know whether it was because of something I chose not to do at a time, like switching to something that may have been coming through then. I'd have to go back and see what was happening in terms of the companies involved or the methods involved and whether or not I hadn't made a switch during the time that a lot of people had, or not. I tested negative and that was that.

LG: Do you remember the impact on your family at that time, or your wife?

WB: Well, it was a sigh of relief and a great deal of gratitude spiritually and otherwise that that had not been our fate.

LG: What role did faith play in your life, Wendell?

WB: Very, very, very strong.

LG: In what way?

WB: I would not be where I am. I could not have gotten through what I've gotten through without my faith in my Lord and Savior. That's something that we grew up with, as a child. It is a very deep part of my being and that of my family. That's what got me through. When it came right down to it, faith got me through some of the periods of time when things were really, really dark.

LG: Why? What would have happened?

WB: Because I just had this abiding faith that things would work out. That God would work it out according to His will and whatever it is, I believe He doesn't put on us any more than we're able to bear, with His help. So you know, whether it was times I was laying in

the hospital, as a result of an injury trying to recuperate from pain and wondering how much of my old self I'd get back, I would just lay there in prayer sometimes just saying, "Well, you know, I don't know what this is all about, but I'm supposed to learn something from this and it's going to make me stronger in some respect and so I'm just kind of excited to see how this all works out. Or whether it was lying, as they told me, near death after food poisoning, totally unrelated to hemophilia. I ate some—drank some pokeberry juice, or what the old folks would call pokeberry wine. I had an old aunt who lived to a hundred and four. A great aunt, I should say, my mother's aunt, who had picked these berries—you see them, they grow up here. This little bush with little berries, kind of look like blueberries on it. Some people down south, they take the leaves and they make salads out of them and the berries, they put in a jar with a little sugar in it and let it sit in the refrigerator on a shelf for awhile, and it's supposed to be good for your blood. She would have this in her refrigerator and she lived to a hundred and four. She'd take a sip every now and then. It wasn't an alcoholic drink or anything. It was like more of a home grown berry juice.

But anyway, one Mother's Day I went over there with my five year old first born daughter Milele visiting, and she said, "Oh, have some pokeberry," and I said, "Okay, and I drank a little glass, probably about two, three fingers worth," and my little five year old daughter had two, three fingers worth, maybe a little less. Finished our visit, went home and that night I was so sick, I was in

the hospital three days. They thought that they thought they were going to lose me.

But Milele, on the other hand, nothing.

LG: You told me this in regard to your faith.

WB: Yes, so even at that point, when I was so sick. Other times recuperating, say, from the double surgeries, when it just seemed like either the pain or the—you can get depressed in the hospital. You spend two weeks in the hospital eating the same old rubber food and seeing the same faces, and getting interrupted every two seconds for somebody checking your blood or whatever. It's a great place in terms of the medical treatment, but it is not home. I would call upon my God and my faith in prayer and know that this, too, will pass, and it will be okay and I'm going to come out stronger than I went in and ready for the next challenge.

If I didn't have that to lean on, a relationship there, I don't know. Maybe I would have snapped somewhere along the line or had a whole different attitude about life. But it's like "no problem."

LG: It's always been a strength, a place for you to go, saying this is okay.

WB: Absolutely.

LG: There's a reason for all this somehow.

WB: Absolutely.

LG: Really?

WB: Absolutely. Absolutely. I mean, when you think about it, I have the battle scars of hemophilia in terms of joints and other limitations and things, but that situation around the HIV, missing

that bullet. Wonderful. Now, on the other hand, a few years ago they told me I had Hep-C. Okay, so that wasn't mine, but this is mine. Okay, that's all right. We'll deal with that. It will be okay. It will work out. You just do what you're supposed to do. It just kind of comes with the territory. The Lord knows, and as I said, anything that comes along, comes along for a reason. It's something that you take. It's part of you. You cannot separate it out anymore than somebody can permanently change the way they look. Even plastic surgery really doesn't change that. But I mean, it's just a part of you and so I said, "Okay, it wasn't that one. It's this one. Okay, we'll deal with that."

LG: Was having hemophilia an issue in falling in love and having girlfriends? Did you ever feel that was something that would impact your love life?

