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

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

Interviewee: David Corkery

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Interviewer: Sarah Schulman

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ACT UP Oral History Project Interview of David Corkery September 4, 2012

SARAH SCHULMAN: So you start by telling us your name, your age, today's date, and where we are.

DAVID CORKERY: Okay. My name's David Corkery, and today is September 4<sup>th</sup>, 19 — 2012, and we're in my apartment. What else did you want to know?

SS: How old are you?

DC: I'm sixty-one.

SS: Okay, great, and thanks for doing the interview.

DC: You're fifty-two or fifty-four?

SS: Fifty-four, I just turned.

DC: Fifty-four, yes, okay.

SS: So where did you grow up?

DC: I grew up all over the country.

SS: Were you from a military family?

DC: My father was an academic administrator in colleges, and I was born in Delaware, lived in upstate New York, Ohio, Arizona, went to college in California.

SS: So when you're growing up, you've seen a lot of different kinds of places, and you're growing up during the sixties, which was a really interesting time. Were you getting messages about political change or political communities that you think affected you, or do you think you avoided that somehow?

DC: Well, no, I was very aware of what was going on in the outside world.

I lived, eighth through twelfth grade, I lived in a small town in Arizona on the Mexican border — it's called Douglas, Arizona — and so it was really remote. You'd fly into

Tucson. It's kind of the end of the world, and then you'd drive two hours out into the desert. So it was a small town literally in the middle of nowhere.

But, it was a tumultuous time, and I was an avid reader of the *Arizona Republic*, which is the main newspaper of the state, and *Time* magazine, which at the time people read, and TV, so I was well aware of everything that was going on. I happened to be awake the night Robert Kennedy was shot, so I sat alone and watched the coverage. So it was a crazy time, and I was aware of it all from TV.

SS: And what was your parents' attitude about what was going on at that time?

DC: My father was conservative. My mother sort of has always been a moderate Democrat. My father was very conservative. In later years, he became — he's to the left of me, which is very far left, which is cool. So he's very progressive. They both are very progressive.

SS: So when do you think you started seeing yourself as someone who could be part of a political movement or community for change?

DC: I ran for — I was junior class president in this high school. It was a regional high school of 1,200 students, and it was a Phelps Dodge copper mining town, and so it was a company town. The main store was the Phelps Dodge Mercantile. The library was the Copper Queen Library. The hospital was the Copper Queen Hospital. And it was, I would say, probably about 80 percent people with Mexican descent and 20 percent Anglo.

I was junior class president, and I ran for student body president, and the guy who gave my nominating speech in the assembly, the assembly for this, his name was Larry Ramirez, and I had no idea what he was going to say, and he gave this very impassioned speech about racism in this little town. This was in the spring of 1968. So all of a sudden, unbeknownst to me, that was the platform that I was running on. So it was a very political, very emotionally charged kind of crazy time. I won the election. I was student body president.

SS: So you were the anti-racism candidate in the company town?

DC: Yes, I was anti-racism. The people I was running against weren't for racism, but they said — they used the word "prejudism." They said, "There's no prejudism here." They kept using the word "prejudism." "There's no prejudism here." And there was no overt prejudism, but it was an issue.

SS: Did you know that you were gay when you were running for president?

DC: Yes. The slogan of the campaign was "Dare to be Different," which is funny.

SS: Do you think the other kids could tell that you were gay?

DC: I think people thought I was gay, yes. It made me very scared and nervous.

SS: But they still elected you president.

DC: I don't think it was widely known and widely thought.

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SS: So what was your perception of the gay community? Did you

know that there was one?

00:05:00

DC: The first connection to the gay community was in a meeting of the

Junior Division of the John Birch Society, and it was really great because they passed out

this horrible stuff for people to look at, and they passed out a copy of the Berkeley Barb,

and the Berkeley Barb had ads, like same-sex personal ads, and it blew my mind. I stole

the newspaper, took it home, and so that's kind of what my first sense of what was going

on in the outside world. So it came from a meeting of the John Birch Society. That's a

true story. It's weird.

SS: That's a great story.

DC: Yes.

SS: So did you then think, "I've got to get to California"?

DC: I knew I needed to get out of Arizona, so I needed to get into the

more active world, so, yes, and I did. I went to school in California.

SS: So where did you go?

DC: I went to Stanford.

SS: So when you get to Stanford, so what year was that, like '70?

DC: Sixty-nine.

SS: Sixty-nine.

DC: Yes.

SS: So what did you get involved in at that time? Were you involved

in gay things? Were you involved in politics or —

DC: I was — well, it was an insane time in universities then, and San Francisco especially. It was the heyday. I think the Summer of Love was in '67, and '69 was still the heyday of Haight-Ashbury and hippiedom and all of that. The music was the Fillmore West.

It was a crazy time in the university. The spring of my freshman year was what we called Cambodia Spring, and the university was actually closed down. They just gave out grades, and the quarter wasn't finished, because there were so many demonstrations and the whole country was kind of in chaos. In the fall of that year, there was a thing called Vietnam Moratorium, which was going door-to-door and lobbying people about the Vietnam War. It was in the fall. Did that, so that was a major thing.

Then I had a tutor, a tutor in my freshman dorm who was very involved in progressive politics. He was a close friend of Allard Lowenstein's, and Allard Lowenstein would come to our dorm and stay. And I ended up going to work for a peace candidate in Santa Barbara, California, a congressional candidate, a guy named Gary Hart, who later, I think, became prominent in the legislature in California. Not the Gary Hart of — not the other Gary Hart; it's the California Gary Hart. So it was a very political — everything was highly politicized, and I was sort of in the middle of it.

SS: And you were going into party politics. But Allard Lowenstein was gay, right? That's what that was his whole —

DC: Yes, but it wasn't really known or obvious or open then. Yes, Al Lowenstein was gay, and the people around him tended to be gay.

SS: Why do you think in the middle of all that you went into party

politics?

DC: Oh, I didn't go into party politics. I just worked on that peace campaign. I wasn't interested in party politics. The guy lost. I was all alone as a community organizer in these godforsaken little towns in California where everybody hated him.

SS: Oh, like Visalia or something like that sort of thing?

DC: I don't — this is going to be on the Internet. I don't want to mention any names.

SS: Okay. Okay.

DC: The house that I was living in, the people that were keeping me, their son had committed suicide, and I was sleeping in his room.

SS: Oh, my god.

DC: Then some other people that I stayed with, they had a — the couple had an open relationship, so it was this wild and kind of wild and crazy California stuff.

SS: So did you stay politically active after that, after the war?

DC: Yes.

SS: How did you avoid the draft? Or were you drafted?

DC: Can we stop for one second?

[Brief pause]

SS: So how did you stay out of the military?

DC: I had a high draft number, and so that wasn't an issue. That was a lucky thing. The people that I went to high school with all went — many of them went to Vietnam. The guy who gave my nominating speech, Larry Ramirez, went to Vietnam. My senior year in high school, a lot of people in my school died in Vietnam, so there were funerals all year, and so there was a very immediate connection of people that I knew going to Vietnam and dying, and us burying them and having memorial services for them.

## SS: So after the moratorium and after the peace candidate, did you remain politically active?

00:10:00

DC: I did, mostly focused on antiwar stuff. After Stanford, I lived in San Francisco and I was involved in a thing called the National Alliance Against Racist and Political Oppression, I think was the name of it, which was Angela Davis's group. She lived in Oakland. She was a very inspiring figure to me. I'd had a philosophy professor who was the monitor for whatever the American Philosophical Association is at the trial, the George Jackson trial of Angela Davis. I didn't know she was — I don't know if she's bi or gay, but she was on the cover of *Out*, of the *Advocate* or something. It was really nice years later to see that she was a lesbian or bi or something.

