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P R O J E C T

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Interviewee: **David Z. Kirschenbaum**

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ACT UP ORAL HISTORY PROJECT

Interview of David Z. Kirschenbaum

October 19, 2003

SARAH SCHULMAN: We usually start: if you could say your name, how old you are, the address of where we are, and today's date?

DAVID KIRSCHENBAUM: Today is October 19th. My name is David Kirschenbaum. This is 56 St. Johns Place, Brooklyn, New York. I'm 43.

SS: So, you're from Ohio – were you born there?

DK: Yes.

SS: And how did your parents come to Ohio?

DK: They were raised there.

SS: Oh, they were born there, too?

DK: Yes.

SS: So who are the Polish people in your ancestry?

DK: My father's family came over – I guess, right after World War I. On my mother's side – they've been here forever. They've been here since 1840.

SS: Is your mother Jewish, also?

DK: Yeah. During the Prussian wars, lots of Jews left and they were very middle class Jews, and so they could afford to leave – at least, that's maternally. Her grandfather came with Lithuania, and was a ship captain and stole the ship to get off.

SS: So when you grew up, did you have an extended Jewish community that you were part of in Cleveland?

DK: I guess yeah, sure – a reformed Jewish community.

SS: Did your parents have any kind of political or social commitments, outside of their family and careers?

DK: My mother was always doing Jewish organizations, whatever. She was

President of Hadassah, President of ORT. She was involved with B'nai-B'rith women, but she doesn't have any strong religious feelings, I would say. We're very reformed.

SS: But, she was very community oriented?

DK: Yes.

SS: And, were you raised with the kind of ethic?

DK: Yeah.

SS: So, when did you first start doing community-based work?

DK: I guess '86, a couple of months after Wall Street.

SS: So, as a child you weren't oriented toward that kind of thing?

DK: No. I mean, I started the Gay and Lesbian Club at Pratt. I was involved with another Gay and Lesbian Club before that.

SS: I guess what I'm trying to ask is, do you see any kind of connection between your mother's community involvement and some kind of ethic of community involvement?

DK: Sure.

SS: How do you understand that?

DK: I think I probably went a little further than she did, but – I'm not sure – I never really thought about it too much. I've just assumed that there probably is some sort of connection.

SS: So you went to high school in Ohio?

DK: Yes.

SS: When did you come out?

DK: The day before my twentieth birthday, I would say.

SS: And where were you on that day?

DK: I was going to school at Case Western Reserve and I had gone to talk to someone who had given a speech on homosexuality, in an Anthropology of Sexual Deviance class at the school.

SS: And you recognized yourself in that description?

DK: Yes. And, he became my boyfriend for a while, [LAUGHS] and we're still friends.

SS: Oh, good. Did he bring you into the gay community around Case Western?

DK: Yes.

SS: What was that community like?

DK: The community around Case Western was very small, because it was an engineering school primarily. So, there were 10 or 20 people who were out. But Cleveland itself has a much larger community.

SS: Did you participate in that community?

DK: Sure.

SS: What kinds of things did you do?

DK: I was involved with the Gay and Lesbian Community Center. I got involved with – there was a thing called the Eleanor Roosevelt Democratic Club that got formed at that time. I started a gay bridge group in Cleveland that became very popular on Wednesday nights and attracted a vast array of people – of gay men – from the community, from upper echelon executives to bathhouse attendants. So, I thought that was pretty cool. And drag queens. It was a good group.

SS: So, what made you decide to create these organizations?

DK: There was a whole or group of people who wanted to do some things, and so I joined them, or I talked to people and it happened.

SS: [DOG BARKING] I'm sorry. I'm a little distracted by your dogs.

SS: Why did you create a gay bridge club, as opposed to an engineer's bridge club?

DK: I did play in an engineer's bridge club, as well. But, my circle seemed to be switching away from the school.

SS: What should we do about your dogs?

DK: I can try putting them outside, because when people come in and out –

SS: So, 1981 you came out and you were at Case Western Reserve and you had your first boyfriend, and you started to do activities in the gay community.

When did you come to New York?

DK: The following year.

SS: For what reason?

