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P R O J E C T

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Interviewee: **David Barr**

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Interviewer: **Sarah Schulman**

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ACT UP Oral History Project
Interview of David Barr
May 15, 2007

SARAH SCHULMAN: Okay, so we just start by your saying your name, your age, today's date, and where we are.

DAVID BARR: I'm David Barr; I'm 51. It's May 15, 2007. And we're in my apartment in New York.

SS: On Second Avenue –

DB: On Second Avenue and 12th Street.

SS: Where you've been since 1979.

DB: Where I've lived since 1979.

SS: A true New Yorker. And full disclosure; your father and my mother worked together at Jewish Board.

DB: Oh –

SS: Sherman Barr, yes.

DB: Yeah. It was a long, long time ago, then.

SS: Yes. So you're a real New Yorker, New Yorker, New Yorker?

DB: I'm a third-generation native.

SS: Native New Yorker. What neighborhood did you grow up in?

DB: In Brooklyn; in Sheepshead Bay, Brighton Beach.

SS: And did you go to Brighton, which high school did you –

DB: I went to John Dewey High School, an experiment in public education.

SS: And did it work for you?

DB: Oh yeah. Yeah. I was –

SS: So you grew up in one of those Jewish socially oriented families.

DB: Very much so, yeah.

SS: And do you think that you were trained to be a community activist by your family?

DB: Yes.

SS: How did they do it?

DB: They took me on demonstrations from when I was a young kid. I went on, I remember going to — and it's a really long answer, but —

SS: Go for it.

DB: — I was taken on demonstrations to integrate housing in Brooklyn; to ban-the-bomb demonstrations in the early '60s. I was a part of, my parents helped to organize a volunteer reversed busing program in Brooklyn in the '60s, where all these sort of white, middle class kids from Brooklyn were bused to a predominantly black and Latino elementary school in Fort Greene, which was a very different neighborhood than it is now. So I was involved in that, and it was a very high profile program, so there was a lot of press involved, and like I remember all that. And then a lot of antiwar, anti-Vietnam War activity in junior high and high school.

SS: How left were your parents?

DB: My mother was thrown out of Erasmus High School for distributing socialist literature. And my father was a member of the Welfare Rights Movement and started Mobilization for Youth on the Lower East Side.

SS: So were they ever Party members, or —

DB: No, they were never, no, so I'm a pink diaper –

SS: Okay. So like solid liberal background.

DB: Nn-, by liberal, liberal would be a sneer to liberal. It would be definitely be more left than that.

SS: Like socialists –

DB: Yeah.

SS: Yeah. But your mother never belonged to a party, or –

DB: No.

SS: No.

DB: She belonged, I guess before, as a teenager, she was a member of the Socialist Party, or the Young Socialist Group.

SS: Oh, the Trotskyites, or something like that?

DB: I don't, now you're getting into –

SS: Now I don't know.

DB: – yeah.

SS: Okay. But anyway, it's been in the family for a long time.

DB: Yeah, yeah.

SS: And do you remember them explaining to you why it was important to show up for social change, or –

DB: Um – yeah. It's sort of most of what we talked about, I guess. It was like that was the discussion in the house. That and food. And just, stopping the kids from fighting with each other.

I went to a radical, leftist summer camp. It was a real –

SS: What was that called?

DB: It was called Camp Thoreau. And it was, it was in New Paltz, outside of New Paltz, and it was – the Rosenberg kids were there; the Robeson kids were there. It was an interesting place to be in the '60s, in terms of the kids that were there, the counselors that were, what the counselors were doing when they weren't at camp and stuff like that.

SS: So what were the first movements that you participated in?

DB: I started a group called Children's Strike for Peace, in junior high school

SS: Wow.

DB: In like seventh grade.

SS: And what did you guys do?

DB: Nothing. We went, we went to, I don't know; what did we do? We, we – I guess we participated in demonstrations, you know. Because I, I remember going to most of the major Vietnam War demonstrations, and volunteering at the – the office was on 17th Street, off of 5th Avenue, and it was like the Mobilization to End the War; I guess that was the name of it. And I would go and volunteer there, and – yeah.

SS: So what do you think your vision was for what your life was going to be like, when you were coming out of high school, at that time?

DB: I got really interested in theater. I got interested in avant garde environmental group theater, because of, there was some program at the high school that

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I got involved in, where we did this very sort of experimental, communal theater piece. And I was taken to see the Performance Group in what was going to become SoHo. And saw their piece called *Commune*. And it really changed my life. I really said, oh, this is what I want to do. And so I got involved in doing that kind of work. And went to theater school at NYU when I got out of high school; moved into the city.

SS: Oh, I never knew that. So who did you study with, or who did you work with?

DB: Well, first I studied with Stella Adler in this program there, and I really hated the program. She was a – very entertaining, but a pain in the ass. But then I got involved with the Performance Group, and I left school to go work with them for a while. And the guy who started, there was a guy in The Performance Group named Steve Borst who started a gay and lesbian theater group – and this was 1972, 1973; three, maybe. So it was probably the first gay and lesbian theater group, ever. And I was 18, and I left college so I could be a part of that. And we created a piece called *Slime Mourning*. Which was, oddly, about death and sort of how gay and lesbian people relate to rituals of death in society, which was kind of odd, that we, that was our focus, given what was to come. And Ron Vawter was a member of the group, because he was the business manager of the Performance Group, and good friends with Steve, and that was sort of how he started acting.

SS: What exactly was The Performance Group? Like, who were the –

DB: The Performance Group was, there was a movement of theater in the city in the '60s that was really, it was primarily done in groups. There were a couple of

very famous groups that were part of the movement; the Living Theater, the Ridiculous Theatrical Company, The Performance Group, Mabou Mines; there were a few others. Robert Wilson's group sort of came out of there eventually, and – The Performance Group really specialized in what, Richard Schechner was the director, and it was sort of environmental theater. So there was a lot of audience participation, and a lot of theater happening in the space that every-, rather than me watching you perform, this theater was happening in the entire room. And they did a lot of somewhat political pieces. They did a really good version of *Mother Courage*; they did *Tooth of Crime* by Sam Shepard. The most famous play was the first one, called – oh, god. I don't remember. I want to say it's *Paradise Now*, but that's wrong, because that's the Living Theater. Anyway.

SS: So was that your first gay organization?

DB: Yeah.

SS: And I guess you were already out, if you were joining something –

DB: Yeah, I was like coming out. And then when Steve asked me to join the group that did it. I was like, okay, I'll accept the identity because I really want to do this.

SS: So were you, where did you, where were you gay? Where did you go to be gay before you joined –?

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DB: Well, I didn't really go anywhere to be gay until – college. I just started sleeping with my friends, from like, as a young teen. And, which I really liked, but it always ended terribly, because I would really like it and they would be really freaked out. And then I met one other gay kid, in high school. This is early, this is – the

Gay Activist Alliance was around. And the first, I think maybe I wandered into the Ninth Circle once, but was terrified and left. But the first place where I went where I felt connected was at the Gay Activists Alliance Firehouse on Wooster Street. Because that was, it just felt – well, it reminded me of the antiwar movement; it was, there was a, it was movement-connected, and they had these really great dances on Friday night, and you paid two dollars, and it was all the beer you could drink. And I spent a whole summer going to those. And that was pretty transformative.

SS: So were you doing straight politics as well as being in these gay –

DB: No, at that time, I really wasn't doing any politics. I was really doing theater and sort of finding gay life, and –

SS: And did you complete the program at NYU?

DB: I left, and then I went back, and I went to the theater program, which was sort of this combined graduate and undergraduate program that was much more to my liking. It was a more experimental approach. Omar Shapli was the director, and Joe Chaikin was there, Richard Schechner was there. It was a good place to be. And yeah, I finished that.

SS: So then you worked in the theater?

DB: Well, I didn't really work very much. It became – what I really liked to do was not something you'd get paid to do. And that movement was beginning to dissipate. After I got out of school, I did some theater, and I spent some time with the Ridiculous Theatrical Company, which was sort of a dream come true; basically helping them build sets, and like, running out to get them Jack Daniel's before a performance,

and things like that. But I would have done anything that they said. And then I, I just kind of drifted away, eventually. And I started cooking.

SS: For a living.

DB: Yeah.

SS: So where were you cooking?

DB: In restaurants around town. And then – my boyfriend and I traveled a little bit, because I'd never been out of New York, and when we came back, I decided I wanted to leave New York and go live in the country. This was in 1980. And so we moved to the Berkshires, in like the middle of nowhere. And we got jobs at this treatment center for autistic kids, that was a really interesting and cool place. It was a really nice place, and the kids were really interesting, and I was the cook. And – this is a really, this is the segue, right?

So I was the cook at High Point School. And that's the first time I heard about AIDS, because it was 1981. Because the director came in one day and said, what – because everybody would hang out in the kitchen. And he said, well, what do you think about this gay disease? And because I was the gay guy; Paul and I were the gay guys at the place. And I had no idea what he was talking about, and it was really 1981, and it must have been the first, the first [*Village*] *Voice* article, because that's what he asked me about: Did you see the article in the *Voice*? So I guess that was '81; must have been.

And then – didn't really hear much more about it. But I moved back to New York in '82. And about six months after I had moved back here, there was an announcement in the paper about a memorial service for Steve Borst, who was the

director of the theater company. And I went to the m-, I hadn't seen him in years, and I went to the memorial service at The Performing Garage, and everybody was there. And clearly, Steve had died of AIDS. And it was before we had the word. So that was –

SS: And you realized that, at the time?

DB: Yeah, yeah, yeah, I was, it was pretty clear.

SS: So how did that affect your behavior and your life? Knowing that this phenomenon was out there, and it was killing people, or at least someone, that you had admired?

DB: Uh, well, it was just really upsetting and scary and – it was the beginning, and it – it didn't – there were other things going on in my life at the same time that were – my father was very sick, and died that year, so that was the death – I mean, both of those deaths, I think, had an impact on me. But even before my father died, I had decided to go back to school, and go to law school. Because I was really interested in sort of taking, I was getting interested in politics. And I was, again. And I wanted to find a way to sort of put my politics into some practice, and find something to, and I didn't want to work in restaurants anymore. I wanted to have some way of making some money where I was able to do something that I cared about. And law school seemed like a good way to do that, because a political science degree would have meant I could wait tables and just have read more.

SS: Right.

DB: So I went to law school, and I went to CUNY Law School, and I was in the first class of CUNY Law School, and CUNY Law School is a very radical — or at

least at the time — was a very radical, really the most radical, experimental legal education ever. It was a law school dedicated to public interest law. Everybody in my class — there were a hundred and thirty of us — were people who'd come from other professions, other walks of life, who had gotten interested in doing some sort of legal work that was attached to values around change. And it was an exciting place to be. It was the first year. And so they were making up the program as we were taking it. We would have to wait around on Friday for them to finish xeroxing our reading materials.

And while I was, through CUNY Law School, almost immediately, I got involved in gay and lesbian rights works. And –

SS: Was that through your professors, or was it –

DB: Yeah, yeah. There was a woman –

SS: Who were they?

DB: — a woman there named Rhonda Copelon, who's still there.

SS: Sure! She argued the Hyde Amendment.

DB: Yeah. Rhonda's an amazing person. She teaches there and was also at the Center for Constitutional Rights. And in my first year of law school, I was helping write an amicus brief for the Uplinger case, which was a gay rights case around loitering in Boston. And went to Washington, and saw the argument. And then the next year, I worked on another brief. And I did an internship at the ACLU with Nan Hunter. Which was an amazing thing, because it was right in the midst of, Nan was having this big battle with Catharine MacKinnon around pornography. And MacKinnon was sort of of this school that pornography is evil and should be wiped out. And Nan represented a large

group of feminists who felt that wasn't the case, and it was sort of how you made pornography and used pornography that –

SS: And you worked on that?

DB: Yeah, I worked on that with her.

SS: Oh, wow.

DB: I was there for a couple of months, and I got to work on that, and got to see this sort of famous debate that they did, at the Women & Law Conference, against each other, that actually broke out into violence. It was wild, and –

SS: Violence at the Women & Law Conference?

DB: Yeah, yeah. It was really cool.

SS: Oh my god! {LAUGHS}

DB: I was, like, the only guy in the room, and it was, it was – but Lambda Legal Defense Fund was in the same building as the ACLU at the time. So I started hanging out downstairs at Lambda, and getting to know people. And Tim Sweeney was the executive director. And Abby Rubinfeld was the legal director. And there were like two other people there, and Lambda was really tiny.

So I started volunteering at Lambda, and became an intern there. And – the first, that was in 1985. And the very first thing that I ever really did in AIDS was — and the first thing I did at Lambda — was, Lambda was going to challenge the licensing of the HIV test: not because people were opposed to the idea of an HIV test, but there were no provisions in place to protect people from using the test results in discriminating ways, and we thought that would probably happen. And so we wanted to delay the

licensing of the test until some provision could be made to protect people, or to limit the use of the test. We weren't opposed to screening the blood supply, you know.

So, and I was the second-year law student. And it was a funny thing.

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Because here was Lambda; Lambda was always about, it was a place, the ACLU was, everybody was in the same situation. The history of the work of those organizations was, and primarily still is, to do human rights-based, constitutional rights work. Yet here we were challenging the Food and Drug Administration's approval of a diagnostic. Nobody in the place knew anything about the food and drug law; about a diagnostic. We had, in order to delay the licensing of the test; we needed to challenge the validity of the test. We couldn't argue it just on the basis of our human rights concerns. We had to say, there's something wrong with, the test isn't good enough to do the job. And so, and nobody knew what that meant. So I was a second-year student, but it didn't really mean that I knew any less than anybody else in the room; we were all at a loss. So we were all pretty ignorant.

