

A C T U P O R A L H I S T O R Y P R O J E C T

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Interviewee: Susan C. Brown

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Interviewer: Sarah Schulman

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**ACT UP Oral History Project
Interview of Susan C. Brown
March 24, 2010**

SARAH SCHULMAN: So just tell us your name, your age, today's date, and where we are.

SUSAN C. BROWN: Susan Brown. My age – 53 –

IRIS TAYLOR-BROWN: No, 54.

A: Fifty-four – my birthday was on Sunday.

SS: Oh, happy birthday.

SB: Today's date is the 24th of March, 2010. And we're in my home; 313 West 47th Street, Apartment 5W, New York.

SS: Right. And your daughter Iris is with us.

SB: Yes.

SS: Hello. So I know you're from Texas.

SB: Yes.

SS: What part of Texas were you born in?

SB: I was born down in Galveston, and spent most of my years around Houston, in and around Houston.

SS: And what was Galveston like when you were a young child?

SB: It was just a town on the coast, which changed dramatically after I graduated from high school. I went down there one time, and the – oil rigs – just, there was no horizon anymore. It was just, it was like I didn't – it was nothing, nothing, nothing like when I grew up.

SS: And what did your parents do?

SB: My – well, my stepfather – and – I mean, I had a – when I lived in Galveston, it was my mother and father. My parents divorced when I was four. My whole family are accountants.

SS: Both your –

SB: Brother, sisters – in-laws, everybody, are accountants.

SS: Now you're such a community-minded person. Was that something you were raised with, or did you come into that on your own?

SB: I don't think that there was like a trend or anything in my family.

SS: Did they belong to a church, or any kind of –

SB: We were Episcopalians, but that was like Easter and – Easter.

SS: So when do you think you first started to develop a social conscience?

SB: I think it's kind of part of being like an otherling ourselves. Just kind of feel for others. That's, I mean I could get, there was not a point, there was not even any, like kind of starting – to do anything that I can recall. Except when Biff got sick. And that's when I ever first took a position of moving out to do something.

SS: So when you were in high school, you weren't – what kind of kids did you hang with?

SB: Well, I was friendly with everybody, but never anything in particular. I was, I debated. That was kind of my identity, as far as I was concerned. I really loved it.

SS: And what kind of future did you, were you thinking of?

Did you already know you wanted to come to New York?

SB: No, not until I was, been in college for a number of years. It never occurred to me. Texans don't like New Yorkers, so – I would never go to New York.

SS: So what happened?

SB: Well, I like to travel. So I had a little station wagon, and every time I got a couple hundred dollars, I would take off. So I had come up here because Brad's brother was here; I could stay here.

SS: Oh, you and Brad met in Texas?

SB: Uh huh.

SS: I did not know that. Oh, okay.

SB: In Boston, yeah.

SS: You met in college?

SB: Um hm. Well, he was finished with school, and I was living in a house that he, of a roommate that had been his. So he came over to meet the new roommate, and that was me.

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SS: Oh, wow, okay. So when did you first realize that his brother was gay?

SB: Oh, when I got off the train in New York {LAUGHS}.

SS: Had you guys, had you had –

SB: Talked about it?

SS: Yeah.

SB: I don't know. I don't think we had. I mean, his brother was graduating from Juilliard at the time. But I don't think there was any communication about it.

SS: Now had you ever been close to gay people before?

SB: My cousin and I were very close – are very close.

SS: Right.

SB: I don't know. Not as a – identified – thing. Sphere of gay people. Oh, yeah, actually, as I think – in Houston, well, just kind of everybody I hung with. Sunday tea dances, and that kind of stuff. I just never really thought about it.

SS: Okay.

SB: It was not a – a group of people that were – doing any kind of identification as being gay, or anything. It was just totally living the Montrose life.

SS: Right. So what year did Biff [Brian Taylor] get diagnosed?

SB: '89.

SS: And did you have friends who had AIDS before that?

SB: No. We were just, well, actually, Gordon Kurtti, I don't know.

Did you know –

SS: Yes, of course.

SB: – Gordon? He was actually in the hospital, and would die very soon, when Iris was born. So she was in an ICU, and I would hang out at St. Vincent's. And went down and saw him a bit, and went back up to the ICU to be with Iris.

SS: So can you just explain for people who don't know; around Gordon's illness and death, what it was like for a person who had AIDS at that time?

SB: He was terrified. It, it really kind of happened quickly, as far as I know. I don't know when he knew – I just remember him being really terrified.

SS: And were there any treatments for him, or – no, nothing.

SB: Nothing. People were giving him advice like macrobiotic – habits, and diet and so forth. But he didn't know – he was just kind of reaching for anything. I don't think he necessarily believed in that, but he, anybody would try anything in those days.

SS: Yeah, right. So when did Biff, how did he tell you that he was positive?

SB: He ended up in the hospital.

SS: That's how he found out.

SB: Yeah.

SS: What was his first symptom?

