

A C T U P
ORAL HISTORY
P R O J E C T

A PROGRAM OF
**MIX – THE NEW YORK LESBIAN &
GAY EXPERIMENTAL FILM FESTIVAL**

Interviewee: **Bob Huff**

Interview Number: **079**

Interviewer: **Sarah Schulman**

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ACT UP Oral History Project
Interview of Bob Huff
May 31, 2007

SARAH SCHULMAN: What was the film you showed in Mix [Festival]?

BOB HUFF: What's, I don't know.

SS: Oh, our film festival, that we started; the gay experimental film festival.

BH: When was it?

SS: It had the word "fugue" in the title.

BH: Fugue? No.

JIM HUBBARD: No, I looked it up. It was *Asshole is a Tense Hole*.

BH: Oh, *The Asshole is a Tense Hole*.

SS: Oh, okay.

BH: Oh. When was that?

JH: '92? Something –

BH: That's about right.

BH: Yeah. That was a 1985 video.

SS: Oh, okay.

BH: Yeah. That's actually pre-ACT UP, but

SS: Okay.

JH: Oh, I'm ready.

SS: You ready? Okay.

BH: He's ready. You ready?

SS: So if we could start by you just saying your name, your age, where we are, and today's date.

BH: Okay. My name's Bob Huff. I'm 54 years old. We are in New York City. And today is May 31st, 19-, no, 2007.

SS: Oh my god, it's 2007.

BH: It's a blue moon.

SS: Okay. Well, where were you –

JAMES WENTZY: – a blue moon?

BH: Yeah. Yeah.

SS: Where were you born?

BH: I was born in Chula Vista, California, which is south of San Diego.

SS: And what was that like, in the '50s, Chula Vista?

BH: I didn't live there very long. But it was, I have an idea about this. It was quiet, it was country, it was suburban. It was the '50s; it was the deep '50s. That's what I remember.

SS: Was your family involved in agriculture at all, or –

BH: No, no.

SS: No.

BH: My father was a printer. And my mother eventually worked in high school libraries. But at the time was a housewife.

SS: So did you mostly grow up in small towns?

BH: No. Eventually we moved to this ki-, we lived at the beach for a while, in this suburban neighborhood, and then moved deep into a very – well not deep, but into the county, which was kind of a new bedroom community, where it was hot. And clean.

SS: You went to high school there?

BH: I went to high school in San Diego, yeah.

SS: So when you were growing up, as a kid or as a teenager, were you aware of what was going on politically in the rest of the country at the time?

BH: Yeah. From the age of 14, 13 or 14 on, basically because of Vietnam, I was aware. I probably had a kind of a shift in consciousness at that age, and the Beatles and Bob Dylan had a lot to do with it. So it was just a cul-, it was in the air, it was a cultural thing. But I had a, I guess more of a political spin on it – a sense of outrage at injustice which made me angry as an angry 14-year-old.

SS: Did you know people who were going to the war?

BH: Politically aware? Not re-

SS: No, going to the war.

BH: Oh. Didn't really. Actually one friend's brother finally went. And I knew, at some point in the future, I would, I was subject to being drafted, which I thought was just unreal. But no, we didn't really know any. Even though it was a big Navy town, and full of military, I really didn't know anybody involved in that.

SS: So where did you get your information about what was going on?

BH: In the world. That's a good question. I think the nightly news would have been the normal channel. And the newspaper, which is a very conservative newspaper. But at some point, we maybe developed this network among like-minded friends; these kids who were also interested in music and counterculture, cultural things. And probably some of that. And actually, the hotbed of really subversive activity was around my church that we went to, because this was, I think they had some older youth

advisors who were a little bit liberal, who snuck in and sort of inculcated their values in the youth.

SS: What church was it?

BH: It was a Lutheran church. It was just sort of a neighborhood church. It wasn't really, I think any heritage to it in our family or anything. Just sort of adopted it because it was convenient.

SS: So was your family community oriented through the church?

Was there any kind of –

BH: Not really.

SS: No?

BH: No. I recently found out that my father – well, I knew he had always been a Democrat, and my mother was a Republican for some reason. And she always used to boast that her vote canceled his out. But I didn't realize it. And later on, my father told me —fairly recently — that his father was a Democrat, and was really involved in the party. He ran a newspaper in a small town in Kansas, and so apparently he actually was a kind of a devoted Democrat. So I was surprised to hear that. But my father didn't have any inclination like – if he did, he kept them close to his vest. He wasn't political.

SS: So this crew of people that you hung out with were they also interested in making art?

BH: Music, mostly.

SS: Music.

BH: Yeah. Yeah.

SS: And you're a musician?

BH: Yeah.

SS: You had a band?

BH: Yeah.

SS: What was it called?

BH: Heh heh heh. Well, different things at different times. At that time, I was really just, oh, I was in some horrible heavy metal band, kind of in high school. It was a proto heavy metal band. But that was just ridiculous. But later on, in New York, I had a band called Crash. But at the time, we were really interested, this friend of mine's a really talented songwriter and singer, and so I was involved with his work, and we did some recordings, and tried to make a record. But that was kind of this country-music, folk-music wing, which I got involved in pretty heavily. And bluegrass bands. It was a time of, back-to-the-land kind of vibe, with the band, which I loved. And sort of discovering all these country roots; roots music that I really, really loved, and my parents just wouldn't have anything to do with. So that was exciting.

SS: So what got you out of town? How did you –

BH: Ultimately. Took a while. through my music stuff, I started building musical instruments. And I was building guitars. And I took a, I dropped out of college for a couple years. And was doing this – whoops.

BH: Yeah, but getting out of town, if you're in San Diego, is a huge deal, because you've got Mexico on one side and the Pacific Ocean on the other side; mountains and a desert on the other side, and a huge, endless Marine base to the north of

you, before you finally get to Los Angeles. So it was really – it took a lot of escape velocity to get out of San Diego.

So I had been building guitars and hanging out with music people. And started meeting art people, and I really was fascinated by that. And I wanted more of a life of the mind, I guess, than the life of the hand, at that point. So I basically applied to school and I went to UCLA, in '76, I think, so that's how I got out of town. And that was great; I'm glad I did that.

Before I did that, though, I hitchhiked to New York.

SS: Uh huh.

BH: Yeah. And saw New York, and totally realized, this is where I had to end up. So that was the ultimate plan.

SS: Now when you were at UCLA, did you start making visual art?

BH: UCLA. Just puttering around. No, I was studying history, actually. So I was much more into the politics of it and ideas and history. I was a terrible student, but I really was just totally involved in that.

SS: So did you come out in college, or –

BH: Yeah, I came out in San Diego, actually, before I left, typical step-by-step process, but –

SS: What was the gay scene like in San Diego for –

BH: I don't know.

SS: – in the early '70s?

BH: I didn't know any gay people in San Diego, so – I wasn't –

SS: So you didn't have a boyfriend, or –

BH: No, no boyfriend, no scene. Just sort of sequential crushes on straight guys. And then I went to LA, and there wasn't really, I didn't, I was just kind of in books for about three years, so didn't do much there, either.

SS: So when did you start really living as a gay man?

BH: I would say, actually, realistically probably when I moved to New York. In that there were, I was out and cruising in Los Angeles, but it just didn't, I never liked gay life in LA. I didn't really get it; I couldn't find it; it didn't make sense to me. And New York really made sense to me. It was just – not that much sense, but at least you could go dancing. It was kind of, that's what I told people at the time. Why are you moving to New York? Because I want to go dancing. And I really did. {LAUGHS}

SS: So where did you used to go dancing?

