Oral History # 30

An Interview With
Rodney Mills

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AN INTERVIEW WITH RODNEY MILLS

ANN PINCHAK: This is Ann Pinchak interviewing Rodney Mills on February 15th, 2017 for The Oral History Project about the early years of the AIDS crisis and hemophilia in Houston, Texas.

What is your full name?

RODNEY MILLS: Rodney Mills.

ANN PINCHAK: Where were you born?

RODNEY MILLS: Jacksonville, North Carolina.

ANN PINCHAK: Tell me some things about your growing up: where you grew up, when you moved. What was it like?

RODNEY MILLS: I grew up in Houston, Texas, near Kashmere Gardens, which is on the north side, north central Houston. That’s it. I spent all my life here in Houston.

ANN PINCHAK: That’s great. Tell me about your parents.

RODNEY MILLS: My mom is still alive. She’s 73. She still lives in the house where she raised me. My father is deceased. He died when I was a young age, actually before it was discovered I was sick. I don’t know exactly what year that is.

ANN PINCHAK: So he never knew you were sick?

RODNEY MILLS: No.

ANN PINCHAK: What year were you born?

RODNEY MILLS: 1965, January.

ANN PINCHAK: Do you have siblings?
MILLS: Yes, one brother, one sister.

PINCHAK: Older? Younger?

MILLS: My sister is younger by three years. My brother is older by three years.

PINCHAK: Have you ever been married or partnered?

MILLS: Never married. No partners. No girlfriends. None of that.

PINCHAK: Your orientation is?

MILLS: Heterosexual.

PINCHAK: Tell me about when you were first aware something was wrong with your health.

MILLS: I guess I was six years old. I just couldn’t walk when I was a kid, when I was playing outside playing with a Christmas gift, a Tonka truck, which they don’t make anymore. I was just playing with it. Then my mother called me to come in the house, and I tried to get up and walk, and I had a lot of pain. I just thought it was going to go away, but then it didn’t go away. It lasted for a while, and then anyway it didn’t ever straighten up, so she finally took me to the doctor.

At that time, it was the neighborhood clinic, and they didn’t know what was wrong. He put me in the hospital. He was affiliated with one of the clinics here in Houston, St. Joseph’s Hospital. I spent a month there with them running tests but didn’t know exactly what was wrong, so my mother removed me from the hospital.

Then she took me to Ben Taub, which is the county hospital here. They didn’t know what was wrong either, but it was just a stroke of luck that they had a visiting doctor from overseas making rounds in the hospital that day. He had seen symptoms and knew of it. He said, “Your child probably has hemophilia.” But
that’s not something they treated at Ben Taub. That was something they treated at Texas Children’s, but at Texas Children’s at that time back then you had to be invited in, so another doctor has to actually invite you in. It’s not like you can just take a child sick and you can walk in. You can today, but not then.

PINCHAK: So what happened?

MILLS: My mother had a job as a bus driver, so she told me she had to go back to work and left me there. That particular clinic, their office closed at 5:00 o’clock, but she didn’t make it back because something had happened, so they put me in the emergency room overnight, and then the next day she came and picked me up, and then they finally gave her a case manager. She had to leave me because she had my brother and sister at home. I was a young kid. My sister was young, and my brother is a little bit older, but they couldn’t take care of themselves.

PINCHAK: Back then, what was it like for a family trying to get treatment for somebody with hemophilia? Did you stay at Texas Children’s? Did they keep you over the years?

MILLS: They finally did, but only after the case manager got involved in it, because my mother said she had to work; that she had to take care of my brother and sister. Other family members knew. They said they didn’t want to be responsible if something happened. They would keep my brother and sister like on the weekend, but they wouldn’t keep me once they found out I was sick.

See, at that time, hemophilia was actually a new disease, one kind, so it was very rare that anybody even heard of it. That’s why they didn’t know what it was here. At that time, Texas Children’s was treating for just sick children who had leukemia, bone cancer, and other stuff that children got sick from that really
was a fatal disease at that time.

PINCHAK: Who would look after you if you needed looking after, if your relatives wouldn’t take you?

MILLS: She found one person, but it wasn’t a relative. It was just a neighbor who was at home during the day. But the rest of them wouldn’t do it, so she had to struggle with me for a long time.

PINCHAK: When they finally diagnosed you, you were how old?

MILLS: Seventh or eighth grade.

PINCHAK: What was it like growing up with hemophilia? What sorts of things happened, and what happened to your body?

MILLS: I’m going to go back as far as I can remember. It was third grade. I think I got hit, and then it didn’t heal. I got hit by a rock up here in that spot [indicating], and that didn’t heal for a long time.

PINCHAK: In the spot on your forehead?

MILLS: Yeah, that was an unlucky spot. Three times, and all of them were just accidents. The first one was the rock accident outside the elementary school. They weren’t throwing it at me. They were throwing it at somebody else, but it hit me instead.

Then later, I was at my aunt’s house. We were playing croquet ball, and the ball hit me. It hit me there too. It was bad.

The last one was my brother and I goofing off at home trying to play Superman, and I missed the bed, hit the wall, and that was bad. It was bad.

Anyway, I think this was 1973? No. Whenever I was in the third or fourth grade, I can’t remember, I had an incident there.
Then I think I was okay during fifth grade. A teacher popped me with a ruler, which she wasn’t supposed to do, but I didn’t have an incident.

Then sixth grade, I can’t remember what teacher that was. I don’t think I had an accident there.

I had started having several incidents with my arm over in the seventh grade, and I had to take a pillow to school.

PINCHAK: Because why?

MILLS: Yeah, my arm was messed up from hemophilia, because when you bleed, which we didn’t know particularly how it works, when you bleed, the bleeding collects in places where you have a cavity, which is the joints. You have elbows, wrists, fingers, toes, knees, hips, and shoulders. You don’t know it’s bleeding there because nothing has happened for a couple of days. What happens, you don’t feel anything until a couple of days have passed by, and you have swelling, and then your muscles will not work properly. Some of the function will be lost, and then the swelling will start. Then you see the swelling, and it causes intense pain.

PINCHAK: What do they do to treat it?

MILLS: You go in the hospital. They give you the medicine. It’s supposed to go down. But what happened is, it bled there so many times that it was like this scar that’s there now. That was the onset, the beginning, early stages of what they call synovitis, which is joint destruction of the synovial fluid and tissue in the joint.

All joints have synovial tissue and fluid, and the blood eats at the cartilage, which is the mushy part between the bones, and then it starts to eat away on bone tissue, and once it eats away the bone tissue, it exposes nerves, so if you just move, you start feeling sharp pains.
That’s what I was experiencing back in the seventh grade, but the bleeding was still bad. I mean, it was going on the guideline where you use this amount, that amount, this amount, and it wasn’t working as quickly as they thought it should happen. So in order for me not to miss so many days of school, they said to go to school but take a pillow in case it gets starting to hurt.

That didn’t go well, because everybody would snatch the pillow. That’s kids. That was probably the first part when I really started having issues in school.

The rest of it was when I was just at home, because my elbows — the second thing, my leg, my right leg and the knee was the first serious incident. That was like when I was back playing with the Tonka truck. Over time, it kept doing that. You’d walk, and then one day it just wouldn’t be right, and it just kept that up.

PINCHAK: Do they ever operate?

MILLS: They did on the arm. That’s what this is [indicating]. That’s why there’s that scar there. They call that a synovectomy, and that was done on my arm in 1989.

PINCHAK: When they operate, what do they do?

MILLS: A bunch of X-rays, two or three different opinions on a doctor, then they decide what they’re going to do and tell you about the operation and what they saw, and then let you decide what you want to do. Your options are either put up with the pain if you can stand it, or if it’s just too bad and you start to lose function, that’s another separate thing, so you need to look at the best outcome for the rest of your life.

The options for me at that time were they either continue with that pain or
do the synovectomy, which makes you have function in the arm, but you lose muscular strength.

PINCHAK: Do they scrape something, or what do they do for that?

MILLS: What they said they did was, they go in because now your bone, when it’s supposed to be smooth, you’ve seen pictures on the X-rays how it’s supposed to be smooth, it’s not like that. It’s kind of like a sawtooth, jagged edge, so what they do is, they shave that down to make it kind of smooth, and then sometimes they have to use pins and different prosthetic devices to make that work. They do that, and they reattach muscles.