Right after university, one of my closest friends was an editor at a thing called Pacific News Service, and he sent me — we had lunch one day, and he said, "Do you want to go to South Dakota? They're murdering — there's a lot of murders there."

So I went to — like three days later, I was on a plane to Rapid City, South Dakota, for —

it was for Pacific News Service, Pacifica Radio, Mother Jones, and there was a news service then that was kind of influential, called Zodiac News Service.

For a year or more I covered the situation at Pine Ridge, the Pine Ridge Reservation, where Wounded Knee took place. In the aftermath of the Wounded Knee occupation in '73, there were — there are various assessments of murders. There were somewhere between, I think, 100 and 150 murders. It was a war between the full-blooded Native Americans who were allied with the American Indian Movement, and the mixed-bloods who were in control at that time and were connected to Nixon and COINTELPRO and all kinds of government programs at the time.

SS: You lived there for a year?

DC: I went back and forth from San Francisco.

SS: Wow. And did you ever write a huge piece, or were you just constantly filing?

DC: No. No, I was doing — there were — I was filing for — I also did it for Metromedia had rock and roll. Metromedia rock and roll stations had the rock hippie news kind of thing. I was filing radio reports from — there were no telephones. There were telephones, like one or two in an area, like on a telephone pole in the winter, and so I was filing radio reports like that.

I wasn't that good a journalist, and so I would file the stories with some news service, and they were basically rewritten by the friend who had sent me there. So there's just spot news. There's no major, major — when I went back to San Francisco, KPFA in Berkeley had some big interview shows about it, but that was sort of the extent

of it. Then later, in later years, I worked on two documentaries on the situation there, one which was finished and the other which wasn't.

SS: What was the finished one called?

DC: It's called *Annie Mae: Brave Hearted Woman*. More recently — well

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SS: Go ahead.

DC: More recently there have been — people have suggested that she was a government agent, but I don't know if she was or wasn't. But the documentary was the story of her life and her death. She was murdered at Pine Ridge around the time that I was there.

The other one was done with a woman named Lan Brookes Ritz. I saw it once in a theater. I saw it at the Museum of Modern Art. The other documentary was a video documentary that I did with a friend of mine that was never finished.

SS: So did you ever imagine at that time that there could be a Gay

Movement in the way that there was an American Indian Movement or a Black

Movement?

DC: No.

SS: What did you think was going to happen? When did you start making those connections about a certain kind of paradigm shift for gay people or a certain kind of identity community for gay people that would be political, after having these experiences?

DC: That, for me, didn't emerge until ACT UP. I didn't feel that until ACT UP. I didn't experience that until ACT UP. That was part of the excitement, I think, for me and, I think, a lot of people. Only, I think, from reading a Frank Rich column in *The New York Times*, in the last year, he was talking about when he was going to Harvard he didn't know any out gay people, and he talked about how people didn't know about Stonewall because there was no coverage of it. It was a very obvious point, but I don't think I was aware of Stonewall until ten or fifteen years after it happened, because it just wasn't something you were aware of as a significant moment. I didn't know people who were involved in gay politics so —

00:15:00

SS: Well, how long were you in San Francisco? Until what year? DC: 1976.

SS: So what was the gay scene like there that —

DC: There were two gay scenes. There was a Polk Street gay scene, which was more sort of punk. And there was a — I don't mean this disrespectfully, but a clone culture out in the Castro. And I was more interested — I lived on Pine Street near Polk Street, so I was more interested in the Polk Street, but it wasn't a defined community for me. I had the prototypical year of coming out of that year in San Francisco, but I didn't have any sense of community or any larger political — there was no political component that I was aware of, really.

SS: So what did it mean? Like, what was the punk scene? I don't even know about it, the Polk Street. I thought Polk Street was a leather scene. I didn't know it was a punk scene.

DC: I wouldn't call it punk. It was just the cooler people. It wasn't clone. It wasn't the clone Castro situation.

SS: Oh, it was the new generation.

DC: Yes, I think.

SS: And how did it show itself?

DC: Just bars. There were a couple main bars there.

SS: What were they? What were your favorites?

DC: One was called Buzzby's and there was another one called something else that I don't remember. Buzzby's was the big one.

SS: So then when did you come to New York, '76?

DC: A block from my house, Patti Smith — there's a place called the Boarding House, and Patti Smith performed there five nights in a row, and I went to see Patti Smith for five nights in a row, and then I said to myself, "I have to go to New York," and so I did.

SS: So where did you move to?

DC: I moved to Manhattan.

SS: Where did you live?

DC: Where did I live? The first apartment I lived in was on 11<sup>th</sup> Street between Fifth and Sixth Avenue. I've always been downtown, mostly in the East Village.

SS: So you still were here for the heyday of the — how did you fit into that community, or were you just a civilian? Were you involved in anything, or did you have places that you hung out?

DC: I wasn't involved politically.

SS: Did you have clubs?

DC: Went to bars, yes.

SS: What were your hangouts?

**JAMES WENTZY: Ninth Circle?** 

DC: Yes, the Ninth Circle. The Ninth Circle was the main downtown place. I don't really remember. I remember the Ninth Circle, but I don't really remember other places.

SS: The Bar or —

DC: The Bar was later. I don't know when The Bar started, but I didn't remember — I didn't go to The Bar until a period after '79 or '80. That was the main place that I went after —

SS: And there were all the bath houses, St. Mark's Bath.

DC: Yes. I didn't go to the bath houses.

JW: The piers, the trucks.

DC: Yeah, all of that. The Piers. The Piers were great.

SS: Yay, the piers, yeah.

DC: I had a boyfriend starting 1979, and he worked on a documentary for a drug company on hepatitis vaccine, and so he was into all this research. At the time,

people were really worried about chronic hepatitis, and I was scared of chronic hepatitis, and so I'd come home and he'd talk about how chronic hepatitis could live on the wall for like a year. So I sort of, because he was my boyfriend and because of all this, I mean, I was practicing sort of with other than him basically a kind of safe sex, which I think saved my life. My sexual activity outside of that relationship was limited.

SS: So just your timing was good. When did you first hear about AIDS?

DC: I read the *New York Native* avidly. I was thinking about this prior to the interview today and yesterday. The *Native* — my memory of the *Native* is that they were very good in their coverage of AIDS. I remember that there were things that were wrong with it, but I don't remember what, but they at least told you what was going on, you knew what was going on, and so I was aware of all their coverage from when it started.

SS: So your first exposure to it was by reading about it?

DC: Yes.

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SS: More than having people close to you.

DC: Yes. There was a friend, a friend of a friend from L.A. who was a professor at UCLA, who was from Maine, and my boyfriend and I spent a week at his house in Maine, and he died six months or a year after that, like a really weird sudden death, unexplained weird sudden death. This would have been around 1980. And I'm sure, in retrospect, that it was AIDS. But so people were kind of disappearing. He disappeared without explanation as to what caused his death.

So I'd say just from the *Native*.

SS: And what were you doing for a living at that time, '76?

DC: I was working — starting in '79, I was segment producer and writer on *Good Morning, America* for the news segments on the program. I did that from '79 to '82. No,'83, till '83.

SS: Did they cover AIDS at all?