WB: Not—no, not up front. Only in the ultimate situation where it really became serious, but I always felt that if I wasn't wearing it on my sleeve and if that wasn't the reason why you fell in love in the first place, that that wasn't the main thing because I didn't see it as a main thing. That it shouldn't be a problem. However, I wasn't totally naïve to the possibilities of how other folks might take it or see it. How that particular friend might not understand. Maybe it was because I always knew kind of genetically that I couldn't have a hemophiliac child. I was very aware, naturally when the first three of our children were all girls, that this was going to be an issue. My oldest daughter, she went over to Children's when she was a young woman and got the whole genetic thing. You know, so it was clear what were the chances

and the risks. Well, she went on to become a physician, clearly understanding it, and today our first grandson, Eric, is a hemophiliac and a twin, but he's also got spina bifida. So he's got multiple things there.

But, you know, it really wasn't something—I don't know if it was because Margo was a nurse. When I met her, we were both in college. She was studying to be an RN. Maybe she had a better understanding of this than someone else may have. I don't know, but it didn't seem to make any difference, at least not one that she ever talked about. Beyond concerns that I might have shown, I guess one thing that I liked about our relationship was that it was never front and center with her—my hemophilia. It was almost like it was the opposite of the way I'd grown up with my mom and my sisters. If I tried to play on it a little bit, she wasn't having any of it, and it wasn't from a standpoint of denial or meanness, it was that she saw how I dealt with it. Meaning that I didn't keep it front and center. I didn't keep it in my way. I didn't let it hold me back and so she wasn't going to let that become a part of anything she brought up with me, nor was she going to let me start feeling sorry for myself at any point.

LG: Do you think that's good, that people don't feel sorry for you?

WB: Yes.

LG: Even though sometimes you're suffering?

WB: Yes. Yes. Yes, I think that's fine. That's fine with me.

LG: Why?

WB: I don't want anybody feeling sorry for me. I want people to see me for who I am in my head, not because of the hemophilia. I don't

want people to think “That’s Wendell, the hemophiliac, who is also a nice guy.” I was a middle school teacher for thirty something years. Eventually, a student would be brave enough to ask the question, usually right out in class, “Mr. Bourne, how come you’ve got a lift on your shoe?” My answer would be, “Well, when I was a kid about your age, twelve years old, I fell. I broke my leg and I broke the growth plate in it and so as I got older, my leg didn’t keep up with my growth and so it’s shorter. So I wear the lift to make up the difference.”

LG: That’s it?

WB: That’s it.

LG: No mention? How come?

WB: I don’t know. I just didn’t want to go into it. I just didn’t think it was important. Now, on the other hand, I’ve had conversations with people who ask “What happened to your leg?” or “Why do you limp?” and I say, “Well, I had surgery on the knee and the hip. I had an arthritic condition that was brought on by hemophilia, which affects the joints.” It depends on what the circumstances are and who’s asking and why and how I feel about it at the particular point, whether I get into it with someone. I never got into it with my students. It’s better now than it used to be. Most people when you say hemophilia, if they’ve heard of it, say it’s the Bleeder’s Disease. You always get, “Better not cut you, huh?” They don’t realize that with most hemophiliacs, you never see a drop of blood when they’re really in trouble. It’s all an internal thing, but most people think visible bleeding. The fact of the matter is most little

paper cuts, scrapes and cuts like that heal up. I scar a little more because it takes longer, but not a big deal.

So, you know, it's better now. A lot more people know about it, have heard about it.

LG: When did you meet someone who had hemophilia?

WB: Well, I remember going to the Hemophilia Association. My mom used to go to the Hemophilia Association meetings, and she'd take me as a youngster and she was more involved in that. I remember meeting other kids with hemophilia at some of those meetings. I remember meeting hemophiliacs in the hospital, who happened to be in the hospital at the same time that I was there. I remember one time I went to a Red Sox game. The local Hemophilia Association gets tickets and so one year I went, and I met a couple of guys, adults, you know.

LG: What was that like? I mean, was it significant to meet other people with hemophilia?