SB: Oh, he got terrible pneumonia. Although I don't even know what we knew when. I guess we were all just kind of – coming to see it here and there. It was not really a known thing. I don't think AIDS was quite, for us, in our sphere, wasn't so readily defined, as it came to be. He, when we had seen him at the Christmas before, he had clearly lost a lot of weight. But he was a dancer, and he really looked really good. And then by May, things had changed dramatically.

SS: So did you think, I wonder if he has AIDS?

SB: I think we wondered a little bit about his health, because – just in general, and then that would – we didn't want to think that. We didn't know enough to really think it, or what.

SS: So what hospital was he in?

SB: Midland. In Midland, Texas.

SS: Midland, Texas.

SB: Um hm.

SS: And you guys were –

SB: We lived here, yeah.

SS: So did he come here at that point?

SB: After he got out of the hospital, I think it was pretty soon thereafter. It was just a given that he would come be with us. There wasn't any question. I don't know whether we talked about it or not.

SS: Was there a hope that there might be something in New York for him, in terms of treatments?

SB: Well, people were starting there with the PWA Health Group, and – there were, yeah, people were definitely moving towards looking. There were things going on. In Midland, they had to do a whole thing of getting emergency use, compassionate use – oh, I thought I would never forget the name of what – Pentamidine and something else, at that time.

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Anyway – a combination of things, and the doctor fortunately got it; that the doctor in Midland even knew to do that.

SS: It was like – can we just take that toy away?

SB: Sound effects by Lucy.

SS: Hi Brad, how are you? We don't want you to listen, so that when we interview you, you're not influenced.

BRAD TAYLOR: It will be fresh material.

SS: Is that okay?

BT: Yeah, that's OK.

JIM HUBBARD: It was before Pentamidine was aerosolized –

SB: Yeah, definitely that.

JH: – injection – or –

SB: Right. It, it was, and it was, it was like really radical. And we were just so fortunate this doctor knew anything. And sought the right treatment in that – I mean, he, it was – as it had been with many people, it was pretty close.

SS: Right. So he came to New York, and the only treatment he had was Pentamidine and Bactrim, or something like that. Some kind of prophylactic.

SB: He didn't even ha-, I don't even think – I was trying to think if he even had Pentamidine then. AZT, I think, was it. And he never wanted to take it, even though we didn't know what we knew. It just felt bad. We were trying to get Compound Q. Do you remember that one?

SS: Yes. Can you just explain, for –

SB: Well – I don't know if we ever knew very much about it.

The way we ever found out about it was through Carl George, who was volunteering at the Health Group. Which is why I came to volunteer at the old CRI [Community Research Initiative]. because he was volunteering upstairs, and, anyway, that's how we came to that.

Compound Q, as far as I knew, was like a Chinese – herb thing.

But at CRI, a couple of, it was sort of being done there, wouldn't want this. It was being done there in kind of an underground way. The Institutional Review Board at CRI would not approve it, because they didn't have any, any reason to. There was no reason to expect that it would be more beneficial than harmful, which is certainly what turned out to be the case. So anyway, the nurses there were kind of doing an underground treatment among themselves, and, and it was really harsh. People would be, you had to have somebody stay with you for a couple of days after you did it, and everybody described it as like being run over by a truck. It was really – and we tried to say, well, maybe it's just expelling the virus and all that kind of stuff.

SS: Did it have any benefits?

SB: Not that I'm aware of. I don't – yeah, I never heard of any, if there were.

SS: Right. So what was it like at CRI when you first got there?

SB: It was – I mean, all I can think of is sort of like, how nice it was, because everybody was so great. But I don't know in terms of what we were doing, because I came in originally as a volunteer, three days a week.

Did you know Joe –

SS: Sonnabend?

SB: No no no.

IRIS: Selvin.

SB: No. Joe –

SS: Oh, the guy with, the DHPG guy?

SB: Yes.

ALL: Walsh.

SB: He was the volunteer coordinator then, I guess, and he, I don't know; I met him, and started working there. He was a great lot of fun. Yeah, there weren't all that much staff. A lot of it was administrative staff.

SS: What was the situation? Can you just give us the context, like what kind of research was CRI doing, and why, and how was it different than what was happening – government research or pharmaceutical research?

SB: I think they had just gotten the first NIH grant when I came around there. In the early part, I really couldn't tell you much, until I got, until I was there for awhile. But I would mention one of the first things that came to be. There was a fellow there named Tom Hannon; really wonderful man. But I was trying, Biff was on his way to New York. And I was trying to find a new doctor. And we knew he would be on Medicaid, of course. And so I, they had a book of all the physicians in New York that would see people with AIDS. And so I had gone through it while I was sitting there. I'd call and call and call and call, and nobody would take Medicaid. Which, I was surprised, because it was a list of

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doctors who would see people with AIDS, so – I, I found it surprising, whatever that means. {LAUGHS}

But I asked Tom Hannon. And he said, call Joe Sonnabend. Here's his number. You'll wake him up, but it's okay.

And that's exactly how it happened. And Joe said, as soon as he gets here, tell him to come see me.

And that was the beginning of a real relationship for him and Biff and all of us, really.

SS: Now can you help us understand a little bit about Joe Sonnabend? I mean, he's like a savior to so many people. How did his vision lead to CRI?