In my case, they reattached the muscles, because when they did all that and moved the muscles, they said they had to crisscross them. It’s a hard thing because now you’ve got to learn — after being in the hospital for 29 days, it was hard, because every day you have to do exercises, and that hurt really bad. It’s either that, or you don’t have any arm to use. You have it, but it doesn’t work.

PINCHAK: All the while you’re in school, all this is going on. You said the leg and the arm.

What was the school’s attitude? How did the school handle your being in and out?

MILLS: Elementary, they advised my mother I should be home-schooled, or at least have a nurse or a teacher come in later, probably on the weekend or some other day. My mother didn’t like that idea, and so that didn’t happen. She decided to try to send me to school, and then if it was just too bad, I’d go to the nurse’s office, but they were like, “Just sit in the nurse’s office or the principal’s office.” Rarely would they send you home. It wasn’t bad until they changed the rules and
they started enforcing truancy laws and all that kind of stuff, where you can only be absent six days out of the whole semester, and it made it hard. Other than that, I got through it.

PINCHAK: She’d do things like send you to school with a pillow?

MILLS: Yeah, because a pillow was necessary. This thing would swell so big, it hurt really bad. I couldn’t even hold a pencil to write. I was there, but I had to try to write with my left hand. I had to learn how to use my left hand because when I had the surgery, I couldn’t use it. I had to use my left hand. I never learned how to write with my left hand.

PINCHAK: When they had the six-day absentee rule, what if you had a bleed and you had to be out?
MILLS: Well, you had to be out. The thing was, you weren’t actually counted absent if you got back before the end of second period, which was probably about 11:00 o’clock. I think it was 11:00 o’clock, just before you went to lunch. So it was always rush to the hospital, get in, get out, and get back to school before the end of second period.

PINCHAK: What did you do after high school?

MILLS: After graduation?

PINCHAK: Yeah, did you go to college?

MILLS: I went to college for two years, or actually three.

PINCHAK: Where did you go?

MILLS: I went to the University of Houston Central Campus.

PINCHAK: What did you study?

MILLS: Engineering. It was undeclared as engineering, but it was mainly in electrical.

PINCHAK: What happened in college? Were you able to continue, or what happened?

MILLS: I had two bleeding episodes. I had two major episodes where I had to drop classes both semesters. The most significant one was the hip bleed, because you couldn’t tell it was a hip bleed. It was just a little pain. I rode the bus to school, so I’m packing books, going all day, walking to class, get off and walk from Scott all the way across the University of Houston campus. I just thought I was just a little tired. I said I’ll rest on the weekend.

Then I tried to type my term paper, and turned it in, because I had to go to the University of Houston to type the paper because they have a typewriter. So it was like leave class, go home, rest, and get back on the bus and go all the way back over there, use the typewriters when they were available, late evening hours
until the library closed at about 11:00 o’clock at night. Anyway, I finished my term paper.

Then I finally went in to get it checked out. They told me if I had waited two more days, my spine would have been stuck out at a 35-degree angle, so it’s like this [demonstrating].

PINCHAK: When that happened and you were bent over, how did they straighten you out?

MILLS: Physical and occupational therapy. They had to go in and put you in a hot bath. I think the temperature was 99 degrees or something. It had to be very hot. It was the equivalent to getting in a hot tub. You stay in there 15 minutes, and then they treat you with medicine at that time, get an infusion, and then they start to literally pull you back into shape. Put you on a table, one person holds you down, the other person tries to push your muscles back in a proper position. That’s painful because the muscles, when they tighten up because — what that physical therapist a couple of years ago told me, when you get injured, the body tries to protect itself by going into this state of shock. Once it’s injured, then it just tightens up so you don’t use that anymore. They said but you have to pull it back out, you have to fight against it, but it’s painful. And that’s what they did.

PINCHAK: How long were you in the hospital?

MILLS: For that particular episode, probably about a couple of days, until they check it out, and they’ll infuse you, check it out, and then release you from the hospital, but then they’ll tell you you can do follow-up. Come back in. Do physical therapy. At that time, I was an outpatient on the physical therapy.

PINCHAK: For how long did you have that physical therapy?
MILLS: Two months.

PINCHAK: What happened to school?

MILLS: I had to drop my classes after that.

PINCHAK: You had to drop. Yeah, that makes sense.

Were there times that you had to relearn how to do things? To walk or eat?

MILLS: I had to learn how to walk three times. The first time, when you were born. The second time, like I said, I had knee problems, and it got to the point where I had to learn how to walk again. Something else happened. There were three times, but I can’t remember the third time. Oh, for the hip. That hip was the third time. It was this hip [indicating].

PINCHAK: It was your right hip?

MILLS: Yeah. When I was typing my term paper, you’re sitting and you don’t feel that muscle. When you go to stand on it, you try to straighten up and you can’t. I’m just like, “I’ve got to go home,” so I’m walking like this [demonstrating].

PINCHAK: So you were walking crippled?

MILLS: Yeah, so that’s how I walked into the hospital. They looked at it, and they couldn’t see any swelling. He had ordered all these X-rays and stuff. They said, “What you probably do is have probably an internal bleed, and it’s probably pinching on something that’s making something not function,” and that’s what was going on, because it didn’t have any outside pain. It was just I just couldn’t straighten up. They said it was the muscles that controlled all that felt they had been injured, and they started to tighten up, and that’s what we had to go in and do. They said, “You have to drop your classes, because you have to come in for
therapy every other day.”

PINCHAK: What happens as you age with hemophilia?

MILLS: You’ve just got to watch your bleeding episodes. If you have too many of them, it can still try to damage your joints, and you just want to try to have as few bleeds as possible, and you watch your activities.

PINCHAK: Are many people still walking? In a wheelchair? Homebound? What?

MILLS: Well, my age, I wasn’t expected to live past they told me the 10th grade. That was the prognosis way back then. Then that came and went. Then they said, well, age 40, and that was just for hemophilia. This age came and went. Today, I’m 52. I just had a birthday in January. So I’m excited, because I thought I was going to die at age 40.

PINCHAK: That’s great. Tell me about the treatment. What is the treatment for hemophilia?

MILLS: The treatment in the early days was what they call fresh frozen plasma, which was actually just the clear part of the blood that’s contained in the blood that people give in donations. They would see you in the hospital or order a package of blood, and it was frozen. They had to wait until it thawed in room temperature. Then when they did that, then they’d separate it in a centrifuge, and that’s what they would give you. That would be packaged into a drip bag, and they would hang that up, and it drips in there for two hours.

PINCHAK: In the early days, was there any testing of blood? I guess for plasma, you said it came from several people.

MILLS: Yeah. It was only tested for blood type, not necessarily plasma type, because plasma type, as I understand it, doesn’t require to be typed. It doesn’t have the
instances of regular blood cells that require it to be typed and matched. That was probably one of the main issues why so many hemophiliacs contracted HIV, because the plasma was separated from many people. To make the package, you have to have a lot. I think that’s what happened.

Nowadays the medicine is made in a laboratory. It’s still made with plasma, but it’s made with some other type of material. When we see it, it’s actually in a powder form. It’s not really called plasma. It’s called a derivative of something. There are many of them, a lot of drugs available for hemophilia. My particular drugs are now for hemophilia B, or factor IX. There are too many to name.

PINCHAK: Tell me about when you learned you had contracted HIV from the blood supply.

MILLS: I guess I was angry that I had it because I was, like everybody else, scared when you’re watching TV and watch the news, everybody is dying. Nobody knows how to treat them. Everybody was in panic mode, and they were trying to kick everybody out, trying to tell everybody they couldn’t get an apartment, they couldn’t work, you’d get fired. It was very scary.

PINCHAK: When did you learn that you had HIV?


PINCHAK: What happened?

MILLS: The doctor came in and said, “How are you going to treat your HIV?”

I said, “What?” because I didn’t know I had HIV until she told me.

I didn’t take the news well. I can’t remember. My reaction was bad, of course, but I don’t think it was — I may have said some bad words. I don’t know.
I was really in a state of hysteria because I was one of those people that believed the TV reports back then. You had to be white, male, and gay. I’m not white, I’m a male, but I’m not gay. And that was it, so I was living on everybody’s radar.

PINCHAK: You’re African American.

MILLS: Right.

PINCHAK: Right.