WB: Yeah. Yes and no. I never really met anybody that I got really close to, you know, to share things, and I do remember—I guess that one thing that pokes through my mind is I met a number of guys, some of whom were very bitter and it turned me off. They had had put it front and center and they seemed to be, for whatever reasons—from my way of interpreting it—milking it for sympathy. They thought people owed them something because of it. I remember meeting a guy like that. I don't remember his name or anything like that—I was not interested.

Now, I'm not saying everybody was like that. I remember going to an event—I can't remember the event, except the Baxter

Corporation was there and they were showing off the new BaxJet needle-less infusion device when it first came out. About four or five years ago, I met a couple of other people there who were hemophiliacs, had nice conversations. Very much like myself, jobs and families and that was neat. To see just some regular looking folks who had dealt with it, I guess much the way I had, and it didn't stop them and that was fine.

I remember getting a call from the social worker before you came to work for the Center, who had had conversations with a mother, an African American mother who had a son, who she was concerned with because her son seemed to be totally, in one sense at least, ignoring the fact that he was a hemophiliac. He was a young man who was very interested in athletics and he, in fact, played organized football and basketball. He was injecting, obviously. He was taking factor, and he had avoided the joint issues. He lifted weights. He just kept himself at a level where he could do this, and she was concerned that he was doing this because he wasn't really being realistic about how far he could go with this, and that he was in denial. So she wanted me to talk to him. I never met him. I was just given a name, a phone number and asked to give him a call, and I called him and I had a conversation with this young man. It never became a warm conversation. I tried to be very tactful about it, realizing, you know, here's some guy on the other end of the line—he has no idea who I am—just calling him out of the blue and wanting to talk to him about how he was doing and what was up. He talked a while about his sports and I said, “Oh, you're playing, huh?” “Yeah, I

play basketball on my school team,” and so forth, and I said, “And have you had any adverse affects?” “No, no.” First of all, that was the only African American person I ever met, the only Black person I ever met—didn’t even meet, but talked to—with hemophilia, and he was a teenager. He was sixteen or seventeen when I talked to him, and this had to be ten years ago.

I met his mom some years later at an event. She said he was still doing okay, but that was it.

LG: And what did you think of him playing sports?

WB: I said, “Oh, that’s great.” If he could take his factor and keep his level up and get whacked around on the basketball court and he’s in good shape and good health, more power to him. I said, “Hey, that speaks volumes for the technology in trying to provide young people with as normal a life as possible with this disease.” I said, “That’s cool. That’s great.” I mean, as you said at the beginning, I kind of lived through a span of time from the four hour visits in the Emergency Ward at Children’s to twenty minutes at my counter in the kitchen taking care of myself, heading off something or treating something. I can see how far the technology has come, and I know there was a period of time, and may still be, where prophylactic treatment was the way they were wanting to treat young kids. Never have them even reach a level where they got into trouble. I said, “Well, that’s cool. That just wasn’t my experience at the beginning,” and I would say to myself—now that I’m older and I kind of can self-control. Knowing my body and understanding my activity level, I didn’t see a need to start a prophylactic treatment at this point. I looked at myself and said,

“Well, if the legs are already shot, there’s no sense in doing that. I can manage this on an as-need basis.”

From a financial standpoint, although I’ve been fortunate to have the kinds of jobs where I had health insurance that covered most of this. Essentially all of it, because when they send me those little ‘this is not a bill,’ and I see what ten doses of this medicine costs per shot, I again thank God that my mother pushed us the way that she did, that I went to school, that I got the education I have, that I was able to get jobs and support a family and be in a situation where this is the case. I know it’s not the case for everybody. [getting emotional, voice is cracking] And also, I’m very fortunate to be here in Boston. I don’t think you could have been anywhere else in the country to get the kind of treatment.

LG: Why are you getting teary now?

WB: [pause] [sighs, clears throat] Because it’s a trait I got from my father. [chuckles]

LG: Because what?