DC: Yes. *New York Magazine* had this history of AIDS. I don't know when they did it, but it was a chart. And it said that *Good Morning, America* had the first report on AIDS. I think it said 1982. Bob Bazell, who's a friend, Bob Bazell is at NBC, who did reports for the *Today Show*. Years later he saw that and he said he was annoyed, because he'd always thought he had had the first TV report on AIDS. So I don't know which was right. It could be checked, but I never checked it.<sup>1</sup>

SS: Were you involved with that?

DC: Yes. It was —

SS: How did that happen? Can you share that with us?

DC: There was a guy who was the booker. His name is Michael Kelly. He went on to become a famous journalist. He died in Iraq. Most of the segments were just sitting around and talking about what to do, and he booked the segments. I don't remember who was the guest was. It was a segment, though. It wasn't part of a newscast. Again, it could be researched as to what it was, but I don't have a memory of

<sup>1</sup> Robert Bazell did a report on AIDS for the NBC *Nightly News* on June 17, 1982. This was the first story on AIDS on a national evening news program. *Good Morning, America* had broadcast a short interview of the CDC's James Curran as early as December 1981.

what it was. I didn't walk around thinking we put the first report. I never remembered it as such till I saw the *New York Magazine* thing.

SS: Well, that's good to know. So from '81 to '87 or '86, 40,000 people died of AIDS, and at that time, as that was just escalating and escalating and escalating completely out of —

DC: Eighty-one to what?

SS: What are the years, Jim? You say it on your film.

JH: Eighty-one to '87.

SS: Eighty-one to '87, 40,000 people died.

DC: Isn't that extraordinary?

SS: It is.

DC: Can I get some water.

SS: Sure

DC: I'm afraid I'm going to get —

SS: Wait you're plugged in.

DC: Oh I forgot, I'm sorry.

SS: Jim will get it for you.

JH: Oh, why don't I just do that for you?

DC: There's a bottle on the wall of the refrigerator, you can just bring the

bottle.

JH: Okay

DC: I've never been interviewed before. Is the camera off?

SS: No, no. It's never off.

DC: Is this going to be part of what's online?

SS: Everybody's interview is like this, David.

DC: Okay.

SS: We just film everything. It's not television, it's not 60 Minutes. It's just raw data.

DC: So in that time was the freaky time, because you'd go to the doctor's office with a cold, and there'd be six people looking like Holocaust Auschwitz survivors sitting there near death. You'd be attracted to someone, and someone would whisper to you that, "He's sick." "He's sick" was the phrase that was used. Everybody had KS. It was just swollen lymph glands, KS. It was just an insane, frightening time.

I was on a plane to Paris for work for ABC, and I read *Time* magazine, an article in it, and it was the first time I read — I believed I was of the multi-factorial theory because of the *Native* and because of Michael Callen and because of Joe Sonnabend, and a multi-factorial theory made sense. And I read in *Time* magazine that there was a growing consensus that it was caused by a virus, and it flipped me out just completely, because it was — it was like we're all going to die. I mean, it's like I'm going to die. We're all going to die. We've all got this. So it was weird because the experience of that was in Paris, like walking around in Paris. It blew my mind.

SS: It's interesting to me that — and this is true for many people in ACT UP as well as for you — but in those years, from '81 to '87, no groups emerged that attracted you.

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DC: I didn't know of any groups.

SS: I mean, there was GMHC. You didn't want to be a buddy or whatever. You know what I mean? But it's interesting that it was ACT UP was the first thing that really made sense to you. Can you explain to us that moment when you made that decision to go to a meeting?

DC: Well, there's a couple of things you need to know. One is that in 1985 I had collapsed. An illness I had was only later diagnosed as central nervous system Lyme disease, and I was extremely ill. I couldn't walk more than like twenty-five yards, I was dizzy, I couldn't — I had memory loss, I was extremely weak. So at the time everybody else had AIDS, I had a catastrophic illness that no one could explain. I was diagnosed with AIDS, two or three times. It was presumed to be AIDS, and they just couldn't prove it. And I was so sick and numb that — I didn't know. I didn't walk around thinking, "Oh, I have AIDS." I didn't know what I had. So I was extremely ill from '85 to '87 when —

## SS: Did they put you on AZT or AIDS meds?

DC: No, no, because I tested negative. The antibody test came out in, '85, sometime in '85, and I was tested and I was HIV-negative. But then some doctor said it just hasn't shown up yet and, — and I was at my parents' in California. I was stuck there for three months or so, just extremely ill.

Florent Morellet, who's a close friend, I lived in this building at the time, and he was a close friend, and he came out and literally got me and brought me back to New York, and it saved my life. If I hadn't, I would have just kind of been there forever

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out there. And it was the days of People's Express, and we took a People's Express flight

back to New York. We lived in the same building. So I lived in that building. He made

a make-work job for me at his restaurant, like a dumb job just to —

SS: You worked at Florent?

DC: Yes.

SS: You were in the epicenter. That was like headquarters. Florent

was like headquarters.

DC: I worked there for a year or two. The make-up job, he just wanted to

get me out of the house. So I would get in a cab and I would go to the restaurant, and I

would sit in the basement and check the addition of the checks, which is just — he's so

sweet. It was just a made-up job. I think he paid me something for it. I don't remember.

But as I got a little bit better and I became — I was a day manager for a while.

He was diagnosed then. He was HIV-positive and had hepatitis. So the

restaurant was hugely successful, but, again, it was an extremely frightening time,

because people that had HIV and hepatitis usually didn't last very long. He traveled a lot,

so I was in the restaurant in the evening when he was away, and for a while at the end I

was the day manager of the restaurant.

My first memory of an AIDS group was somebody — somebody from

GMHC bringing in some kind of a promotional thing for GMHC into the restaurant, and I

didn't know of anything else until it was probably the early part of GMHC.

SS: What got you to ACT UP?

DC: Article in the *Native*.

SS: So what was your first — when did you first go, and what was the meeting like?

DC: I think it was the fall of '87. There was a whole — there was a massive room of people on the ground floor of the Center. It was a lot of people's first memory, it was David Robinson and Maria Maggenti facilitating, and it was just wild and crazy. And I wanted to do something to help. It was kind of what everybody did. They just kind of found a thing for them. Everybody there was — found a thing that they could do that would matter. So I went to the Communications Committee, which at the time met at Vito Russo's living room. So that was my first experience of ACT UP, was basically the meeting and then being in Vito Russo's living room.

SS: So what did you guys do on the Communications Committee?

DC: Well, what I did — I remember what I did, which is I did the media outreach, because a guy named Drew Hopkins — does that name ring a bell?

SS: Yes.

00:30:00

DC: Is he alive? Do you know whatever happened to him?

SS: No, don't know.

DC: I never heard anything else about him, so I don't. He worked on documentaries. He worked with Trudie Styler on documentaries. Trudie Styler is the wife of Sting.

SS: Right.

DC: Sorry. I just — so he had done the media outreach, and then there was nobody doing it, so I made media lists and sort of — there was nobody else doing it, so I took over doing media outreach.

SS: And what kind of response did you get from the media?

DC: They were interested. I just did all the basics of calling them all the time, building lists, which was an important thing, of just figuring out who you go to, like if you want to be on Channel 2 News, who are the assignments editors that you go to and all that kind of basic stuff.

SS: How did you help people who had never covered gay anything adjust to feeling that they could cover AIDS?