And the first thing I was asked to do was to go out and meet with scientists and doctors to get them to write affidavits in support of our petition. And we wanted them to claim that the test was not sensitive or specific enough. And I had no idea what that meant. And the first person I talked to was Mathilde Krim, who I didn't know. And she was very nice, and explained what the terms meant. And the second person I talked to was Joe Sonnabend. So it was, it was just kind of wild, that –

SS: Did you have awareness at that moment that this was going to be a whole new world of law?

DB: You know – no, I don't think so. I, it's hard to – it's been so long, you know. It was all moving really fast. And I think there was a sense that things were in crisis. I mean, obviously, AIDS was a crisis. But there was a lot going on very quickly, and there was no sense of having any control over what was happening. And so I think there was that sense of urgency that we've got to do something to control the situation.

We lost that, and the test was licensed. And almost immediately, the AIDS legal crisis ensued. And Lambda started getting flooded with calls from attorneys around the country saying, I have a client. He got tested without him knowing it, and they've thrown him out of his job. Or, the doctor was testing people in his office; he got thrown out of the office. And there was a case like –

SS: They were all discrimination cases?

DB: They were all discrimination cases. And I was the intern answering the phone. So I was sort of the first person to hear all this stuff. And people were filing suits. And there was no precedent; there was nothing. So I just started collecting the information about the different cases, and started passing the information around. And started a newsletter called *AIDS Update*, I think. And I guess it was the first AIDS legal newsletter that just started reporting on these cases that were coming up. And giving phone numbers and stuff so that attorneys could start talking to each other and exchange information about the approaches that they were taking.

And I did that till I graduated from law school, and then I went to clerk for a housing court judge, a civil court judge, in Brooklyn.

SS: And were you concerned about your own status at that time?

DB: Um – yeah. Though – I wasn't going to test. Because our position, at the time, was to not test. Right? There was really no reason to test. We felt there's nothing you can do with the information. Right? There's no medical intervention that you can, you can do. So that if you test, and if you test, you're subject to discrimination; there's all sorts of emotional trauma. So we really were encouraging people to not test.

SS: Now at that time, did you see people you knew, or friends of yours who were not testing become symptomatic?

DB: No, actually. Well, let me not say "no" so quickly. Um – no. Because – I was, Paul, my boyfriend and I, had gotten together in 1974, 1975. And we were together for 15, 16 years. And we weren't involved in the gay scene at all, really. I didn't, I didn't have a large gay social circle. And there were very few gay people in my law school. One man in my class, two men, one of whom wasn't out; the other of whom wasn't terribly active; and the rest were women. So we didn't have, I just didn't have that much interaction. And it wasn't the case at Lambda, either. Lambda was really small. So I didn't have that kind of personal connection at the time. And was I nervous? Yeah. But I was nervous. At that time, there was – it was all myth and rumor and oh, well, you couldn't get it unless you had sex with a thousand guys. That was one –

SS: On Fire Island, right?

DB: Yeah. Unless you had sex with a thousand guys – for some reason, it had to be a thousand. You only got it if you did poppers a lot. You only got it if you fisted. There were all, there was all this kind of misinformation, that I think was – so I

felt like, well, I don't think I've done a thousand guys, certainly. Because I wasn't running around very much. But I was running around a little bit, and I wasn't supposed to be. So there was – I couldn't talk about how I felt about it at home, because that would have opened up a whole other set of issues with Paul. And – so yeah, so it wasn't, it had yet to really become that personal.

SS: So then after you clerked, okay, so that's, we're in '86 now, right?

DB: Yeah, '86, that's right; yeah, '87.

SS: So you stepped out of the AIDS world for a couple o' years.

DB: Yeah, I remember when I was clerking, I noticed white spots in my mouth. And that freaked me out. Right? That, and I didn't know what it was, and I just – conveniently forget about it. And then, in '87, Lambda called. Abby Rubinfeld called me and said, look, we've got some money, and we want to hire two attorneys to be our AIDS program. And do you want to apply for the job?

So I was hired and Mickey Wheatley was hired. And so in '87, I joined the staff of Lambda.

SS: Mickey Wheelie?

DB: Mickey Wheatley, yeah.

SS: Wheatley, okay, I don't know who that is.

DB: Mickey was also in ACT UP New York for a while.

SS: Oh, okay.

DB: And Mickey was, Mickey came in to sort of do the litigation; and I came in to do the policy work. Which is good, because I wasn't interested in being a

litigator, at all. I was a little interested in it, but not really. And so I started doing policy work. I kept doing the *AIDS Update*. My work, initially, at Lambda focused on discrimination work, immigration, confident-, the confidentiality law in New York State was being drafted at the time. And Richard Gottlieb had people working on that, and at GMHC and at Lambda. I remember working on a piece of it. It wasn't my primary responsibility, but I worked on a piece of it.

And there was a guy at Lambda named Jay Lipner. He wasn't, he was a, Jay was a volunteer. He was an attorney. He started the Legal Services Program at GMHC; it was the first AIDS legal services program ever. And a person with AIDS. I mean, that was really, Jay was one of my very f-, I'd met Michael Callen earlier, while I was in law school, because Michael's band came to play at my law school party. So that's when I met Michael.

SS: What were they called again?

DB: I don't know. It wasn't the, it wasn't the a capella group; it was a band before that. It was a rock band. And I knew he had AIDS. And he was like the first person with AIDS that I actually met, and it made me nervous. And then I thought he was so cute. And then I got to know him.

But Jay was, Jay was really one of the very first people to get involved in treatment work; working very closely with Marty Delaney, and had had a couple of conversations with the FDA and the NIH at that point. This was, this was '87; it was really early. And Jay sort of, I got interested in the subject, and Jay just became my mentor. And Jay died in – I don't know; '92, '93; '92.

And – it was also in '87 that I went to my first ACT UP meeting.

SS: How did you get there?

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Q: I saw the poster on the street. And I thought, ooh, what's this? I saw the Silence Equals Death poster, and I was just immediately drawn to it. And then, maybe the Reagan poster also. And it all sort of happened about the same time I was starting at Lambda, so I'd heard about this thing. I guess I read about the Wall Street demo, the first demo.

SS: Oh, okay.

DB: Because I wasn't there. The first meeting I went to was after that. So I read about the Wall Street demo. So I knew that there was this thing happening, and it sounded really interesting to me; sounded like something I would like.

SS: And so what happened to you when you walked in that room?

DB: It was a meeting at the NYU Law School, for some reason. I don't know. It might have been the only ACT UP meeting at the NYU Law School. It was a general assembly meeting. And the major topic of conversation was about planning the concentration camp float.

SS: Okay.

DB: And I just, I don't know, I remember being really nervous; because I really liked it. And I really thought, I thought, oh, oh, I've got to, I, I, I'm home. This is, I'm home. And then, and that made me really nervous, because I had to figure out, I need to find a place here, and how am I going to do it? And it felt that way for a bunch of reasons. One, because I liked what they were talking about, and I liked the energy in

room, and everybody was fighting, and it was, but it was passionate and I liked it and I liked the idea of the float. But also the, the, the, the – erotic energy in the room was also really compelling and –

SS: Did you recognize people that first time?

DB: No, no, I didn't know anybody there. I don't, no; I didn't know anybody.

SS: So how did you start out in ACT UP? Where did you plug in at first?

DB: Well, I was working, I was a staff attorney at Lambda, so it meant that I could – I was doing my Lambda work, and then I began to do some ACT UP work, and it immediately became about how do I integrate those things; how can I bring Lambda into ACT UP, how can I bring ACT UP into Lambda? And ACT UP had no organization, it had no money; and it wanted to do civil disobedience, and I was working for a legal organization. So I immediately went to Lambda, and I said, they're going to do these demonstrations. They want to do civil disobedience. We should provide them with legal support. So we did.

SS: Now had Lambda ever done that before?

DB: No.

SS: Right.

DB: Never. And it didn't do that much of it. It was a bit of a struggle to get them to do it. Not, not to get them to do – and it wasn't that Lambda provided the support itself. Lambda let me do it. Lambda let me –

SS: Okay.

DB: – work on it, right, as part, and I could say, I’m here from Lambda. So I didn’t have to worry so much that I was not doing my work, I wasn’t doing my job. It became part of my job to do some legal organizing for ACT UP. So Lambda allowed that.

But it also, Lambda also allowed me to reach out to the large network of volunteer attorneys that were connected to Lambda. So that, it gave me a way of communicating to lawyers, to say, do you want to provide these kinds of services: to monitor what goes on at demonstrations; to represent people who were arrested.

SS: So who were some of the people who you seduced into ACT UP that way?

DB: Oh, god – Joan –

SS: Gibbs?

DB: Yeah, Joan Gibbs and I didn’t seduce, I don’t know, who seduced who? I don’t know. Eh, Bill Dobbs. And I have to say, really unfortunately, if there’s, if – and I won’t speak ill of too many people on this interview. But we can put him on the list of people I will speak ill about. A dangerous guy, I think. And very dangerous in ACT UP. Very destructive.

But, and who else? Oh – I can’t remember who else initially. But eventually, as like, when we started doing the national demos, then more, Sue Hyde got involved; Kevin Cathcart got involved; there were different people in different parts of

the country. So that became part of my work; organizing legal support for demonstrations through Lambda. So that was one way that I hooked into ACT UP.

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And then I just looked at, well, what are the committees in ACT UP, and which committee should I join? I figured I should join a committee, and that was how I should get involved. And it seemed like the committee that was going to relate best to my other work was to be on the Issues Committee. And I was, already had some interest in treatment stuff, so I started going to the Issue Committee meetings. And that's what became Treatment and Data. And we met at Herb – it was, Iris couldn't remember the name in her interview; it's Herb Spiers.

SS: Oh, okay.

DB: And he had a loft on, I think, 19th Street, off of Park. And we met there. And those were the first treatment meetings.

SS: And you still had not tested at that point.

DB: No, no. I didn't test until '89.

SS: Do you think that there was any subconscious thing that led you to Treatment, in terms of your own health? Because you had no science background then whatsoever, right?

DB: No. I don't know. I don't know. It was – I'd worked on the testing thing. So that kind of introduced me to this world. It wasn't, it, I mean, it didn't take a lot to think that this is a scientific challenge. There's a lot of challenges here, but this is primarily, first, a scientific challenge. And – I don't know if I thought about it that much, beyond, just that it was going to be important to be able to treat people. It became – I

mean, once I tested, that — and I tested positive — that — it just upped the importance to me. I was already really involved in treatment work by that time.

SS: So when you first got into T&D, who were the personnel and what were the agendas, at the beginning?

DB: The first, at Herb's, the people who were there were Iris; David Kirschenbaum; Margaret McCarthy, who was fantastic; Bill Bahlman; Marty Robinson; John Bowne — who was a lovely, lovely guy; a Quaker. There's this group of Quaker guys. There was John; and there was a whole group o' them. This one face just flashed, but I can't remember his name; David. So many Davids, so many. Carrie Stiegel was there. Jim Eigo started, came, while I was starting, Jim started. I can't remember anybody else, but that, that was —

SS: And what were they thinking at the time?

DB: The issues then, the very first issues were DHPG, and the clinical trials; what was going on with the clinical trials. And it was really at an early stage of that discussion. So it wasn't a discussion yet about this trial or that trial, but what trials? Where are the trials? Who's doing them? How do we get information about them? How do we contact the NIH and get information about the trials that they were doing?

And David and Margaret were particularly important — really important — in getting that information first. We filed Freedom of, I, so I was at Lambda, so we filed a Freedom of Information Act to get the, all the clinical trial data from NIAID, because they didn't want to give it to us.

SS: Why didn't they want to?

DB: {sigh} I forget what they said. It wasn't that they said that it was confidential. I think aspects of it were confidential. They didn't have it in formats that they felt we could use; that was part of it. And they didn't know who we were. Who are you people? Why are you asking for this information?

Iris was, was – Iris is a little strange, but she was – she – she started it. She was the one who came in and said, you people need to learn about how drugs are developed, you need to understand the biology, you need to understand clinical research. And she just started to teach everybody. It was really Iris who did that.

SS: So up until the moment when you were systemati-, oh. We need to change tapes?

James Wentzy: We have to change tapes.

DB: Yeah, sure.

SS: Okay.

SS: So up until the time that T&D got this systematic information about clinical trials, how did anyone get into a clinical trial?

DB: By going, I guess by really going through their doctor or being in a hospital. That was how people – it came to people through the hospitals.

SS: So if you just happened to be in a hospital that had a clinical trial and your doctor was connected, you could find out about it.

DB: Yeah.

SS: I see. And what was being tried, at the time?

DB: Well, I guess DHPG, AZT; what else? It's hard to remember the continuity of when things actually came into play. There were the drugs that – there were the drugs that were being sort of studied through traditional, through mainstream channels — AZT, I guess being the best example — and – oh, I can't remember the names.

SS: Okay.

DB: But then there were also drugs that became, all of a sudden, dextran sulfate. Do something, take dextran sulfate. And it became available through the underground, and so people would start taking it. And then there'd be some study to see how it didn't work. And there were other things like that.

SS: So when you guys got that information together, what did you do with it?

DB: Well – the first thing, really, was to put the information out there about where you could go to be in a study. That was one thing. And AmFAR played a really important role in taking that work on by creating the directory, the Clinical Trials Directory. But the other thing that I think Treatment and Data started to do was look at, what are the conditions for being in the study? Is it a placebo study; and if so, is the placebo warranted? What other things can you not do if you participate in this study?