SB: He and Mathilde [Krim]– as I understand it, from him; they worked together in a lab. And he had this idea for the American Medical Foundation, I think is what – or AIDS Medical Foundation, I believe is what the very original thing was. And he wanted to do research. And he needed somebody who had a little bit of flair to get the thing off the ground. She had money in her family, and so forth. So that's how the two of them came together to do that.

And he was, he's purely a scientist. And it governs everything he ever did. So that he did not prescribe things if he didn't think there was real chance of benefit. Well that's not true, because sometimes he would say: it won't

hurt, it – it won't hurt, it might help. But he basically always went by the research. That's why he totally understood that AZT was not on. He actually had a whole transcript of all the, I guess the FDA hearings on that. Just that it was based on — I'm trying to think — can't remember what the, what the flaw in all of that was.

But you were just asking me about him.

SS: Yeah. How did he come to start CRI?

SB: There were no therapies out there. Oh, and he was working with — or being with — my mind — Michael Callen; and –

SS: Richard.

SB: – Richard Berkowitz. Yeah, and that's what it was. He – he worked in a lab out at Kings County Hospital. And then he was at NYU, or something. But he started doing, seeing people with STDs, because it was coming up more and more. So he started a little practice, where he just saw men with STDs.

So – in the course of that, he began to see the trend of what was going on; that men were showing up with multiple STDs. And so the behavior was causing them to be sick.

So that's – I mean, as far as I understand – they went into their own community to try to articulate this. And it was not met with very much enthusiasm, because people felt like they were being indicted for their lifestyle,

rather than, we know you're going to, we know we're all going to continue to do this, but let's find a way to do it where we don't make ourselves and each other sick.

So that's what they did. Originally Joe and Michael and I guess Richard went into the bathhouses, and tried to do some teaching, instruction, education, I guess, about that. But I don't even know where, what happened to that. I don't know, I know they were not met with – much appreciation. So I don't know whether it had any effect at that time. I don't know what happened after that.

But there was certainly no, there were no treatments or therapies or drugs or anything. And I don't really know what Joe's – how he made his decisions on where to go. Oh, they were doing the egg lipids thing.

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SS: Oh, right, yeah.

SB: That –

SS: AL-721?

SB: Yeah. And I don't know how they came to do that. I don't know what the reasoning was behind that particular concoction, which they literally made in their bathtub. I don't know what the mechanism of action was supposed to be with that.

But they were trying anything. And of course, like the people like Michael and Richard would come to Joe to, for guidance – where to go next.

What can we do? What might work? That sort of thing. And I don't really know how he made his decisions about what to try. Initially, it was basically about keeping people alive. And he started using, well, of course, Pentamidine – did the trials with the West Coast – San Francisco had a similar organization, and the two organizations together did the aerosolized Pentamidine studies. And it was approved, based on their data.

SS: With Marty Delaney. Was that it? Project Inform?

SB: No, no.

SS: Oh.

SB: It was a community – something Community [Clinic] Consortium.

SS: Okay.

SB: CCC, but I can't think of the first – very similar to CRI.

SS: So they got Pentamidine approved –

SB: Aerosolized –

SS: – outside of the government and corporate structure for –

SB: Oh, as far as money and stuff? Yes.

SS: Yes. Well –

SB: Yeah, and I don't know what, how that was funded. Maybe it was through AmFAR, at that time.

SS: Um hm.

SB: That would just be my guess.

SS: Wow.

SB: Yeah.

SS: So when you came onboard – it was the height of the AZT craze when you came into CRI. What was it like to be in the anti-AZT camp at that time?

SB: Well, I had no reference to others – at that time, I didn't know other organizations, I didn't know other people or other physicians that were prescribing. I do think that Biff's doctor had prescribed 1200 milligrams. And Joe wouldn't do that. And I don't know whether – anyway, they ended up with 300. And I think it was one of those things where Joe said – at that dosage, probably won't hurt and might help – just as a, more than anything, probably to give a sense of there being something.

SS: Was it hard for Biff to decide not to take high-dose AZT?

SB: Oh, no. He –

SS: Okay.

SB: – I think he probably even proposed it, as much as anything. And I don't know whether that was based on information that he had, or just more of a gut thing, which is what a lot of his decisions were based on. And I think that's part of why he and Joe worked so well together, is because Joe was very respectful of that. He would have to push sometimes for real therapeutic –

whatever, because Biff might not be so – interested in a, like – was it Cipro, or – there was another one. There were some very harsh medications, even early on, like – a real intense antibiotic. Which in his case, he actually had serious gut problems – MAI.

But your last question –

SS: I'm just wondering about the atmosphere –

SB: At CRI, or in general?

SS: Well, both. What was happening with Biff, and what his therapy trajectory was, and at the same time, what was going on at CRI?

SB: Like I said, I can't remember what there was at that time. Bits and pieces. There were things like, the DHPG thing was happening. And it was, of course, very harsh, and reduced people's white cell count to deathly levels.

So then there was EPO, erythropoetin. Which elevates – I guess it gives you more red blood cells. I don't know; it's what, we would balance. That's what people would – and extremely, extremely expensive drugs.