DK: I changed majors in school and went to Pratt

SS: To become?

DK: An architect. I was in biomedical engineering and then I went to architecture.

SS: So, when you moved to New York, how did you fit in with the gay community here?

DK: I'm not sure what your question means?

SS: How did you meet gay people?

DK: Well, it depends on at what period.

SS: When you first came to Pratt?

DK: I started a gay and lesbian organization there. Since there wasn't one there, at the time. There had been at certain moments and, along the way, I became the Faculty Advisor because I got a staff position at the school. So, we didn't need to go through anyone else to get things done.

SS: What were some of the issues for gay students at Pratt, in the early '80s?

DK: Some of it was just coming out, period. And meeting other gay students there. There are a lot of them, I assume.

SS: So, when did AIDS first make itself known to you?

DK: Through the *New York Native*, I would assume – you know, the various reports that were coming out – some of it real, some of it hysterical. Their dolphin connection and stuff was a little sensationalism.

SS: Right, but the dolphin coverage was later – '81 and '82.

DK: '81 and '82 there wasn't, basically, anything. There was stuff appearing – I don't think it became apparent, really, until '83.

SS: So, the first ways that you heard about AIDS was by reading the gay newspaper.

DK: Yeah.

SS: And what did you think, do you remember?

DK: Not a whole lot. I wasn't really affected at that time. I had a boyfriend at that time, who had dated someone who we read about during our relationship, who had

died of it. But, methods of transmission and stuff, at that moment, we didn't really think about it.

SS: So, when did it first become something that was really relevant in your life?

DK: One of the guys who I played bridge with in Cleveland, who was a close friend, moved to Texas, and he got involved with the IMREG trial.

SS: What was that?

DK: It was one of the bogus drugs that came out along the way that didn't do anything. And he was abused, horribly in the trial. He was under the impression that he was going to be medically taken care of – because he didn't have any insurance and things – and they didn't take care of him, and they just let him progress, even when other things came along. I thought that was pretty bad.

SS: Who was running the trial?

DK: I don't remember. It was a small –

SS: And the drug was called “ImRick”?

DK: IMREG[-1].

SS: I don't remember that drug. So, that's when you started to have awareness about AIDS?

DK: Yeah. And, then he got into another trial on co-enzyme [Compound] Q, to get some care, and that also didn't do anything. And then, he would go to emergency rooms at other hospitals, and in Texas, they just turned you away.

SS: And you guys were talking on the phone?

DK: I went to visit and I actually went to the hospital one time with him, to go

for the trial. And then, basically, shortly thereafter, I came back to New York, and I discovered ACT UP was functioning evidently in May or June.

SS: Do you remember how you found out about ACT UP?

DK: At a Columbia dance.

SS: Were you at Columbia at the time?

DK: No, but it was a social thing to do you. If you were a young person in New York, they had Columbia dances, and you meet other people around your own age.

SS: Did ACT UP have a table there?

DK: Yeah. So, that's how I found out about it.

SS: So, you came to your first meeting -- did you come by yourself?

DK: Yeah.

SS: What did you find when you got there?

DK: I don't remember. But, I stayed for a while.

SS: Yes, you certainly did. So, how did you start getting involved in ACT UP? What were some of the first activities you were involved with?

DK: I got involved with Issues Committee.

SS: What was that? Can you explain that to us?

DK: It was the pre-cursor to Treatment and Data. Iris [Long] and I formed that, after not getting enough attention with the Issues Committee. And, we researched things going on and, basically, it became T&D, in just a different location.

SS: So, what was the Issues Committee? Who was on it and what were they working on, when you got involved?

DK: It was at Herb Spiers's house. I know Margaret McCarthy was there, Bill

Bahlman was there, Iris was there. Various people would come and go that weren't so regular. Steven Spinella was there. I'm not sure if Gary Kleinman had started going there yet. I'm not sure who the core was. There weren't that many people. It was about 10 to 12 people.

SS: And, what were you guys working on?

DK: Just general AIDS issues. A lot of that, at that time, was still “drugs into bodies.” I don't remember everything. During some of that time, I know we had started going to meetings with the NIH, talking with Fauci and Ellen Cooper at the FDA.