That became more of an issue a little later, in '89, when PCP prophylaxis became something that we knew was working, and then an antiviral study wouldn't allow you to take PCP prophylaxis.

What was the number, who was in the studies? We wanted that information. And that's what they didn't want to give us. That, they felt, was proprietary. How many women are in the studies; how many people of color are in the studies? And all, we really wanted to look at demographics, and we did all of that, and did analysis of that. What wasn't being studied, I think was an issue.

SS: Were you able to overcome the habit of having placebo built into tests and trials?

DB: Yeah, yeah. In the very beginning – well, it took some time. But eventually, yes, we were able to overcome the placebo issue and make sure that there were no placebo-controlled studies any longer. But it only really became viable once there was something to, some substantial, at least, possibility of treatment. Right?

SS: What was the obstacle? Was it just doctors and their habits? Or was it that they weren't seeing the patients in a fully humanized way?

DB: No. The obstacle was that they wanted to do good clinical research. I mean, really. If you want to really know if the drug is working, you want clean data. And that's the best way to get it. If we were studying AZT without any idea of whether or not it worked; without a placebo; we wouldn't have known, unless it was so good that it was miraculous. Right?

Tape II
00:05:00

SS: No, I mean, ACT UP never took a position on AZT. Isn't that true?

DB: What do you mean?

SS: That ACT UP believed that you should just put out all the information, let people make their own decisions. But it never came out pro or con on AZT. But that was a controversial issue inside ACT UP.

A: Was it?

SS: You didn't experience it?

DB: I think that ACT UP, I think the first thing you said was absolutely right; that it wasn't our job to second guess, really – that our fundamental principle was that people should have information, and that it is up to the individual to have control and make the most informed medical decisions for him- or herself. So it wasn't our job to say, you should take this or you shouldn't take that.

SS: But didn't people come to you and ask for advice because they knew that you were in T&D?

DB: Yeah.

SS: And what would you do?

DB: I would say, here's what we know. Here's what we don't know.

SS: Do you remember which medications were really difficult for people to make decisions about?

DB: Well, anything that was particularly toxic or expensive.

SS: But like when Larry came in and said, cucumber –

DB: Yeah, Larry came in. I mean, there, there is a good example of not following through on that fundamental principle of just providing information. Larry walks, strolls back into ACT UP. I don't have anything good to say about Larry. That's

the second person. Since you have so many people saying negative things about Larry in the clips, I assume there's some editorial policy going on in choosing the clips. But Larry walks in and says, they're dancing in the streets in San Francisco. Literally. I mean, that's what he said, right?

SS: Right, I was there, yeah.

DB: And people got killed. It killed people – Compound Q.

SS: Did you see people in ACT UP running to use Compound Q?

DB: Yeah, oh yeah. Yeah, people were dying to get it.

SS: And what was T&D's view on Compound Q?

DB: We wanted information. We wanted a study. I think – there was a transformation in the work at T&D. It started, we started knowing nothing, and in an incredibly desperate situation, so anything, anything, anything we can get. But if anything became possibilities, and as we started to understand what clinical research is about, we began to respect research and how research gets done and the need for good research.

SS: So which projects did you work on in T&D?

DB: I worked on a lot of projects. I was really, let's see. I worked on the expanded access program for ddi. And that was pretty early on.

SS: What did that involve?

DB: Well, that was kind of a wild thing, because there we were, sort of calling for, well no, the first thing I worked on was the notion of expanded access. And I did that with Jay Lipner. And that was very much a Lambda piece of work, and an ACT

UP piece of work. I was doing that on both ends. And usually, at the meetings, I was wearing my Lambda hat. Because there would be another person wearing an ACT UP hat there, so it was a way of having another organization represented. And the very first stuff I did was around developing the notion of expanded access, and fighting with the FDA over its expanded access regulations.

And Jay and I went to Washington — this is before ACT UP had ever met with the FDA — and Jay and I went to Washington, and we met with the, we had a meeting with the commissioner. He –

SS: Who was the commissioner?

DB: Frank Young, who looked a lot like Captain Kangaroo, and wore his Public Health Service uniform.

SS: Oh my god.

DB: So he's wearing this uniform, and he just, he looked absurd. And he came in with, and he was the commissioner. Who were we? We were, we were nobody. But we were this legal organization, so that kind of made some difference. And – we read those regs. And the fight, the drug was a drug called trimetrexate. It was experimental drug to treat PCP. And what happened was, was that for people who were failing Bactrim and who were failing pentamidine — or for whom those drugs were too toxic — here was a third possibility. And there was Phase I and some early Phase II data that the drug might be effective. So we read the regs. And we said, this drug is available for expanded access, because it meets the conditions of the regs. Right? There is some safety data; there is some evidence of effectiveness; and you could create an expanded

access program limited to people who have failed standard therapy. And that way, they would have some option. Their only other option would be to die from PCP, right? So why not give this to them? It's not interfering with further research on the drug; it's only for this limited group of people who are failing other therapy.

And so we had this, that was the issue that we went there to talk to him about. He pulled 15, 20 of the top FDA brass into the room; all of whom were men, except for one woman, who was Ellen Cooper, who was the head of the antiviral division. All of the guys were incredibly placating to us. They were like being, just like falling over themselves to be nice to us.

SS: Do you think they felt sorry for you?

DB: I don't, I think they wanted to get us out of the room. So they were going, uh, yeah, yeah, yeah, yeah, you poor nice people, and you know. And she was – she was nicknamed the Ice Queen. She was brutal. I could do a lot more for people with AIDS if I didn't have to waste my time meeting with people like you. She was, and I loved her. Because she was just, she, because she was the only one in the room telling the truth, from their point of view. This is our point of view; this isn't what we want to do; you people don't understand science; don't waste my time.

And Jay said, I'm not just a person with AIDS. I'm an attorney. I have read your regulations, and I'm going to sue you. Right? And – and so we left. And then a couple of weeks later, I went to the AIDS conference, the International AIDS Conference, in Stockholm; 1988, and my first International AIDS Conference. And there were very, there weren't very many activists at the AIDS conference. It was in

Stockholm; nobody was, it wasn't the thing to do yet, to go to this. It was expensive. And Lambda was able to send me, so I went. And there was Ellen Cooper. And we got drunk together at the reception. And by the end of the conversation, I had her and the dialog kept going. And they changed. Then we got an expanded access program for trimetrexate. Which wasn't a particularly important drug. But it changed the standard by which FDA reviewed every other drug. So it was important. And –

SS: Did it turn out to be effective?

DB: I don't remember. It certainly, it was very toxic. So it wasn't something that people were going to use on a regular basis. And it certainly never replaced the standard, already standard of care.

Then Bristol Myers – now I'm trying to remember if ddI came before or after the FDA demo. And we should talk about the FDA demo, right? But Bristol Myers called us. They called ACT UP. And said, we want to do an expanded access program for ddI. And we want you to help us design it.

SS: Who did they call?

DB: I don't remember who they called. It wasn't me. I didn't come in until like two weeks later. Because we held the meeting at Lambda. But I don't know who they called. Maybe they called Jim –

SS: Eigo?

DB: – Eigo. Maybe they called Mark Harrington, who had gotten involved by that point. I'm not sure. But we had a meeting, and we designed the program with them. And it got approved. And 25,000 people got ddI in expanded

access, for free, who would have had no other drug to take, because those were all people who had failed on AZT. And all of the important information about pancreatitis associated with ddI came out of the expanded access program, and wasn't seen in the clinical studies.

SS: Why is that?

Tape II
00:15:00

DB: Because there weren't enough people in the trials, you know. And so you've got this large number of people taking it, and they were able to see that there was a side effect, a very serious side effect that they hadn't seen before.

SS: Now before you get to the FDA action, so since you tested positive in '87 –

DB: Eighty-nine.

SS: Oh, okay, so we're not there yet.

DB: It was '89.

SS: Yeah. I mean –

DB: And I –

SS: Go ahead.

DB: Yeah.

SS: The thing I wanted to ask you about that is, what did you decide, treatment-wise, when you first tested, based on your knowledge from T&D?

DB: Well, I tested in '89. I was still at Lambda. I had developed a close relationship with Marty Delaney. And Marty was the one who had pushed me to get tested. He really pushed hard. He said, you have to go and get a test; you have to stop

putting this off. And by that point, AZT was around. But it wasn't about AZT; it was about PCP prophylaxis. I didn't know about AZT, whether it was going to be useful or not, given that I was still healthy. But PCP prophylaxis, not knowing my T-cells; and that I could take PCP prophylaxis; was the reason why I tested.

SS: And you had thrush, you said.

DB: Nah, I didn't have thrush. I had a hairy oral leukoplakia.

SS: Okay.

DB: Which isn't as problematic as thrush. It doesn't get worse, really. And so I tested because Marty told me to test. And I did. And I tested positive. And – immediately came out, like within a day, that I had tested positive. And became, like the HIV poster boy for Lambda. They had an HIV person on the staff, so they could, they could cart me around, and let me talk to reporters and things.

And then I, and I got my first T-cell test, and it was like, 385? And Howard Grossman was my doctor, and he said I should start AZT. So I did. And fortunately, I didn't do it for too long. I stopped after about six months. I didn't consciously stop. I didn't say, I'm going to stop taking it. I just kind of stopped taking it. Because I felt like, eh, I don't, I don't really know if this is doing anything, and I feel okay, and I don't know if this is really working for people out there. Because I was seeing, we were learning more about it. And so I just stopped taking it.

SS: Now do you think he was taking AZT, and that that –

DB: Who?

SS: Howard Grossman?

DB: Howard's not positive.

SS: Oh, okay.

DB: Yeah.

SS: Okay.

DB: No, he was, that was what people should do at the time.

SS: Okay, so I understand. But you did decide to do PCP prophylaxis.

DB: I didn't. I didn't start PCP prophylaxis then, because I had 385 T-cells, so I didn't need it yet.

SS: So as a patient, you already had more information than your doctor, from being in T&D, on some level.

DB: Yeah. Yeah.

SS: That's significant.

DB: I mean, Howard was a knowledgeable AIDS doc and involved in the work, not just in being a doctor. But yeah. I was already, at that point, dealing at a fairly high le-, at a high, very high level, with FDA: with the NIH; with Pharma. So I was getting a lot of information.

SS: Okay. All right, let's go back to the FDA demonstration. What did you want to say about that?

DB: Oh, okay. Well that's a good story. Well, I don't know if, have people spoken about the FDA demonstration?

SS: Everyone has a different story.

DB: Oh. Well, all right. Then I have my story.

SS: Okay.

DB: I have to tell the story this way; I can't tell it any other way.

SS: Go for it.

DB: All right? All of this work was about a lot of people. Right? You're interviewing me, so I'm going to tend to focus on my work.

SS: That's what everybody does.

DB: Okay.

SS: Yeah.

DB: I just don't want to make – I just want to acknowledge that this was about a lot, a lot of people.

The idea for the FDA demonstration came out of a lunch that Gregg Bordowitz and I had at Dojo, on St. Mark's Place. And we were talking, Gregg was talking about the need to do a national action. Because all these ACT UPs had sprung up around the country, sort of by, just by word of mouth. I don't know if anybody's spoken about that. But that, that's an incredible phenomenon that happened, I think. Nobody organized any ACT UP, ever. It wasn't like ACT UP in New York said, let's create ACT UP Kansas City. Somebody would read an article in some paper; and say, oh, let's do it here. And that, and, and it was global; it happened all over the world. They just sort of took that model. I don't know if they knew what we were actually doing, or what the model really was. But it meant, it, it flashed for people, and they took it on. So all of a sudden, there were these ACT UPs all over the country. And we were getting

information about them, and it seemed like it was time to bring everybody together and do something together. And Gregg wanted to organize a national action; the first national action. And I was heavily involved in fighting with the FDA over expanded access, and felt like this, right now, that is our key issue, is access to experimental drugs, and dealing with the FDA on this. And that should be the focal point for this demonstration. We need to go there en masse.

And so Gregg and I sort of talked it through. We came up with the vision of what it ought to be; and we brought it to the floor. And presented the idea, and said, we want this to be an, we want to do a major demonstration at the Food and Drug Administration. Do you want to do it? The floor talked about it; voted, and voted on it, and approved it, that night.

Then, two, three weeks later — it was July 4th weekend — there was the first meeting of representatives from different ACT UP chapters. I think the very first one. It was in San Francisco. And Gregg and Robert Vazquez and I went, on behalf of New York.

SS: And did New York pay your ticket?

DB: No, Lambda paid my ticket. New Yo-, uh, ACT UP paid for Gregg and Robert's ticket. And Sue Hyde — I remember Sue Hyde being there. But I don't remember anybody, I can't, I was trying to think of this the other day; who else was at that meeting? But I can't remember anybody, and I can't remember anybody from San Francisco. Yeah. Maybe [Andy] [Zeissman], but maybe not. And they were all talking about, we need to do a national action; we need to all come together and do a national

action. And they were all fighting with each other about, well, we should go to the White House; we should go to the Capitol; and we should go to Health and Human Services.

And they were all having this discussion, and I don't know; I felt like Gregg and I were just kind of sitting back. Because, we were New York. We were three times more people than all those other chapters put together, and we just kind of let the conversation go on. And then eventually, we said, the action's going to be at the Food and Drug Administration. New York's already made this decision. You can go anywhere you want, but New York is going to the FDA.

And – that shook everybody up real bad. And then there was some compromise, which was, there'll be a rally the day before at HHS. That was the rally where Vito made The Speech; the “One day people will remember” speech. But that the action would be at the FDA.