BH: Oh, what was – a great place – oh, a far West Side meatpacking place; had a great dance floor upstairs, and had a backroom downstairs. Anybody? It'll come, it won't come to me. But it was fantastic. It was fantastic. And there was Crisco Disco, and –

JH: The Anvil?

BH: The Anvil!

SS: Oh, okay.

BH: Yes. The Anvil was amazing. I loved it. And – there were rock clubs at the time, too, that I went to. So places like that; it was great. Typical coming home at sunup every night. I liked the Anvil because there was sex and music, great music, at the same place. In fact, the other place I liked was called the Stud — the

International Stud — which had a fantastic jukebox, and had a backroom in the back. So you had both working together.

And my favorite bar, which was The Bar, on Fourth Street.

SS: Oh, The Bar.

BH: The Bar. Which I grew, which was my living room, essentially, from 1981 on.

SS: Were you living in the East Village?

BH: Yeah.

SS: Oh, so you could just roll right in.

BH: It's just where I went for every, all my social activities. And it had a great jukebox. This was the requisite for me, actually more than what the guys were or anything; the music had to be great.

SS: So at that time, had you started making film or video yet?

BH: Not at that time. I was interested in it. I'd been making recordings, recording songs and did a punk record with some friends in LA, and another record for a friend here. But video, I was really fascinated with. I was fascinated more with television, because I loved, I was just, gobsmacked about what I would see on the news at night. I just couldn't believe the way the news was told. So I was really into how political reality was represented and fed to people through the news, and that was just fascinating to me; how culture was reinforced and disseminated through, from sitcoms to everything that was on the news, especially the news. And because MTV had woven itself in, and that was really peculiar, too, at that time. I think I must have had cable at some point, and started to see that.

But yeah, I couldn't make video because I didn't have any equipment to make video. So it wasn't until, I think, '85 that I actually bought some video equipment and started editing. And what I would do was tape stuff off the news and cut it up and kind of reframe it, and try to make it funny, but also make it educational. I always liked an educational component to my work. Had to be a little bit boring for me to like it.

SS: What were you doing for a living at the time; in the mid '70s?

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BH: That was neat. I had some temp job; I was working at a place, in an office. And in '82 or so, they kind of threw this IBM computer on my desk; this new personal computer. And said, figure out how to use this. Which I did. And wrote some programs that did useful things. And this was very early. So then I, I don't know. I followed some people who found me – oh, somebody found me some jobs doing this for someone else. So in a short time, I was writing these computer programs. Which I could charge a lot of money for. So in a very short period of time, I went from having no money to having more money than I'd ever even thought I would have. Which was maybe ten thousand dollars. But it was enough to go blow it all on video equipment, which I immediately did.

And then I started editing. Which I was just obsessed with, just, just obsessed with editing video, for a few years.

SS: Now up until the time you started making video, where did you see gay film?

BH: Ah. Well, anywhere I could, really. That's one thing that really interests me. One of the first things I – there was this, Guy Hocquenghem had a film called *Race d'Ep*, I think. Which I saw here, in New York, probably in '79. And –

SS: Do you remember where?

BH: I think it was at Columbia. Something tells me it was at Columbia. Or maybe, if not Columbia, we ended up going to a dance at Columbia. They used to have a gay dance at Columbia. And I went with this friend that I had met who was at some other social strata in New York, and knew someone who knew Guy Hocquenghem, who was there, and we all hooked up and shared a cab downtown, and – so anyway, maybe they did show it there. I think they must have shown it. Because I came home with a poster for it. That's what I remember. And that was something that I understood intuitively, what he was doing, and I liked what he was doing, and it made sense to me, because it came out of the same kind of historical – I came out of this history background, so that made sense to me.

SS: Can you just explain what he was doing?

BH: I'm trying to remember what he was doing. What I seem to remember him doing was these, wearing of historical – it probably was a very unsophisticated film, now. But I seem to remember historical reenactments – Baron von Gloeden posing these boys; those were some scenes. And then some scenes of, who was the, the sex researcher in Berlin in the '20s?

JH: Magnus Hirschfeld?

BH: Yes. Someone acting out, playing that role, and acting out – so I liked taking the history and re-, playing it out. But also, it was a bit, I think there was some humor to it, it was a bit arch; had a little, this touch of Godard to it; it was funny, which I liked. And that's really, I haven't seen this film in 30 years, so I don't really know much about it. But that's what I remember about it. He had a book, too.

SS: What was his book?

BH: His book was called – The problem is not homosexuality; the problem is fear of homosexual desire? I think that's the book. At least that's the idea, and that's an idea that made sense to me, at the time, so that's great, let's go with that.

SS: So were you involved in anything political before ACT UP?

BH: Well, anti-, antiwar stuff. I'd been to some demonstrations. I went to a police riot in San Diego over a people's park, which was kind of exciting. And I filmed that, actually. That was back in '72, I would say. And I had a regular 8 camera; and filmed running from the police. It was really cool footage.

But, yeah. And there was stuff going on in New York, like the anti-nuke rallies. And big marches that I would go to, just because I kind of liked the scene; was curious what they were doing; curious to see how people – what they would do creatively, with the big puppets, and Bread and Puppets, and stuff like that. I was, it wasn't my thing exactly, but I was impressed by what they were doing, and it really made a march kind of fun and exciting.

SS: You didn't belong to any gay organizations, or anything like –

BH: Gay stuff, no. I went to – I was really into, and 1979 was this amazing year for revolutions around the world, and everything. So I was really, it was kind of exciting, and a hopeful year, in a certain way. Because this American imperialism was kind of, the tide had receded a little bit. It felt that way for around half a minute.

And I actually went, a friend of mine was going to Nicaragua one summer. And so I went down there to study Spanish and be in a program, sort of learn about the

state of the revolution at that point. I think that was, it must have been '83 — just to see what was going, so I was really interested in that, in those kind of movements, those kind of liberation movements, and especially in Latin America. So I was really curious to go see, see what it was like, because it was under attack at that time. So that was interesting.

SS: You went on a brigade, or something like that?

BH: It was really just kind of a, it was a program that was set up to bring Americans to Nicaragua, and study Spanish, and learn about the revolution. It lasted a month or so. And it was really interesting.

SS: So did you have to be in the closet when you did that?

BH: No, it was interesting. My friend, who's actually much more, Rick Sugdon –

SS: Um hm.

BH: – who was bolder than I, was always standing up at these meetings, these public meetings, and asking about: What is the situation for gays here in Nicaragua? And it was really great; I'm glad he was doing that. And the official answer was, from Daniel Ortega, who was the president, was that, they had, the cultural minister was gay, and it was well known. So it wasn't a big deal within the people who were in government. But the official line was, anybody who wants to participate in a mass organization or start an organization is free to do so, because that's how you participate in the revolution; you make an organization, and you bring your issues forward. And that's what we respect, and that's what we respond to; and that's how this society works. So that was really interesting.

But it was also interesting; if there were Cuban advisers standing around, they would just become furious, and start screaming: Homosexuals are absolutely incompatible with the revolution! And they're deviant and perverts! So it was, I really got to see, there was really a cultural, cultural differences between these, at least these people from different countries.

SS: Now do you remember when you first started to hear about AIDS?

BH: Well, not AIDS, but, "gay cancer" is what I remember. And I'm trying to think if I went to a, I would go to the, I went to the gay march every year. And there may, if there was some special political, I went to a – maybe it was the Supreme Court march — and I don't know what year that was, but it was well pre-ACT UP; probably –

SS: It was the early '80s, right, the sodomy –

JW: Eighty-six.