SS: And these were all being infused through a Hickman [catheter]? Is that how people were taking them at the time?

SB: The EPO, I think, was just an injection. And DHPG was that terrible concoction that you had to, yourself, you had to put it all together, and do that.

SS: Did Biff do DHPG?

SB: Mm-mm.

SS: No.

SB: And I guess because whatever; it was actually – intended for, whatever, was not one of his conditions at the time. He was really, really sick within the pneumonia; never really got – well, I was going to say he didn't really get past that, but I don't think that's true, I think he did. Because then, the aerosolized pentamidine. So that was one of his therapies across the board all the time.

It seemed like there were a few things that were, that carried through, but I can't remember. I know he tried DNCB, which is another just – it's like, I think you can buy it in the health food store, which is something we were doing a study of that. And I don't really remember what the mechanism of action with that was, either.

None of these were things were so compelling. Basically, we were trying to keep people healthy as long as we could. So dealing with the opportunistic infections, which of course, pentamidine was the most significant, because at that time, I'm sure, as you know, everybody died from pneumonia, and they died real quickly.

Oh, I know another study that CRI, and it might have also been the West Coast, did a Bactrim desensitization study, because when people take Bactrim, they very very often are allergic to it; have terrible, terrible, deadly

reactions to it. But it's an excellent drug. And one reason that was on Joe's list was because when he worked in King's County, he worked with transplant patients — kidney transplant, I think primarily — so in order to do the transplant, their immune systems are taken way down. And then, of course, they're subject to all kinds of other infections. And that's where his train of thinking, I think, came from; just watching what happens – in a suppressed immune system like that.

So – it was just a timing thing, and I think that's probably what he would say. It was really a timing thing, relative to his knowledge, his working arrangements, and just kind of happened.

SS: But also, wasn't it that the corporate, the pharmaceuticals really had no interest; that they were just restudying and restudying AZT. So when you guys would do a trial, often you were the only people doing it.

SB: Oh – I don't know – I don't know what anybody else was doing, like the West Coast, or I think that – New England CRI was there. But yeah, there were definitely not pharmaceutical studies. It was not until I had been there for four or five years that we actually took in pharmaceutical studies, as far as I recall.

The first one I remember was rifabutin.

SS: How did that go?

SB: Well – it was being used – I want to say it was being used for MAI, but I'm not sure that's true, what its usage was. I think any of these drugs alone, given, not in the same way that now combination drugs are so much more beneficial – effective – but even then, if people weren't being treated otherwise, then shooting at one thing, part of their illness or another, was only partly effective.

SS: Right. Now were people clamoring to get into these CRI trials? Did you have to exclude people?

SB: I just don't remember anything being that hot –

SS: Um hm.

SB: – anything –

SS: Did you have trouble accruing people for the trials?

SB: I don't think so. We had a good, a large staff of nurses. Even by what I work with now, and we do a lot o' studies. They had four nurses, at least. I just don't even know what the – early drugs were, that they –

SS: So what were the conversations like? When you have someone in your family who's dying of AIDS, and there's no treatment, and you're working in a frontline organization, and you know there's no treatment; how do you deal with that emotionally? How did you guys talk about it?

SB: I don't know whether there were very many frontal conversations about it. I think there was frustration because there wasn't anything to help Biff. So as he got sicker, or couldn't get much better – because he would go up and down. He would be fine sometimes. He continued to work on his masters degree in dance, outside of Dallas. He'd perform, and stuff like that. But he would go really up and down, with his two T-cells.

SS: He had two T-cells?

SB: Uh-huh.

SS: Oh, my god.

SB: So there was frustration for him, and all of us for him. But I don't recall – Brad would actually have more of a, something to say about that, because he had the more – angry response to that. Because he was with a group of people also doing that. But I don't think that Biff had any interest in ACT UP, or – I don't know what his thinking was, whether he thought that pressure on the industry would yield him anything. I don't recall anything like that.

SS: So did he end up doing any other treatments?

SB: Well, not like AIDS treatments; more like OI kind of things. He was a patient of Don Kotler's, because Joe and Don worked together quite a bit. And he had MAI, which really was his, caused him the most sickness, because it causes terrible gastrointestinal problems. And he wasn't absorbing

food, because his gut was just a mess. It was – necrotizing was the word they used.

And Don put a tube in his stomach. I guess we were doing, feeding that way. I was trying to think that there might have been something more beneficial than just feeding. He did stuff like – what are the – oils that people use now? Triple-something – tri-omega, [Omega 3] or something, I don't remember. But whatever it was, that's what Don was doing, in an attempt to help him absorb food. And it worked very little, and he didn't get any satisfaction out of eating – and he had all of the visual symptoms of AIDS at that time. For this beautiful dancer, whose body was – not everything, but it was definitely nice. And it withered.

SS: So when did he finally die?

SB: August of '92.

SS: So he went from '89 to '92.

SB: Mm hm.

SS: Right.

IRIS: August 18th.

SS: August 18th. And did he die in the hospital?

SB: He died here.

IRIS: He died –

SS: In this house?