And so we did it. And it was, there was a lot about that demonstration that was really, it was key, it was really pivotal; for a whole bunch of reasons.

It really created, it really solidified the affinity group structure; because all these affinity groups were created for that action. It was the first national action. It, it really was the point where the media machine, the ACT UP media machine, and the joining together of the theater and the media machine, really, really also became solidified. It was brilliant, you know. It was, they had done the press work so well that I remember people being on bullhorn — press people, Michelangelo [Signorile], being on the bullhorn; in that weird rubber jacket he used to wear — “person with AIDS from Minnesota, here,” to bring the Minnesota-paper guy over there.

Tape II
00:25:00

And – there were only a thousand people at the demonstration. It looked much, much larger than it was, when you saw it on television, because it was so theatrical. And there had never been a demonstration at the Food and Drug Administration before, ever. And it was this completely nondescript office building in the middle of suburban Maryland. Nobody knew what to make of it.

The FDA was really smart. They told everybody they could stay home if they wanted to. But they didn't shut it down. And they told the police, who let us, as long as we weren't breaking anything at the building, we could do whatever we wanted. So we could shut down traffic; we could do, and the police just let us do it; they weren't going to arrest us for that.

We were only allowed to enter one door. And then people tried to enter other doors. And then, it was a turning point, because it was the front page of every major newspaper in the country; it was the lead story on all the nightly newscasts; every paper except the *New York Times*. It was really the start of a national, of the national AIDS movement, was the FDA demonstration.

SS: And what did it win?

DB: Well, it won, well, first of all, the FDA, I had had meetings with Jay at the FDA, but mostly they were not returning our calls. They would meet with select people. They met with Marty, they met with Jay and I. But mostly, they weren't returning ACT UP's calls. They returned the call the next day. It opened the doors to an ongoing relationship and to communication. And the relationship with the FDA was really transformed, it changed tremendously from where it started — you're wasting my

time — to we need to work with you people. And the expanded access definition changed; the drug approval standards changed. And the demonstration was really — one, not the only — but a really important piece in forcing the agency to realize that they had to deal with us in a way that they weren't used to dealing with consumers. And so that was important.

It also created — the FDA action was by far, but certainly not the only thing that did this. But because it was such national visibility, for the first time; it presented a different vision of what a person with AIDS is. Right? And we can't, I can't stress enough how important that was. We were victims; and we were vectors. We were bad guys and victims. And, through the work of the people involved in Denver, creating the Denver Principles; through the work of ACT UP; and others; we developed a different vision of the person with AIDS as hero. And that really was personified at the FDA. Look at these people, they're fighting for their lives. And they may not look like we all look out there, in, in America. But, oh, they're dying, and they want medicine. Hm. I can, I can wrap my mind around that.

SS: Right.

DB: Right? And so it, it was a sympathetic image to the public. The press — the press said, ooh, we love these people. They put on a good show for us. We're going to follow them everywhere, because we're going to get great stuff out of it.

But most important, it provided an image for ourselves, as heroes, and as, as community, and — let's — what could be a more heroic image to me than, than Stephen

Gendin with his “Motherfucker” leather jacket* at the FDA demonstration? Stephen, who was stupid at the demonstration, as much as I loved him, because he decided to pick up a big cloth banner as a motorcycle cop was heading right towards it, so that he knocked the cop off of the motorcycle, and he was the only person charged with anything other than disorderly conduct.

So I think, the FDA demonstration was important for many, many reasons.

SS: Okay, thank you. When did you start your support group inside ACT UP?

DB: The support group started in 1990. And by that point, I had left Lambda and had gone to GMHC. Tim Sweeney was the director of policy at GMHC; I was already friends with Tim from when he had been at Lambda. Tom Stoddard was the director at Lambda now. The relationship had run its course. And Tim called, and said they were going to hire an assistant director of policy and was I interested, and, I would, if Tim called me and asked me to empty his garbage can, I would do that for Tim Sweeney. So I moved over to GMHC.

And about the same time, I decided that what I really wanted, I wanted a support group of people who – I wanted it to be gay men who, obviously, were HIV-positive; and who were working full-time in AIDS. Because I felt like there were issues that I had around my personal life, my professional life, how these two things interact; the lack of any boundaries between my work and my personal life. And so I just asked

* In an e-mail to Sarah Schulman dated May 16, 2007, David Barr wrote: “Stephen Gendin's jacket said ‘Cocksucker’ on the back, not ‘Motherfucker.’ To me, it’s an important personal distinction, being one and not the other.”

my friends, who were really, my closest friends, and also my closest workmates at the time. It was a very communal situation for all of us. We were all just together, all the time; all of our playtime, all of our, there was just no line between all of it. It was all about the meeting and the dinner after the meeting. And –

SS: Were you in a relationship at the time?

DB: Yeah, but – um – yes. But my relationship with Paul is, would require another couple of hours, and it was a very volatile relationship, and Paul had no interest in anything I was doing at ACT UP.

SS: Oh, okay. So you were having a whole new life.

DB: Yes, I was – completely, ACT UP completely changed my life. Every relationship I had. There was my life before ACT UP and my life after ACT UP.

SS: Right.

DB: Everything changed with ACT UP. It was very cult-like.

SS: Cult-like?

DB: Cult, very, very cult-like.

SS: Do you mean that in a negative way?

DB: There were aspects of it that I think were negative. But there were, mostly I mean it in a positive way.

SS: Okay.

DB: It was all-consuming; there was, particularly at that time, I think those of us that were really heavily immersed were – there was this whole city, world going on in the city. But I felt like, I think we felt like we were living in a war; we were part of

this resistance; and there was – and nobody who was outside of that sphere could understand what we were going through and what our lives were like.

SS: Okay.

DB: Right?

SS: Are you trying to tell me something, James?

James Wentzy: I was wondering about the Montreal AIDS

Conference –

SS: Oh, we'll get to that.

DB: Oh, okay.

JW: – and its relationship to –

SS: Okay, okay –

DB: Oh, yeah.

SS: But let's talk about the – how much time do you have left on this reel?

JW: Ten, nine minutes.

SS: Nine minutes.

DB: Let me do the support group, and get it finished.

SS: Get it finished? Okay, so who was in the support group?

DB: Mark Harrington, Derek Link; Spencer Cox; Gregg Gonsalves – I'm sorry, Gregg Bordowitz – and Peter Staley and me.

SS: Okay.

DB: And we met every other week, for dinner; we would rotate houses. And we would meet for dinner. And we did it for seven years. And – it was, there were, it was everybody I was with all the time anyway, except that was always a different conversation. We had a structure to the conversation, where everybody sort of went around and took a turn, and just said how they're doing and what's going on with them. And so it wasn't a conversation about work and it wasn't a gossip conversation. So it was, it was much more personal and –

SS: And all those people are still alive.

DB: And everybody's still alive. And we, we all went into it thinking, this is going to be the group of people that, we'll all be with each other as we get sick and die. And that part of the purpose of the group is to create that structure now. And we're all st- , we're all still alive.

SS: So what kind of things would you talk about?

DB: We, well, besides the stuff about just how people are feeling, who's getting, people got sick during that time; Gregg Bordowitz got very sick with zoster; Ray Navarro died during that time; Mark Harrington lost an ex-boyfriend during it. A lot of people died; there were a lot of people sick. So obviously, we talked about that. We also, we talked about relationships. I broke up with Paul, but there was also discussion just about how do we – I don't know, this is an issue that I, I'm obsessed with, and that I've spent a, a lot of time writing and just thinking about, but what is the nexus between my work, as an AIDS activist, and my life, as a person with AIDS? And the two things are obviously intertwined; but they shouldn't always be intertwined. That when I'm

Tape II
00:35:00

working, it's not about me. And sometimes it is about me, but sometimes it isn't about me, and I got to really not, I've got to be, I've got to walk into whatever room I'm walking into really cognizant about what are my personal issues, and what am I here to do in this room. And – for me – I think that's mostly manifested in thinking about using my status in my work. When is it appropriate to do it and when is it not appropriate to do it? It's, I never stopped letting people know that I was positive. But I did stop working as an advocate on behalf of people with AIDS.

SS: Oh, okay.

DB: I, very, that was a very, very conscious decision.

SS: So you left GMHC?

DB: I left GM-, when I left GMHC in '97, I stopped being an advocate, and I've never done it again. I've worked in AIDS ever since. But not as an advocate representing people with AIDS. I felt that the epidemic had changed a great deal; that it wasn't my voice that needed to be up front. And that there were other ways that I could help. But most important at that time was to deal with anger. Because all of us — all seven of us — would find ourselves in rooms — meaning with, who knows with who — and become furious. And we would all become furious. ACT UP was about, united, what were we? United in Anger.

The anger was very – useful, at times. It was unavoidable all the time. It was useful sometimes. And it was very, and it was harmful at other times. And I kind of had to figure out, well, why am I yelling right now? Am I yelling because the people I'm sitting at the table with need to be yelled at, and I'm going to, I have a goal to reach at

this meeting, I have a policy I want changed? Right? And if I'm yelling at these people, will I get the policy changed?

Or, should I really not be yelling right now, and being calm, and that's the way I'm going to get the policy changed. And the reason I'm yelling is because I'm angry that my friend died yesterday, and that's what I'm yelling about. And if that's the case, I need to make some boundaries here, and deal with my anger about my friend somewhere else, because it's not serving my needs in the room.

And I think that's really the hardest job for an AIDS activist to do, and really crucial. The job isn't, and, and to me, it, it, it's really where ACT UP fell apart.

SS: Well, we'll certainly get to that.

DB: All right.

SS: I want to ask you –

JW: We could change now.

SS: Let's change tapes. Okay. Because I have a lot of –

DB: [Foo], you're being very good, aren't you?

SS: What a pretty dog.

DB: She's a stray. She showed up on my porch. She's a lucky, lucky dog.

SS: We ready? So in the support group, did you guys discuss treatments?

DB: Yeah, all the t-, a lot.

SS: And you made your treatment decisions together?

DB: Yeah. Yeah.

SS: Do you think the fact that you guys were involved in the most advanced treatment research is part of the reason that you're all still alive today?

DB: Mm – yes. But – in most cases, not because of the personal treatment decisions that we made while we were in the group. We changed, we were involved in work that changed the course of drug development in AIDS. And the drugs that, I guess, have saved my life wouldn't have been available for me to take had that work not been done.

SS: Right.

DB: Right?

SS: But like with Grossman, you knew more than he did.

DB: Yeah. But there wasn't that much, there weren't that many options to, the reason I'm s-, I wasn't – I didn't have AIDS. Right? I was, I was healthy. And so I didn't ha-, and the same was true for Mark; the same was true for Peter; for Spencer; Derek is a whole other story; and Gregg was the one who really got sick first. And so there, it was, I think, some of that expertise was used in helping him figure out what to do about both his antiviral stuff and his shingles.

SS: Do you think that you guys knew how to navigate advanced treatments and get access to them in a way that most people with AIDS at the time did not?

DB: Certainly navigate. And yeah, yes, yes. Because we had access to that information. We had access to people. But I can't really remember an instance

where the fact that I knew Tony Fauci and could call him meant that I, or any of my friends, got something that other people didn't get.

SS: Right. No, I understand that.

DB: Right, but, but because, I mean, I had more in-, I knew every expanded access program and I knew everything about which drugs were where, how they were being studied, when they were going to be approved. So yes, I had all that information, and –

SS: So in a way, you guys were the best informed people with AIDS in the world, maybe.

DB: Maybe.

SS: Okay. So let's talk about –

DB: About some things.

SS: Let's talk about Derek Link.

DB: Oh, Derek. All right.

SS: So what happened?

DB: All right. Derek, there's a lot of other stuff to talk about, so I'm going to do the Derek story really fast –

SS: Okay.

DB: – okay? Derek arrived in New York in 1990 from Boston. He was adorable. A little nerdy boy; cute, as cute as can be. And clearly smart. Immediately attached himself to Treatment and Data. Started coming to the meetings. After a couple of months, he changed his look entirely and became a punk, and had a green Mohawk.

And he was like whip-smart. He started learning the stuff; he did really good AIDS work. Whatever the end of this story is, Derek did really important, good AIDS work. Derek was, Derek and Garance [Franke-Ruta]; I mean they were k-, they were kids, they were little kids. They were 20 years old. Garance wasn't 20 years old.

Transformed OI research. They created this project where they selected the seven OI drugs. It was Derek, Garance, Scott Slutsky — I forget who else — but those three, certainly. And each person took a drug and followed, and they learned everything about that drug; where it was in the system. And they just began to advocate to move that research faster. They went to Congress, and they said, they went to the NIH and said, you've got to put more effort into OI research. Because we don't know what's going on with this antiviral stuff. And look at all the progress that we could be making treating OIs.

Tape III
00:05:00

And they NIH didn't want to do it. And they went to Congress. And Tim Westmoreland pushed it through. And they got an appropriation for OI research. And really groundbreaking work. And it resulted in fluconazole; DHPG was already further along, but – oh, fuck. Anyway. A lot of drugs. I used to know all this. I don't do this work. I do different work now. So I don't follow the drugs so much.

It was very important work. Derek also uncovered over 50 million dollars' worth of AIDS research money that was being not spent on AIDS in the National Cancer Institute. That was one of the reasons Sam Broder lost his job. And Derek's work was very important. That said, he was very crazy.