BH: Yeah, '86, okay. That was an amazing manifestation. That was great. And in fact, that felt a lot like subsequent ACT UP demos and things.

SS: Can you describe that demonstration a little bit?

BH: Oh, it was, I think what it was – no, we first, it was some kind of a – a spontaneous thing out in front of Stonewall, when this decision was announced. And I came from the East Village over to the West Village to go to that. And I don't know if that was the march – I may be mixing this up with something that happened later.

SS: This is the sodomy decision, right?

BH: Yeah, the Hardwick –

SS: That's what you're talking about, yeah –

BH: – decision.

SS: – Hardwick, right.

BH: And what I remember, and really remember, was a march down to Federal Plaza, probably; this demonstration in front of the courthouse; kind of a die-in. And there was a truck set up, and there were speakers, and one of the speakers was Barry Gingell, from GMHC, who was talking about AIDS, and putting a political interpretation, and a real call to action there. So I don't think I'd seen that before. That was significant. And that was at least a year before ACT UP.

But to the other question, when did I first hear of the, the disease, I guess, or what was happening – and I don't remember the – maybe some talk about – what I remember is all these, these, this place, like International Stud and all these great – at the end of 1981, they were all shutting down, they were all ending, finishing. Or a bathhouse that I used to like was closing. That whole, suddenly, by the end of 1981, and in the, when the news came out — June of '81? —

SS: Um hm.

BH: — so in that short period of time, this amazing, I-want-to go-to-New York-and-dance culture was pretty much dying; it was the end –

SS: Now, were these places shut down by the city, or did they just –

BH: I don't think so.

SS: – not have business?

BH: I think they just – I don't even know if they just – I think they did shut, naw, it wasn't shut by the city; I don't think much was shut by the city, but I think

they just – I don't know why they shut. They just, either they shut, or they just changed, and they weren't fun, or something was changing. But at the same time, at the end of '81, a lot of life started springing up closer to home. I didn't have to go to the West Village to get things, because things were happening, the Pyramid Club opened up in December of 1981. So suddenly, we had much more cultural life in the neighborhood. And that was actually much more interesting and distracting than what I had been doing, so going – I always thought the West Village was very alien to me. I never identified or understood, really, West Village gay life. I was an East Village person.

SS: What was the difference? Can you explain it?

BH: It was probably to do with – values, in a classic way. The East Village people were – I understood, we were interested in the same thing. Music, primarily, and art. And politics. And the West Village, which is much more about all the, it was the end of the high clone, I guess. So that was changing, anyway. But it was – it was just goofier, and less familiar, less, a bit alien.

It's interesting, because I held onto that sort of bias for a long time, even into, that's what made going to ACT UP different. Because it was, sort of involved repenetrating that world a bit.

But I remember stories about gay cancer, and thinking that at one time I was, sick in love with someone. And thinking, oh, this is it, this is the end of my life. I'm in love now, and I'm going to have cancer and die. So I just felt, this, is this terminal, this is how the world ends, kind of.

SS: So you thought it was inevitable that as a gay man, you were going to get this illness?

BH: I just thought, it was sort of a momentary black day. But actually what I did is I – no, I know what it was. I had these, something on my legs. And I don't know what they, they were an odd symptom. And I sort of looked them up, and they sounded like shingles. And I really didn't know what shingles were. But then I found out that shingles were one of the symptoms of gay cancer. But my response, interestingly enough, was to go over to the library, and first look up what shingles were; then start reading what I could find out about the symptoms of GRID or whatever it was called at that moment. And that, so I guess that was 1982, first part of 1982. So I went to find out what I could find out about it. But I don't think it was much. I don't know that I learned a lot.

SS: Did you change your social life or sexual life when you first heard about AIDS?

BH: Not – well, I think the, it was changed because the venues changed. So there's an argument for closing the bathhouses. Because I, oh well, because I'll do something else now. I didn't really go out and transfer my activity to other venues.

SS: That's interesting. I've never heard –

BH: Yeah.

SS: – anyone say that before. So that maybe the Pyramid and all that other stuff was because, partially because these other places were no longer available, in some way.

BH: Could be. It was definitely a shift. And around that time the East Village was blossoming anyway. But the Pyramid, 8 BC another couple places like that

all blew up in the mid-'80s, and there's lots going on, and you'd go out every night, and you'd see friends in the neighborhood, which actually I liked a lot better.

SS: So when was the –

BH: But when did I hear "AIDS"? I don't know, I don't –

SS: Well, do you remember when you first became aware that people you knew had AIDS?

BH: The first person that I knew, or I was told, who had it was this pal of a pal of ours, whose name's Robbie. And somebody said, oh, he's got it. And I said, oh, that's terrible; he's going to die. And didn't know much more about it than that. And I ran into Robbie once at The Bar, and we were talking about it, and he seemed fine. But he did die not long afterwards.

But it was just very, it was still, I have to say, it was very strange and alien, and it really, some friends of mine were infected, but didn't know it until much later. But no one I knew from my East Village circle really had AIDS, or died, or got sick until the '90s, really. So you would hear about people, like a famous DJ named Iolo, who, one of the first people I heard about. And he was, a famous person. And then what I heard is, he had become macrobiotic to treat it.

So I did pay attention to what people were doing to treat. And a lot of people were interested in macrobiotics. So that's an association I, a very early association I have. But it wasn't anyone, and other than Robbie, and then my pal, who was his pal, subsequently left. And I didn't find out exactly when he died, or what happened to him until, again, the '90s, although he died in 1987. But he was gone by then. He went to San Francisco.

So it really didn't impact, it wasn't like Larry Kramer's generation, or his friends, where he was going to a memorial or a funeral every week. It just didn't come our direction — East Village — and in my circle until much later.

SS: So what brought you to ACT UP?

BH: That poster. An amazing poster.

SS: Silence Equals Death?

BH: Silence Equals Death poster. My god. It's just, I was walking along Fourth Street, going to Tower Records. And I remember this vividly. And it was wheat-pasted on a building. And I saw it. And I just, I just knew instantly what it was: what it was about; what it had to do. It was so simple. It was that triangle, inverted, pointing up; because I never liked the other one. And "Silence Equals Death" was so stark and clear. What else? Take action. Then there were some statistics at the bottom, and there was some information. It was just great. And it was black. Which was, of course I related to. And — it was great. And I think it had information about where the meetings were. I don't think I went to a meeting from that. But then I started hearing people talk about, or I asked somebody if they'd seen it, what it meant. Oh, I think that's this thing that our friend Brantley went to last week. And so I decided to go to the next meeting. Went with a couple of friends. And that was in — May or June of '87. And that was amazing. That was a life-altering encounter with a poster. I think I would have ended up there anyway, but the poster was so, meeting that poster was just shock.

SS: Well, you came to ACT UP three months after it was founded. So can you describe for us a little bit what those early days of ACT UP were like?

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BH: What I remember – well, there was the room, and everybody probably talks about the room. But the room at that point was flipped over, and pointed in a different direction than the room subsequently. So it was – pointing, the crowd was pointing west, if I translated that right. And within a few months it had flipped over, and they were on the other side. But it was still a big packed room full of people. And – I don't have a lot of –

SS: Who were the facilitators? Do you remember?