SB: Um hm.

IRIS: He died in my mom and dad's room.

SS: Okay. Did he know he was dying?

SB: Yeah.

SS: Yeah. So that was all on the table.

SB: Yeah.

SS: Yeah.

SB: And he was – when, we didn't speak about, I mean, he and Brad very well may have. But he was certainly angry. He would go through sort of, an understanding of it, I guess – what are you going to do? You know what's happening to you. He became unable to go out. Although he did, I'd say, up until the end, he would get dressed and go out most days, even if just for a minute, and climb the stairs and come back. But he was pretty angry towards the end.

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SS: Now how did his death affect your work at CRI?

SB: Everybody there knew him.

SS: Um hm.

SB: I don't know, I just think we were in this, we were kind of plodding along, is kind of the best way I can see it. At that time, we were still just doing, uh – the fairly benign opportunistic and drugs for opportunistic infections. And I don't know why I can't tell you about them. The first – anti-HIV drug, I'm

trying to think – what that might have been. I don't remember whether we did – I think we did d4T –

SS: Oh, okay.

SB: – oh yes, we did. Which was very toxic. But it worked real well with 3TC, so a lot of people made it with that combination, to where we are now.

SS: They got them through to the –

SB: Yes.

SS: – protease inhibitors.

SB: Yeah.

SS: And that's the one where people were injecting in their stomachs? Is that what that was?

SB: Oh, no. I don't know –

SS: Oh, okay.

SB: Yeah. And ddI – we didn't do the ddI studies, I don't believe.

SS: So you think that that d4T was a real bridge transition –

SB: Well really, it was 3TC.

SS: 3TC.

SB: And then having another drug; just having something, I guess, that would work together, d4T. Because there were no drugs. I mean, there was AZT; ddI; 3TC; and then d4T, in that order. So the 3TC and d4T just, the first

time they used a combination. The minute they – I don't know how it came to be understood. But that made all the difference. Peter, that was his first combination.

SS: Peter Staley.

SB: Peter –

SS: Peter Cramer.

SB: – Cramer.

SS: Right.

SB: I'm pretty certain that was his first. And it lasted him for years. And Jack, unfortunately – I mean, he's certainly fine – but he was kind of on the one drug at a time, because he was more in need of, he got so sick, early on. And he did, we did do the first – ritonavir study. And that was one of those times when there was, there was a list, there was a clamoring for spots to get into that. And he did.

SS: Jack Waters got in.

SB: Jack got into it. And it wasn't until some time later that we realized that that was probably not to his benefit, because then there's resistance – taking all these drugs one at a time, sequentially. But that certainly opened the doors.

SS: How many people could you get into the ritonovir study?

SB: That one, I think we had 30.

SS: Wow.

SB: Which was huge. That was huge.

SS: That is so small.

SB: That was huge!

SS: Oh.

SB: It might not even have been 30, but that's the number that sticks in my mind. Certainly I know it wasn't more than that.

SS: Now when did you start shifting your understanding from looking for a cure — I think early on, there was a conception that there was going to be like a pill that you would take, and AIDS would go away — to the idea of combo therapy, as a conceptual shift?

SB: I don't know, from a scientific level, or – I guess they can just see that what, all of what they were doing was not actually improving people's health; it was just keeping it from getting worse. I don't think that people were actually getting better. I can't say that, as a non-medical person, but I don't think there was much improvement. People might have gained a few T-cells here and there, but didn't stop, stopped losing them, at least. And then all those early drugs, as they all do, had lots of side effects. Ended up with all the facial wasting, and the buffalo hump, and all of those many things. But people, it certainly kept people going. And that's what it felt like at the time. It was like, oh, if you can just make it to this, then by then, we'll have more drugs. And that's really what it

felt like. Because they were coming then. And I'm sure it was ACT UP – pressure that led to that.

JAMES WENTZY: We have to change the tape.

SS: Okay, we're going to change tape.

SS: Okay, so we want to just correct the – go ahead.

Tape II
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SB: 3TC and d4T – actually, I think after AZT, 3TC – I mean, AZT, ddI; then ddC –

SS: Right.

SB: – and I think that that's the one that was actually, had some bad side effects. And then there was d4T; 3TC and d4T, and those were actually workable, and not so terrible, I think. And I don't know that anybody uses d4T anymore, but 3TC's in a number of the combinations –

SS: It is, still. What was it like for you, just emotionally, being at CRI at that time, and constantly be testing things that weren't working?

SB: Mostly what I remember is just being in that building on 26th Street. And we were on the basement and ground floor. And then the Health Group and – David Meieran and –

JIM HUBBARD: Testing the Limits.

SB: – Testing the Limits; they were above. And in that building, with so many people who were sick; it's just like you got to a point where passing each other in the hallway, it was very – very often terrible news. And that's really

what a lot of people who passed in and out of there at that point — other volunteers and all of that — were losing people. And I think, I remember a feeling of it being — it was not exciting, like we're getting somewhere, we're doing something. I think it was just sort of — I don't know — not hoping it wouldn't get any worse, but really wishing that something would change.