MILLS: All right. But I don’t meet that, so that’s not something that people want to discuss. That’s what it was. That’s all the commercials were on. If you’re this, white, this, this, and this, then you should see a doctor. I never listened, of course, because it didn’t include me. And so I went in, and it was a total shock.

At this time, I had so many things I was trying to get done. At that point, I had left school. That was in 1991. I left school in 1983. In 1989, I got my real estate license. That’s what I was trying to move on to. Then I started having other problems. I thought hemophilia was over with, but it lay dormant for about a year or something and then started to come back. That was tricky, because I didn’t know it can do that.

Anyway, I didn’t have any money, trying to get into a new career, college didn’t work out, and I just didn’t want to go back, because I was just tired. I had finally gotten decided on what to work, and now I was at the age of 26. As I say, I really wanted to get a job because I wanted some money, and that was it. I kind of liked the real estate career, but it just didn’t work out.

PINCHAK: You learn that you have AIDS. The doctor says, “What are you going to do about your HIV?” That was 1991.
When did you learn that the doctors actually knew and it was in your chart that you had HIV? How much earlier?

MILLS: At that particular clinic, I asked them whether they know. They said, “We knew when you came in from Texas Children’s, because we were doing secret testing.”

PINCHAK: That would have been in —


PINCHAK: So in 1985 they knew you had AIDS, and they didn’t tell you?

MILLS: Didn’t tell me. I was transferred because I aged out of Texas Children’s. I was 20 at the time, and I was supposed to be gone in two years, when I turned 18, but they left me in there in the hopes I can learn to stick myself and do that, but the transition was not that good.

They finally said, “Look, you are too old. You’ve got to leave. You go over there. They can treat this illness over at this facility in the Medical Center.”

So I went there to see them, and that was in August of 1985.

PINCHAK: What facility?

MILLS: At the Hemophilia Treatment Center.

PINCHAK: What happened to the doctor who asked you what you were going to do about your HIV?

MILLS: She was unfortunately terminated. I didn’t have any fight with her. It’s just that I was ignorant and didn’t know because I was going by what they said on the TV and the information that was released to the general public. A lot of people probably had it, but the message wasn’t for them. I was upset with them and angry for a long time, but then I had to decide what am I going to do when I get
sick? There’s no other place to go but back to them. I didn’t trust them, but —

PINCHAK: So you were trapped even though they —

MILLS: Yeah.

PINCHAK: Where did you get, initially, treatment for your HIV?

MILLS: At the county facility, through Ben Taub.

PINCHAK: As far as the plasma that the HIV was in, was there any controversy about
when the agencies figured out that the supply had HIV?

MILLS: No, there was no controversy, because they never disclosed anything. They
never admitted any wrongdoing. In Texas, you’ve got two years from the day that
you find out something to make a decision. Unfortunately, I waited too late. I
waited until the third year, way too late, but the lawyers who took the case said it
was just too late, but at that time it was not a winnable case, as I was told.

PINCHAK: Was there later a treatment to treat the supply that would kill the AIDS but
keep the clotting factor?

MILLS: I think something came available. I’m not sure exactly what, and I can’t really
answer that in great detail because I’m not a doctor and I don’t have any
information on that. That’s something for a pharmacist.

PINCHAK: I know that you talked about how the doctor told you in 1991 you had HIV,
but you really had it since 1985. Were you scared about the supply, the blood
supply? Did you have fears that, “What have they been giving me that keeps me
alive but gives me this?”

MILLS: Well, I didn’t really think about it until after I was told I had it. I never thought
about what happened between me and there, because that was a medical facility.

Now, “Sue them,” they would say, they were supposed to have been
saying. “That’s when they failed everybody.”

By the time I was clear enough to think about it, like I said, I was my past my time to file a lawsuit against anybody, and then because of the facilities involved.

I was at University of Texas Health Science Center, which operates the Gulf States Hemophilia Center here. Lawyers did not want to take a case against them, and they really didn’t want to pursue anything against Texas Children’s either.

Then after that, they told me that, and they said, “Well, we’re going to give you” — they gave me the name of another lawyer, and they finally said, “The only one you should really talk to at that time was John O’Quinn.”

I decided not to pursue it because at that time I was also offered as part of a lawsuit, and the other people said there’s a lawsuit coming, a class-action lawsuit. “It’s probably wise for you to really consider just accepting it, but if you accept it, you sign away your right to sue.” There was a big but yet small amount of compensation.

PINCHAK: In 1991 when you found out, then what were you thinking about the blood supply and what was —

MILLS: I’m like, “I don’t want to deal with this.” You’re looking at it on TV of how people get treated. People get beat up. People get murdered. I called my job, immediately told my — “I need a few days off.” After I got the news, I was supposed to go to work that day? I said, “I just found out some bad news. I’ve got some issues here, and I need some time off.” Finally, I got well enough to go back to work, but my health was not clear. Then other things that I had to take
care of came into play.

PINCHAK: Back then were there any groups for people like you?

MILLS: No. There were really no support groups except — I found them only after I got treated at Montrose Center.

PINCHAK: What kind of treatment did you get at Montrose Center?

MILLS: I was referred to them by a doctor after I had a car accident. My car accident was because I fell asleep at the wheel. Once I was released from Ben Taub and I did follow-up, because they would come in because they wanted to do a CAT [computer-assisted tomography] scan once I got well, the doctor said, “You’ve got a lot of issues here. The only thing I can tell you is” — he gave me a piece of paper with the name of Montrose Center on there and a phone number.

I looked at it, put it in my wallet for about a month. Then finally I decided, “Well, I guess I need to call and hear what they’ve got to say.”

So I called them, and then they told me to come in for intake. Once I got in, then they told me what they do. They said try to help people with HIV, newly diagnosed people with HIV, and they said they’d see if they can help my situation.

I was assigned to a counselor for mental stability for about two years, and then that person left. I was assigned another counselor, and I was with her for seven years. My world was just unstable because I had such a lot of bad luck coupled with getting this and then getting it in a clinic setting. I was already feeling left out. Now I’m feeling further left out, and I just couldn’t focus on anything.

PINCHAK: What was it like in the early days of AIDS?
MILLS: It was just bad, because like when I finally tried to talk to lawyers, and I waited because I didn’t have any money, at that time it was like out of a job, things were just bad. Then as I started getting help, someone else actually worked for a doctor’s office and was able to get my medical records. We went through those, and that person also got me in contact with some attorneys.

Attorneys did some research and said that, “A lawsuit in your case is not looking good.” He pulled a lot of things out, particularly the disease itself. They cited some jury verdicts in the people who had sued, and they were getting $1 payments for their pain and suffering, and that was it.

In my case, they said, “You already had it bad,” because back then, it was like the early 1990s, the country was still reeling from segregation, and that was back in the days of affirmative action, which was a bad taste in a lot of folks’ mouths, and they saw I am trying to get a job and I got limited resources and physical disabilities. It was just a lot of stuff.

PINCHAK: Where did you get your information about AIDS? How did you find out research, or what was going on, or what to do? Was there an Internet back then? Were there newspapers?

MILLS: There was a group I was in called B HIVE. It was some positive people, and it was founded by another hemophiliac who lost his wife that he infected. She died before he did. He started it. He would get people’s names, and then he would send you a letter that he paid for himself, mailed, printed himself, and we would go meet in the park on a Saturday afternoon just to have a gathering of people.

That went on until he died, for about two or three years, and then it was picked up by another person who then worked for AFH, AIDS Foundation
Houston. She did it for three or four years, and then she left the facility.

 Somebody else tried to do it, but it finally fell by the wayside. With that group, there were one or two persons in the very, very early stages of Internet, because they would get information and then they would on their own make copies and pass it out at the meetings.

 While there were no medicines actually able to treat AIDS or HIV, there was shark cartilage and certain herbs and vitamins that proved well enough to help. There was still a lot of self-medication and self-thinking about how to do this since there was no medical treatment. That kind of helped a lot, so we shared a lot of information about what works, what not works, or where to find stuff, and that kind of information. That was 1990–1991, before I actually went to Montrose Center.

 Then once I went to Montrose Center, I just started reading the magazines there, which were for their community, which was a gay and lesbian community. Was it TWT [This Week in Texas]? The Triangle. There were a few others I really can’t remember right now.

 PINCHAK: You and others would piece together your own care. That would include nutrition. Did it also include exercise or moving?