BH: Yeah. Well, I think –if I, all the facilitators were smart and funny. And there were men and women. And they seemed to be on a, have a little bit of, little bit of distance that made them tolerable and they were cool, in a way. So I'm guessing — and I can't really remember — but I think it was Michael Nesline. And – there was that woman who subsequently had a gardening television show.

SS: Rebecca Cole.

BH: Yes, yes. She was there. And – I know, I'm blanking on all the names right now. I'm not good with names.

SS: So did you –

BH: But they ran a lively meeting. That's what I remember.

SS: So how did you plug into the organization?

BH: Well, the first thing I did: I wanted to go, they were announcing all these little committees and things. And I thought, wow, it's just – so I had – actually thinking about where the needs were. And so I just, I picked one. And it had to do with housing. And it was at someone's apartment. I had this idea, because there was the NENA Clinic on Third Street, and there was this apartment building, which had an

elevator, and it had air conditioning ports all over it, but it was uninhabited. I thought, this would make a fantastic hospice space or something. And I was so excited about this.

So I went to this meeting at someone's apartment. And I presume this is the same group that formed Housing Works later. I don't know if they were formed, if it came out of that group.

SS: Whose apartment was it at?

BH: Don't know.

SS: Was it east or west?

BH: Oh, it was – I'm sure it was west. Unless I chose it because it was east. But I don't remember.

SS: Okay.

BH: I think everything was west. It was always a trip to go to, in more ways than one. So I don't remember where it was; whose apartment it was. It was a fancy apartment. These were all spacious-- actually had furniture in them. Amazing.

So I went to that. But I didn't really, I talked to one guy; this guy named Hal, who was around for a long time, and I know he subsequently died. But he was the only person I talked to at that meeting. But he was nice and welcoming and friendly. But it was socially so intimidating to me that I just, whoa, was boggled. I couldn't even imagine participating. So I went to that.

And then the next thing we did was a demonstration at Memorial Sloan Kettering. It was several days of demonstrations. And –

SS: Do you remember why?

BH: Yeah, I was just wondering; what was, who knows? It was some injustice! Why? There was some reason. It seemed like a good reason, but I can't remember what it was. I think it was denial of service of some kind; someone was not being – I wish I remembered. Do you remember?

SS: I do know, actually.

BH: Lay it on me.

SS: It was, they weren't accruing people for experimental drug trials.

BH: Oh!

SS: Right

JH: Yeah.

BH: Oh, god forbid what they were actually to trying to test at that time.

SS: What was the demonstration like? You said it went on for days.

BH: Well that was really, really interesting. Because I remember when they were announcing it, there was someone up there who was organizing it. And there were several organizers. So you could take your pick, which group of, you felt more affinity with. And they called them affinity groups, I guess. And this one guy, he was trying to organize all these people who, and we're going to show up wearing suits and ties, so we look really – I'm sorry. We're going to show up wearing suits and ties so we look really respectable, and that way we'll get on the news. And that was his thing. So I was impressed that they had that sense of theater. I was also really impressed that these people actually owned suits and ties. This, just, wow. So I went up to that.

And there was a training, I think, for being arrested. And it was all very, a negotiated theatrical arrest. So it was, we knew ahead of time what was going to happen.

It was a perfect introduction to civil disobedience, because it had the training on a Saturday or something. Whenever this day was, we went up there. And stepped up, sat down, whatever. When they came and got us, and they picked us up, and threw us in a van; took us over to the precinct a couple blocks away. And wrote desk appearance tickets. And we were done. It was just like clockwork. So it was really painless civil disobedience. But it was a good, good introduction, so me and me cohort, my gang, we all went and did that.

And got out. And then I think we went over to, because we were uptown, in this alien neighborhood. So we went over to a hustler bar on 53rd Street. And we actually ran into somebody from ACT UP meetings who was there working. So it was very interesting.

So anyway, that was my first demo, that was my first arrest, and that was my first experie- it's funny, I don't remember what the issue was. But at that time, I wasn't keyed on treatments at all. I'd be really curious to know now what exactly the clinical trial was. Because it –

JW: We have to stop and change tapes.

SS: Change tapes.

BH: Sure.

SS: Okay.

Tape II
00:00:00

SS: Now at this time, when you were making your videos and you're just joining ACT UP, had you connected AIDS and videomaking?

BH: The videos I was making were about TV news, terrorism; just – not, I was collecting, actually. I was collecting anything on AIDS, off the air. I would tape news specials and – so I was getting a collection of stuff. But I didn't exactly know why. It's just that it was, anything that was just – what I really loved is when, if it's about sex, usually; and it ends up on national TV, at that point especially, it's just so, uhhh! They just didn't know how to handle it. And so much – so much leaked out in there, because they didn't have a real cooked response to give. So all this underlying fear would leak out. So I thought that was really fascinating. And AIDS brought up a lot of that.

But now, I'm, but I'm not so sure when I started collecting it. It actually might have been after that; after I joined ACT UP. So I'm not sure.

SS: Okay.

BH: But I was making-- terrorism was big at the time, so I was doing stuff on –

SS: What kind of terrorism, in the mid-'80s?

BH: Beirut.

SS: Oh, okay.

BH: That was the first big one. No, I did a video about, I was doing, there was a music video using TV news images about terrorism. So I, it was actually to a Jimi Hendrix song or something silly. But it was, it was sort of how terrorism was a sexy visual language; and there were terrorism experts. It's surprising, really, now that we're

in the heyday of terrorism here. But the way that it was discussed and used isn't actually all that different. In fact, you see some of the same experts, heh.

SS: Okay, so continuing with after Sloan Kettering; where did you really make your stand in ACT UP?

BH: Yeah. Well, I was going to the meetings, and there was a – I didn't really, there was a, I was just trying different things, and – there was a big demonstration in Washington, probably around the Quilt. And I don't remember when that was, either. But I think it was in October or November. And I went to that. And that was really amazing, actually, because there were so many people there. And I loved flyering, and I loved handing out fliers to people. Because I'm sort of introverted, but going up and handing fliers to people was liberating, in a way. It was fun to do.

But I probably went to, I was thinking rationally; well, what did we really need here? We need some kind of treatment or a cure. So what's the status of that? And I have this sort of tendency to want to find out all about something.

And so I, there was the Treatment and Data Subcommittee of ACT UP New York, that I ultimately went to, and that's where I stayed, pretty much. And it is my strong affiliation with the work. And I probably went there – November – I'm guessing. And it was a meeting some other night of the week, at the Center, at first. And Iris Long – that was her thing. She initiated it. And it was treatment and data. The emphasis was on data, on collecting information and collecting data. And her big thing was, we have to collect this data, and then we have to tell other people. We, and it was a real, it was a really clear mission. Which made ultimate sense, really.

So who else was there at that time? It was Jim Eigo, who was incredibly articulate about framing the policy issues about treatment; just fantastic. And David [Z.] Kirschenbaum was there, and Gary Kleinman was there. Michael Cowling may have been there. It's really interesting. It wasn't a lot of people. And those were the, that was the core group, I think. And I'm probably leaving someone out, several people out. But those were the people that seemed that they knew what was going on.

SS: So how did you get data; how did you get the information?

BH: Ah, it was fantastic! Iris wanted to create a registry of all the clinical research for AIDS that was going on in New York, New Jersey and Connecticut. And she wanted to publish this. So we started. She took us down to the Worth Street Health Department offices. And we went upstairs. And we went in some little backroom office. And she got them to show us all the protocols for all the research that was being conducted in New York City hospitals. Which was really my first exposure to anything. So our job was to look at these protocols and abstract the information; the title, who it was for; the inclusion criteria – who was excluded, who was eligible; what the drugs were, what the doses were; how long it would last, how many people enrolled, where it was going to be.