WB: It’s a trait I got from my father. He was very emotional, too. I got to know him a little bit more in the years before he passed. I’ve always thought God has been very good. I’ve been so fortunate to have come up in the circumstances that I’ve come up in here. I’ve read stories in the Hemophilia Magazine about different challenges that different families have had to go through. People living in rural areas where it’s a three hour drive to the nearest hospital that can treat their child—and I understand that people can’t chose where they’re born, to whom they’re born, their situations in life, what country they’re born in, what race they’re born to. You just

don't get a choice. That's the way it is. I could have been somebody else, anywhere else, at any time and that would have been the way it was. And that would have been all right, but it just so happens that I'm me and I've had what I consider to be just a wonderful, blessed, life and family in a situation where I've been able to deal with this the way that I have.

So I think about that. I'm very thankful for that.

LG: What do you think about when you think of your grandson with hemophilia. Of course, I understand he has spina bifida, too.

WB: I had to think that eventually when my daughters got married and had children, that this was a possibility. My oldest daughter Milele knew that, too. In one sense he's being born at a time when the treatments for hemophilia are state of the art. Eventually I think that they'll find a cure for the disease somewhere. It will have to be something genetic because we know its roots are in genetics, but I think they'll get it to the point of where treatment is such that the devastating effects of the disease can be minimalized. Young men will be able to live lives pretty much uninterrupted by hemophilia. I think Eric has come on the cusp of that.

Of course, he's got the other issues. Milele being a physician and her husband, Alvin, being the curious and analytical person he is, they are right on top of it. I hope and I think that they will be able to bring him along much the way that I was brought along, giving him all the various opportunities that they can, and hopefully giving him the room to grow without having this become an impediment to where he can go. He'll grow up learning to understand his limitations, but to push them to the limit within

common sense and reason. I mean, in terms of mental and other kinds of capacities that he has, and even physically, to stay in good shape so that he goes on to do whatever he wants to do.

I hope that after he's grown up and I'm gone and he gets a chance to maybe ask some questions about grandpa and how he dealt with it, that something I did helps him to understand that you can just go ahead and do what you've got to do and live a life with God's help that is normal, just, good and contributes. [voice cracking] You don't have to let this disease or anything else stop you.

LG: Did your daughters ever wonder, "Should we have children?" having seen what you've gone through?

WB: I'm sure they have. My three daughter are Milele, Dara, and Noni. Milele is married and she and her husband I'm sure have had much conversation about it. In fact, they had some difficult conceiving, but wanted to have a child really, really badly.

LG: If they had come to you and said, "Dad, should we have children?" do you think the fact that "I could pass hemophilia onto my child," would be a reason not to? Would you have thoughts about that?

WB: I don't think I could have ever said, "Don't do it." I'd say "Well, it just wouldn't be bad," because it's not a reason not to do it. You know, there's a fifty-fifty chance that the child's going to be a hemophiliac, if it's a boy. Maybe better than fifty percent, I guess—I never did understand totally the genetics—but I know it's there and that's the way it came out. But like I said, it's not the same—hemophilia today, in 2004. The treatment is different, the disease is the same. It's still medically defined and physiologically

defined as what it is—the lack of factor VIII or IX. However, as I said, the technology has come so far. In the early days, just after Eric was born, they were getting factor for him because he had to have several surgeries for the spina bifida—they had to close up the opening. They had to do some leg surgeries. She (Milele) showed me the same old bottle of factor that I'm taking now. That was his first thing. All he needs is one little bottle. I'm thinking three. He gets just one and I think it was the monoclonal right off the bat, so they were past all that stuff I went through. So he's past all the human stuff. He went through his two or three surgeries just fine. They got the level up. Boom, they did the surgeries, and I said to her, "Well, how often do you guys give factor, are you giving it prophylactically?" and she said, "No, we just watch him and he takes it when he needs it, and he hasn't taken any in months." He hasn't had to have any. Now, he's just getting to the crawling stages now. His sister, Arin, is almost stepping, and if his little legs were straightened out—he's got the turned in legs—he'd be starting to pitter-patter around, too. But even with the crawling, Milele puts little pads up on his knees, and his sister's too, especially if they're out on the porch or something. But if you look at him, you can see sometimes little black and blue bruises, but these are little things that go away.

So when I hold Eric, I tell him, [chuckles], "We've got a little something in common here, buddy." But his experience is going to be different because he's just born in a different time. He hasn't got a clue right now, and it will be awhile before he does. He gets to interface with the disease and how he understands it to

be will be light years, light years ahead of what my experiences were. He's probably ninety percent less likely to develop any kind of joint problems like I did. He's not likely to have to deal with the levels of pain that I've had to deal with. There are things that I've experienced, he just won't have to deal with, as far as the hemophilia's concerned.