SS: So when you did finally start to get a result, did that motivate you as an organization? Did that affect CRI?

SB: I actually was out of there by then.

SS: Okay.

SB: By the time the protease inhibitors came around, except for the one ritonavir study, I had moved on to NYU. And it did have all this energy behind it, because it was working, so there was, it started, things were really moving by then.

SS: Now what was your expertise at that time? What was your title?

SB: Early on?

SS: No, when you moved to NYU.

SB: Regulatory affairs, is what I do, is basically all the approvals that are required to do human subjects research; both institutional approvals and this that.

SS: So when you got to NYU, what studies were you involved in?

SB: We had a Merck study, which started right when I began. And it was – it was a triple combination. But I can't remember what it would have been, what the drugs would have been. And it was a pretty good-sized study.

SS: And what year was that?

SB: '96.

SS: So in other words, triple combination has been around since '96? because isn't that standard of care now?

SB: Oh, yeah.

SS: Okay. So –

SB: Yeah.

SS: So they knew that that was the configuration; they just didn't know what the drugs were going to be.

SB: Well, they didn't have any, enough drugs to choose from. Once they – yeah, that's, a lot of it was they only had one drug, and – another drug that was the same, but worse, or something, with AZT, and ddI and stuff. And I guess it wasn't until they started getting different classes of drugs – that they could put a combination together, and see that it actually had effect.

SS: So for example, now, I know, Atripla is what everyone's on. And it has Sustiva in it. And so many people can't tolerate Sustiva. But

it's built in to the drug. So is that – it seems so not optimal, to have something that's so toxic be a required part of the beginning of medication.

Why is that the case?

SB: I don't know. And I think that all the time. But apparently, the side effects with Sustiva are short-lived. They don't generally stay with somebody after the first couple of weeks. That's my understanding entirely, with individuals and from the way it's presented, in informed consents and so forth, when people ever first started taking it. But everybody has, across the board, had pretty much the same initial response to it, which is terrifying, but they were halfway expecting it, because they knew that was the side effect.

Tape II
00:05:00

SS: Now in terms of the way that the people doing research, their attitude towards patients from when you first got to CRI to now; and this is totally anecdotally, it seems to me that people are not told accurately how bad the side effects are going to be; that the medical practitioners don't experience bad side effects as bad as a new patient might actually understand it. Do you think that that's become systematized? Or does that really just depend on the doctor?

SB: I think it probably depends on the doctor. And in fact, when we were talking about Bactrim; I could never understand why physicians didn't – I mean, it was such a known side effect, and so likely to occur, but people

dispensed it, and didn't warn, if, in a couple of days, you start to have a rash or whatever; call me. Even – name that antihistamine – Benadryl –

SS: Benadryl.

SB: – was very useful, at least in the beginning, if you started to have that effect –

ITB: – side effect.

SB: So the doctors, in that case, were just thinking, this will work; but they were not concerned about the patient's response to that. And I guess that may be the case – now, I don't know; we're very concerned about side effects, because that's, now, that's what a lot of our research is about; and has been for awhile, in terms of new drugs. And drug companies and everything too, trying to maintain effectiveness and reduce side effects.

SS: So is that what everyone studies? What is the level of research on AIDS drugs now?

SB: Like are there new drugs, or –

SS: Yeah. Are people looking at new drugs?

SB: There have been some new things. We had – the – entry inhibitors. There are new classes of drugs. I can't think that there's anything right this second that is so novel.

SS: But are people still looking for a vaccine, or is all of that still happening?

SB: Not where we are. And there is an enormous vaccine –

SS: Industry.

SB: – industry, I guess, yeah. And study – but I don't think that people have – very much. Certainly in terms of preventive vaccine. I don't even think there's much discussion about, I mean I'm sure that people who are trying to get money to do it, and – there probably is. But a therapeutic vaccine, we didn't do the study ourselves. Oh, we did do some.

SS: So just from your point of view, what are the most pressing things that need to be done in AIDS research?

SB: I think there are really effective drugs at this point. So really, the side effects are – the work to be done, at this moment. Because I don't know where people fail. I don't think people fail their drugs; the drugs fail the people. Important distinction. We determined years ago that the wording of people failing their drugs was – negative. It was like putting the onus on them that they had failed their drugs, other than the drugs failing them.

Most of the times, when people, when the drugs appear to be ineffective, it's because they haven't maintained adherence to the regimen. Because really, the drugs are very effective. I'm sure that there are – people have so many different variations of virus, and their own health, and all that. So some people may not respond well. But by and large, I think the drugs are pretty effective.

SS: So you think that at this point, most people should be able to live a full life?

SB: I do think that.

SS: Yes.

SB: I know so many people now who have been here for 30 years; 30 years.

SS: Right.

SB: I mean, and as we hit our mid-50s, my dad died at 60, so –

Tape II
00:10:00

SS: Right. So when I was talking to you about this interview, you said that you did attend one ACT UP demonstration.

SB: Oh, right.

SS: Can you tell us about that?

SB: It was at St. Patrick's.

SS: Yes.