DC: Well, specifically a lot of it was leading up to the second Wall Street demo. This all — my active involvement I did it full-time for probably six to nine months, and it was when the modern Communications [Media] Committee came about. It was when Signorile got involved and Jay Blotcher got involved, and so it was all tied to the PR for that rally, for that demonstration. And it was just the idea of closing Wall Street was exciting enough to get all the reporters out and I'd been in touch with them for a while, so it was — it was relatively easy getting them out. The media, the media turnout for that thing was just amazing, everybody in the world was there. It was really exciting.

SS: It's interesting because, on one hand, we were very successful with media, but we always had trouble with *The New York Times*. Why were they different than everybody else?

DC: Hmm. The *Voice* was a problem too. The media was a problem.

That was a focus of what we did. I remember specifically, for example, the *MacNeil/Lehrer NewsHour* was bad. They'd had an interview with the FDA 
commissioner with no opposing point of view. They just interviewed him, and he was 
bad, and they just didn't — Robert MacNeil did the interview. I wrote a — I wrote a — I 
don't know what it was. It wouldn't have been an email. I guess I wrote a letter.

#### SS: A letter.

DC: A letter to him, a nasty letter, and he responded with a handwritten note saying he took the point and that they would do better. It turned out that he had a son that was gay. So, in his case he was a well-meaning person who just didn't know better.

## SS: Did they do better?

DC: I think they did, yes, but I don't — I mean, I can't — it was so many years ago, I don't know. I think they did.

## SS: What was the problem at the *Voice*?

DC: I remember that there was lobbying of Richard Goldstein to get them to do more coverage and better coverage, that they weren't really covering it in a serious way. I forget who did that lobbying, but I know there was specific lobbying of him, telling him that they had to — arguing that they had to do more.

In terms of the *Times*, I had pretty good relations with the *Times*. In the early days, they were really bad. But I had a very good relationship with a guy named Bruce Lambert, who covered a lot of the AIDS stories for — he was on the AIDS beat. I

had a very good relationship with Gina Kolata. I could always get to them, talk to them, pitch them stories, so that they were — by the time I was involved, they were accessible to me. So the problem with them may have been earlier. They were bad with all that stuff. They just — but it was a time when they were bad on a lot of things. They were just — stereotypical, all the stuff of the Rosenthal era. It was —

SS: Well, it's interesting that television was more responsive than these established print venues, even if they had gay editors, etc.

DC: Mm-hmm. But I didn't ever have a sense that they were reluctant — that there was a weirdness about covering — the people I dealt with, it was just a news story, and they accepted that it was a good news story, and then they covered it.

Vito, he was taking stuff like egg lipids. The stuff that was going on then when you look back on it, it's wild, but you had to have hope. Sort of the story I was remembering in the last few days is that at the time *AIDS Treatment News* had a story — *AIDS Treatment News* was saying AIDS was going to become a chronic manageable disease, and so we all wanted it to be. And I did this outreach for ACT UP to people to do stories about, hey, it could become a chronic manageable disease, and it was inspired by an article in *AIDS Treatment News* that cited Bernie Bihari and, Naltrexone. I mean, it was — it was a wild flight of imagination that AIDS would ever become, you know, a treatable disease, but you had to create the atmosphere in which potentially that could be possible to encourage research, to encourage funding, all of that kind of stuff.

SS: But that also was a sophisticated vision. It wasn't saying one pill that will cure you.

00.35.00

DC: Yes.

SS: I mean, it was a realistic look into the future. Who was Bernie Bahari? That sounds so familiar.

DC: He was the — for a while he was the medical director at CRI.

SS: Okay. Okay.

DC: He came from drug treatment, and Naltrexon was used for drug treatment. But Joe Sonnabend used that too.

SS: Now, what was the relationship between Michael Callen and Joe Sonnabend in ACT UP? How did you understand that?

DC: Well, I have to back up a second and talk about Michael Callen.

SS: Okay.

DC: Okay. So Michael Callen, I had this idea to do a documentary on Michael Callen because to me he was the great hero of AIDS activism before, long before ACT UP. I went to meet him to propose to him that I would do a documentary, and he was — he basically immediately put me to work. You know Michael. I don't feel like going into the Michael imitations, but you know what his first questions would have been upon meeting someone. He was a character. And I ended up doing the PR for his album. I don't know if it was his first album, but it was his biggest album. It was called *Purple Heart*. So I did the PR for it, and I think the idea of the documentary just kind of faded away because he was in the middle of so many things.

It's hard to imagine, but it was a time when it wasn't accepted that you did prophylaxis for opportunistic infections, which gives me a chill just saying that. But he

was fighting with Fauci and going around the country and testifying, and he was fighting for prophylaxis of opportunistic infections, stuff like that. He was in the middle of sort of everything.

## SS: Why did the government oppose that?

DC: I don't know that they opposed it. I think that they just didn't — it wasn't part of the standard of care. It wasn't the accepted thinking, which is nuts, because when you get a bone marrow transplant — in the whole world of oncology, you get a bone marrow transplant, you're extremely immune suppressed. They know medically that they have to do things so that you don't get opportunistic infections. So, it was just like it hadn't been put together.

I mean, just for this conversation, it's known generally, but Michael created the PWA Coalition — I mean co-founded PWA Coalition and he edited the PWA News Line. He created what was the Buyers Club called?

SS: The Buyers Club. What was it called?

JH: PWA Health Group.

DC: What was the Callen Lorde called before? He created that, too, the medical clinic, the medical clinic, and he co-founded CRI, Community Research Initiative. So, I mean, he was a busy guy. He was in the middle of everything, and he was a very, very intelligent and very, very inspiring person, and he inspired me to get active and to be active.

I think it was after that I got connected to ACT UP. ACT UP became the focus of what I was doing. Michael was never active in ACT UP, but I always

thought Michael was sort of — Larry Kramer is famous as the original AIDS activist and stuff, but I see Michael Callen as being the other original — sort of the original AIDS activist, now dead, and, that's not — those of us who are still alive and remember him know, but, I think he was — for me, he was the original inspiration in terms of AIDS activism, because he wrote so well and he was such a voice and such a strong voice on for everything.

SS: Did you see the musical at Dixon Place?

DC: No.

SS: Anyway, it was about Michael. It was a one-day thing.

Now, you were involved in the FDA action, right?

DC: No.

SS: No, you were not. Okay. So where did you go from

**Communications Committee?** 

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DC: What did I do after that?

SS: Yeah.

DC: Maria Maggenti's mother, who was a PR lady in Washington, was looking for a job in New York, and she'd interviewed at major PR firms and she'd also interviewed at amfAR. It must have been at a dinner, after a meeting or something, I don't remember the circumstance, but it was a meeting — it was a dinner that Roberta Maggenti, her mother, was there, and she said, "That job's not right for me, but you're perfect for that. Let me connect you to those people," and so I did.

I had an interview with two people, one named Terry Beirn and the other, Sally Morrison, were two of the main people sort of inspiration people running amfAR. So I was hired there right away. I didn't want to go there because people hated them.

Larry Kramer hated them.

## SS: Why did ACT UP hate amfAR?

DC: Well, Larry Kramer hated them. He said he didn't ever know where the money went. He called them, the luxury liner of AIDS, didn't feel they were connected to the community. They were rich people, not really sincere in their commitment to AIDS. Callen hated them because Joe Sonnabend had been part of the founding of the organization, had been kicked out and —

#### SS: Why?

DC: Why was Joe Sonnabend kicked out? He wasn't buttoned up enough for them. He was too wild and crazy for them. He wasn't their image of what they wanted.

So Michael Callen — and it was a sore point that they were against community research, so Joe and Michael's big thing was community-based research. The whole thing, the core of the thing that they wanted was access, for people to have access to experimental treatments as early as was reasonable. And amfAR was against that.