 MILLS: It included exercise, moving, nutrition, the importance of eating vitamins, particularly antioxidants, which now is like all of the vitamins. The alphabet vitamins, A through K, as they call them, you had to know what each one does, and it was particularly useful because the vitamin K in the carrots, if I’m correct, check for yourself, because if people have eyesight problems and not necessarily knowing it was caused by HIV, and you have to lower a lot of stuff, so you have
to modify your diet even before they told you to or not in the actual facility once they found out, once they got caught up, I was going to say, about how to treat certain things.

PINCHAK: You learned a lot on your own and read a lot on your own. When the drugs came out, did you take AZT [azidothymidine]?

MILLS: I didn’t take AZT. Honestly, I didn’t trust any medicine at that time.

PINCHAK: It turned out that that probably a good thing.

MILLS: It probably was, probably saw it was for me.

PINCHAK: Yeah. Did people get sick from the high doses of AZT initially?

MILLS: A lot of people got sick from AZT partly because it was a drug designed to treat cancer, so they had a good outcome with some of the cancers they were treating even though the side effects were pretty bad. It was still what you see nowadays: hair falling out, your voice changes, you get skin discoloration, and forgetfulness and that kind of thing. I didn’t ever take it, but I knew some people who did, and they said the drug was bad. It had a lot of side effects to it. Some, they just couldn’t tolerate it.

PINCHAK: Tell me about what it was like at the clinic. I think you had mentioned that you went to Thomas Street Clinic? What was that like?

MILLS: Thomas Street Clinic is a separate clinic. It is a clinic that is run under Ben Taub Hospital. So when they mail you stuff from their clinic, it always says the words “Ben Taub” on it, but it was a freestanding clinic, the first in the nation to treat people with HIV, dedicated for just that purpose. It was a very new clinic. It became online in 1989, and it was hard to get people to work there.

People who were assigned there were not — my first instances were, the
doctors didn’t want to see you. They were there and you got an appointment, but they just made you sit there all day, and you couldn’t ask any questions or even participate in your own healthcare. It was just, “Do as we tell you,” and that’s it.

I at first wanted to stop going there, but then I said, “Well, there’s no other place to go, so I’m going to back there and just try to stick with it,” but it was just a lot of mindwashing. People of good intelligence and education were not designed to go there because you couldn’t do anything because they were always like, “Well, you have to do this. You have to do that and do it the way we tell you to.” It really changed your outlook, and that took a long time to get over.

PINCHAK: It sounds like there were long waits. Did they have any special security there?

MILLS: At first, when I got there, they had the county sheriffs there. Being the hospital district, over time it developed its own police department, which was always there. The other thing that made it bad was like when I got there in late 1995, the two big hospitals in town were trying to do research, and they were there just for the publicity of it. It was UT [University of Texas] against Baylor. Baylor was on the south; UT was on the north. If you were in the Baylor side, and you ended up on the UT side, “Oh, we can’t see you. You’re on their side.” It was partly that. It was the internal structure between the two big research hospitals who were there were brought in because of their expertise on certain cancers, but it was a new disease, nobody knew what it was, and they brought their attitudes and their, “I’m this and that, and do you know who I am?” and all that will.

I’m like, “Okay.”

I got kicked off of the Baylor side because my attitude was like, "Well,
okay. I don’t think that was right, so I did this.”

“Okay. You’re not going to follow instructions. You don’t need to come here anymore,” so I got transferred to the UT side.

PINCHAK: Did you get involved with anybody to try to change things at Thomas Street Clinic? You had mentioned ACT UP.

MILLS: Yeah. I got medication, but it didn’t seem like it was working, or something was — I had some issues. This was another incidence where you go to the desk, and they stand there and look at you but they don’t ask you a question about why you’re there. So you stand there, and after 30 minutes of just standing there, I said, “Look, I need to talk to you-all about this and this and ask some questions.” Then by that time — they had a flair for making you get agitated. I guarantee you, back in the early days, that’s where you went if you wanted to get agitated. I think they did it intentionally. That was also another reason why I also stopped going there, because I said I didn’t have to go there to get an attitude.

Anyway, I started playing with the pill bottles, and these were these stupid tops that you’ve got to put into one hand and you’ve got to be a muscleman to push down on that thing and twist it. It’s the same kind that elderly people hate because you can’t get your medicine, that thing. The top just flew off. I was just banging it against the counter. It flew up in the air. Pills, bottles went everywhere, and they were like, “You better go get those pills. Do you know how much those things cost?”

Someone was sitting in the waiting room. “Hell, man, you’ve got issues. You need to join ACT UP,” and it happened to be Matt Locklin, my mentor and one of my best friends until he passed away. He put me on his board of West
Heights, which is also known as AIDS Housing Coalition Houston. I was on that board with him until he passed in 2014.

[END OF AUDIO PART 1]

PINCHAK: What did you and Matt and ACT UP do to change things at the clinic? What changed because of you guys?

MILLS: He said, “You need to be on the Thomas Street Council, which is still active today. I got on that. I was on the council for six years. It was supposed to have been you serve two years, and then you have to be reelected, and there was an actual election. We had ballots. The first year, I went, “What?” They had to be certified and all that kind of stuff, but the people were just checking. Anyway, they go through, and they had to go through a procedure.

Anyway, I was on there for the first two years, and I said, “Well, I guess things were” — we just worked to try to change it and make things better for other patients. Particularly somebody there that would be there all day, we were trying to cut their wait down from six hours down to four. People couldn’t get their pharmacy, and that was a whole different thing because pharmacy was dictated by all kinds of rules we don’t know about. That was another problem, all day just for medications. There were just a lot of issues, internal issues with running a hospital. Then the employees trying to follow the rules of the hospital but lacking patient skills to deal with patients. That’s what we focused our energy on to change the demeanor between the staff and the patients coming to Thomas Street for treatment.

PINCHAK: That’s great. Tell me about work and working with AIDS and HIV, and how has that been?
MILLS: I’m sorry, repeat the first part.

PINCHAK: Has it been hard to work with hemophilia and HIV?

MILLS: Yes, it was already hard. That doctor who told me to go to Montrose Center, in the hallway, I’ll never forget his reaction. He said, “I’d be mad if this happened to me. You already had issues.

And that’s at this time where you’d go turn on the TV, you’d see all kinds of disasters happen. Now we see it even more. That kind of thing.

He said, “If anybody has got any issue, a reason to blow up something, you’ve got plenty of reason.”

I’m like, “Don’t give me any ideas. I see enough on the TV.” And that’s also why I needed psych treatment, because things in my mind were not right. I would think something. I’d go home, turn the TV on, catch the news, bam, somebody had done it.

PINCHAK: Did you ever lose work because of having HIV and hemophilia?

MILLS: I did. That was the real estate career, but it was hemophilia. My leg wasn’t functioning well, and then my doctors advised me, “If you have to go out, use crutches the next two weeks.”

At that time, I had a lot of clients in the real estate office, and they were saying, “We’re ready to close on the house,” so I had to go in and meet with the clients. I came in in my suit and my tie and on crutches, the metal kind, because they were new at that time. They were the brand new kind you get.

He said, “You can’t work on those. I will see your clients today, and when you’re well, come back.”

Two weeks later, when I got well enough to not have the crutches, he said,
“You’re not working with us anymore. I sent your license back to the State,” and that kind of hurt a lot. There was no recourse, because in real estate you work as an independent contractor, so you have no employer to sue.

I really wanted to, the first year I think I held my license, pay and try to get back into the business. Things just didn’t work out, and then from there things progressed worse.

Then after I left that, I think I had gotten a job at — I worked at Kinko’s for four years, and they were pretty good, except when I started working for them in 1989, after I left school, that’s when I started having problems. I had to have this operation, so they told me I would have to have the operation, and he told me the operation would take a week, so I’m thinking I’ll be off a week, and it turned out I was in the hospital a whole month. Now I worried about having a job.

Well, they held my job, but then I had to use my hand and arm to load paper, which I couldn’t do. I couldn’t operate any of the copy machines, so they put me on the cash register, so I’d deal with the customers. And then, they said, “Open your right hand.”

I was like, “This is as far as I can do it.” It’s supposed to be like this [demonstrating].

PINCHAK: It’s supposed to be fully extended.

MILLS: Yeah, and so it was like this [demonstrating].

PINCHAK: So it was partially?