So we collected all this information, abstracted it, put it on forms. And we started collecting these forms. And through that, I learned, I learned what a protocol was, I learned what all these terms meant, all these things. And we, ultimately, her idea was to create a book that would publish all this information. And ultimately it turned into a nonprofit, standalone nonprofit called AIDS Treatment Registry, that published these

directories of clinical trials in New York. And that went on for a few years, and then it morphed into something else.

SS: Now –

BH: But it actually still publishes in another form. I think it lives at ACRIA now.

SS: At CRIA?

BH: ACRIA.

SS: ACRIA.

BH: Yeah.

SS: What is ACRIA? Can you just say?

BH: Well, it used to be the Community Research Initiative; CRI. Which was founded by Joe Sonnabend and Michael –

SS: Callen.

BH: – Callen, thank you; and [Thomas] Hannan. Sorry. And then it became, it went through several organizational shakeups, and each time it did, it added one initial to its name. And it next was AIDS Community Research. And finally, after the last one's, they tacked "America" onto the end of it, which is weird. So now it's ACRIA.

SS: But when you went through these protocols –

BH: Yeah.

SS: – what did you discover? What was the state of these clinical trials?

BH: I have a pile of them probably, at home. I hope I do. Because, well they were s-, they were – there were various AZT trials in special populations; they were

trials of other drugs that at the time thought might be promising, but weren't. And some of them were pretty nasty, like beta interferon was one that was tried at one point, and it's—

So we, basically, but we were agnostic about the value of them. We weren't really putting commentary on them, at that point. We were just saying, here's what's out here; here's what's available.

It took us a long time to actually get it together to publish anything. And we were collecting information and learning early; but it took a long to actually translate it into an effective organization that got it out, so.

But in the meantime, other things happened, in Treatment and Data. Which were probably more, it spun it much more up into the political level. Mark Harrington, when he came, I think, in first part of '88; I think January or February. And I had met him a few months before, so I knew who he was. So he showed up, with his gang. And the next time he came back, he had taken all the words he heard that he didn't know, and went and looked up definitions for them, and created a glossary. Which was actually an absolutely brilliant thing to do, because it's such an elemental way of educating yourself and educating others. And he xeroxed it and passed it out. So suddenly there was this product information product that gave people an entrée into this really arcane world of protocols and inclusion and exclusion criteria, and forms of administration of drugs and things.

So that was his first contribution, which is pretty revolutionary. And he just had a real natural grasp for what was wrong, and where s-, he would go investigate

Tape II
00:10:00

the bigger systems — the National Institutes of Health, and what they were doing, and would come back with critiques.

So out of this started to flow, from the group, ideas about – and this would come back to the floor of ACT UP, and I don't know who thought of going to the FDA the first time. But we went to the FDA in October of '88, I think; at least that part of the year. It was amazingly successful demonstration.

SS: Let's have a question here. So if initially T&D was to gather data; at what point did it start having its own agenda?

BH: Well, that was an agenda.

SS: But, starting to feel that certain drugs should be investigated with more depth, or –

BH: Oh. It started with data – well, there was always, Jim Eigo always had, I think, an analysis, a policy analysis, behind what we were doing. And so that was always there. I don't know what the particular drugs. There weren't many drugs to comment on until later. But how they were studied; it was much more about, the critique that mattered then was, how are you studying what you're studying; and what is your process.

SS: Do you remember any specific issues?

BH: Probably the issues, I made a video about this; the issues of actually why we went to the FDA. It's called *Rockville is Burning*. And it's based on a nightly-network news show that's taken over by three AIDS activists. And they hijack the satellite links, and they're AIDS terrorists. And they present their demands to the nation

on what, what we think is wrong with how AIDS treatments are being studied. So the demands are all right there.

Interestingly enough — and I just watched this about a month ago, because I showed it to a group of people in Wisconsin — and all but one of the issues were totally right on. We still think the same thing.

SS: Well, can you tell us what they were?

BH: Yes. If you let me go really slowly. Because I'll have to recall them all. The placebo issue was one. And this was that — if there are treatments that are shown to be effective, you can't withhold them from someone in the control arm just to prove that you're — that your other drug, this new drug you're testing, how it does versus no treatment. Because there's an effective treatment, you've got to show how it does compared to the effective treatment. It's actually more efficient to compare it to nothing, but then you're withholding an effective treatment, a proven treatment, from people. And that's not right.

So that was one really easy to grasp issue. It's not that placebos are bad. Unfortunately, a lot of this stuff got translated into lore as misinformation, too; like all placebos are bad, which they're not. It's just, under those conditions, it's completely unethical, really. You have to argue that.

Another — this is really going to be a strain to pull these out. Because it's—

SS: Okay. Well, what was the —

BH: But that's an example of one.

SS: Okay.

BH: Another one was equity from, they were studying things in adults but not studying them in children; women weren't being included in clinical trials. Twenty years later, it's still the same. That's still as viable a critique now as it was then.

SS: Now I have a conceptual question for you. So you imagined AIDS activists taking over the nightly news, making demands, and being terrorists. Now two of those did actually happen, right?

BH: They, yeah. Not –

SS: But not the terrorist thing.

BH: – it didn't last as long. They didn't stay on for 25 minutes.

SS: Why do you think that gay people and people with AIDS have never committed any acts of violence?

BH: That's an interesting question. Because they're inherently peaceful people. No, I don't know. It's such a, part of the fabric of American political life. It is – but I'm glad they haven't, because it makes things pretty icky.

SS: But in your film, you imagined that they would.

BH: Yeah. But they didn't commit violence; they threatened violence. But it was all in, it was also a play on – the loose definition of terrorism. Making it slippery enough just to include anybody who's a little bit outside the norm. Which happens in this day, too.

SS: So what was won at the FDA?

BH: What was going on at the FDA — and this is –

SS: What was won?

BH: What was won?

SS: Yeah, what did we win at the FDA?

BH: Ah. A more rational – this is complicated, because a lot of thing-, this was a moment of convergence, too. There were – things were going to change, probably, in drug development, anyway, because there was pressure to speed up drug development. But here was a, from, on the industry side, because they wanted to develop drugs faster. But they were –I went to an early advisory meeting for aerosolized pentamidine. And saw who was on the panel, evaluating the data and making their recommendations to the FDA. And it was really obvious to say, it's just a bunch of dads running science. They were just harumphing and grrr-, well, this is, this means we're abandoning the gold standard of, of how we test drugs if we, if we go down this path. And they were just absolutely against it; any, any kind of change that didn't have this absolute rigor of comparisons; anything that muddied the waters that let them get a very pure look at how a drug behaved, they thought was just a slippery slope into hell. And we were arguing that, well, it just isn't possible. Yet we still need the drugs. What are we going to do? There must be other ways. Let's be creative.

What if the populations are more homogeneous? What if people are on other drugs at the same time that they're taking your experimental drug? And you can show that there is no interaction. It just brought a little more logic to it.

We ultimately got a lot of backing and support. We had these intuitional arguments. And a lot of them, randomization. I think the first time I thought of randomization, which means randomly allocating, deciding if you're going to get the experimental drug, or if you're going to get the control, or maybe the placebo. And it's a flip of the coin.

Tape II
00:20:00

So it seems unfair to people when they first hear about that. It's actually a very fair way of evaluating something. But at the ti- we thought that, there was one point where we said, this is not good. But we weren't exactly right on that.