Well, they weren't against it, but they weren't interested in it. They wouldn't do it. So Michael didn't like them for that.

So going from ACT UP to amfAR was a really big step, and I wasn't anxious to do it, and I was really devoted to the work I was doing in ACT UP. They

hired me. They said, "Come and see if you can get something done. Come for three months, see if you can get something done, and if you can't, then don't stay. It's fine." Basically, they gave me carte blanche to come and try to do stuff there.

Soon after I went there, there'd been a proposal that had been rejected for the first needle exchange program in the — research program in the country. It was at an organization in Portland called Outside In, I think. It was like a Berkeley free clinic in Portland. It was a study by Don DesJarlais at that clinic. Don DesJarlais later became sort of the owner of the needle exchange research.

So the politics were done internally to get amfAR to approve the grant to them. It was outside of the normal grant process. It was called the President's Fund. I was the PR guy, so, and I got front-page stories in all the major newspapers about the grant, big stories, like in the *Washington Post*, and it was kind of everywhere, and to position amfAR, which my goal — my PR goal was to position them as cutting edge but responsible and rigorous and blah, blah, blah, and the story was that we're going to do a research project to see if it was effective, and, how can you argue with that? It's a research project. You can't be against a research project. And so it was approved, and then amfAR was real excited at the PR implications of that. They liked that, and they hadn't really gotten substantive PR. My goal was to have them do something and to have substantive PR, not just PR about the benefits.

The other main story of amfAR related to that was that not long after that, then the next thing that happened was the start of the amfAR community-based clinical trials program. For many years, the two things that amfAR — they did a whole lot of

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stuff in needle exchange after that, and then community-based clinical research was the other big thing that they did.

The story I don't know if anyone's told, but it's a great story, which is that the amfAR board was against community-based research. AmfAR was the combination of a West Coast and East Coast group, and the West Coast was led by a doctor named Michael Gottlieb, and the West Coast people were very against — they didn't want community-based research. The East Coast people, led by Mathilde [Krim] did, but weren't — they hadn't pushed for it.

Terry Beirn, who I mentioned before, and Sally Morrison, the people who hired me, Terry Beirn ran amfAR and Sally raised all the money. There was a big benefit at Carnegie Hall called Music for Mathilde. It was organized by Leonard Bernstein, and it had a lot of really famous people performing. Terry and Sally went to Leonard Bernstein and Harry Kraut, his manager, and sold them on the idea of community-based research, and so they got them to designate that the first million dollars from the benefit would be for community-based clinical research. So they did an end run around the board, and then the politics were really intense, and then Mathilde ended up prevailing. There was always a struggle between Mathilde and the West Coast people. In the end, Mathilde won out and became the chairman of amfAR.

## SS: What was Gottlieb's reason for opposing this?

DC: It was the discomfort with the community. It was science kind of versus the community.

## SS: And how come she understood?

DC: She was — I just have to say it for posterity, but she was, and is, a really progressive person. She was an Interferon researcher at Sloan-Kettering. She knew Joe Sonnabend because they were researchers together in Interferon, and I think Joe Sonnabend is the one who got her involved in AIDS.

Her husband — her husband was the head of United Artists. Her husband was one of the two most powerful people in Hollywood for many years. He was the main fundraiser for the Democratic Party for thirty or forty years. They were close personal friends of Lyndon Johnson and had their own bedroom in the White House kind of thing. So they were very politically powerful and connected.

When Nelson Mandela got out of prison when he first came to New York, the big reception for him was at their home. They'd given money to ANC, African National Congress, for years and years. They were involved — they have a whole history of being involved in progressive causes. She's instinctively — she instinctively likes progressive things, cool things.

SS: Let me ask you something about interferon. First of all, who has the patent on Interferon?

DC: I have no idea.

SS: Okay. So she was involved in interferon. So interferon was a failed cancer drug, right?

DC: Mm-hmm.

SS: Like many failed cancer drugs, like AZT and many other drugs got recycled through AIDS, Alpha interferon and beta interferon, and ultimately

they didn't pan out. What I find is that I still see those drugs being recycled through every possible illness you could have. Wherever you go, somebody's offering you Interferon, but it doesn't seem to actually work for anything. I thought, my god, the mechanism behind Interferon, whoever owns that patent is extremely powerful.

DC: Yes, I don't know. It's being used now for — it's the main treatment, one of the main treatments for hepatitis. I have a friend, who's on it in a clinical trial involving new drugs plus Interferon, and it's a clinical trial that goes for three months, and he's extremely ill.

SS: Yeah, I know that right now there's clinical trials for hepatitis.

It's also been used for multiple sclerosis, for thrombocytosis. I mean, whatever their apparatus is, it's extremely — it gets them into everything, and I just was wondering. Okay, so you don't know who is propelling that.

Okay. So you're in amfAR, and were you still in ACT UP while you were in amfAR?

DC: I wasn't active in ACT UP. I don't think — I don't personally feel that I ever left ACT UP. I was still close, close to key people that I'd work with in ACT UP.

SS: But what happened if amfAR and ACT UP had a disagreement or had a different agenda? Can you think of an example of that?

DC: I don't think that — I don't remember that ever happening. There was one example, which we can talk about in a minute, if you want, which was the Woody Myers thing.

SS: Okay, let's talk about it.

DC: Do you want to go to that?

SS: Sure. Why don't you just explain it.

DC: Woody Myers had been on the — was on the amfAR board, and Mathilde was a supporter of him. She had a whole history of supporting African American progressive issues, and she supported him to be the health commissioner under David Dinkins. She may have nominated him. I don't know.

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And after he was nominated, it started to come out that he had a really bad record on AIDS in Indiana, and at that point I was overseeing communications policy and the community-based clinical trials program. So I was responsible for all three of those areas. There were people under me doing it, but it was under me. So my immediate reaction was one of great concern.

This gets to the point of the connection between ACT UP people and amfAR. So Mike Barr was actually working at amfAR then, and he was working for the policy director, but Mike Barr is the one who actually did the research on Woody Myers in Indiana, like what his record was in Indiana, and it was bad. So it was really one of the ugliest situations I was ever in in AIDS because the black community was all for Woody Myers, and the AIDS, the white AIDS community was all against him. I was in a

meeting at GMHC where all the key people were in the same meeting, and it was really ugly. It was really bad.

SS: What was your view?

DC: My view what?

SS: On Woody Myers at the time.

DC: That there's no way that he could be the health commissioner. There was no issue of it. And so ACT UP — so amfAR was in a weird position because Mathilde had sort of supported him, but I think she backed off, so it was unclear whether amfAR was for him or against him, and it was just kind of a — it was just kind of a mess. Then he became the health commissioner.

SS: Which shows the lack of power on the part of what you called the white AIDS community.

DC: In that situation, yes.

SS: Yeah. And how did he do vis-à-vis AIDS as health commissioner?

DC: I don't know. I don't really have an opinion on that.

But there was no other situation where there was, I think, a policy disagreement between ACT UP and amfAR because there were people from ACT UP working at amfAR and there was just never a situation that I can remember where there was — there was one other controversial situation, which was the Compound Q trial, and it was widely thought that amfAR paid for that, and I didn't know it at the time, and I don't have any evidence to whether they did or they didn't, but all the circumstantial evidence is that they did. I personally was on the side of great concern about how that

trial was conducted. It was just a — it was a nasty fight between the East Coast AIDS world and the West Coast AIDS world, and within CRI. It was a struggle within CRI.

SS: Because Compound Q came from California, right?