MILLS: Yeah. They say, “Well, you know what? We can help you with your therapy,” because one of the other guys who I was training on, but he was pretty good, “Are you anxious for some therapy trying to get that arm back?”
“Yeah.”

So they say, “You come in every day and collect change in that hand, so we can help you with the therapy,” so that was pretty good.

And then the manager asked about the disease and all this kind of stuff. Then she said, “Okay.”

ADA [Americans with Disabilities Act] was new, 1990. So in 1991, after having some other problems, they came back and asked is there anything they need to do? They were scared. They didn’t want to fire me. They didn’t want me hurt or any of that thing. That went well.

Then like I said, other things happened before I left there. Then I had to deal with some other issues, and then I got in trouble with the federal government because they know a lot of stuff about I was a young person and I was on disability at that time and didn’t know I wasn’t supposed to be working. I made too much money when I was working at Kinko’s and had to repay them the money. Then my mother had to repay them their money.

PINCHAK: On a bus driver’s salary?

MILLS: Yeah, so she was upset, and they wanted their money in 30 days, standard protocol that’s still used today.

Anyway, she made a payment plan with them, and he told me I could still keep my disability but now I had to go into their work program, disability while working, just basically a nine-month trial period. If you stay under your disability amount, that’s fine, you can get that and still get your check. But if you make any cent over that, you don’t get your check for that month, and that happened quite a lot because they paid us bonus pay. We didn’t know when it was coming. They
paid it consistently when the store made a profit, so nobody knew about when
they were going to get a bonus check. You just pick up your check, and you get
two checks. The second check was a bonus check.

PINCHAK: Was there an incident where you were taking out some trash and there was
some glass in it?

MILLS: Yeah, after I left Kinko’s, because my job was played out, there was an incident
in the store. It was in a downtown location. They raised the rent, and the store
was now out of its monthly budget, and the sales weren’t coming in because
computers were relatively new. Everybody could go out and buy their own
printer. They didn’t need to come in and have stuff duplicated. That’s what
happened. I was last hired after four years but had to be first fired under the rules.

So I went to work for Fox Photo, and that was exciting because it was
different. It was printing photographs and using chemicals that produced real
silver, silver dust, and I got in trouble for throwing it out, because I didn’t know it
was worth money.

Anyway, on the last day that I was supposed to leave from there, I was
told to take out the trash, which I did, and somebody had broken a dish from
home. They brought their lunch there. It was a Pyrex glass that had cracked and
broken. They put it in a plastic bag and didn’t say anything. So I took out the
bag. It cut me through the bag. That’s how sharp the glass was. It didn’t stick
out through the bag. It was just sharp enough to cut you through the bag.

I’d been walking around, and they finally told me, “There’s something
wrong with you.”

I’m like, “What?”
And they said, “You’re leaving a blood trail.”

I’m like, “What?”

They said, “Pull up your pants leg.”

I pulled up my pants leg. There’s the scar. There it is [indicating].

PINCHAK: So you had a big scar?

MILLS: Yeah, it was cut pretty bad.

So I said, “Man.” It was like blistered. It was like really cut open.

They said, “What do we do?”

I said, “Well, take me to Hermann Hospital because I’m a hemophiliac. They know what to do.”

So they took me there, and then they did all kinds of stuff. But like I said, it happened on the very last day of my employment.

Then about two weeks later, I went in and claimed my last check and wrapped up some stuff, returning a couple of their aprons, and then I was told by some other employees that, “Man, it’s a good thing you don’t work here anymore, because you were going to get fired.”

They sent the district supervisor in. No, they sent the regional supervisor in for the whole business. He managed six states. So you’ve got a manager, in-store manager; regional supervisor; and then district manager.

They said, “When they got the hospital bill, they wanted to know what the hell went on here. They came in here and did all kinds of stuff to figure out — interviewed everybody to figure out what had happened, because the hospital bill was huge.”

PINCHAK: With insurance over the years, did people try to fire you because of
insurance? How did insurance play into —

MILLS: At Kinko’s, insurance was electable, if it was. I don’t think it was required.

But at Fox Photo, it was a requirement, so they took it out of your pay regardless of whether you wanted it or not. I don’t think I put it on there, because I needed a job. I had a preexisting condition, which I knew when I heard that that was a condition for people not to hire you. But anyway, later on, I found out there was a consequence for all that.

Nothing bad happened to me, but when I had to go back and actually reapply for Social Security back in 1995, the Social Security office did their own research about my job history — I had 10 years by then — about being let go, and they said I had a lot of intelligence, a lot of smarts, and college educated, but I had been let go, and I wasn’t given opportunities to pursue in a job. They said, “You have some insurance issues that probably played into that.” It was just a lot of things that went on.

PINCHAK: Because back then, they didn’t have preexisting conditions, and they’d have to pay more if someone had a preexisting condition.

MILLS: Just a condition, right. That was true.

PINCHAK: What about insurance? Like seeing doctors, did everybody take your insurance? Was it a challenge?

MILLS: The problem is, for the most part I was never sick. I only got sick when I had to go to the hospital, right? HIV, I really wasn’t sick. I didn’t have a lot of issues a lot of other people had, so I thought I was healthy. That’s why I’m like, “I’m sick?” And then I was only sick from hemophilia when something actually happened. Other than that, I was healthy, but there’s no such thing as a part-time
disease. You’re disabled or you’re not. You have to be declared disabled to get

certain benefits from the federal government. That’s what happened. That’s what

I was explaining. That’s why you have to stop working in order to get these

benefits because hemophilia in itself is a covered disability. HIV in itself is a

covered disability. You must stop working.

I was being coy and saying like, “Okay. Two more years.” That way I
can save up something and stop.

“No, you have to stop today so we can move forward with the process.”

Of course, I didn’t like that.

PINCHAK: Was there a time that you learned you had yet another disease?

MILLS: When was it? 2006, I think. Yeah, I think it was 2006. That’s when it showed

up, but I think they were just monitoring, not really saying anything. In 2008,

they said, “You probably should see a hep C doctor.”

I said, “What’s this for?”

The explanation they gave me, all hemophiliacs have hepatitis C.

Probably the end of 2013, beginning of 2014, they found out that a lot of

people with HIV also have developed hepatitis C.

PINCHAK: Would that have come from the blood supply?

MILLS: Yes, it would, because they’re saying the blood contains a lot of impurities, and

while we’re thinking it’s safe, it’s still not as safe as we presume it to be.

PINCHAK: You were told in 2006 that you had hep C?

MILLS: I think they mentioned it. You know, they give you a bunch of information, and

then they don’t really say anything, and then they come back and say, “We’re

monitoring your — your tests showed this; that your liver has enzymes that are
elevated.” And then they monitor some other tests, and they say like this, this, and that.

What they were doing was a viral load for hepatitis, and they told me mine got bad when it reached 500,000. See, the only time I ever heard of viral load was for HIV. They have another viral load for just that. They said when it got that far, it’s not that bad yet, because it’s still halfway from 1 million, and 1 million, they really want you in treatment. That’s the viral load for hepatitis C. Mine was 500,000, so we had time to work on it.

Then I was like, “I’m not sick. I don’t want to do this.”

Then they told me what the treatment was. It was two drugs. It was ribavirin and interferon. They had to be injected into a piece of the tissue on your belly one day a week for nine months or something like that.

I’m like, “No more sticks. No, no, no. Can’t do it.”

PINCHAK: And then?

MILLS: And then, I did not do anything. Then by that time, the hemophilia center here developed programs for hemophiliacs, particularly for people who were past the age of 40, who survived their HIV crisis. In other words, you have HIV but you’re still alive, and now you have hepatitis and hemophilia. They developed a particular, unique program just for us, and what they started doing was having us meet up once every three months to chitchat among each other, develop a bond, and then what they actually did was develop a program where they would send us out of town for a weekend retreat.

That worked well for a long, and I met this guy named Barry Haarde, and we became good friends, and then he told me he had hepatitis C, and he asked me
I told him yeah.

He asked me whether I was going to the doctor.

I told him no, I wasn’t.

He said, “Well, you need to go see the doctor for it.”

It just happened I think that next month, we happened to have a visit at the Hemophilia Treatment Center at the same time, so we spoke to each other, and he said, “Did you ever see a doctor?”

I said, “No.”

He said, “Well, you’re going to see one today,” because actually the doctor’s office was upstairs in the same building. He did like so many other people. “If you aren’t coming, we’re going to drag you up here.”