So at some point, we started to talk to people in the research establishment in the government, at NIAID. And the first group of people who really responded to what we were, our problems were biostatisticians. This is where it gets really boring. But this is where I love it.

The biostatisticians actually said—

SS: Tell me, how did you make contact with them?

BH: There are multiple levels, all the time. Okay, for example: There has always been kind of a, I learned later, this behind-the-scenes activity that was pushing AZT to approval faster than it would have been. And people, like Terry Beirn at AmFar, and probably Mathilde Krim, and other powerful people, were pushing this forward, exerting influence to speed things up. Probably as soon as they had any hint that this was an effective medication. And they were probably doing that before then, looking at anything that was out there. And that was the first thing that really emerged in a kind of provable way to have some activity, at least.

And the way this really works is you get a little consensus, a ball of consensus rolling; and if it's the right people involved, and they're influential, they draw on other people. And it starts to create change. It's not all data. It's expert opinion. And that's exactly the same now. Everything we have is a mix of data and expert opinion and a touch of it can shift with the times. There is a bit of fashion involved.

But at the time, their people were working other levels, and Jay Lipner was plugged in, and doing fantastic work, talking to people; probably talking to Fauci. And David Barr was plugged in on some other levels. And so there was stuff going on. And I'm talking about later now. And Fauci had been hearing the arguments. And Mark can tell the story much better, because I really don't know what went on. But saw which way the wind was blowing. And say, there's some reasonable stuff here, and there's some not-so-reasonable stuff.

So one place we encountered, the first place I encountered the biostatisticians, I think I started work at AmFAR – in, I don't remember when; maybe it was '89. So that would have been later. So I had gone up there, I had been doing some work out of the offer, or meeting with some people.

Anyway, I got invited to this meeting in Washington, to meet with a group of government biostatisticians who were having a, their own little data meeting. Oh, what it was? It was actually, it was an AmFAR-sponsored meeting up at Columbia on the Community Research. It was probably the first time. And it was a secret meeting, but I got into it because I was videotaping it. And we –

SS: Why was it secret?

BH: I don't remember. It was closed somehow. It was closed, it wasn't, there were, these elites were nervous about the community, the, the ra-, the rabble from ACT UP and stuff, crashing their, their high-level meetings. But we found ways to crash them anyway.

And I remember really being impressed that the people that, who really held the keys to the kingdom, in terms of what was true, what was knowledge, what was

viable knowledge; would stand up. And they would be the biostatisticians from, say, the FDA. And there was one man named Hauptmann, I think. And everybody would turn to him, and he said, yes, you can show this, you can show this, but you can't show this. And everybody backed off, and believed him, because what he was basing it on was this incredibly dense math, and nobody really, everybody understands the concepts, but maybe they couldn't reproduce exactly how he got there. But they believed what he said. And somehow they deferred to him. And I thought, oh, this is a powerful role that they're playing.

So we got invited to this other meeting, from this man named David Byars, who worked at the National Cancer Institute. And it was a gay man, with AIDS, and he was their biostatistician. And he had, one of his claim to fame was he had shown that Laetrile was not an effective cancer remedy. But he was really interested in this question. And he brought together a group of people, which included Susan Ellenburg, who was a biostatistician for NIAID and the AIDS Clinical Trials Group; and a bunch of other people, and I don't know who all was there.

And they wanted to take this ACT UP agenda, this T&D agenda, and examine it, and see, and really –take it seriously. Which is amazing.

So that was a fascinating e-, and they said you're right about a lot o' these things.

So with that backing, and the times changing anyway, and an incredible emotional and humanitarian and justice argument for, for, for speeding up access to treatment. Things changed, and things changed pretty quickly, especially after we

surrounded the FDA and shut. And people from all over the country came to that. It was huge. And there's enough people to literally surround the building.

SS: I want to ask you: you said AmFAR didn't want the rabble from ACT UP. Were you guys the rabble from ACT UP, or was it other people in ACT UP who were the rabble?

BH: Well, anybody who was – I don't know if it was AmFAR, but it was – I'm trying to remember who put on this – I remember it was not, they were keeping it from, they, from the Treatment and Data Committee somehow didn't officially know, or we weren't invited to this. So somehow – and I don't remember the details. But we weren't invited. And the only way I could get inside – and, and it was CRI, it was Michael Callen – so it was other community organizations in New York. So there was probably tension between ACT UP and other, and Michael Callen's generation. And then maybe GMHC was involved. So it was probably something at a community freezeout level more than – I don't really know. But I remember it was difficult to get in. But I did get in through AmFAR, because they hired me to shoot the video. And it was really an eye-opening meeting for me.

SS: Can you point to really specific drugs that were made available because of the work of T&D? And let us know a little bit about how that unfolded?

BH: I'm not sure I – for some reason, I don't have a strong chronology of the history of what T&D actually accomplished at hand.

SS: Was there anything that you worked on?

BH: Not so much about the drugs – the drugs – have their own life. The AIDS Clinical Trials Group was this government research effort that was, tended to move

pretty slowly. But we were very focused on that. And that was another closed system, and that was really, especially after FDA, that was, they would have meetings, and they were going to discuss what the AIDS research agenda was and report clinical results. And we wanted to be there. So we were not invited. But we – somehow went, once. The sky didn't fall in. And then they we were invited back. And then it – actually, they started creating community advisory boards, and they brought the community in in a structured way. Which largely neutralized them, but this took years to happen.

And if the question is, what did T&D do –

SS: Well, what about you? Did you work on a specific drug or a specific OI, or –

BH: My thing, well, my thing was research methodology.

SS: Okay.

BH: That was my specialty, I guess. And then – I actually got this job, they had hired me at AmFAR – now I'm thinking it must have been '89. There was this directory. They put out this fantastic book, called the Treatment Directory. And it was the compendium of every drug and every bit or scrap of information that was known about these drugs; even the experimental one, the holistic complementary therapies, as well as the pharmaceutical drugs. And they were all in this book. A little description of Clinical Trials. And this was our bible for information.

Tape II
00:30:00

So I actually got hired to work on this, and help write it, and collect the information. So that was fantastic; exactly what I wanted to be doing.

Well, it seems so. I was going to go to law school. And then the day before I was going to start, I got this job offer, and I said, this is what I want to do, so – it worked out okay.

SS: Can you give us an example of a specific research method that you feel ACT UP helped transform?

BH: Yeah. I think – the – in general – well, community-based research was a very important idea, and others had it before; a Joe Sonnabend idea, to have community-based research. It was a huge idea, and that's something we supported. And it did come to pass. But it wasn't T&D so much that caused it. AmFAR had a huge amount to do with that. In fact, they championed it. And Terry Beirn made that happen; had his name on the, after he died, he had his name on the clinical trials network for many years. They just took it off.

One thing I did was sort of actually – that more nega-, more in opposition to – there was this, some clinical trial that, and T&D was going to vote to oppose it and protest it because it was – and this, ACTG 175, which I think was an AZT/ddI combination therapy. And what was new about it was it was looking at combination of drugs. And in kind of a large trial. So it was going to answer some questions that hadn't been answered before.

And there was this movement to, outrage that we were still studying the same things, and we have to shut this down. And I wrote some screed that said, no, this is actually important. We can't, it's really, we shouldn't oppose research. It's a very, you can really motivate people maybe; you can, this is a dangerous thing. Because, and it's easy to actually get people motivated against something, and get them to demand, it's

an easy-to-grasp demand: We're going to stop this. And I said, but this would be really bad if we did this. And ultimately, we didn't do it. So that was one of the things I did.