So Derek came in; he's a person with AIDS. Joins the support group. He, Derek once wrote – a thing that he handed out on the ACT UP floor: HIV-negatives get out of our way. This is during all of this, all the disputes about who we should or should not be meeting with, at T&D, and Derek went on a rant. Derek not only was in a support group with me for seven years, we shared a house together, we traveled the world together. I supervised him for three years at GMHC, and he sat in the cubicle next to me.

We eventually learned that every single thing that Derek had said about himself was not true. He was not HIV-positive. His grandparents did not die in the Holocaust. He was not Jewish. His mother is not a paleobotanist who lives in New Orleans. Just on, on, on, and on and on.

SS: What was true?

DB: Um, he, I, I don't know. I don't know what's true. I know what he, I know the last version of the truth that I heard. I think he grew up in Kansas. I think. His father, I think, was involved in the aviation industry. Other than that –

SS: So how do you explain it?

DB: He didn't go to, he didn't go to boarding school in England and have a nervous breakdown there. None of that was true. I don't know. The astounding thing about the lying isn't just the extent of the lying; it's how long he lived with it. It was everything about him, about his identity, was a lie. And he lived with us, and – it must have been so exhausting, to have to continually remember all of the components that he had made up. And, detailed discussions in the support group about his trip to New Orleans to visit his mother. He wasn't, hadn't even been to New Orleans. His mother

didn't live there. So it was, it, it was – it's kind of a great story. But it was terribly upsetting.

SS: Now do you think, now you said before that there was a cult. If he had told the truth about himself, do you think he would have had the kind of close relationships and attention that he got by pretending?

DB: Yes! Yes, of course he would have. Because he was brilliant. And he did good work. And he was fun to be with. So that was, that's all you needed. Gregg Gonsalves wasn't positive. Most of us weren't positive when we started, because we didn't know. I, Mark didn't know; I didn't know; Gregg seroconverted later on; Spencer seroconverted later on. Peter knew.

SS: Now when you confronted him, was he upset?

Tape III
00:10:00

DB: Ah, that was the – it was years later. Right? It wasn't like we were in the thick of it then. Gregg Bordowitz and I had been suspecting that there were things that were just not right about the story. For one, he wasn't progressing at all. And it wasn't like he was a long-term nonprogressor, because it wasn't like he had 800 T-cells. He had 300 T-cells, and it was always 300. And there were just chinks, in the story that I kept uncovering. And so one day, I just, I said, Derek, we got to talk.

And we went out to dinner. I said, okay, let's start from the beginning. What's your name?

And he said his name was really Derek Link, and he just sort of spilled everything.

Was there a sense of remorse? Uh – I guess. There was, clearly, there was some guilt. And more, I guess more than guilt, there was, not so much guilt; it was embarrassment. It was embarrassment. There wasn't really an understanding – I tried to continue to be friends with him, and to work it through. But that didn't last very long, because I got, because there was never really any remorse, there was never an understanding as to how deeply he betrayed me; all of us, by lying to us all that time. It was like I had this friend that didn't exist.

SS: So what became of him?

DB: Well, he went to school — he says — and went to Hunter, to study computerized mapping. And I never saw him at Hunter, so I don't know if it's true. But I think it is. And the last I heard, he was doing computerized mapping on electrical grids in northern Vermont. But I don't know if that's true.

SS: And what's the story with the girlfriend from New Jersey?

DB: The girlfriend from New Jersey; Mark Harrington got an e-mail, I guess about a year ago, year and a half ago, from a woman saying that she had been going out with this guy named Derek Link. And she'd Googled his name, and all this AIDS stuff came up. And she asked him about it. And he told her, he fabricated this story about his brother dying of AIDS, and that's how he had gotten involved. So Mark wrote back and said that none of that is true; that he has a history of lying, and you should know that.

And then – Gregg Gonsalves made, put the story out there, somewhere.
Maybe it was in the interview?

SS: I don't know.

DB: It was somewhere. And Derek saw it, and responded to Gregg. And Gregg sent that response around to people. And Sam responded to that. And Derek wrote to Sam. And that's how we found out about Vermont. But that was the last we've heard.

SS: Okay. So let's move on to totally unrelated: AIDS conferences.

DB: Oh, okay.

SS: Can you tell us a little bit about that? Can you tell us the story of your experience at the Montreal conference?

DB: Yeah. The Montreal conference: I've been to every AIDS conference except the very first two and to Yokohama. I've been to every other one. And every time now, I vow I'll never go again. But then my work gets me there. I need to be there to do something. But I don't enjoy it. It's –

Okay, Montreal was completely incredible and completely unplanned. What happened was, it was Montreal. So ACT UP New York — this is 1989; ACT UP New York was really in its heyday; it would get bigger, but it would never get better than, I think, '89 — but it was close. So ACT UP New York could bring a lot o' people there. And the idea was just to do a picket outside of the entrance to the convention center as people were going in for the opening ceremony.

Some people were delegates, to go to the conference; and many of the ACT UP people were not, because it cost money to go in. And we were doing this picket. I was working at Lambda, I was a delegate, I could go to the conference. And I

was sort of, there was like a picket going on outside; and then there were doors and there was a lobby; and there were escalators up. And you had to go up the escalators to get to the hall. And the hall wasn't open yet. And people were beginning, it was getting crowded, because people were coming in to go, but it wasn't open yet, so the lobby was filling up, and people were picketing and chanting. And it kind of got a little crazy; not because anybody was doing anything crazy, but just because it was getting crowded.

Tape III
00:15:00

And I was right at the escalator, with a couple of other people. And we just said, we're going in. And we just went up. And so all of the ACT UP people, we all just went up the escalator. We were the very first people in this hall that fits 15,000 people. And we were making a lot of noise, and we had all of our posters. And so we, we were the first people in the room, and we just walked right in and took the stage. There was nobody in there.

So, and none of it was planned. It was completely just impromptu. And they, they couldn't do anything to stop us. Because – because it was dangerous, because of the escalators. Because they couldn't stop us because there were people pushing onto the escalators, and somebody was going to fall down and get hurt. So they let us go up.

And so we took the stage, and we, we held the stage. And we were quite the sight, you know. And as everybody entered into the hall to attend the opening ceremonies, there we were. And we were really noisy and we were quite fabulous. And Conyers Thompson read a manifesto, in English and in French. The problem was — as always, always the same problem — how to end the demonstration.

SS: Oh.

DB: You, how do you end it, you never know. And we didn't want to leave the stage, because we felt we were ceding power. But after a while, we realized we had to get off the stage, because it was over. And then, we had a lot of applause from people. People didn't seem to mind us being there.

And then, so we, we left the stage en masse, and we took the seats in the front. And then there was a dispute about that, because those were reserved for dignitaries, and so they couldn't start the opening ceremony, and they wanted us to leave those seats, and we didn't.

But it was, it was ACT UP's entry into the international arena, because there were delegates from all over the world, and there was press from all over the world. And there was our agenda.

We thought, we are the front page of everything tomorrow. Except that the picture on the front page the next day was a picture of a guy standing in front of a tank in China. And that's, so there was another demonstration going on at the time that I guess was a little more, um, formidable than our –

SS: What was the agenda?

DB: People with AIDS need care, we need respect, we need, it was our agenda; we need good prevention.

SS: So what was the result of that on future AIDS conferences?

DB: A lot more security {laughs}. An expectation that the AIDS conference was going to be a focal point for that kind of activity. Right? From then on in, they knew we were coming. And from then on in, we knew, here's a good platform

for us. So it helped, in many ways, transform the conference from being a pretty much purely scientific conference to being the conference where the science and the social agenda that AIDS is all comes together. And there were times where that was really exciting. It was the only place that would happen. That's not the case any longer. There is no more science at the AIDS conference. The scientists left.

SS: Why is that?

DB: They got tired of the circus, and they planned another meeting. It got too big, it got too – so they have other meetings where the science is presented. And if there's like some, there are science tracks; but nobody saves their good data for the AIDS conference.

SS: So what happens at an AIDS conference now?

DB: Well, in Toronto — maybe the largest one ever — there were a lot of celebrities. We heard a lot from Richard Gere. I have no interest in what Richard Gere has to say about AIDS. Basically, everybody said the same thing — Act UP Paris and Bill Gates — everybody said the exact same thing; there was no controversy at the AIDS conference.

SS: And what do you make of that?

DB: It's just this big piece of theater now that is no longer really valuable.

SS: And what do you think is the real issue right now?

DB: Political will.

SS: Political will, to do what?

DB: To – in 1985, there were all sorts of political challenges, right? The president hadn't said the word "AIDS"; all of it. But the major challenge was scientific. We didn't know what caused it, we didn't know how to treat it, we didn't know how it was spread, in '84; we didn't know any of that stuff. The major hurdles were scientific.

That's not the case anymore. We know how the virus is transmitted, we know how to stop transmission, we know how to treat people and keep them alive for a long period of time. All we have to do is do it. We know how to feed people; we don't do that, either.

SS: And how come there's no voice saying that at an AIDS conference?

DB: There are a lot of, everybody says it at the AIDS conference –

SS: Oh.

DB: – that's all everybody says. We have to, we have to do this, we can do it. Time to deliver it. That's the, every year, it's a slogan: Time to deliver; that was the last year's slogan. Everybody says it. It doesn't mean anything. That's the problem, right?

SS: And who has the power to carry it out?

DB: Well, everybody. Ev-, everybody.

SS: But, governments?

DB: Government, industry; people. All of our institutions have a role to play, and all of them need to, and they play that role, in varying degrees. And I don't

want to make it sound like, and I don't feel like nothing's being done. There's a lot of progress. There's a lot, a lot of progress. And it's nowhere near what it ought to be.

SS: Okay. So I want to move on to TAG and all of that.

DB: Okay.

SS: So when did TAG get started, and why?

DB: Well, let me ask you a question first.

SS: Okay.

DB: All right? Because I don't know how much more time you want to do this. And – I'm happy to talk about TAG and all of that. But it seems to me that there's a –

SS: All right, what do you think is more important?

DB: Well, it isn't so much what's more important, it's what led us to TAG.

SS: That's fine.

DB: And sort of like, how, what happened to ACT UP.

SS: Good to go. That's what I'm asking you, actually.

DB: Okay, okay. All right.

SS: Yeah. That's my question.

DB: So, well, what happened to ACT UP – a bunch of things happened. One, we were incredibly successful – I think beyond anybody's wildest expectation: in our ability to change the agenda about AIDS; create a governmental and industrial response; change the community's notion of what it means to respond; just very, very

successful. As it grew, and become more and more successful, the agenda grew. So there was this sort of primary focus, first, on drugs into bodies, on treatment, and on people being treated well and with respect and respecting the primacy of people with AIDS. Right? It's that core agenda. But then it also became all these other agendas: housing; education. All of which were great; I'm not, no criticism at all, it was great work that people did. But it sort of became unruly. It became too difficult to manage all of this different stuff under one roof.

So you began to see organizations splinter. TAG was one; Housing Works was another; Treatment and Data became – whatever Ken Fornataro's organization is called [AIDS Treatment Data Network]. There were others. So that was one reason that it kind of exploded into other things. But I think –

ACT UP provided the success of the work was all one thing. But — and I'm glad I was there for the work to be successful and to be involved in that work — but I don't think that was the primary reason that brought us into that room. The real primary reason was that it was a home. It provided us all with a safe space and with a sense of community. We really did think that if we could just be together, we could end the AIDS crisis. It was, that was an illusion. But that was a really vital illusion for us. It gave us a place to be, and people to be with. And there were, I think, lots and lots of people in that room who had no other place. So ACT UP provided that strength and that community. And it was sexy, it was all those things.

And that began to change, just because it got so big, too. So that you couldn't hang out with a thousand people, the way you could when it was less. So you,

you had your group that you lived with. There were lots of different organizations within, lots of different communes within the giant commune.

I think that there was a turning point in what happened, that was – and to me, it happened with the Church action, and the Church action was the beginning of the end. Because – and the Church action was very successful, in terms of draw. There was, what, five, six thousand people? It was probably the largest demonstration ACT UP ever organized. And I think that's right.

But there was a lot of debate in ACT UP about the Church action; whether to do it. There was no debate about whether or not the Church's policies around condom use and how the Church was dealing with vast amounts of city money in providing services; there was no debate that the agenda was correct. But there was a lot of concern as to whether or not it was really appropriate for us to do a demonstration at the church. And the people who were most vociferous about doing it were primarily Catholic. And there was a lot of their personal stuff going on.

SS: Okay, just for the record –

DB: Yeah.

SS: – who are you talking about, so that I can actually think about whether that's true.

DB: Well, the person who comes to mind first, of course, is – now I can't think of his name, but I'm seeing his face. Keating, Tom – well, who threw the wafer on the floor?

Jim Hubbard: Tom Keane.

SS: Tom Keane.

DB: Tom Keane, Tom Keane.

SS: But he wasn't a primary organizer of that.

DB: He's v-, I don't know, I – so who was? Tell me who was.

SS: I don't really know. Who was?

DB: I ju-, I c-, I don't –

SS: Robert Hilferty. He's certainly not Catholic.

DB: I just remember lots of people – I remember the discussion on the floor, and people getting up and talking with great passion about how angry they are at their church.

SS: Okay, that's true.

DB: And that was a component of what brought people into doing that demonstration. But we had a lot of discussion about whether – what we were going to do. Were we going to go inside or not go inside? That was the debate –

SS: Right.

DB: – right?

SS: Um hm.

DB: We were going to enter the church or not. It was a very heated discussion; it ended in a vote; the vote was to not go in the church. Because, for one, we didn't, we didn't have any interest in offending people about – doing something in this place of worship. That wasn't what it was, it wasn't about that, it was about a political agenda with the Church. And if we were being strategic, and we were really committed

to coalition building with communities affected by AIDS all over New York, particularly the Latino community; we probably do not want to go into the church. Right? And at that point in ACT UP's history, building coalitions was a primary concern.