Now, he's got some struggles to deal with around the spina bifida. I had students that I taught in school that had spina bifida, and there's nothing wrong with those kids. Nothing they couldn't do. There are limitations on the physical, but I was talking to one of my students awhile ago, and she's graduated from high school and she's out doing things in the world, so I'm not worried about that.

My daughter and my son-in-law, they're on top of that.

Those kids, God willing, will get the best, and will be just fine.

LG: Do you have anything that you would want to say to the healthcare providers, as far as any advice for them in taking care of guys with hemophilia or children coming up in the world with hemophilia? Or nurses? Or social workers? Do you have any suggestions for us?

WB: As I said earlier, I think my experience with the healthcare providers that I've dealt with has been very, very positive. I remember those that I encountered and who interacted with me in my early days, as well as the ones that have dealt with me in adult life. I think the ones that interfaced with me as a child were the most crucial because so much of how you deal with this is formulated by your parents, and by those healthcare professionals

that work with you. I would just say—my sense was that they were always caring, and they were always encouraging. They were always encouraging. They would always give you a word of encouragement, whether you were kind of fighting your way back through physical therapy or you were getting better or you were getting a needle and you didn't crying. Also I'd like to believe—I do believe that the doctors and the nurses that I spoke with and explained things to me, explained everything honestly and as openly as they knew, at that particular point.

LG: Why are you saying that this way? Is it because of what happened in the '80s and some question about that?

LG: I—I don't get the feeling that anyone was—at Children's Hospital or later, ever deceptive about anything they said to me about what was going on. I would always ask questions about risk and other things, but as I said earlier, I wasn't even thinking about Factor and HIV. Maybe it was part of the way they were always describing HIV as being transmitted through "IV drug users," or "drug users and sex." I always saw the product that I was taking as being checked out. Maybe it was just this faith in the system, so-to-speak that I came to have over the years, given that so much of my life, health and well-being, from a medical standpoint, really depended on where the medical system was at that time.

When we went into the hospital, certainly my mother and father in the early days, they had no clue what this was and they were told what was going on and what happened, they had to have a certain abiding faith that the medical professionals were telling them the truth and doing their best. And mom is not one you get

much over on, so she was going to question. She was going to ask. She didn't have a naivety of trust. In fact, she's probably very, very suspicious and has gotten more so in her older age about things. I'm sure she asked a lot of questions. She was there a lot watching and checking and so forth.

But, as I say, between my family support, my own faith and the medical care I was getting, I came through it. I got out and it worked. So I never had a kind of a devastating big problem that kind of shook the foundations of my support and belief that I was getting the best possible care.

LG: Do you have anything to say to the mothers that are giving birth to boys with hemophilia? Your daughter? To your grandson, to the boys? Would you want to share any of your experience?

WB: I would just say that the medical advances for this, and the treatment of this disease has come light years from the late '40s and '50s. In the half century, they have come a long way in understanding this disease and treating it. There's still a way to go, but I think they've reached a point where your sons can live pretty darn near normal lives in terms of managing this disease, more so than it was fifty or forty years ago. I think we still have a way to go. I've begun even more recently to follow some of the things that are happening at the national level around the research that's needed to get closer to a cure. I know that hemophilia has gotten more national recognition in the medical community and among lawmakers and funding sources. That's due, I'm sure, largely to the hard work of the medical professionals and families who have

been fighting this disease for years, so they should keep up that work, definitely.

But I'd also say, they could take a page from my mom's book around doing whatever they can to make their sons feel as normal as possible. Aside from the normal mother's love and the hugs and the way mom's are with their kids, to not put their sons in a situation where they wear this disease as some, pardon the expression, red badge of courage, in a way that clouds a clear vision to their goals and aspirations and what they can do in life.

LG: Do you think having hemophilia has affected the teacher that you are, or the educator at this point that you are?