But a lot of it was me reading and researching and writing and advising and sort of back, backroom support, I guess, for a lot of this. Because I didn't do a lot of the, I didn't do so much on the policy and the upfront and political, in-front-of-the-room call-to-action stuff. I was a, just a little shy guy. So.

And of course, we finally did start the Treatment Registry, and put out that information for awhile. And hopefully that was a useful thing.

But those – and these were big ACT UP, I don't see them as T&D demonstrations, they were ACT UP demonstrations, but going to FDA, going to NIH, which just – storm the NIH, yeah. And it had a huge impact in breaking down the barriers – getting community people involved in these really hard-to-understand structures.

But, it sped things up, definitely.

SS: Now did you leave ACT UP with TAG? Or did you –

BH: I wasn't too happy about the schism when it happened. Because I, my, everyone I knew was going with TAG. But I had a lot of affection for T&D, so I would, I continued to go to both for a while.

SS: Looking back now, with hindsight, what would you say was really the cause of that separation?

BH: What was the cause of it?

SS: Um hm.

BH: It was – well, there's a lot of ways to interpret it. It was just – sort of became – intolerability of personalities and methods and interpretations of what was the

right way to proceed. But more abstractly, analytically, there was the belief in, ACT UP, what Act UP did best was mass action pressure. And you compromise that or you abandon that when you talk to your, your enemy. But by talking to them, you find out that they're not actually the enemy; that you actually solve the problems or identify the problems or understand what, why the problems are in this form. And if you're smart and creative, you come up with ideas to improve that, and then use some, any trick you can in order to unstuck the problem — which is usually personalities too, on the other side — and move it forward. And it was easy, for the most part, because what we were asking for, what we were criticizing, were a lot of them due to personalities, and could get unstuck. Like opening the doors to the ACTG meetings. It was dumb to ever have them closed in the first place.

But some people really — also, the learning curve of the content, the material that we dealt with, was getting steeper and steeper; biostatistics and antiretroviral drugs and the pathogenesis of AIDS, which nobody knew, really, anything about; and in some respects, still lots of unknowns. But they — oh, and then we opened it up, into the opportunistic infection drugs, and that was, each pathogen had its own bag of science, and different therapies, and — incredibly complicated.

Oh, I remember, that was one issue: treating someone for an opportunistic infection not allowing them to be on, say, an antiretroviral, or something. Another unnecessary and unjust way to keep the science pure, but really made no sense. Because even if you got results, they wouldn't be useful in the real world.

So anyway, there were people who didn't understand what some people in T&D were doing; who really just wanted to do actions, and wanted to remain angry; and

anger was a part of it. And it wasn't fun. It was counterproductive; it wasn't that much fun. And it was getting dumb. So I think that's what pushed the move. It was, let's go where we can actually work, and continue to make progress.

SS: So then why did you stay on T&D?

BH: I liked the mass movement, too. I liked the feeling of being in the mass movement. I thought it still had, they were doing all these other issues that were just as important. And I didn't want to, I didn't have tunnel vision on drugs or anything. I thought all the other, the access issues were going to be important.

I thought they, I didn't think they were incompatible. But if some people did think it was incompatible, and it just made it more practical to separate.

And T&D people continued to work within T&D. So it's not like they shut down overnight. It did happen eventually, but –

SS: What did T&D do after TAG left?

BH: I don't remember. I actually couldn't tell you.

SS: Okay. So when did you leave ACT UP?

BH: I would say – I don't know why I'm so vague on these years. This whole –

SS: Or what made you leave, if you don't know when?

BH: Well, just – the dumbness, and – I had actually – started, I wanted to study basics. Because I was writing about science, but I didn't have any science background at all. So I wanted to go back to college, and take basic science classes; undergrad science. So I started doing that, in, I think in '91. So – and I started hanging out with Gregg Gonsalves during that period, because he was working up at Columbia,

right next to me. And we would spend all the time, our lunch hours, talking about clinical trials and [the designs] and stuff. And it was really great.

And I was going to some TAG meetings, Treatment Action Group meetings; and some T&D meetings. But then I just got too busy, and I just, I wasn't finding either of them very satisfying. And after I was getting more involved in my studies, which lasted two or three years. So I kind of took a hiatus. I think probably '92, '93; '93, I would say.

Also, this is the time when finally, this wave of death reached my group. And – it just started happening really quickly. And this was like a close friend was dying every day. So we were –

SS: Friends who were in ACT UP, or friends from outside?

BH: Friends from outside. A few friends from ACT UP, like Jon Greenberg – died in July of '94, I think. And –

SS: Were you involved in his care at all?

BH: Yeah. Yeah. And I was, so I was doing these occasional –nursing stints. Brian Damage, I think he died in '89. And he was the first close friend that we were all involved in. And of course, he was from ACT UP.

SS: Oh, we need to change tapes?

Tape III
00:00:00

SS: So I want to ask you about the whole care group structure inside

ACT UP. So were you in Brian's care group?

BH: Yeah.

SS: How was that formed?

BH: Brian Damage

SS: Like how would a care group get started?

BH: It came out of Wave 3.

SS: The affinity group.

BH: The affinity group. So that was from – Wall Street '88. Right.

That's how they came. So they, I think they all went through their CD training together.

And – and that was Wave 3. And they were –

SS: Were you in Wave 3?

BH: – a sprightly bunch. No, I was in Wave – forgotten to the ages, whatever wave I was. I didn't hang with my Wave after that. But I – but that Wave fi-, some other wave. But our role was we went and sat down in front of the bus that was leaving with everybody else, and blocked the bus. That was really –

SS: So how did it happen? Did Brian say, I'm so sick I need a support group? Or did you realize –

BH: No, I think it just organic came together. The people who – he, he's in *Rockville is Burning*. He has a stint in it. Because that was Wave 3, actually. That video came out of Wave 3. In fact, I got to do that because Richard Elovich tossed me the project, and said, you do it. And so we did it with all the members of Wave 3.

Anyway. And Brian lived downstairs from me. And all the people in Wave 3, they just, I don't know how it came, it just seems very organic. Because they stuck together, and he needed help.

So he was in and out of the hospital for a while. I can't remember all the details. I just know that he –

SS: How come his family didn't take care of him?

BH: Oh, he probably didn't want them to.

SS: Did you ever talk to him about that?

BH: I never did. I met his father after he died, though, because – and his father was, they lived in D.C. A great story about Brian surfaced after, at one of the memorials after he died. Which I won't repeat, because I don't know if it's true. it's crazy. But –

SS: Oh, come on. How do we know anything you said is true?

BH: {LAUGHS} But it makes – bank robbery look pale.

SS: Oh, okay.

BH: No, it was Debbie Gavito, and Mark, and oh – I don't know. A lot of people were coming by to help him. But he, it was easy for me to pop downstairs, because he had the storefront in the building right next to mine. And he would just have his door open to the street. And –

SS: What street were you on?

BH: Fifth Street, between [Avenues] A and B. So people would just pop in, and he'd be there. And he had to go in the hospital for awhile. He didn't like that, but – he would get out as often as possible.

SS: So what was it like to sit with somebody who knew they were going to die?