So he dragged me up there to see the hep C doctor, and the doctor was pretty good. I got in. I saw him for about a year, and he did his tests and monitoring. He said I was okay. “We’re going to look at this and see what your body shows as far as hepatitis C.”

We actually got two years of good results. My numbers changed very slowly, unlike everybody else, they jump and change fast.

Then we were going to take the treatment, and I went through all the classes. After I finally had various urgings to go through, take the class, went in to take — that class, they have to teach you certain things about it, and then I made up my mind to go ahead and do this for nine more months. I’m going to stick. I didn’t want it.

And then they told me, well, you know, they had made — didn’t take my
insurance; that’s what it was. I had the best insurance possible, Medicare. There was some reason that he couldn’t get it — whatever he was trying to do, it didn’t happen. He was trying to get you set up, and he had to go into the hospital to do something, and all that fell through. It was on something the doctor had to do. They said he never had it, because when the doctor was over, he assigned me a particular — his resident nurse doctor, and they said they didn’t know what was going on and they just couldn’t do it at that time.

I said, “Okay.” My feelings were hurt again. Then I’m like, “Screw healthcare. I’m going to die eventually. I’m tired of this. I’m going to have a normal life.”

By that time, I went back up for another out-of-town meeting, met up with Barry there and had some discussion. After about another six months, I had a change of mind, so I went off. Whatever happened, maybe it was time to go back.

That was good because the doctor said, “Well, it’s a good thing you came back,” but it was bad. “The bad news is that” — it really wasn’t bad news. I guess it would be good news. “The good news is that you’re not sick enough yet, but we would still like to start you on treatment, but we’re going to wait, because there is medicine coming out in pill form so you won’t have to take the interferon and stick yourself.” I guess that was kind of good news. The bad news, I just had to wait for another year. That’s what happened.

PINCHAK: Did you take the new medicine?

MILLS: Finally, I got the new medicine, took the new medicine in 2015. It started in August 2015. It was done by February of 2016.

PINCHAK: And that got rid of the hepatitis C?
MILLS: Yes, it’s gone.

PINCHAK: Does that reverse the damage that hepatitis C has caused?

MILLS: That’s a good question. I don’t think so.

PINCHAK: What does hepatitis C damage? What organ?

MILLS: It damages the liver. It’s very important for people with hepatitis C to take this very seriously because if not, you end up with end-stage liver disease, and if you’re diagnosed at that point it’s really too late. You’re at death’s door at that point. Unfortunately, I’ve lost a friend that I was working with — I saw him on the Ryan White Planning Council — had died from cirrhosis. It was caught too late.

PINCHAK: Tell me about some of your volunteer activities.

MILLS: Right now, I’m on the Ryan White Planning Council, which is good. I’ve been on there for a year now. It’s supposedly five more years to go. We’ll see about that, because my rule was I never worked for any one employer more than five years. It’s been nice. I’ve met a lot of people who were HIV positive, been around a long time. My world has been changed just because I have people who are willing to talk about this and know exactly what I’m going through and have a different understanding and a better outlook than other folk. It’s my joy now to add every moment I can get to meet up with these people.

There are so many different things I’m working with. When I joined that council, I got hooked up with someone who got me involved with Bering Omega House. I’m a volunteer there and do three times per month. My first year is under the bag, so I’m looking forward to another nice year.

PINCHAK: What do you do at Bering Omega House?
MILLS: Actually, I do janitorial work. I mop the floors. I sweep. Wash the clothes. There’s a dishwasher. There’s no handwashing of dishes. That’s it. I wasn’t sure that they were going to allow me to continue working there because I disclosed that I had hemophilia, which I had a stability problem, because I walk with a cane now, and I can’t do really patient contact because patients are so fragile, and I didn’t want to be a danger to the patients. I thought I was not going to be allowed to continue there, but they said that’s not going to be a problem.

PINCHAK: Are you on a committee? You mentioned you were on a planning committee, a planning council, but are you also doing a committee at Ryan White?

MILLS: I’ve been on their affairs committee for one year after I went through the L.E.A.P. class, which is learn, empowerment, advocate, and participate. They teach you about funding mechanisms from Ryan White. After I went through the class, all the people who graduate, they put you on a committee, which is not the actual Ryan White Planning Council, which the county judge appoints you to. I work with that, and we did a lot last year. It was an exciting year last year; that we got to review all the epidemiology and HIV reports for Harris County in Houston, Texas, and then this year we had to write a new plan for the CDC [Centers for Disease Control], the five-year draft plan that we want to attempt to implement in Houston.

PINCHAK: That’s great. Now, did you do something with teaching students and youth?

MILLS: Yeah, that was the National Youth Leadership Forum. What they would do, would bring medical students from across the country, high schools, who said they were going to go into medicine, they will bring them to Houston for two
weeks and they’ll visit a lot of medical facilities and sit and talk and have a
discussion about what they were going to do in medicine, which I found was
fascinating.

I was invited, probably that third year they came here, by someone else,
who was a Caucasian female who was HIV positive. She actually had an AIDS
diagnosis. I never got low enough to have an AIDS diagnosis. I worked with her,
and then the program was very good, and then they gave us feedback about how
we did.

We just go in and just talk about ourselves and our condition. I can only
say what I did, because everybody was separated, so you had about 40 students,
but there were thousands there and they were all separated to see different
speakers.

In my group, I kind of focused on my issues, which were hemophilia,
HIV, and I think near the end was hepatitis C, because at the beginning, it wasn’t
really talked about. I just had it. There was really nothing going on with that. I
talked to them about what hemophilia was and my HIV status and how I got HIV
from the tainted blood and that kind of thing. The first three years, the students
were good because they heard a lot of stuff about hemophilia, and they heard stuff
about HIV, and a few heard about hepatitis C.

At the end of the presentation, I noticed several of the students crying. I
was like, “What are you-all crying about?”

“Because,” they said, “you’re going to die.”

I’m like, “Really? How do you-all know that?”

“Because everybody I know who had hemophilia, they died. Everybody I
heard who had HIV died. Everybody I knew who had hep C died.”

PINCHAK: You’re a survivor.

MILLS: Yeah, so I thought that was funny, so I’m like, okay. So I wanted to make it a little bit more interesting. I think I changed it, actually taking my medications, my hemophilia medications, to look at, so I could take it out of the bottle to show them what they do in — if they go to medical school but they don’t pursue a degree as a doctor, there are opportunities in pharmaceutical drugs because now you’ve got these different powders and this medicine that you could mix and inject, and then you can make — everything is packaged. The syringes are smaller. The tubes are bigger. They used to be 6 inches, and lengthened out at 12 inches so you can operate with both hands.

Everything is packaged to go, so there’s no longer you’re stuck somewhere. You can go out of town, you pack this medicine in your carry-on bag in the airport, and keep going, infuse in your hotel room and don’t have to see a hospital.

That’s what I wanted to show them, aware from where we were a long time ago to where we are today, and give them that outsight that not everybody — that they’re thinking they want somebody — it’s not everybody — sometimes they — that’s what they hear, but they don’t know it until they actually start taking the classes, because I heard some actually decided they didn’t want to be doctors. They were in it because their parents wanted them to go to the school, but they didn’t want to do that.

Then after I heard that, then I started telling them, “Well, you can also be in insurance. You can have some expertise in the medical field, and you can go
into pharmaceutical, or you can go into the business aspect, the administration, because these are my bills.” I don’t have a copy. I wish I had brought them, for my medicine for my HIV, my medicine is separate for my hemophilia, and I didn’t ever get a bill for hepatitis C. The state took care of that. The great state of Texas took care of that.

Anyway, it just shows how much all this stuff costs. My medical bills, I have to have insurance. That’s why I had to leave. They told me I had to stop working. I couldn’t pay for the medicine. The HIV medicines, last count, was $1,500 a month. If you’ve got to have three, it’s $4,500. My weekly dosage is $50,000 for the hemophilia medication.

PINCHAK: Wow! That must have been really helpful for them. Were you involved in PFLAG [Parents, Families and Friends of Lesbians and Gays] at all?

MILLS: I was in PFLAG for two years. I was doing it just because I wanted to be more involved with the community because as I began to work with Matt, I worked with Matt but I was — he named me on his board of directors, but I had no real contact with any of the people at the house. We would just have our business meetings.