WB: Well, yes, I think to the extent that it's affected the person that I am because even though I never kind of put it out front, it's part of me. So having to deal with what I've had to deal with, I think has made me stronger and able to deal with situations in life outside of hemophilia and as far as my professional career as a teacher. I don't know if I could distinguish what that is. I just know I always loved teaching and I love kids and I love history and I managed to put them together into a career where I loved getting up in the morning every day.

LG: That's wonderful.

WB: From that standpoint, what else can you ask for? I've always thought if you can like getting up in the morning and going to work, what else do you want? So many people get up or go into careers for the wrong reasons. I suppose if I had pursued any other one of two other career choices that I think I could have had—

LG: What were those?

WB: I probably would have maybe made a lot more money, but I don't think I would have been as happy. One was that I started my college career in pharmacy. I was going to be a pharmacist. I was interested in pharmacy and I did two and a half years as a pharmacy major. I was at Northeastern, so we had coops. I worked in pharmacies.

[end of Side B, Tape 1]

WB: I could have been a pharmacist, and I thought about working for the FDA, in a lab somewhere, but I changed midstream. I don't think I really put in the kind of concentration I needed to. I ended up changing over to history and graduating with a history degree. I went to graduate school and got a Master's in African American history and studies, and went into what I thought was my second love, but what I think was really my first, which was teaching. Had a ball. Love it.

The other was that I did some work in radio and then eventually in television—community television. But I did have a radio show in a major market—talk radio. It was a public service program that I was doing for the Boston NAACP. I had guests and we talked about issues of the day and so forth and so on. One day the radio station was getting ready to move into a national call-in talk show format. The general manager asked me if I wanted to do that. If I wanted to be the talk show host in this national call-in—people anywhere in the country could call in and ask questions. I was young and feeling a little bit big of myself. I was doing this other show as a public service and just for experience and getting no money, and so he said, “Yeah, we'll pay you,” and I think he

was going to pay me—now, this is late ‘70s, early ‘80s, so it was going to be twenty-five dollars or fifty dollars a show. It was just going to be an hour show once a week. I said, “No, you need to pay me a hundred dollars,” and he wasn’t hearing it and—so I said, “Forget it, I’m not doing that.” So that—

LG: That was that.

WB: That was that. Maybe it wouldn’t have gone any more than just that, but that was—that’s still an area that I like and I’ve dabbled in and even as a teacher, I still dabbled in it.

LG: You said to me that you think hemophilia in some ways made you stronger. You know, could tolerate pain. Is there anything else that you feel positively came out of having to deal with hemophilia?

WB: Yes. I think it made me understand people who are wheelchair bound or have a disability when they say, “I don’t want to be treated any different than anybody else. This is who I am. This is where I am, but I can think, I can contribute, I can do.” I think it helped me understand what that means when you hear somebody say that or when you see the way somebody is treated. It’s kind of made me more sensitive and open to students that I’ve had because we’ve had a wide array of students. I’ve had students on crutches. I’ve had students who had everything from special aides in the classroom, to ADD, to spina bifida, to polio, to mental illnesses. I tried to the best of my ability to slice right through that. Go right through. I don’t see that. You know, “We’re going to deal with this straight on and you’re going to produce, just like anybody

else.” So if they tried to wear that, they weren’t wearing it with me. [chuckles]

Now, I wasn’t oblivious to specific kinds of accommodations—adjustments and things that needed to happen.

LG: Did it take anything away from you?

WB: Did it take anything away from me?

LG: You know, you’re talking about the strengths, the positives. Do you think it had a negative impact on you?

WB: Can’t think of any. [chuckles] Did I ever sit around and say, “If it weren’t for this, I’d be...” No. No. I never cursed the disease because it kept me from becoming a—even though I said earlier, I’m a basketball fan, I never I had the burn deep enough that I resented that I never played. I enjoyed watching basketball so much that I was able to vicariously play the sport. At one point the radio station—the Celtics were having some anniversary—was offering an opportunity for you to pay an amount of money and they would have the sports announcer, announce a game as if you were the player. They’d say, “Wendell’s dribbling down the court. He stops. He—swoosh. He won the game!” It would work you into a playoff game victory, you know what I mean? And I thought about it for a minute and then I said, “Nah, I don’t need that.” I didn’t need that, you know. I’d rather watch—I’d rather watch old reruns of the seventh game in a playoff series with Larry Bird and McHale and Robert Parrish tipping one in in the last seconds of the game and I just go nuts, and that would be fine with me.