So we took a vote. And we said, we're not going on. And then people went in anyway. So they, they disregarded the process. They said, well, we're an affinity group of our own. But that was just bullshit. There was a floor vote; there was a process; they disregarded it; and there were 5,000 people outside. There was a really important agenda that we had; very good, rational, viable agenda that should have been on the front page of the paper the next day. But instead, the front page of the paper was, gay boy spits out body of Christ on the floor. Right?

And that, there was never going to be a coalition with the Latino community after that. There was, it changed the view people had of ACT UP. But that's not important.

What's important is that the process was corrupted. And in the discussions that took place after, there were some people who were very upset about that, and about the outcome of the demonstration. But what won the day was the people who got up and said, what Tom did was great, because he expressed himself; and that's what's important. And that, to me, was this crucial moment, where a decision, group decision got made, somehow, that the personal expression of one's anger was more important than strategy to change policy and to make people's lives better.

Tape III
00:30:00

SS: David, I have to say, I've never heard this analysis from anybody, and I've interviewed over 70 people. So let me, I just have to ask you a couple of questions about it.

DB: Yeah.

SS: First thing is, are you saying this is the first time that there had been civil disobedience that was planned secretly, in the history of ACT UP?

DB: No. But there was certainly – no. But – because there were all sorts of zaps and stuff –

SS: Um hm.

DB: But here, there was a specific decision to not do something that people violated.

SS: Okay.

DB: All right? So that was a difference.

SS: Okay. And now, what you're saying is that because of the Church action, that broke down specific coalitions with Latino organizations? I have never heard that before.

DB: I, I, I'm using it as an example. Right? It wasn't –

SS: Oh.

DB: – I think, I think there were certainly lots of organizations out there that were appalled by what we did at the church. And I remember, I was, I was at GMHC then, so I was interacting with a lot of community organizations outside of my ACT UP work. And they didn't want to deal with ACT UP, because of the Church stuff.

SS: Could you give any specific example?

DB: I can't. I just can't remember. But –

SS: Okay. But it's your general impression.

DB: Yes. But I think more important than that was that — and it wasn't the only example of it, but I really do think it was the personification of a value; that the expression of individual anger was more valued than coalition-building, than strategic thinking, and a vision about making change. And that, to me, was really the beginning of the end.

SS: And so you're saying that the people who had a different view than you, a different analysis, that that was a division that ended up, that those two constituencies remained precise? Because I don't see the personnel breaking down that way.

DB: I, I think, I think it was – no, it was more – it was what happened in the room after the action was over.

SS: Okay.

DB: Right? That when Tom, or people who were supporting Tom and the other folks who were in the church stood up to support them, they got the loudest applause. And to me, I saw it as a turning point. It was a breakdown in trust; it meant, well, we can't plan all this stuff, and make these decisions, because if people disagree, they're going to go off and do what they want to do, anyway. Right? So that we'd spent an awful lot of time in CD training previously, saying, the group has to make group decisions. And the decision of the group lands with the person who is least comfortable.

Right? That's, that was the found-, the, the – if I'm afraid to do something with the group, the group doesn't do it, because I'm saying no, I am afraid.

That was the principle behind the group decision-making process in the CD trainings. And that principle was abandoned with that decision to go into the church. And I just felt that, for me, it really marked a turning point.

It wasn't the only example. I think that that was happening in many ways all over the place. But I do think that that was part of what went wrong; was, it really became more, that personal expression was valued over strategic thinking, and really, the desire to build strong coalitions. That our way is the only way. And we saw it, we saw it, I saw it with United for AIDS action, in '92.

SS: Okay, so what happened there?

DB: Well – I left ACT UP with a group of people in '91. We all left together and formed TAG.

SS: Okay, so why did that happen?

DB: Well, there was – there was an awful lot of increased fighting going on, about – well, the work that was going on in Treatment and Data transformed. It was, in that – once we took control of the FDA, the nature of the relationship changed. Once we chained ourselves to the fence at Hoffman-La Roche — bad choice of company, but the relationship changed with Pharma, the relationship changed with NIH. I was very involved in the development of the Community Constituency Group at the AIDS Clinical Trial Group; where, after beating down their, after them not giving us information about clinical trials in the beginning, that David and Margaret requested; they were now saying,

we want you in this process, and now let's figure out how we're going to do that. And that really meant being members of the groups of people that designed and implemented the clinical trials program. I was the first person with AIDS to sit on the Executive Committee of the ACTG.[†] The first time a patient had ever sat in that kind of capacity, ever before.

So the nature of our work changed. It wasn't that there was no longer a value to demonstrations. But our work was going on inside meeting rooms. It was about doing our homework and writing these letters and making these phone calls and going to these meetings and that was where our work was at that point. The nature of our activism had changed. It wasn't the only thing going on, and it wasn't the only important thing to go on, but that was the work we were doing. And we were getting increasingly vilified by other people in ACT UP about who we were meeting with, how we were conducting our activities. We were certainly reporting on everything. But people didn't like, there were groups within ACT UP that didn't like the way we were working.

SS: Why?

DB: I don't know, you've asked them; they'll tell you why.

SS: Well, what do you think is the real reason?

DB: I, I don't, I don't know what, the real reasons are personal for people, and what they were going through at the time. So it was whatever their real reasons were for them then. I think – and I think there was a lot of different components to it. I think

[†] For a further discussion of the CCGs, ACTGs and, specifically, clinical trial 076, see Appendix 1.

you can only run a participatory democracy with a thousand people in the room for so long, and it just begins to unravel. I think there were a lot of crazy people in the room, that were just attracted to us, you know. And they became problematic. They took up a lot of time. They, they created disputes on the floor that would take all this time and energy. Joe Franco; Bill Dobbs; there were a lot of those people.

I think the agenda that we were working on in Treatment and Data, we were seeing a lot of success with. It was moving faster and in a different way than other equally important agendas were moving. So that – how the CDC was addressing the needs of women with AIDS was an agenda that was moving at a very different pace than drug development activism was moving. And that meant that the tactics that needed to be used were different.

SS: Why were they moving differently?

DB: There were – well, because I think that – a lot of reasons. The CDC is a very different place. There's a different institutional culture. I think, most important, though, is that the agenda around addressing the needs, just identifying the needs of women with AIDS — then, and even more so, now — is an agenda that has to do with sexism; it's an agenda that has to do with poverty; and those are bigger, more complicated, longer-term issues than how you get a drug approved. Right?

And the pharmaceutical industry, as difficult as they were for us to work with them, had no problem with getting their drugs approved faster. Right? There was a lot of common ground on different ends of the table in the stuff that we were doing.

So, I, yeah.

Tape III
00:40:00

SS: Well, looking back now — and I'm sure you've thought about this all a lot — what do you think would have been the way to have both of those projects coexist in a healthy organizational structure?

DB: Well, you had to have a healthy organizational structure first.

SS: Well, let me ask you this even harder question.

DB: Yeah.

SS: What do you think you could have done differently?

DB: Been a little less arrogant. I think we, it's not like we all didn't, on all ends of this discussion, spend time trying to come to some terms, and find mutual ground. But I think we could have done it more.

SS: Okay.

DB: And – there was very little – everything was so – everything was so rushed; everything was happening so fast. And there was such a sense of urgency; we can't lose a minute. Right? And on that, that discussion takes, it's a long discussion. I'm still having that discussion –

SS: Right.

DB: – every day. That's a never-ending discussion. I think there were issues of serostatus.

SS: Well, do we need to – okay, so let's hold that.

DB: Let me pee.

SS: Okay.

Tape IV
00:00:00

SS: You made the very provocative statement at the end of the last tape that it came down to serostatus.

DB: No, I didn't say it came down to serostatus; I think that there were issues of serostatus.

SS: Okay. Can you elaborate on that, please?

DB: Well – not all, but most of the mostly guys in Treatment and Data were positive. And most of the people we were fighting with were women — not all — and most of them, not all, were seronegative. So there was a serostatus issue going on. It wasn't the only issue, by far.

SS: And why do think that was the issue? What was it about that that created the difference?

DB: The treatment agenda was very specific: we need these drugs to save our lives. And I think the agenda on the other side was, there was nothing about it that I disagreed with. But it was a very broad agenda for social change. Which is fine. But it's, it's a lifelong endeavor. It's not about immediacy and what I need right now because I'm going to die, or my friend is going to die.

SS: Obviously, we've interviewed a lot of people on this. And you could look at, I mean you did see, you did express a polarity between the AIDS treatment agenda and the issue of women with AIDS and how they were being treated by the system. And what you just described could be described as being broken down by gender instead of serostatus.

DB: Nn–

SS: So you're just saying, you think that – go ahead.

DB: But the women with AIDS that I was working with on the treatment front; they wanted treatment. Right? They had that immediate need.

SS: Right.

DB: And we were all interested in the broader agenda for social change. But we had a specific piece of work that we felt we needed to get done to save our lives.

SS: So there were women with AIDS in TAG?

DB: Um – no, but they, the, we weren't just working in TAG.

SS: Okay.

DB: Were there women with AIDS in TAG; well, nobody [that jumps] into my mind.

SS: Okay.

DB: All right?

SS: Okay.

DB: But there were other women that I was working with within the CCG at the NIH, the Community Constituency Group; within a lot of other, I was, we weren't just working ourselves.

SS: Right. So –

DB: Look at the great work that WORLD [Women Organized to Respond to Life-threatening Disease] did in Oakland; that Rebecca Denison was doing in Oakland. Look at, the work that Life Force and Health Force were doing here. And there was –

SS: Right.

DB: – a lot of interesting –

SS: But that's separate than the split inside ACT UP.

DB: Yeah.

SS: Yeah.

DB: Yeah, but those were women with AIDS.

SS: Right. But they were –

DB: And there was never a, there was never a group, that I can remember, of women with AIDS within ACT UP that said, we are the women with AIDS of ACT UP; and this is our voice; this is our agenda.

SS: Katrina Haslip and Marina Alvarez –

DB: I'm not saying there were no women with AIDS –

SS: Oh, okay.

DB: – but there was not, it wasn't, I'm not saying that at all.

SS: Okay.

DB: There wasn't a contingent of women with AIDS saying, we are the women with AIDS of ACT UP; that created a place just of themselves. At least it wasn't – yeah. I think –

SS: Because, okay.

DB: All right? I'm not saying, there were, there were many women with AIDS. They were very involved and very engaged in what was going on in ACT UP. But there was, it's – it's just, if you look at – a housing group formed, of housing activists. An education group formed, of education activists. There were lots of different

ways that, there were all these instances of people sort of banding together within ACT UP and creating this identity, and there was no, we're the women with AIDS group in ACT UP.

SS: Okay.

DB: Right? That's what I mean.

SS: Okay. So those are my major topics. Is there something else that you think is important?

Tape IV
00:05:00

DB: Well, you wanted to talk about TAG and how that came about. And so we all left, and we formed TAG.

SS: All right. And when you say "we," who is that?

DB: Peter. TAG didn't actually start as the Treatment and Data spin-off. Peter started TAG as a guerilla actions group to do CDs that were small, that were very targeted, and that Peter could control completely without, without having to go through any process.

SS: Right.

DB: Peter's a dear friend of mine, and we all know he's the most controlling person in the world. So that's how it started, right? It started with the action they did in South Carolina, at Burroughs Wellcome; and then the condom action and the Wall Street action. The Jesse Helms condom, house condom action and the Wall Street action were all TAG. I think he even called it Treatment Action Guerillas first, I think. And then, when most of us in Treatment and Data decided to leave ACT UP, it became, we were going to become TAG. It was Charlie Franchino, Peter, Mark Harrington,

Gregg Gonsalves, Derek Link, Garance, me; a lot of other people, though, a lot of other guys. Michael Becker, Bob Rafsky; Scott Slutsky; Jason Childers –

SS: But a lot of those people stayed in ACT UP and were in TAG.

DB: Yes.

SS: Right.

DB: Yeah. But –

SS: But who were the ones who left ACT UP?

DB: Well, the core. We, you know.

SS: You, Peter –

DB: Me, Peter, Mark, Gregg, Derek.

SS: So it's pretty much the –

DB: Spencer –

SS: – support group.

DB: – Spencer. Not just those; it was bigger than that. It was –

SS: Okay.

DB: – it was a larger group than that. But the core of it was the support group. And the core of the support group was the core of TAG. We just had had it, you know. It was just time to move on. It was very, it wasn't an easy decision. It was very painful. Losing ACT UP took years and years to get over; losing ACT UP. And I've never had a sense of community again, the way ACT UP provided me – in the way that ACT UP provided me with that – Never. And –

SS: What do you do now?

DB: I'm the director of something called the Collaborative Fund, the HIV Collaborative Fund. And it's, the Collaborative Fund is a funding mechanism that funds treatment activism around the world.

SS: Oh, okay.

DB: And we fund treatment education and community mobilization and literacy and advocacy projects — mostly to small groups; mostly people living with AIDS — all over the world. And all of the funding decisions are completely made by the folks in the regions. It's mostly people with AIDS who, they set funding priorities for their region; they create a funding application; they, we do a peer review process; and they select the projects to be funded.

SS: So you're not really a lawyer anymore.

DB: I've never been a lawyer.

SS: Okay.

DB: I've never practiced law —

SS: Okay.

DB: — except when I clerked, really. And then I wasn't even practicing.

SS: Okay.

DB: So —

SS: So my final question —

DB: Yeah.