DC: Well, it comes from cucumbers, so I mean, but, yes, Project Inform did the trial, yes, and was pushing it.

SS: Because I remember Larry saying at the meeting, "They're dancing in the streets in San Francisco because the cure has been found."

DC: Barbara Starrett was the doctor doing the trial in New York. I just am reading the manuscript of Mark Harrington's book that he wrote ten years ago, and I've only read the first half of it, but I just read that, that manuscript about that period, and it just sort of brought it all back. It was really an ugly — it was an ugly situation.

SS: So who was behind Compound — I mean, who favored

Compound Q?

DC: The West Coast.

SS: But why?

DC: Because everybody was desperate for a cure, and the M.O. of Project Inform was always to have the next — the next cure product sort of in the — you know what I mean? They were always promoting a new sort of cure in kind of an aggressive way. I have huge respect for Marty Delaney, and may he rest in peace, but there was kind of a profound difference between the East Coast treatment people and Project Inform.

SS: And did they ever actually produce something that became useful, Project Inform?

DC: No. I think it was found to not work. I mean, that was what the conclusion —

SS: Yes, it was actually toxic, I believe, yes.

DC: Yes, because a couple people — that was the controversy, because a couple people died, and it was unclear how and the circumstances under which they died.

At amfAR there was a couple — Mark Harrington worked there. He and Debbie Levine organized after the community-based clinical — the first round of community-based clinical trials grants went out, there was a huge conference at Columbia University, which brought all the grantees together, and it was sort of a big moment in AIDS. It was a conference that included all the top people from the FDA, NIH. Fauci was there. It was at the law school at Columbia, and it was the first time all those people had been together in one place working together for the first time. It was sort of a really big moment, and that was staffed by Mark Harrington and Debbie Levine did all this, organized the whole meeting, working for amfAR.

There were situations. AmfAR was sort of the — like a focal point for navigating consensus on big issues and would organize consensus statements on things. An example of that was parallel track. All of the — it was a statement written for — it was a statement written by Mark Harrington for all the AIDS organizations to sign, I mean organized by amfAR, so they were all on board on the policy, what the policy should be on parallel track, access to experimental treatments, on unapproved treatments.

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SS: Which was actually conceptualized by Jim Eigo, yes.

DC: Mm-hmm.

SS: So as TAG —

DC: Wait, can I tell one more story?

SS: Yes.

DC: The other — the other story was that — just an illustration that there was a lot of coordination behind the scenes. For example, there were demonstrations around AZT drug pricing, and then ACT UP — amfAR had a consensus statement of all the AIDS organizations on drug pricing. So there was an action and then there was a policy piece of it that brought all the middle of the — all the mainstream AIDS organizations speaking with one voice in concert with what the action is calling for. So that happened. That happened a number of times.

SS: What was amfAR's budget?

DC: When I left, it was probably around somewhere around 12 million.

SS: And that was mostly spent on research?

DC: I think 3 or 4 million of it was spent on research.

SS: Because they had very high overhead. That was the criticism, right? It's all coming back to me now. That was one of the issues, I believe.

DC: They didn't spend that much on research. I mean, they never spent that much on research.

SS: So what did they spend all those millions of dollars on?

DC: I don't know.

SS: Call Larry Kramer and ask him.

DC: Well, you just interviewed Kevin Frost. He can tell you the whole

history of that.

SS: I didn't ask him that, though. I didn't think of it. But I will. I

will ask him.

DC: No, but the whole thing was nobody knew where the money went. It

was — amfAR's never put that much money into research, and it's named a research

organization. And after 1988, 1989, there wasn't really any rationale for a privately

funded research thing. I mean, '88, '89, the U.S. government research budget — I'm

making up these numbers, but it went from something like 300,000 a year to 1.2 billion,

like, almost overnight in the late eighties.

SS: So you were working there. Where do you think the money went?

DC: It was — it didn't go — it was — it was well used, but I couldn't — I

mean, how many years ago is that? I don't remember.

SS: Okay, that's fine.

DC: And I'm not — I was thrown out of there so —

SS: Oh, you were? When was that?

DC: 1991.

SS: Why?

DC: They brought in somebody from the March of Dimes to run it.

**SS:** They went more corporate?

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DC: They went more corporate. I have the image of the day Heidi Dorow

was working there, and she came in. She came in with an ACT UP shirt on, and she had

the flaming red hair, and it was the moment that the whole thing, the whole ACT UP

penetration of amfAR had gone too far. Do you know what I mean?

SS: But with having all those ACT UP people at amfAR, did it affect

amfAR, or did it affect ACT UP more?

DC: AmfAR was doing good things. AmfAR was doing things that were

consistent with what ACT UP wanted.

SS: So you left in '91.

JH: Can I clarify something? You were talking about ACT UP doing

a demonstration and amfAR doing the policy part, but I wasn't clear about what

demonstration you were —

DC: I'm not clear of the timing of — there was a demonstration on AZT

pricing, and I don't remember the details of when or what that was.

SS: At the Stock Exchange?

DC: I don't remember. And then there was Peter Staley chaining himself

inside Burroughs Wellcome, and I don't remember what links up with what. I just don't

remember.

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SS: So did you go back to ACT UP after you left amfAR?

DC: No.

SS: Why not?

DC: Because I was connected to the people in ACT UP that I was doing the work with. I was close to Signorile. I was most close to Harrington, so I was involved in all the treatment stuff.

SS: Oh, so you went to TAG?

DC: No.

SS: Well, you said you were close to them, so why didn't you go back to work with people?

DC: No, but I did work with them, but I mean I didn't — I wasn't as working at amfAR.

SS: Okay, but after you left amfAR in '91 —

DC: Yes.

SS: — then what was your AIDS involvement?

DC: In '91, I was forty years old and I had no career. I had been in AIDS and before that I was a TV producer. And to go back to what I said earlier in my story, I was sick, really ill with Lyme disease. I had that for thirteen years. It wasn't diagnosed till seven or eight years in, and then I was on massive antibiotics, IV, and oral antibiotics for six years or so. It controlled it; didn't cure it. I was finally cured of it through a Chinese doctor in 1998.

So I wasn't well, and I needed a job and I didn't want to go back to TV.

And I had offers from the big PR firms. It was the logical place to have a career. I was forty years old, and I felt like I needed to have a way to make an income, because I didn't

have any regular way to make an income. So I went to — I was at Ogilvy & Mather PR for eight years, so I worked in a PR firm.

SS: So you had no AIDS involvement after you left amfAR?

DC: I don't remember that period that well.

SS: But then you started your own health company.

DC: Yes, that was in '98. I started my own PR firm. Then, so, for example — you want to hear about that?

SS: Sure. Does it relate to AIDS?

DC: Yes.

SS: Okay. Tell us.

DC: For example, the clients at that firm, we did all of the PR for UNAIDS for — I note in your book the reference to the brand of HIV. I did that, okay? It was like, sorry, guilty. It seemed like a good idea at the time. But we did — it was a contract that was outsourced to us. We did most of the PR. We did all the PR for them for eight years.

SS: For the U.N.?

DC: For UNAIDS. We also worked for the CDC for HIV prevention for CDC.

SS: Which prevention programs? What was the strategy that you guys were putting forward at the time?

DC: I can't — I'm not going to speak to that.

SS: You don't remember? Oh, okay.

DC: No. You'll have to find other people to speak to that.

SS: Okay.