SB: We had Iris in a stroller. It was, it was big. I think it was a Sunday afternoon. I guess that would make sense, if people were at St. Patrick's. And, heh. We had our, Iris had her little ACT UP T-shirt on. And – and her two- or three-year-old voice was chanting – ACT UP, Fight AIDS.

ITB: ACT UP, fight back, fight AIDS.

SB: Thank you. She knows. She knows.

ITB: Because I was, I was, I was at millions of ACT UP demonstrations—

SS: Yeah, you probably were.

SB: Yeah, there was a lot of energy by then. I think there was a lot of energy. And there was a lot of anger. There was specifically, at that moment, against the Church — yeah, against the Church — for not supporting condom use. Which is just kind of deadly. That was a spirited demonstration.

SS: So from your point of view, as someone who was involved with the development of drugs, what was the greatest contribution, or ACT UP's greatest success, from your point of view, in terms of the AIDS activist movement? What was its biggest contribution?

SB: I think it was awareness. I think it was bringing, forcing — both regular folk to see what was going on; and certainly, the industry itself, and the government, to just not back off. I think it took really screaming in their faces. Because they would like everybody to just, I'm sorry, we're, we're trying, or something. But it was really the — maintained pressure, and — lively work, for a long time. I think it took a lot.

SS: And what would you say was its biggest disappointment? What did the activist movement not get to do, or not achieve?

SB: Well I don't know, in terms of from a drug point of view. I'm not sure how representative it was. There were certainly other communities

besides the gay community that were heavily affected. And I don't even know that they ever really took it on, like ACT UP's sphere, took it on to bring any awareness to – like, black and Hispanic women; remains, or –

The most devastating area these years is black and Hispanic women. And I don't think that ACT UP – certainly, they didn't promote any kind of awareness. And I don't even know if they thought about it, or cared. I know that there came a time when there were – men of color, I think, began their groups. But I think that when you're fighting so hard for something, for – rights and respect and attention and – that it was a little bit unfortunate that they didn't see beyond their own – group.

SS: And that division is still at play.

SB: Well probably, as far as activism. I have so little to do with it. I don't –

SS: But what about in terms of drug research?

SB: Well, our studies are almost entirely black and Hispanic. We have – because everybody else has access to the drugs. White people have insurance, or they have ADAP. And actually, so do a lot of the black and Hispanic, people in New York; ADAP is great, and it's available. But – not everybody has all the social services, and all of that. I don't think – we don't have very many white gay men anymore. We certainly have some. But I think

Tape I
00:15:00

our greatest population is Hispanic, and we have like a 28 percent enrollment of women.

SS: And so are drugs being developed differently, for the new populations – “new,” in quotes.

SB: Right. I don't know that there's different development. I think it's only, oh, I was going to say it's in terms of – studies. Like trial participation. Yeah, I don't think that there's any kind of a direction, any kind of a concern that other groups of people might have different – biological or whatever concerns with the disease. I don't know that there's any kind of –

SS: Because early on, there was all that – the CDC definition didn't meet women's symptoms, and –

SB: Absolutely.

SS: – drugs were not being tested on women, and drug users had totally different general health –

SB: Right.

SS: – situations. But all of that now, you feel, is completely factored in.

SB: I think – well – I don't know whether it's factored in, or nobody's making a distinction anymore. I couldn't really say.

SS: Okay.

SB: We just do have more participation of – women and people of color.

SS: Jim?

JIM HUBBARD: Yeah, that's what I was going to ask about the participation of women. In the beginning, they were specifically excluded because of the possibility of pregnancy.

SB: Right.

JH: So that's no longer the case.

SB: And it was just, I think it is still the case, across the board, that in general drug research, that women, they always excluded women, because it was just too much of a variable. Like with men, they knew what they were dealing with, and they didn't want any kind of variation in the results, and so forth. So we all have, all the antihistamines and all the this and that that were approved were never even studied on women. Not at all. And they all went to market, all that stuff. I don't know if they're, they're probably required, at this point, to have –

SS: We don't know if that's true. Is there, in the research community, is there any discussion about prevention?

SB: Oh yeah. That had become a whole swing for a while. I think even in our trials, that's a big component of – when you have someone in trial, it's a constant conversation. Even though these people are largely suppressed, in

which case they're probably not as likely to transmit. But yeah; prevention is certainly still discussed, and I think there was a time when there was actually money associated with the idea of – prevention. It's just my mouth –

SS: It's okay.

SB: It's affecting my brain.

SS: I just have one more question anyway.

SB: Like I recall when they were trying to do condoms outside of high schools and stuff. Because it was just so clear, once we understood how you get the disease; it was so clear; condoms and clean needles, and why we had to continue to have people become infected after we knew that. And it would be 10 years before they would even ever talk about any of that. And ACT UP did their needle exchange work early on, which was extremely important.

JAMES WENTZY: This is a longshot. When you were working there were you aware of the AIDS Cure Project at ACT UP –

SB: AIDS Cure?

JW: Yeah.

SS: No.

JW: They were going to establish, it was a plan to establish a separate research body –

SB: Was that later, with the Peter Staley crew?

SS: No, that's Maxine.

JW: No. It was –

SS: What are you thinking, James?