SS: – and thank you, because you’ve been great: Looking back, what would you say was ACT UP’s greatest achievement and what do you say is its biggest disappointment?

DB: I really have to say, I have to say the greatest achievement, that there were two different components to it. One is that it – it did change – it changed – it changed drug development in clinical research and everything that Larry says in his clip — I mean, I’ll give him that much — I agree with that. Right? ACT UP was not the only organization that made that change happen, but ACT UP’s work in that area was really vital.

Tape IV
00:10:00

But the other piece of it is that it was an amazing example of true grassroots mobilization; spontaneous; completely, truly grassroots. Nobody founded ACT UP. I mean, that’s the myth that his press agent came up with. But nobody founded ACT UP. It emerged out of the need and out of desire. It was a truly grassroots mobilization of people in crisis, responding to that crisis. And responding to it in so many ways, all at once. But, most important, by creating a community that we could live in, and work in and play in and be safe in.

And you see different examples of that happen. I think that’s the nature of social movements; they emerge and they dissipate. And then they emerge again in another form, and it’s fine, that that happens. I’m not sad that there isn’t an ACT UP anymore. It played a really vital role. And then it was time to move on, and change the way you do it. I love what I do now. We created, and that it was based around this sort of, we created this mythology of the person with AIDS, that gave everybody strength.

The person with AIDS became the, the – the hub off of which everybody grew strength. The individual. We created this image of the person with AIDS as hero. I am not a victim. I'm a hero. I am in control of my decision-making, right? So that helps the individual. And then all the people around that person sort of take from that notion, so that it helps you with your grief. And it helps you, and you can fight the battle after they die because that's what they would want you to do. And it's all crazy stuff.

The greatest failing – was its, was ACT UP's ability to look beyond itself and build coalitions and emerge stronger. And so I do want to talk a little bit about United for AIDS Action –

SS: Okay.

DB: – about that, all right? But first, I'll say that – its greatest failing was its dependence upon this myth of the person with AIDS as hero. There was no place for grief. There was, grief was a bad thing. It was, we could be *angry*. That was, we could be angry or we could be joyous. Those were sort of the two emotions we were permitted in ACT UP.

SS: How was that enforced?

DB: Culturally.

SS: What would happen if somebody was sad?

DB: Oh, everybody would say, oh, we're sorry you're sad. And it's not like somebody would say, stop being sad. But it just wasn't the thing to do. The thing to do was to go on, and be mad, and to fight. And yes, there was a little time to be sad. But then move on from it. And it was this dependence on this, this idea that we could end the

AIDS crisis. We couldn't end the AIDS crisis. We couldn't; we didn't know how. And not just us; nobody knew how. So I think –

SS: Although now you say that everyone knows how, but there's no political will.

DB: Yeah, it's not that time anymore.

SS: Right.

DB: Things changed, you know? Things, there were some –

SS: Well, let me ask you –

DB: Yeah.

SS: I want to ask you this: Do you think that there's a relationship between the global access crisis and early policy decisions of ACT UP?

DB: Like what?

SS: Like our relationships with pharmaceuticals and – was there something that we could have done differently, way at the beginning, when there were just a few factors that would have made this current situation not what it is now?

DB: Um, no.

SS: No.

DB: You mean like, could we have made issues of, I mean – no, no. No. Did we make issues of pricing and availability of drugs up front? Yeah. The very first action was about the price of AZT, on Wall Street. Right? It was right there, from the beginning. So, no, I think no.

Tape IV
00:15:00

SS: So –

DB: Also, your question, your question is assuming that – is there a global access crisis? Yes. But, it is the work of AIDS activists that we have the Global Fund; it is the world of AIDS activists that we have PEPFAR, for all of its problems. For all of its problems, it's got a lot of people on treatment. It's the work of AIDS activists that have gotten hundreds of thousands of people on treatment since 2002.

So, is there a crisis? Yes. But you also, I think, need to look at the tremendous advances and success that have occurred.

SS: Okay.

DB: have drug price-, can you get ARVs [antiretrovirals] for, less than \$50 for a, per person now, for a year? Yes. Yes. Why? Because we did our job.

SS: So what's the obstacle?

Q: The obst-, well. Well first of all, the obstacle, the biggest obstacle — besides political will — is that, the biggest obstacle is that there is a lot of poverty and corruption and a lack of infrastructure that could, if everybody, if the leaders of the world woke up and said, let's cure AIDS today, or let's treat everybody for AIDS today, we couldn't do it. We, we're, it's amazing how much we've been able to do with so little infrastructure in such a short amount of time.

And – the – the turning point was the AIDS conference in Durban, when – up until Durban, it wasn't, there wasn't a discussion about how do we treat everybody. It was really, you can't do it. There is no infra-, it wasn't that we don't want to. It's that

there is no infrastructure; it's just not possible. The treatment is too complex; we can't do it in Africa. There is no infrastructure for it.

In Durban, because of the work of TAC, but mostly because one person with AIDS made a speech that transformed everything. I mean, I've never seen, I've never seen a, one person speaking create so much change as Edwin Cameron's speech at the AIDS conference. It was, I don't know how it happened. But when he, when that speech was over, the discussion was about how do we do this; from then on in. And you could watch it. I was standing with Tony Fauci. I watched him listen to this speech. And he was transformed. It was –

SS: So the idea that it's First World greed or racism is not the truth; that the problem is –

DB: Of course it's the –

SS: – underdevelopment.

DB: Of course it's the truth.

SS: – I'm serious, I'm asking you.

DB: Of, of course it's First World greed and racism and sexism –

SS: Uh huh.

DB: – and homophobia and drug-ism – what do we call it, I don't know. Of course it's all of those things. But that's not all that it is. And – and are those things the greatest obstacles at the moment? Um – I don't know.

SS: You think underdevelopment is the greatest obstacle.

DB: Poverty. Yeah. Is probably the greatest obstacle at the moment.

SS: Okay. Very interesting.

DB: It doesn't take away from any of the other. I think poverty, and with poverty, gender, gender inequity. I think those two things are the greatest, the two greatest obstacles.

SS: Okay, so let's talk about United for AIDS Action.

DB: So in United for AIDS Action, I was not at ACT UP. I was talking to people at ACT UP, but I wasn't going to the meetings. And the Democratic Convention was going to be in New York; it was 1992. And I was at GMHC. And I said to Tim Sweeney, we should make AIDS, the number-one agenda while they're here. And what are we going to do to do that? Here's, every reporter in the world's going to be here.

So he said, oh yeah, that's a good idea. And so we held a, we, I organized a meeting, and we brought all these people into the room, just from organizations all over the city, including ACT UP. And said, what should we do? So we decided we would create an agenda; what the next president should do about AIDS. A platform. Bring it to all the candidates, and talk to them; ask to meet with them and talk to them about it. Get them to endorse our platform. And we would hold a march and a rally. And that was the focal point of the whole thing, was we were going to do a march and a rally during the Democratic Convention. And I was adamant about it. We're going to do a demonstration.

And the point, to me, was, here's going to be an opportunity to bring service providers into doing demonstration work. So we're going to take the idea of an AIDS demonstration, and we're going to bring it to here. Let's get a hundred thousand

people in the street now, instead of the five. And that means a different way of working. It means it's going to be a different kind of demonstration, because it's got to be palatable to a lot more people, who don't, who aren't comfortable in ACT UP's clothes.

And it was, how do we get the, there are all these hundreds of service providers around the city. There are healthcare workers all over the city. Why aren't they coming out for an AIDS demonstration? That's what we should do, is get, is build this coalition that is service providers, hospital workers, unions, churches, everybody. We should get everybody out there that's affected by this, and really, and, and –

And we got 400 organizations to sign on to the platform. And we held a meeting. Aldyn McKean – I hired Aldyn to sort of take on coordinating stuff with me. So Aldyn and I organized a meeting of ACT UP members. First we, I'd gone to ACT UP. ACT UP had been participating in the coalition meetings; I went to the floor, I described the thing. But there were a lot of people who were key in ACT UP who were no longer going to the meetings.

So I organized this meeting at PS 41. You were there. And you asked me a question. You said, well, I don't understand: why are we, why doesn't ACT UP do this? Why isn't this just an ACT UP thing? Why are you asking ACT UP to participate in this? It should just *be* ACT UP.

And – I, I was annoyed.

SS: I have no memory of this event. You sure it was me?

DB: Yes, I'm positive –

SS: Okay.

DB: – it was you.

SS: For the record, I don't think I was there. Go ahead.

DB: No, you, it was, it was absolutely you. It was you. And I mean, it wasn't a terrible question.

SS: That's fine. I just don't remember –

DB: And it was –

SS: – being there.

DB: – it was – there were all these African American organizations that were involved. And so we did this — Broadway Cares was involved — we did this march and rally, in Times Square. We got the mayor to give us a permit for Times Square in the middle of a weekday afternoon. Right? And a march permit, to go from Central Park West into Times Square. We got the Jumbotron donated to us, so that the rally could be on the, for everybody to see it. We got stars — I don't know — Chris, Jessica Lange spoke; Gregory, they were all on Broadway at the time. Gregory Hines spoke. The mayor spoke; Jesse Jackson spoke; Dennis Rivera spoke.

ACT UP was livid. Livid. First of all, because they didn't like that these people were speaking. How dare we allow them there?

SS: And who said this to you, from ACT UP?

DB: Oh, a, a lot of people. But at the demonstration, I, I just remember, because I made a speech. And Richard Deagle was standing on the side, screaming at me, like apoplectic. And at one point, I had to stop the speech, and say, Richard, will you shut up? And the ACT UP people were really upset because we marched down, and then

the police penned people the way they do for New Year's Eve. And ACT UP was really pissed off that they were penned in. And, and that we had spoken to the police. We negotiated everything with the police ahead of time. People were pissed off about that.

Walter Armstrong picked up one of the police barricades and threw it at a cop, and spent the night in jail because of it. ACT UP was screaming and yelling so loudly so that, to drown out the speakers, because they were so mad about being penned in. And Gerri Wells got up and said, ACT UP, we love you; we're dealing with the police about bringing you up more forward. But please, we're here to talk about AIDS. And then ACT UP marched out en masse, and went up to 6th Avenue and came around and down 43rd Street, so they would be clo-, it was all about being closer to the stage. And so – again, there was sort of this feeling of, we're really not int-, we're not interested in this coalition. We're interested in doing this the way *we* like to do it, because it serves our need for self-expression. And that doesn't serve the goal.

Tape IV
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SS: Okay. Now I have a question for you, from before. Okay. I'm back to the construction that you set up about how, on one hand, you have people going for a treatment agenda whose agenda corresponds with the pharmaceutical agenda of getting drugs released quicker. On the other hand, you have these people doing the CDC definition, who are dealing with a very different kind of organization, the CDC, and issues, as you expressed, of poverty and racism and various discrimination issues.

Was there any way that you guys — the support group, TAG — that could have helped the people doing the women’s CDC thing have more access, or bring them into access?

DB: We did that.

SS: How?

DB: We participated in, not only in those demonstrations, but a lot of those discussions. It wasn’t like none of us were there and engaged in –

SS: No, that’s not what I said.

DB: Yeah.

SS: But was there a way, for example, I know, I’m in the theater, right? And I know that there’s a lot of guys who have access. And they never say to the guy in power, hey, here’s this girl, and she’s really, really –

DB: I, I, I really do think we did do that.

SS: Did you?

DB: And, and I think that the, the work to change the definition was very successful work.

SS: Um hm.

DB: And it was groundbreaking work, very important. And it was successful, and it happened.

SS: But so if you were bringing those people to the table, why were they so upset?

DB: We were all really arrogant. And I mean, there were a lot of personality pieces to this, as well.

SS: Um hm.

DB: Maxine [Wolfe], Heidi [Dorow]; Tracy [Morgan]; there were, there were other issues. There were issues of style, there were issues of arrogance. Who could be more arrogant; Tracy or Mark? It's a draw. And Mark is about as arrogant as you can get.

SS: But you believe that you were bringing those people to the table. But see, the women, the people working on the CDC thing –

DB: Yes.

SS: – not Tracy — I wouldn't bring her to the table, either – but people who were involved in real policy change; Marion –

DB: Yes –

SS: – Banzhaf –

DB: – yes.

SS: – people like that.

DB: Mari-, I never had any problem with Marion Banzhaf. Marion was fantastic.

SS: And so you were calling her and saying, we're meeting –

DB: Yes.

SS: – we seven guys are meeting with this and can you come, and we want you to meet them, and we want you to be part of this?

DB: Yes. Not, not – to the ex-, yes, though not always, and not, not in the NIH.

SS: Um hm.

DB: Were we, did we covet the relationships that we had particularly with Tony? Yeah.

SS: Okay.

DB: Can I, do we have time for me to say one more thing?

SS: Go for it.

DB: We made a lot of mistakes. And we learned some stuff. And – we – and I — we didn't talk about this before, and that's why I'm bringing it up, because I think it's important.

SS: Okay.

DB: All right? When we started, in work around drug approval, it was about getting stuff out, fast. Fuck it. We're dying; we need the drugs. And as time went on, and as we learned, we realized the value of clinical research, and the value of data. And by the time we got to '96, it was the patients sitting — I was on the guidelines panel, right, and it was the patients sitting at the table who were saying, whoa! Wait a minute. We made a mistake in '89 with AZT, with early use of AZT. We had data in people with AIDS, and there was survival data. But there was no data that showed that early use was effective. We had some T-cell data, and they made a recommendation for everybody to start using it early; and it was dead wrong. Okay? So we, first time.