As he had bed space, then I thought we should be able to help — the call came out that a lot of the children who went to meet at PFLAG were actually on the street, homeless. That was between 2008 and 2012, there were a large number of teens being homeless and on the street,
and again there was a call in the community to go out and try to pull resources together to see who could be helped.

I went in to talk about what we had; that some of the people who were clients of PFLAG, some of the teens, could come and try to use some of our resources at West Heights Shelter. We changed the name after we actually moved from the Montrose area to The Heights because we were evicted because the property was sold and the location was torn down, and we changed the name. We still wanted to have ties back to the Montrose community.

Basically the West Heights Shelter offered three months of shelter. In other words, a roof over your head and food, as long as you had some income. He worked to get people. Matt interviewed people and was able to provide them with that until they got back on their feet. That’s when I went to PFLAG, to just let them know that we had space available, trying to get some of these teens off the street.

And then I personally, I also wanted to know what issues they faced because like when HIV, as I got further up into HIV, teens who were newly diagnosed didn’t know where to go, didn’t know what the resources were, and I was still learning resources at that time. The places you used to go changed or went out of business or had moved locations, and nobody knew where they were. I went up and made a personal mission to go in and help my community and tackle some of these community issues.

PINCHAK: That’s great. Were you involved with designing a transportation plan with Metro?

MILLS: Yeah, that was back in 1990. I wish I had brought that picture. It was a call,
begged me, and I really had nothing to do but go to a lot of stuff. I was on their mailing. I used to go to their meetings, just go to have something to do. Back then, it was different from now, how it was now. They would invite you out, and they would talk about how they are going to do different things in different parts of the community. They wanted community input. What they really did was, they made an invested effort back then to go out into the community, set up in different — and go to churches and schools, meet you at 6:00 o’clock, at 6:00 to 8:00, and talk to you one-on-one about what Metro as a company’s plans were for the Houston area, and they needed the input to know what area was bad, how the bus service could be improved, what you thought about it that they didn’t know.

PINCHAK: Because that’s what you use.

MILLS: Yeah. A lot of people were there, and I thought that was very helpful, and over the many, many years that they worked, they did a lot. They invited the news, and they gave us forms to take home to fill out, and you just write what you envision and send it back to them, and they incorporated all that.

Early back then, the good thing was their vision back then. That’s what the HOV [high-occupancy vehicle] lane was supposed to do, get many cars off the road, because the emissions from automobiles are a cause that Houston has a pollution area, and that’s what their solution was to tackle Houston’s pollution area.

They said if you got one big bus, you can move as many as 10 to 15 cars off the freeways, and then they’d give you all these statistics and all these graphics that showed this is what they want to do. And then with all that, they got this money to do other stuff, and they were continuing to try to get money, and
still the federal government, they can do highway funding, but now the political climate has changed and all that has gone away.

Anyway, at that time, my design was, I used the bus system, because I was already on disability and things in my world were really bad, and I said if I had a future, how was I going to get around? There were places I needed to get to. I said I really wanted to get to the edge of the county. “What, you’re still not there yet?” There’s no transportation to take you from the edge of the northern part of Harris County to the southern edge of the county. Still working on that. And from the eastern part to the western part.

My plan was to do HOV lanes, use what was there, what they were trying to build, and give them a patched-on idea that will make it cost-wise to do.

They kind of liked the idea and said it was simply to build an HOV lane from Interstate 45 to FM 2920 in Montgomery County along back then what was FM 149, which is now State Highway 249. Apparently, I don’t know who paid for it, but from Beltway 8 out to 2920, there’s a tollway. I don’t know any information about that. But that’s what my idea was, and they kind of liked that, and they put that as part of their draft plan to the Federal Highway Administration, and they sent me a big letter from the president at that time, sent me a big letter saying that my presentation was attached to their application and would always be part of Houston’s application for traffic improvement to the Federal Highway Administration, and that information is always in the Federal Register in the Library of Congress.

PINCHAK: That’s great. Did you also get involved with an organization for heterosexuals with AIDS to teach that not just gays get AIDS?
MILLS: That’s relatively new volunteer work. This is something that came out of discussion in 2015, very new. What happened was, now I’m a member of the Ryan White Planning. What it is, that has nothing to do with Ryan White Planning Council in a sense. It’s some people who were on the council were now on the out, and they were just trying to be an advocate for minorities with HIV who weren’t necessarily gay or transgender, and so we were trying to get together and show a face of the minority community who was not gay or lesbian or transgender or a crossdresser or whatnot. We were as we were, because we just get looked over, and that’s what our goal is, so we call it the Heterosexual HIV Task Force, and we just go out into the community and try to set up in different locations and present a face of minorities who are positive but not meet the standard, the general criteria of being gay with HIV.

PINCHAK: That’s great. Tell me about the Coalition for Hemophilia and when you got involved and what that is like and what you do.

MILLS: That’s a great institution. Coalition for Hemophilia B is headquartered out of New York, New York. I got involved with them in 2010 when I was at another national meeting for the NHF, National Hemophilia Federation, which is a national organization for the advancement of all hemophiliacs, no matter what type of bleeding disorders.

There was this group that had this flyer, just a piece of paper they were handing, and somebody, one of these people, walked in. At the registration table, they gave you this piece of paper, and they’d say, “If you have known that you have a factor this, come to our lunch. Have lunch with us today.” That’s what happened. That’s how I got involved with them.
I got on their newsletter, and they started sending me brochures. Then it became a stack of papers, and I was like, “Look at all these people. I’m going to try to start finding some of these folks.” It became a real game to me. It was like, “You got in with the wrong bunch,” because I didn’t know anybody with hemophilia. I didn’t know anybody in different places.

I kind of do that with *OutSmart* too. I always get a copy every month, look in it. Who do I know in here? Who am I going to follow?

Anyway, I was looking through names, and then they had this lottery thing that you submit your application. It’s just your name, your age, and family members, and that’s it. You mail it back to them, and they contact you if you win. I don’t know the process. It’s a total mystery. I’ve asked. Everybody says they don’t know.

They pick your name, and they contact you. The first year I got a phone call, they said, “We’ve been trying to contact you for two days,” because I had bad phone service. And they said, “Well, you won, and you’re coming at our expense to New York.”

I was like, “Well, I’ve never been to New York,” so that was the first time there. Well, I take that back. That was the first time there under them. I did go there on my own in 2011 for crisis management. I had issues going on, and a vacation, because I thought I wasn’t going to be here a long time. I wasn’t getting my medicines at that time, and I was having a lot of mental issues and stuff, and so I needed a vacation, so I went there.

But anyway, getting back to the Coalition for Hemophilia B, as it’s known, what they do is provide you with the latest information on hemophilia
drugs that treat hemophilia B, or factor IX deficiency, as they call it. Hemophilia, its designation is given by the different types of impurities in the blood, in whole blood, and so there’s a lot of them, but the main factors are factor VIII, or hemophilia A; and hemophilia B, or factor IX.

Sometimes, there’s an old term called Christmas disease. If you ever hear that, that still describes hemophilia. They did a genetic diagram of the mother and father and which offspring got hemophilia, then which one of his offspring got hemophilia, and so forth and so on. As you go through the tree, it makes this big family tree of who gets hemophilia. Now it’s just known as factor VIII, factor IX, or hemophilia A, hemophilia B.

The institution is great because what they do is, they present for answers to all persons with hemophilia, and they allowed me to meet up with a lot of people and then this take these fabulous trips which they pay for. Living on a fixed income, I could never afford any of this, never, and it’s been my world changing and then I can make friends. The best part for me is that I’ve been on so many different places that when I step into the hotel, everybody says, “Hi.” They know who you are.

I was like, “Where did we meet?”

There are videos of us back here, and it’s not just the patients, but it’s the pharmaceutical companies and the other nurses who work for different hemophilia treatment centers.

PINCHAK: That’s great. Do you see other people like you with your similar issues?

MILLS: Oh, yeah, especially there. Last year what was really exciting and really eye-opening for me is that we were in New York City, because the Coalition for
Hemophilia B pays for the whole family, so if it’s a child there, the mother and father can go, and there’s one assembly. The children are separated, the females are separated together, and the men are separated together.