DC: We did all of the PR for global health for the Gates Foundation for eight years, so we were deeply involved in not just AIDS, but all of global health. But when we started with them, for example, there was a thing created with Helene Gayle had just gone there, and there was an HIV prevention working group, a global HIV prevention working group, which became the focal point for HIV prevention globally. So we were involved in that.

Then in later years, we were the main PR firm for Gilead, which has the main product for HIV treatment now. So I was involved in that. So that was 1988—1998 until 2011.

SS: So that brings us up to present. So let me ask you a few questions, difficult questions. What does the term "AIDS Inc." mean to you?

DC: Am I AIDS Inc.?

SS: I'm asking you what is AIDS Inc.

DC: People that took advantage of their AIDS connections to make money.

SS: And do you think that that's a false category, or do you think that that's legitimate?

DC: I was — see, the way I see it is I was thrown out of domestic AIDS when I was thrown out of amfAR. Community people didn't support me. I was thrown out the same day. It was like, "You're gone. Today, you have to leave today," kind of

thing. So it was sad, because a lot of good stuff, in my opinion, had been done over the previous four years.

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It was the height of extraordinary accomplishment in HIV, late eighties and early nineties. The legislation that was passed in Congress and the research budget, like I said, in one year went, I think, from 300,000 to 1.2 billion. The major money for HIV prevention was passed. You can argue about what it did.

The Ryan White Care Act, which is crazy, why does AIDS have money for care and no other disease has money for care, but it was passed. The ADA, I don't know that most people are aware the degree to which AIDS and AIDS activists were involved in the staffing of Americans With Disability Act. Those—

## SS: Can you tell us? I don't know that.

DC: Yes. Bill Rubenstein is — I don't know if he's on your list of people to interview, but he's —

## SS: No, but he should be.

DC: But he should be. He went to ACT UP. He was part of ACT UP. I mean, he was the head of the ACLU. He was the number-two person under Nan Hunter for a while, and then he became the head of the ACLU AIDS program, AIDS project. A woman named Chai Feldblum staffed the work on the ADA, so the ACLU staffed that. It was led by a woman named Pat Wright. I don't know if she's still alive. She's a disabilities person — disability rights person from Berkeley, who basically singlehandedly did the ADA. And again, it was pushed because people with AIDS, they wanted protection from being discriminated against, and the only way to do that was to

get protection for everybody. So the AIDS world was very supportive, very supportive of that whole project. But Chai Feldblum, what I knew at the time, I think she provided the main staff work for the legislation.

SS: So are you saying that people with AIDS were the most powerful in the coalition?

DC: Hm-mm.

SS: No, okay.

DC: I don't know, actually. I just know that — I just know that the ACLU played a really important role in that. I'm not aware of the overall —

SS: I'm going to ask him.

DC: I just wasn't that close to it.

SS: Let me ask you another very controversial question. You're very familiar with the TAG-ACT UP split and —

DC: I didn't really answer the first one.

SS: Oh, sorry, go ahead.

DC: You should put me more — you should be like 60 Minutes and ask and redirect.

SS: I'm not. I'm like if you don't want to tell, whatever. That's fine.

DC: So I didn't — there wasn't really a place for me in domestic AIDS, and I didn't really see any way to be useful. But part of me was — part of me was the only thing you can do is be useful in that situation. Like all of us, you have — the whole experience of that time, I had two former lovers die. All of that. It's just like you can't

— you just have to do what you can do. And also, I was really sick, personally sick, so I was hard pressed just to be useful in the world, because it made me feel better, even though I was so sick.

So when I left amfAR, I didn't know what to do, and that was before global AIDS happened. Do you know what I mean? It was like — global AIDS was launched at the Geneva AIDS Conference in 1998. That was in the period right after the massive explosion in South Africa, which no one knew was happening as it was happening. It was really crazy.

So then global AIDS became the focus, — just because it was something that no one else was doing, and I was very into that. I was very into the drug access in the developing world. UNAIDS had a pilot project for that. It was where all of the political work was done to get people to agree to do a pricing of drugs, because nobody — that was like an unthinkable thing. UNAIDS navigated all of that. Health GAP and all the other people came along.

I remember in 1996 Eric Sawyer gave a speech at the Vancouver AIDS Conference calling for treatments for people in the developing world, and everybody thought it was crazy. It was just at the moment where there were treatments that really worked. Somebody told me he'd done it at the previous conference, but I don't remember. I just remember a speech in Vancouver.

So I worked for UNAIDS. I had — so that's what I focused on. So, yes it was business, but it was my way of contributing. I don't have any shame or discomfort about it. It was just my way of contributing. And there wasn't anything for me to do

domestically. There wasn't an ACT UP, an active ACT UP anymore. I don't know. I don't know if I answered your question.

01:10:00 SS: It makes sense. Yes, you did. That makes sense. So given how much you understand global AIDS, if it was up to you, what would be the strategy that we should be pursuing now?

DC: Not enough is being done to promote HIV prevention. HIV prevention is like a whole box in and of itself, the complexity of that, and what works and what doesn't. I'm all for providing treatment to people in the developing world, but with the rate of infection increasing as much as it is, it's a vast challenge to come up with the money on a sustaining basis for the people that will survive.

We worked for WHO when Jim [Yong] Kim was there, and he did the "Get three million people in treatment by 2005," and that was hugely controversial and again thought of as wild and crazy and it will never happen. At that point, there were like a half million people in treatment in the developing world, and they didn't get to three million by 2005, but the PR around all of that and the political work that was done led to that. There's now like eight million people in the world, developing world, on HIV treatment, which is, like, really incredible.

## SS: Out of how many people who are infected?

DC: I don't know. I don't know the numbers, but my guess would be something like twenty million, twenty million that need treatment. I think there's probably thirty or forty million infected. But I think — but I'm making that up. I don't know for sure. That's off the top of my head.

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SS: So if you think that the key is prevention, what needs to be done?

DC: Again, it's a bottomless pit. People need to promote it. People need to do it. People need to put programs in place to do it.

After South Africa there was a very, very great urgency around prevention activities, particularly in China and India, because there was a great fear that they would become situations like South Africa, and it didn't happen, I think not necessarily because of HIV-prevention things that were done. I think the nature of epidemics there — I'm not sure why it didn't happen there, but it didn't. But the fear was that there would be an explosive growth of HIV particularly in those two countries the way it had happened in Africa.

SS: What's the problem with prevention? I mean, prevention is not working in the United States, internationally. There's no arena in which it's working. What's the problem?

DC: It's just beyond me.

SS: It's beyond you. Okay.

DC: I spent years worrying about it. To be honest, it's beyond me. Is that

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SS: Okay. Fair enough. Fair enough.

DC: I think it worked here. It worked here in the eighties because we would go to the doctor's office with a cold and everybody was dying, was dead. I mean, we all helped people die. You know, it's sobering. It makes you adjust your behavior.

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SS: Right. I only have one question left. Is there anything else that

we've missed or that you think we should be — you want to —

DC: Didn't you have one other difficult question, or was that it,

prevention?

SS: I did. I had a question about TAG.

DC: Well, what about TAG?

SS: So what is your understanding of why TAG split from ACT UP?

DC: I never was — I never was — I never was in that loop. I know that

everybody was angry. In seeing your movie, I was far from that at that point, but it just

seems so sad and pointless that that all happened. Your movie kind of glosses over it.

SS: As the director.

DC: The movie glosses over it, and I give you full license to do that,

because it made a better movie. Like, it was so in the weeds, the way — that was so in

the weeds, that to get into any more detail would have taken away from the overall thrust

of the film, which was very positive. I wasn't aware of that later years parts of the

movie. I didn't know certain things had happened. But just, from a distance, it's like

there should have been room for both. ACT UP was always a million things, so why at

that point couldn't it have been a million things? ACT UP was everybody just doing

what they were doing.