SS: What were you talking to them about?

DK: More compassionate protocols, more drugs into the system, because the ACTG [AIDS Clinical Trial Group] system really hadn't started going yet, and they didn't have many sites. Getting Bactrim and aerosol Pentamidine in, prophylaxis in trials, which they weren't allowing –

SS: Can you just take a moment to try to evoke for us what those meetings were like? Say, a whole bunch of you, you and Margaret and Iris and a few other people were going to go down to Washington to meet with the NIH. Can you just sort of take me through what the whole thing – did you drive down together? What would happen when you arrived?

DK: Sometimes we took the train. Sometimes I drove, because I had a car. I don't think we ever flew. I'm not sure what you're asking.

SS: We're making this tape for people who really don't know what happened or what it was like. And since you're one of the really key people who was involved in talking to the government and creating – you're someone who really

contributed to changing the way AIDS is in the world today. And, if you could just let us in a little bit to what the whole experience was like – how you guys felt on the way down, what it was like to walk into that room?

DK: Well, some of it was information gathering from what was going on in the government because, basically, there was very little information coming out of the government, and what they were even looking at, which will lead to other segues, I guess. I had started doing Freedom of Information Requests, which doesn't have to do with what you're talking about, through the ACLU – I forget his first name, [William B.] Rubinstein, filed it for me. And along the process, Congress changed the law so that certain information could be withheld from what my Freedom of Information Requests were asking for. And eventually, they all did come through, and I started getting piles of documents.

SS: What were you trying to find out?

DK: What drugs they were trying, who was being enrolled, the distribution of those people – whether they were white, gay men or whether they were black or Latino or women with children they were enrolling, were they looking at any children?

SS: So, basically, when ACT UP would ask the government this information, they withheld it.

DK: Yes.

SS: And you had to sue to get this information?

DK: We did a FOIA request.

SS: Why did they withhold it?

DK: I think the government up to that point took the position that, "We don't

need to tell anybody anything. We're not accountable.” And so, we held them accountable and the FOIA, the Freedom of Information laws were such that they had to release certain amounts of information to us.

SS: And who is they?

DK: Tony Fauci at NIAID and, I'm not sure – Kessler, I guess, at the FDA.

Tape I
00:20:00

SS: So, literally ACT UP asked Tony Fauci to tell us –

DK: What trials were going on, who was being enrolled.

SS: And he refused?

DK: Yes.

SS: And it was only going through legal channels that ACT UP was able to get that information at the top. So, when you would go down and meet with these people, it wasn't very friendly.

DK: No, it was controversial. There was a conflict going on. It was not a kissing match, which sort of later happened.

SS: How did you get them to agree to meet with you?

DK: I think I would be calling all these people all the time, and some of them thought I was a doctor, because I knew enough of the lingo in what was supposedly testing, to talk intelligently to them. I assume Iris was doing the same. Bill Bahlman was doing the same. At that time, I don't think there were that many people doing phone calls. Jim Eigo got involved – I'm not sure if he was in Issues. He must have been in the Issues Committee, as well.

SS: So, you would literally call Tony Fauci on the phone?

DK: Yeah.

SS: And what would a conversation be like with him?

DK: Actually, the conversations were pleasant – less so, pleasant than the in-person stuff.

SS: So, you'd call, and you'd finally get a meeting?

DK: Right.

SS: And you guys would go down –

DK: Right.

SS: Super prepared –

DK: Yes.

SS: And walk into the room, and who would be in the room, and how would it go?

DK: When it was with Tony, it was with him and Peggy Hamburg, who later became the Health Commissioner of New York City. There was Jack Killen, who was his assistant, as well. And, I don't know, a couple of other people – I don't remember names. I probably have notes on it somewhere, but I don't remember all the names.

SS: So, how would it go? Who would set the agenda?

DK: We would set an agenda of what we wanted to talk about, and I'm not sure

–

SS: How much time would you have with them?

DK: Generally, an hour – maybe, an hour and a half.

SS: And, you would try to get specific promises from them?

DK: Yeah, and more information. Occasionally, they would leak information to us.

SS: Deliberately?