The men were separated. We walked four or five blocks from the hotel to a bar. We were in a closed section to have our discussion. Then we had about four or five people that couldn’t walk, and they were on a scooter. This young guy, younger than myself, he’s an African-American guy, he couldn’t walk, and his legs were really swollen in the knees, so he couldn’t really bend, but he was on the scooter, and he couldn’t bring the scooter in because we had to walk up the steps. I turned around, and it was like the other guys who had health and strength picked up him, and his scooter, and carried him up the stairs and brought him in.

PINCHAK: That’s great.

MILLS: I just wanted to cry because I didn’t have the strength to pick up anybody, and they picked him up with the scooter and brought him in there so he could be part of that. The thing I get out of it is, it’s so personal to me because I hate to stay on the discussion, so we don’t talk about it in America, is the race relations here, but as a minority dealing with this, this is something I can’t ignore. These were gentlemen from all different parts of the country. I’ve been able in my own eyes to see how this country has changed from being white against black, or black separate from white. It’s just a family there as well as what we do here.

Like I tell people, I’m very happy now this day in 2017 about my community, my community of hemophilia, my community of my HIV friends, the gay and lesbian community, and the transgender community, because we are all fighting for the same cause: It’s to be accepted and to be treated as a whole
You talked about how so many years you spent disappointed and angry, but that this coalition and getting to travel really opened your eyes and brought you hope.

MILLS: Yeah. I was not angry at one person. As they would say when I was getting therapy, “Are you angry at the Universe?”

I’m like, “I’m always angry.”

But then they always told us that people with hemophilia were just upset always because of what it does. It shows up when you don’t want it to show up, and it limits your activities. Like what’s prohibited, there’s motorcycle riding, horseback riding, no contact sports. That means no football, no basketball, no hockey. The man sports, so to speak. I haven’t heard, but they probably will limit snow skiing. It’s those kind of things that you want to be like everybody else, but you’re not normal because your body won’t allow it.

PINCHAK: That makes total sense.

Given all you’ve had to deal with, what kept you going, and what just kept you moving forward through it all?

MILLS: There were times I wanted to give up. I thought that car wreck, I really didn’t want to wake up from that car wreck. It was not that it was something I was planning. I really did fall asleep because I was working a full-time job at Kinko’s, then I was trying to do my real estate career, so I switched and started working at night, eight hours, and then I could do real estate for four hours during
the day, and it just got to me. They needed to show how I was needing to meet with clients, because that’s what I really loved, loved a career. Then when it folded, I’m like, “Damn, there goes something else.” And then just things after a sale, like this and this and that, you’ve got to have this, got to have that, dealing with the Social Security rules and other stuff. They said really I had a lot to deal with. They said I was off sort of bad.

But what really kept me going is just, I think, it was just instances of people saying. One of the things that gave me hope was that they held the door open at the Social Security office when I was downtown, when they found out I was there to talk about my hemophilia and HIV. That’s when they told me I needed to start working. I needed to do some interview. I said, “I don’t know what you-all wanted, so I brought the whole two boxes full of documents.”

They said, “That’s fine.”

A director thought I was going to die, so she held the door open. They said, “They never held the door open for anybody. They saw that you struggled with that door.” It was one of those crazy kinds. You think you’re supposed to push; now you’ve got to pull it.

There was the other one, the other guy who said, “You have real issues. That’s why I was brought in, just to handle your case. I’m a regional Social Security administrator. I’m not even from Texas. Your case is just that bad.”

See, I didn’t even think it was that bad, because I’m like, well, it’s just people have got stuff in general. Everybody has got to get a job. Everybody has got to go through that interview. There’s always something anyway, some reason they don’t get the job.
I was like, I don’t want to be a product of affirmative action. I want to get there on my own merits. I want to compete with the best. That’s why I chose to go the University of Houston as opposed to Texas Southern University, because I wanted to be able to compete with the brightest students in America, but that was not to be, so that’s like what kept me — that was one thing, but man, I still think about that. It’s what he said, “Your case is really bad, but you were able to work 10 years, something I hadn’t even seen.” They said that was a milestone in itself, if they have hemophilia and to be able to work 10 years. They had never seen that case. Then the HIV was pretty good. It wasn’t that it was bad. I didn’t have a lot of the problems that other people had. They said, “You’re not going back to work.”

Then other people told me like, “You’re not. The nurses and the doctors get some. You aren’t going back to work.”

Then the last doctor, “You can forget that dream. You aren’t ever going back. You’ve got too many issues to put up with. You’re a minority. You’ve got racism issues still in this country. I hate to tell you, but you think you aren’t facing it.”

So with that card holding and just like I am, my mother and religious people always say, “God always gives you what you can handle.”

At first, I’ll still be. I’m like, “Wow, I believe there’s a God that exists.”

Well, I have my own question, but then he said, “Don’t question God.”

I was like, “Well, now, this is what I was given to deal with.” That’s what I tell people. “I don’t like it, but this is what I was given to deal with. Nobody did anything to me.” That’s what keeps me going.
So what’s the answer here? What am I supposed to do?

I guess you’re supposed to help others move along with this, because they didn’t ask for it either.

PINCHAK: Which is what you’re doing.

Is there something from the AIDS crisis in the early years and the struggles that you had and you saw other people, that you feel like, for future outbreaks, we could learn?

MILLS: I think we learned it with Ebola. They realized they made a mistake when it came to HIV. They waited, and the federal government didn’t want to do anything when they were under Ronald Reagan, and then all the state governments didn’t want to do anything, and everybody sat back and looked at it. But when this thing came through, everybody had a change of heart.

I saw our own governor, Rick Perry, develop his own plan. He said he was not waiting for the federal government to develop a plan. He developed one for the state of Texas. I saw it on TV myself, and that was a good day for this state. I said that’s what they need to do. Get this thing before it gets out of control, so they did learn. Our country did learn something, not to dismiss the challenges and credit that the ACT UP people and all the people at that time back in the 1980s who stood up for us to have medicine and to be treated with respect. I owe part of my existence to those people, and I also owe part of my existence to the hemophiliacs who died, particularly Ryan White, who died at age 20, and the things he went through.

As an African-American person in America who understood they’re studying and had heard how this country would harm even people of their own
race and have innocent children who got a disease, the Ricky Ray brothers who were burned out of their house, I simply cried when I read their story. I said, “Well, if they can do this to them, what’s in it for me?” So I fight for all those people whose voices were silenced.

PINCHAK: That’s beautiful. Is there anything else that you want to say or add?

MILLS: This is a very scary time because of who we have as a new president, 2017. I’ll leave you-all to find out who that is. Everybody that I do business with just shrivels over the mention of Donald Trump’s name. Nobody knows what’s going to happen. Everybody is scared that things are going to be dismantled in such a way that nobody is ever going to be able to put it back together. If the Republicans really have their way and do what they say they’re going to do, a lot of people are going to get hurt.

This country needs a lot of work, and we need to really check ourselves about our religious beliefs and our political beliefs on what this nation should be. We all are a nation of immigrants. We all come here from different countries.

If anybody should be fighting, it should be the Indians, because that’s who the land was stolen from. Now, the rest of us need to be on a boat and thrown out of here and told we can’t come to this country.

With that said, I still have to remind people that this is one of the best countries because they took care of me and my expenses, and I feel it’s my obligation back to the American people for paying for these expensive medications. That’s why I’m here alive today, and that’s why I do what I do, because it doesn’t make sense for me to be at home just doing stuff. I mean, this is really expensive medication. This is taxpayers’ money, and my federal
government has not failed me, as my state has not failed me, and my city and my county has not failed me.

I always have a good word for Harris County Hospital District, or now as it’s known, Harris Health System. They have a tremendous round of people there that don’t get the respect that they deserve in the city. The county judges don’t get the respect that they deserve in the city. They help the indigent in the city.

Working in Ryan White, we encompass a lot of issues that I no longer face. We have to provide services and care about the homeless. We have to provide services about the teens who are out there on the street. We have to try to provide insurance for people who are infected with HIV to help pay for their medication.

We are just putting things in place, and this new administration wants to dismantle half of that, so we need to move forward and make our country better and not start tearing it up, making it worse. I know we can do better. We are the country that put men on the moon and brought them back. We can do better than what we’re doing. It takes all of us to be able to make this country the best that it can be.

PINCHAK: So true. Thank you. Thank you for doing this, and thank you for all you do.

[END OF AUDIO PART 3]

[INTERVIEW CONCLUDED]

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