BH: And this was the first, my first exposure to someone who was that sick. Well, it, it was – bittersweet. It was like, I didn't want them to be in pain; I wanted them to get what they needed to feel like they were being respected, and have some dignity. But also I was, sort of learning and watching, too, and observing. So I had a bit of distance. And – just sort of thought the right thing to do was, which everybody sort of naturally intuited, was just to make life as good as possible, as enjoyable; in terms of the food you like; having people around that you like; things that he wanted to do. He wanted to be outside a little bit every day.

SS: Did you have to help him bathe or go to the bathroom or eat; that kind of thing? Was it of that –

BH: I had to clean up some messes. And this is the, sort of the limits of my nursing capabilities. I'm a bit squeamish. So I – I think there was some – preparing food or feeding or something. He was, he was really sick sometimes. But then he'd go in the hospital, and he resisted that, but he would wind up there.

I don't remember all the details. It's a bit of a blur, because he was in and out.

I remember the second — not the second Wall Street, the – the Brooklyn Bridge demonstration. He wasn't feeling very good. He couldn't go. I was going. But I wanted to, I bought a police scanner from Radio Shack, because I wanted to tape-record all the police traffic to use in a video of the day. So I brought him upstairs to my apartment. And that wore him out, and he didn't feel very good. But I just got him to

listen to it on the police scanner, and change cassette tapes during the day. So he could, because I knew he wouldn't be going to the thing. So he helped, helped with that.

But something is, I have a blank spot about actually the, I know the, I must know about the day he died, because he was, I saw his father later on, and had a talk with him about the family and stuff, and what his mother – there was something odd. They didn't really come up, and I never saw his father before that, so.

SS: You didn't see the family until after he died.

BH: No, yeah.

SS: Yeah. Now Jon Greenberg is of course the opposite situation.

BH: Yeah.

SS: Because he had his brother –

BH: His brother was there. Oh yeah. Of course. Neil was there. And at a later part another brother came. Yeah. And he, he also had Risa taking care of him.

SS: Risa Denenberg –

BH: Yeah.

SS: – yeah.

BH: Who was a nurse. And Barbara Hughes was involved. He had a great, he, probably a more professional support system. And he, he knew a lot more. He really knew what he wanted. And there was more information then. It wasn't good information, but it was, he had ideas about, he had theories — which can be a dangerous thing — about coexistence with a virus, and coexistence with cryptococcal meningitis, which is really not a good idea. So he, he didn't want to go to the hospital; he wanted to lay in his bed at home, and have someone come and give him spinal taps and infusions.

And he had a doctor that would go along with that. Which is probably not such a good idea. But – he was so, he was really sick and uncomfortable. That was a terrible illness to have; to have your, the headaches and things that he had.

SS: What were the tensions or what were the affinities between the ACT UP friends and the family in a situation like that?

BH: I was not even aware of anyone with that. Another friend, Steve Brown, who I was involved with – very sad, tragic story, because he died in January of '95, when really, of something that had you had the right combination of antiretrovirals, you could have stopped it. It was PML [Progressive Multifocal leukoencephalopathy], this brain infection. And the best treatment for it is simply to get rid of, to bring your HIV down again.

And he had been in a drug trial, and – had a drug that, on its own, which of course he was, developed resistance to almost immediately. We just didn't know, and we were so close. This is the worst one. And that was the last death, really, like that. But, it was – and we were closer than any of the others. So this was the – the worst. We sh-, should have known, or could have known, or we could have put the drugs together. But it just happened so fast. And we really didn't know for another nine months to a year what to do.

But with his family, he didn't want his family around him. His family was very involved, and there was a lot of tension. So I, I was the one that was his medical proxy. And it was my job, according to him, while he was alive, to keep, keep things in balance. So I received a lot of stress from trying to keep his friends involved in his care,

and keep the family visits balanced. And it was not, not good. But I think it's what he wanted. Of course, he lost his mind at the end, so I don't know. But –

SS: Well, he chose you because he trusted your judgment, so.

BH: Yeah. And I lived across the street, and we had been in, he had – he started coming to T&D. I must have known him. Yeah, yeah. Funny. This is the thing: I kept going to T&D. Because I met a lot of pe-, I met Steve there. So stuff was still going on at T&D, even later, later, into '92, '93. And we were meeting at some weird warehouse space over in the West Village. I don't know.

SS: When did you finally leave ACT UP?

BH: It had to be '93, I think. I just stopped going. Well, certainly, They were meeting over at the, at Cooper Union. And I don't, I didn't mark the date; I didn't make a conscious decision to. It's just that I, it wasn't, I wasn't hearing anything – that I considered information; I wasn't getting the feedback; I thought it was a pretty diffuse energy at the time. It was – it was hard to hear in that big space. I didn't like the new space as much as the old space. It just felt like it had changed. And – I was sort of retrenching a little bit myself. So.

SS: Do you guys have anything else that you want to ask Bob?

Is there something that you feel that we haven't covered that's important?

JAMES WENTZY: DIVA TV?

SS: DIVA TV?

JW: What your contribution was?

BH: I never did anything with DIVA TV.

SS: Oh, okay.

BH: Actually. The videos I made in ACT UP; I did a video – I came home from, we were arrested at the second Wall Street demonstration; taken to this precinct over on the West Side below Canal Street where they had stables for horses; sat there a while; were released. Came home; and videotaped all the nightly news shows, and collected all the news reports. And I was so wired up, and had so much energy. I spent the night editing that into, one was a music video; it was a song by X, called “We’re Desperate, Get Used to It.” And just instant – I like these really instant products, this reactive products. And then made another one that was more an analytical piece of one particular newscast; called *AIDS News: a Demonstration*, which sort of explained how AIDS stories were told; the story of a demonstration was told on the nightly news, and what the hidden messages were.

So that was one collection. Then there was this *Rockville is Burning*, and I, I went to the 1988 Republican Convention –

SS: Aha.

BH: – with a whole bunch of people. And, oh, that was a frightening experience.

SS: Who did you go with?

BH: It was an ACT, it was an ACT UP group, I think. Neil Broome was there. You know who was there? Oh my god, it was so great. He’s dead now. Rod Sorge was there. They’re all in my video. Because I made a video at that, called *We’re Not Republicans*. And horrifying; just these monsters. If you’ve got monsters on your video, it’s easy to make it entertaining. But just these awful people, full of hate. Were truly just, you see the monster underneath. That is just shocking.

So those were the main videos.

SS: Well, I just have one last question, then.

BH: Sure.

SS: So looking back, what would you say was ACT UP's greatest achievement; and what would you say was its greatest disappointment?

BH: Well, the greatest achievement was just existing, crystalizing, the outrage into this fairly coherent form that people understood, people innately responded to and people felt they could be a part of, because it was, it was, it was an appropriate response; it was an understandable response to be so angry, to be so frustrated, and to be in the streets. And it was actually the right thing to do, and I think people understood that at the time.

And it was so successful because it was so diverse. And had so much, so many great brains offering wisdom that people could respond to; like from Maxine Wolfe to Jim [Eigo].

So it provided leadership in this classic way, without any leader. And I think that's really an amazing accomplishment. So it's a very ideal thing.

So that's such an ideal, amazing accomplishment, it couldn't last forever. It became imbalanced, and the times changed; certainly after the therapies came, changed, and became available after '95, '96, you wouldn't have the same, you wouldn't be able to mobilize the same – frustration, the same desperation. Because it wasn't there. People are also burned out on it.

So the failure: I don't know if there was a fail-. I did, exactly what it needed to do at a time, and it totally changed my life, and, and I don't see any failure.

SS: Great. Okay, thank you.

BH: Okay.

SS: Thank you so much.

Wow, now I want to see all your videos.