So, no, I never did have resentment because, you know what? This was me. [laughs] There's never another me. There's never been a Wendell Chester Bourne, Junior, without hemophilia, so I have no clue what it's like to be me without hemophilia. So if I was, then I just wouldn't be me then, would I? [laughs]

LG: Wendell, have I not asked you something that you'd like to say as part of this Gift of Experience about living with hemophilia? Have I missed something?

WB: I don't know that you've missed something.

LG: I'm offering you an opportunity—

WB: There might be something. I'm thinking about something. One of the things that I think that I will say that being a hemophiliac—and it wasn't so much the hemophilia—maybe it's more the fact that I've kind of had to temper my physical activities a bit. Is that, although I've never missed bungee jumping or water skiing or doing some of those—rock climbing and mountain climbing. I don't think I'd ever want to mountain climb or rock climb, but I've taken helicopter rides. Those are fun. [laughs] But I think, in some respects, it may have combined with my—well, I like to think I'm a little wiser now than I was when I was eighteen or twenty-five or even thirty-five. Is that maybe engendered a certain amount of conservativeness in me over time. I had a pretty radical college life. I was very much involved in everything from student protests to the Black Panthers. I was involved in situations in the 1960s, when I was coming through college, could have been and were very dangerous. I mean, just demonstrations and things. I would always kind of pull myself back to the fringes of that. I

wouldn't be up in the front line because I was cognizant that I couldn't take a bad fall or a whack or anything like that. So I always preferred not to be involved in that particular aspect of what I believed in.

I was more the intellectual side. I was more the reader, the studier, the researcher, the teacher, the thinker on these kinds of things. I think to that extent—my knowledge of myself and hemophilia kind of took me along those lines, more than out front and in the physical side of that particular era. But I think that was kind of a natural part of me, too, because as I was growing up, I was the kind of young man who always had to avoid the physical stuff. I had to learn to negotiate. I had tiffs and beefs with people, to a certain extent. The macho thing on the basketball court or on the playground or eying the same girl, or whatever the case may be, but I always had to have—and I think they just kind of self-developed—these negotiating skills, rather than the nose-to-nose, “Come on, come on, come on. I'll meet you outside.” Things would kind of rise to those levels, and I learned how to ease it down. I think that's why sometimes some people, even in situations now, they see me as a peacemaker and a negotiator. Those skills were honed when I was younger.

I remember one time at a college party coming face-to-face with this guy who—you know, sometimes there's people in life who just from the first minute you see them, they don't like you and you don't even know them. There was this guy, and I won't mention his name, but for some reason he and I just never hit it off. There was nothing I ever did to him or he ever did to me. We were

at a party one time. The room wasn't very full. I was with two buddies of mine and somehow there was some issue, and I think he said something to me and I might have just responded. Before you know it, we were face-to-face. This guy was much bigger than me. If he had socked me, I would have been out on the floor.

I don't know if my negotiation skills were in high gear then or not, but my buddies were in the room at the same time. One of whom was twice as big as this guy, he just kind of stepped in between the two of us and he just said, "It's time to go," and that was the end of that. That was about as close as I ever came to really any kind of a fight. I don't remember ever being in a physical fight that I can recall, where I beat someone up or somebody beat me up.

LG: So hemophilia gave you a framework of how you had to move through the world.

WB: Move through the world, yes. And so, those kinds of things, physical kinds of things, I kind of compensate for in other ways. I love action movies. [chuckles] You know, the more explosions, car chases, fights and everything there is, the better. Spy movies, like the Bourne Identity. You know, the Bourne Supremacy. Things like that, Bond movies. I really enjoy those kinds of movies. I also like the thinking movies, like *The Dangerous Mind*.

LG: You've had a very rich experience.

WB: I guess.

LG: Very rich experience.

WB: That's the way it is.

LG: Well, I think I've asked you most everything I've had to ask you, and I want to thank you.

WB: Well, as I said, it's my pleasure. I don't know if much of what I said makes sense, but it's been good to be able to talk about it.

End of Interview