Tape IV
00:30:00

Then we go into dual therapy, with AZT and ddI. And the researchers start — Margaret Fischl, all of them — start saying, dual therapy; start early; that's what we're going to do. Start everybody early. Market share of AIDS; market share of HIV; right? Start early, start early. And we're there. Right? We're there, going, yes! Yes! We got to get these drugs to people! We got to get these out! Early approval! Get everybody on drug!

It wasn't that we were saying, on a personal level, I can't tell you what to do, you've got to make your own decision.

SS: Um hm.

DB: But on a policy level, get those drugs out there. You know. And, and get them paid for.

Then, in '93, the data comes out; dual therapy is not effective. Okay? Boom; we're wrong again. In '93, we learned our lesson. And then 3TC comes out; they do the same thing again; and that's the first time that we go to the FDA and say, wait a minute: you cannot license the drug for early use, because you have no data for early use. And once you license it for early use, you're never going to be able to get the data. Right? And okay. So they license it dead wrong, again.

Ninety-six comes along; protease inhibitors come out. And the virologists at the table are saying, everybody with under 500 T-cells; hit hard, hit early. Hit hard, hit early, hit hard, hit early. And we're sitting there, going, whoa, whoa, whoa. We don't have any data in early use; we have no long-term data; we've made this mistake again

and again and again. The guidelines should say, for people with 200 T-cells and under, and then we study when to start.

And this was a really crucial, crucial issue. And the NIH did not do a when-to-start study; they did not create a new cohort to look at long-term follow-up in people. We pleaded with them to do it. I spent four years on that fight. I left treatment work, really; I left that kind of treatment work when the, I got, the guidelines got changed. We got enough data in, finally, from the European cohort studies, from the Canadian cohort studies, that showed that early use wasn't doing any better than later use, and instead was causing side effects, was causing poor adherence, and people developing resistance, so that when they needed the drugs, they were no longer there for them. And the guidelines were changed to two hundred; now they're back up to three.

But that, it was, it was this really important process, I think, that we went through, as activists, in learning – really how important research and data is. And we have, as people with AIDS, nobody needs that data — and it's got to be good data — nobody needs it more than we do.

SS: Okay.

DB: Okay?

SS: Thank you, David.

DB: Sure.

SS: This is really one of the best interviews we've ever done.

DB: Oh, no.

SS: And I'm serious, I mean it. Thank you very much.

DB: Oh, it's a pleasure. I love –

SS: It's good.

DB: – I like to talk.

Appendix 1

Oh, 76
by David Barr

ACTG 076 was a clinical study to test the use of a regimen of AZT to prevent vertical transmission of HIV. The study was to enroll a large number of pregnant women and have half of them take AZT according to the prescribed regimen and the other half would not. The goal was to see if AZT reduced the rate of mother-to-child infection. From the beginning, there was serious concern about this study. Questions included whether it would be safe to use AZT in this way, whether the hypothesis was credible, was the study designed properly, and there were questions about the focus of this study, the first to really look at a specific question involving women with HIV, was appropriate as there were feelings that this study only viewed women as vessels for their infants. I remember my initial reaction, and the reaction I maintained through much of this debate, was that the idea itself seemed incredible and could not work. I engaged in the issues somewhat, but never got too worked up over it because I thought it was a silly idea. This is perhaps the best example of what an idiot I can be. The study showed that AZT was very effective in reducing vertical transmission and was a major breakthrough in clinical research.

From day one, this study was viewed critically by many of the women activists, particularly those in ACT UP New York, led by Maxine Wolfe. There were several meetings, letters, screeds about the study that that group organized, with several women getting involved, moving past it and then others getting involved and the process starting all over again. From the beginning the discourse was riddled with a politics about how women are used as vessels. The major contention seemed to be that the researchers only cared about the babies, not about the mothers. Why weren't they doing a study for women, to learn about HIV in women? I don't remember any real proposal put forth about what that ought to be. It was the focus on pregnancy, particularly since there really was so little focus or attention or respect paid to the needs of women with AIDS, that was irksome and that reminded the group – and many others – of times past and present where the health care needs of women were not considered except in the context of childbearing. At this time, there was also debate about the exclusion of women from some treatment trials because of the risk of pregnancy – if you put these two things together – one, that women could not enroll in treatment studies because it might hurt a child they might conceive, and, two, that the major study they could enroll in was meant to look a treatment effect on a child, not a woman – it did not smell good. As the discussions about the study continued, additional issues about what kinds of care would be offered to women in the study became important. While these were important and valid issues, there reached a point where it seemed that whatever was proposed would not be good enough. Despite whatever discussion and negotiations were held, the underlying demand was STOP 076. Again, this was a battle going on mostly between the researchers in the study and a group of women mostly from ACT UP New York, but also

from other ACT UP affiliates around the country.

In addition to the politics between this group and NIAID, there were also brewing conflicts within ACT UP NY that affected things. The faction with which these women were associated was increasingly uncomfortable with the treatment boys. They felt that we were now working as insiders, too much involved in our own access to power, and elitist. We were certainly elitist and flush with success. We were difficult to approach, wanted everyone to notice how smart we were and were probably overly enticed by the access to power we had achieved. However, the claim that we should not be working on the inside was unfair. That was exactly where we needed to be. We had made progress; the first battle was to get the door open. We had done that and it was crazy to think that we should not walk inside. Also, while we were aloof, we were also accountable. No one put out more paper or gave more reports to the full group than we. Further, we might have been elitist boys waving our dicks all over the place, but many of the people within ACT UP with whom we were in conflict were also manipulative, vicious and underhanded in their dealings. Their attacks were often personal, they would lie and they would accuse us of things they knew were false in front of everyone to win favor. There was something of a HIV positive/negative split here as well, with the negative (mostly) women pushing a broad political (leftist) agenda and the positive (mostly) boys pushing a more specific agenda around AIDS research and drug development. The floor of ACT UP was manipulated terribly in this growing war, which ultimately led to our departure from ACT UP.

The trial was a complicated one and everyone, including NIAID and the researchers were nervous about it. It needed to be large (about 700 women total); it needed to provide good pre-natal care, education, support and follow-up with the infant. They were worried about whether they would be able to enroll all these women, as at the time, women with HIV were not forthcoming or identified and they were certainly not hooked into a research infrastructure. Further, everyone was concerned about safety. The earlier safety studies were inconclusive and the data was not long-term. It is especially important to remember that the majority of infants born to HIV-infected mothers were not infected, so if AZT caused any harm to the infant during pregnancy, it would be very bad medically, ethically and politically. Negotiations and discussions went on for months.

Late in these discussions, as the trial was finally set to go, the AIDS Clinical Trial Group (ACTG) Community Constituency Group (CCG) – the first body of community representation in NIH's history, got involved. The CCG was barely on its feet through most of the early discussions. People, particularly the people of color within the CCG, began to get interested in 076. It was about time, too, because it was primarily black and Latina women who would be impacted by this study. Here were community people that actually came from the communities that the trial was going to impact, not just activists purporting to represent those interests, but who were not necessarily from those communities. Now, the CCG was seen as suspect by the ACT UP groups because: it was the creation of NIAID, it contained community people they did not know and who did not

look as radical as they did, it was the turf of the ACT UP boys, and it was bogged down in process. So, there was little attempt – though some – made by the ACT UP group to include the CCG members in debate, information sharing and, particularly, strategy. At the ACTG conference (and it would be really good to pinpoint which one), an open session was scheduled to present the study to the conferees with an opportunity to ask the investigators questions. The chair of the session would be Janet Mitchell, a black physician from Harlem Hospital. The CCG members were now very interested in the debate and heard the complaints about the study from the ACT UP group. These CCG members had not had their own meetings with the investigators, as ACT UP had, and this was their opportunity to hear about the study from the researchers, ask their questions and raise their concerns. Additionally, here, finally, was a session being run by a researcher of color in a sea of white doctors. They were eager to attend and it was really their first foray into the ACTG where they were getting involved in a research issue – an important step into the process and successful development of the CCG.

What they didn't know, and what ACT UP did not tell them or consult with them about, was that ACT UP – or this contingent of ACT UP, as this action was not discussed or approved by the floor of ACT UP New York - was planning to disrupt the meeting and not let the presentations take place. They felt that the study was unjustifiable under any circumstances and therefore, there was nothing to talk about. The action was organized before the conference and many of the members of this faction, who would normally not have attended the ACTG meeting, came down, including many men associated with this group.

The session was crowded. It was held in an amphitheater, which meant the speakers were looking up to the audience and the audience looked down on the speaker. There was some introduction, probably by Dan Hoth, and then Janet Mitchell got up to present the study. I am not sure how long she spoke and if the study was presented and then took questions. I don't think that happened. I think that she was interrupted pretty quickly. Individuals from the demonstrators would yell out something or ask a question that was rhetorical and derogatory. They got louder and then started yelling, making it impossible for Dr. Mitchell to go on. The boys from the demo were the most vociferous, being boys, and getting caught up in the heat of it. The CCG members began yelling at the demonstrators to be quiet and to let the meeting proceed. Things went from bad to worse and then, Janet Mitchell lost it. She is a very small, but very powerful woman. She got so angry that she seemed to be lifted off the ground. She accused the demonstrators of being racists, just screamed at them. Security moved in, Dan Hoth took over at the mike, saying the meeting was over and people started walking out. The CCG members of color were absolutely furious. Other CCG members, who were mostly white and ACT UP affiliated were mortified. I remember trying to approach Rochelle Rollins and several others, but it was not possible. They did not want to hear anything. The immediate assumption was that this was a planned action that all the ACT UP people were part of, because that was always their assumption, that we were a unified group, even if we pretended not to be. That pretense was just part of the trick to keep control of everything

and shut people of color out. That is certainly not how all or most of them felt (though most probably did at that moment and who could blame them), but it was certainly how Debra Fraser-Howe and Rochelle felt and they always used their influence to push the group in a more paranoid direction. Here was all the proof they needed. Rochelle said, angrily that it was time for the people of color to meet by themselves and that she doubted they would remain in the CCG any longer (Ironically, Ben Cheng was not included or invited to this meeting. His color wasn't the right one.)

I was furious and scared. The ACT UP group had behaved terribly. Not only was it childish, it was so politically stupid it was astounding. Now, the white CCG members, most of whom were ACT UP affiliated in one way or another had to determine what to do. We were shut out of the POC meeting, which we knew was taking place and we also knew that the CCG was in real danger of breaking up over this incident. We knew that our actions could make or break things. We held our own impromptu meeting to discuss the situation. I don't remember anyone in the room speaking in defense of the demo. There must have been discussion about the position to take, but I think that there was pretty quick consensus that we disagreed with the demonstration, that the researchers should have been able to present and that we were particularly upset that the other CCG members were deprived of the opportunity to ask questions and make their points. Once that was settled, which, again, I don't think was difficult, we had to figure out what to do about it. We could not put out a statement as ACT UP, because we could not get approval for it while in Washington and it would be doing the same thing that the other group had done, which was speaking for ACT UP without getting permission to do so (*this was always a constant problem with ACT UP procedure because anyone could say they were ACT UP and say whatever they wanted. There was a process for approval of policy and position, but no real requirement to follow it and no enforcement mechanism at all if you didn't. You couldn't fire someone from ACT UP; you couldn't keep them from acting as a spokesperson. You could call the press or whoever afterwards and say that they weren't really speaking for the group, but by then it was too late.*) We also could not put out a statement as the CCG because we were not the full group and the rest of them weren't speaking to us yet. We decided to write a statement condemning the action of the ACT UP group, with some detailed reasons why we felt the action was inappropriate and harmful and supporting the POC members of the CCG, who it turned out were preparing their own statement for distribution. We each signed our names – and our affiliations – to the statement and had copies made. The next morning, both statements were handed out to the conferees. The POC group decided that they would not break off from the CCG. Our statement was very helpful in convincing many of those members that we were not a part of that action and that we believed in the CCG process. In some ways, the incident made the POC members stronger and pushed them to take more leadership in the CCG, but that was not a very good way to have had this happen.

The repercussions of our putting out this statement were much greater for us at home than within the CCG. The demonstrators mostly left the conference and went home to speak of their great victory in shutting down the evil meeting and to speak of our betrayal of

them and ACT UP. By the time we got back to New York and to the Monday night ACT UP meeting, enough people had been told about how we had betrayed the cause. Paper described how successful the action was and how terribly the CCG and the ACT UP T&D boys were. We were left to defend our actions, which few people wanted to hear. Our side of the story involved a more sophisticated political sense and the intricacies of group process. It also involved explaining why we put out a statement at the ACTG condemning an ACT UP demonstration, especially a demonstration that was about women. It was not as sexy as “we shut the meeting down and saved women with AIDS”. It all played right into the hands of Maxine and her evil manipulations of the group. Here was proof positive that we had betrayed ACT UP, were now only concerned with our own image inside NIAID, that the CCG was a front, and that we didn’t care about women. This debate grew much worse over the next year as our work on treatment continued to proceed and the overall ACT UP agenda continued to dissipate. Eventually, this battle grew so vicious and time-consuming, that it became the most visible cause for our departure from ACT UP. But, there were actually many reasons for this, most important being that we saw that ACT UP’s time had passed, but that our work could carry on if we could find a different model.

076 could have been an important way of bringing the people of color from the CCG into the scientific work. It could have been an important bridge between the two factions within the CCG. The ACT UP action, supposedly done to protect poor women and women of color from the research system, actually kept those women from advocating for themselves. We lost an opportunity there. Though the POC CCG members did become more aggressive as a group after this incident, they never again focused on a research question. After that, it was identity politics and nothing more.