JW: If you had any thought about state of basic research?

SB: Currently, or –

SS: At the time, right?

JW: Well, maybe now, too.

Tape I
00:20:00

SB: Well, that was a lot of Joe's work, was in that. I'm not sure how much he ever saw himself as a clinician. He was always a scientist. And like I said, that's still how he sees treatments and so forth, from a scientific standpoint. Like the mechanism of action; is it possible that it would work in this situation, or –

And as far as what's being done: I think there's definitely still work – and I think there is actually still that hope, of a vaccine and so forth. But I don't know enough about it, about basic research. But I think it's still a big component of – I know that at NYU, they – certainly have – areas of work. But I think that they're so basic science that I don't even know what – they're so molecular, or something, on such a level that I don't know about it.

SS: My last question has to do with the Obama administration. This last year; has there been any kind of impact? Have you seen any consequence or result of Obama being elected – on research, funding, or anything?

SB: Well, no. Certainly our – we're NIH, then DAIDS, Division of AIDS, is who we're under, who funds our, the ACTG. And the funds have changed considerably. And I don't really know where the direction is coming from so much. But now, they don't want to have – because the illnesses overlap now, because of the side effects; like instead of just treating people with AIDS, they want to put heart disease, and have it an area, and then have people with AIDS who are having heart problems there, rather than treating them as people with AIDS.

So there's changes like that. But I don't know where they come –

SS: But do you think that that's positive? Or how do you experience that?

SB: I don't think that's how we feel. I think we think that those are side effects of the disease and the drug, and not to be managed in the same way as someone who has maybe an organic heart problem –

SS: So it's redirecting people with AIDS into larger categories of illness.

SB: Yes.

SS: So in a way, starting to eliminate the category of people with AIDS.

SB: I guess that's, yeah. Like I know there's a whole kidney thing, and like that –

SS: And that's coming from the Feds.

SB: Well, I would suppose so. I don't know how – in the time that he's been in – I don't know what effect that has had on the stream downward.

SS: Right. Okay, thank you, Susan.

SB: Um hm.

SS: Thank you so much. You told us many things we had never heard before, and probably didn't know. So thank you. I really appreciate it.

SB: Well, thank you. I can't see that there's much – between my –

OFF-MIC DISCUSSION CONTINUES

SS: There's so much.

JW: Well there were the good slurred words.

SS: No, you know a lot that nobody else knows. Yeah.

SB: I should go back and read the history myself. You know, I still have tapes from IRB meetings, and discussion. But not even remembering what drugs we were looking at at the time. But we certainly had – the IRB determined whether, about the risk worth it ratio– it's equitable enough to consider doing them, a study, or putting people on a study.

JW: Remember the old days – '91? Urine therapy? That was a contender.

SB: Oh, I know, with – HEAL [Health Education AIDS Liaison].

SS: Oh, god.

JW: HEAL became a fashion –

{ALL TALKING AT ONCE}

SB: God, there were so many – well, I was just trying to throw the net large.

SS: There was shark cartilage.

SB: Yes.

SS: There was dextran sulfate.

Tape I
00:25:00

SB: Yeah. I remember it by name. The shark cartilage, I definitely –

SS: Michael Callen was into shark cartilage. But I think that the reason that everyone was taking Compound Q was that Larry Kramer stood up on the floor of ACT UP and said, They're dancing in the streets in San Francisco, because they've found the cure, Compound Q. And that's why everyone was running around –

JW : How was the music?

SS: The sea cucumber, or whatever it was.

JH: Yeah, that's –

JW: I swear, that's what killed Jon Greenberg.

JH: Chinese.

SB: You know, there was at least one death directly –

JW: This wasn't direct but -.

SB: – Barbara Starrett ended up – I don't think she ended up in trouble. But I remember the *Times* article, and her name was included in it. Because I guess she was willing to give it to patients, even though it wouldn't be under study with us.

JW: At least you cook with it.

SS: Would have died anyway.

SB: Yeah, absolutely.

SS: Yeah,

SB: But I guess indirectly to –

But that's why I ever began doing the work, because we were trying to get a lot for Biff. And I guess by the time he actually got out of the hospital and got up to New York, it was already known it wasn't going to be a usable therapy. And I was always grateful for that. The timing, we hadn't gotten in that program

SS: Well just people clamoring to get into studies for drugs that just killed them. Yeah.

JH: So wait: I'm confused. Because I was trying to – when is Carl [Michael George]'s film? Of Biff?

SB: Oh.

SS: Three dancers.

JH: Six, 6 Feet.

SB: Oh. Yeah, 6 Feet.

JH: Yeah.

SB: Well, that must have been – for some reason, I, I have it in mind that it was in autumn. I don't know if that's true. And if that's the case, it was probably '91, before he died in '92.

JH: Oh, oh.

SB: I know that he was – pretty sick at that time.

JH: Yeah.

SS: Although he pulled it off.

JH: Yeah.

SB: I think he even did — and I can't imagine — performance of *Threepenny Opera* in Dallas, right before he died. Which sounds terrible to me.

SS: Well he lived until he died.