SS: Do you have an answer for that question?

DC: What?

SS: Why it couldn't just be that way.

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DC: To be honest, I think that there were deep — there was a lack of respect on both sides, a shameful disrespect on both sides, anger. Everybody just got like really angry. And I don't know why it had to be one thing or the other.

SS: You know, it's interesting. I've interviewed like how — what number is David, 149?

JH: 146 [145].

SS: 146, you're number 146, and most people have this answer about the split, like both sides were wrong. There was something on both sides. But a few people have political answers. But I am suspicious of this both-sides argument, because I think these things happen for concrete reasons, and when consensus changes — as you've articulated, there was a consensus of simultaneity of action, and then suddenly that was not acceptable, and I think that there were real reasons for that. But it's hard for people to go there. Maybe it's time. I don't know. But my experience is that things happen for reasons. I don't know.

Anyway. So is there anything else that I've missed?

DC: I just haven't — your movie captured the extraordinariness of ACT UP. I haven't spoken in broad brushstrokes to the extraordinariness of it. Could I speak to that for a minute?

SS: Go for it. Tell us about it.

DC: It was just the most extraordinary experience of my life, that whole period. The period in amfAR, I didn't seem not connected to ACT UP, so I felt like I was still part of ACT UP, even though — one of the most thrilling things in my life, was — I

think it happened twice; it may have happened once — was Signorile getting up in the front of the room and praising me for work that I'd done. And he went on and on and on, you know — I don't even remember what it was for, but I just remember just the bizarreness of — it was the most extraordinary praise you could get to have that room of people think you've done an amazing thing. Probably it was for the PR for the Wall Street demonstration. There was no competition. There was no — there was cooperation. There was everybody was — everybody was just working. Everybody was just doing their work. There was no — there was hierarchy stuff, but not, I don't think, in an important way. There was hierarchy in like who you were sleeping with and stuff like that.

But everybody was just doing work, and there was so many people doing such extraordinary work that it was just exciting. It was — I think of Eric Sawyer when I think of like — you asked what the PR was like. So we had a thing of getting people with AIDS to be visible, and Eric Sawyer was — I don't know if I still have it, an address book from the ACT UP days. I had the media and I had the PWA. There was a PWA page. It was hard to get the PWAs who would talk publicly. Your book talks about Mark Fotopoulos, and he was just like a presence. You know what I mean? He was a PWA that was willing to do interviews. He was one of my interview people.

But Eric Sawyer, I remember Eric Sawyer was on the *Donahue Show*. He was like the poster boy on the *Donahue Show*, and Eric was a great guest. There are just so many extraordinary people, like Gregg Bordowitz was wild and crazy. Maria was wild and crazy. The action people, Charlie Franchino, who you interviewed, has been a

chiropractor and friend since then. It was just an — I don't know. It was an extraordinary time, and you captured it in the movie. I was just so, so happy the way you captured it, and I was touched that all the key people that we knew and loved were — most of them, there was like a scene where you could see them, and you would remember people that were long gone. It was a — I don't know, it was really moving.

SS: I think, speaking for Jim, so correct me if I'm wrong, but I think that this film is from ACT UP's point of view.

DC: Yes.

SS: And that's who it's for.

DC: And it captured that, yes.

SS: I'm happy to hear you say that.

DC: No, no, I was just thrilled. And it's beautifully — we're still rolling, but it's just from a film production point of view, it's really beautifully done. The pacing and the editing, because otherwise it can kind of be like a — in Cuba there's a history of the revolution and it's this battle and then that battle and then that battle. And if you're not careful, you can end up sort of with a "And then we did this and then we did that," and then you don't get the overall sense of the whole thing.

SS: Thank you. So let me ask you my last question. So looking back
— this is what we ask everybody at the end — what would you say was ACT UP's
great accomplishment and what was its biggest disappointment?

DC: I haven't even spoken to its biggest accomplishments. So the list is kind of long. Signorile, in my opinion, singlehandedly pushed the whole outing thing, his

01:20:00

rants and raves in *Out Week*, and then he wrote the incredible book, just the poignant outing of certain people. You get into the whole politics of that, but it was necessary in order to have it okay to people.

So ACT UP made it okay for everybody to be out. ACT UP made it wrong, bordering on shameful for you not to be out. You had to be out because you had to be visible and you had to be fighting, doing your part. So I think there were a lot of professional people. It just made the whole gay world much more bold. So I think in terms of Gay Liberation, it was a huge moment in Gay Liberation.

I think that the policies — almost all of the things that ACT UP focused on or did demonstrations about led to policy change or things happening in the real world. So the list of that stuff is extraordinary. Housing. I don't know the politics, but I mean housing, treatment, women's issues, the whole perception of how clinical research is done profoundly changed. The whole — the story about Michael Callen, that the whole perception of what it means to be a person living with a disease.

You know, the website, they were our client, American Society of Clinical Oncology, the website for patients is called peoplelivingwithcancer.org. Do you know what I mean? It's like — and we forget that they were AIDS victims and they were dying and it was like — it was a kind of a weird thing to stand up on at the time, but it completely changed the consciousness of people, about how active they are in their own treatment, of understanding what's going on, of not being called victims.

Clinical research, there was — I'm forgetting his name. David Byars.

David Byars. The whole way, just the statistics, the whole way clinical research is

designed was transformed as a result through AIDS. The openness and the transparency of institutions, the involvement of patients and community spokespeople in the major decision-making of NIH and other organizations, that was all transformative. That all — that all came from ACT UP and people who came from ACT UP or worked with ACT UP or were sympathetic to ACT UP.

I don't see disappointments, because ACT UP was needed when it was needed. I think that the pressure — the drug companies were motivated, they wanted to make money to find treatments, and blah, blah, blah, blah, blah, but I think the whole culture of urgency and commitment to research came from this whole movement.

David France's movie is kind of — that's kind of a storyline in that movie, and the cause/effect isn't necessarily that clear, but I think activism was central to creating a consciousness where we need to make this a treatable disease and we need to do it in an urgent way, which led to the legislation that got money for NIH. There was constant pressure on drug companies, like all of that. That's not a negative. I don't see any negative. I mean, what would the negative be?

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I think that the split happened at a time when ACT UP had — ACT UP, there wasn't as urgent a need for ACT UP as it had functioned previously, because so many people had gone off and done other things. You know what I mean? I went off and played a — spurred by ACT UP, went and played a whole role at amfAR and then later in some of the PR clients, Housing Works, did housing.

I don't know if I've captured — it was extraordinary. It was the most exciting work period of my life, like — that period of it was like '88 to '91, '92. I mean,

you were there. It's just extraordinary. There's a respect among the people

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and excitement, and everybody did something. Everybody did work. And seeing the

movie, there were groups and generations of people after me that — famous faces that I

didn't know that weren't in ACT UP when I was there. The whole time I was at ACT

UP, Larry Kramer was never there.

SS: Well, he had quit a couple of times.

DC: But he wasn't there the whole time I was there. He went one time

toward the end of when I was there, and he got up to speak, and he was going to give a

big Larry Kramer speech, and I remember Maria Maggenti telling him his time was up.

Maybe you were there that night when Maria Maggenti told him his time was up after,

like, two minutes. So thank you for this time.

SS: Thank you, David. I learned a lot.

DC: You did?

SS: A lot, yes.