DK: Yes.

SS: Can you think of an example?

DK: DHPG. The FDA was going to going to make – It was on compassionate use protocol, and the FDA wanted a real clinical trial of it, and Tony mentioned this to us in a meeting so we would create a big huff about it. And, it did happen. We made a big huff, and compassionate use protocol stayed.

SS: So at some point, he realized that he could actually work with you, to achieve certain goals.

DK: I think at some point he learned to use us, as well – not just work with us, but to use us for his goals, which were not necessarily in conflict with our goals.

SS: So, he ended up –

DK: Here's a story.

SS: Yeah, tell us the story.

DK: It's not particular. It's a theoretical story that a friend of mine, who is close friends to Peggy Hamburg – and so, I'm taking it as, that this may have actually happened. Tony Fauci and Peggy Hamburg are sitting in a room and thinking, these people are yelling at us, trying to get us, blah, blah, blah. And, they're having this conversation – what should we do? And it was decided at the meeting that the best way to get them to work with us, is to invite them in and that's what happened. They invited us in to all the ACTG meetings. They put people in ACT UP on these committees. And, of course, that's what happened. We started arguing for their funding – more so – to keep them going. And we became their vocal advocates.

SS: Did they ever try to use you to do things that were not on your agenda, or that were contrary to your agenda?

DK: I don't perceive any of that. But, I'm sure it could have happened. The fact that they invited us in, rather quickly at one point – obviously, they figured they could use us.

SS: Do you think that they had the same goals that you had?

DK: Some of their goals were simply to keep the money stream going, which isn't necessarily doing good research. They're not the same.

SS: Do you think they understood the moral issues involved?

DK: Often, no.

SS: Can you give an example?

DK: Let's say – I was a major advocate of children in clinical trials – specifically in giving them Bactrim. At one meeting, we were sitting with the NIH gang, and they were saying they were going to now allow Bactrim prophylaxis for all their adult trials. And I said, “Adult trials? What about children?” And they were going on and on – “Well, there's just not enough data.” So, that became a major rally cry that I kept screaming about. And eventually through their meeting minutes, I got the recommendations that they were talking about, and I published it before they published at it at the San Francisco AIDS Conference, with the help of Garance Franke-Ruta, distributing it to every member in one of the plenary sessions – that these were the recommendations. And then, Project Inform then published it in their newsletter.

SS: So, what happened, in terms of the policy?

DK: It took too long, but eventually, children were given prophylaxis, as well.

And I always thought you worked for the weakest denominator in any link to get the most for everybody. And if you could get children certain things, as well as adults, then you could get everybody to get everything.

SS: Why do you think they didn't understand that, or they didn't hold that value?

DK: They wanted their end point.

SS: What do you mean by that?

DK: They wanted clear, clinical outcomes. Death is a clear, clinical outcome.

SS: Did they have people in their lives who had AIDS?

DK: I don't know personal history of some of them. One of the members, I heard rumor, was gay. So he would have. I know at the National Cancer Institute that there was a statistician who later died, who was involved in a lot of stuff and we had meetings with. So obviously, there were some.

SS: But that wasn't compelling enough for them.

DK: Evidently not. I don't know if anything ever actually came out super beneficial from NIAID anyway. Most of the stuff was developed through private pharmacies.

SS: So, you feel that strongly – that it was private research that produced the beneficial results?

DK: Yes.

SS: What were the obstacles in government research?

DK: They didn't control the rights to the drugs. Pharmaceutical companies had to allow them to use the drugs, even though they may have originally found the drugs in

their AIDS discovery process of what drugs may do something. But, they immediately licensed them out to pharmaceutical companies to develop.

SS: Can you give some specific examples – trajectories of specific drugs?

DK: All the nucleosides – analogs – were discovered probably by the National Cancer Institute, and then they were licensed out to various companies to do work on. Also, Pentamidine was licensed privately, after being – I think it had been approved as a malaria drug or something, for years and years – it's been a long time since I've thought about a lot of this shit – had been available, and then it became discovered that it could be aerosolized and so it became privatized.

SS: And what's your assessment of that process? What do you think about the government licensing out successful research to private companies?

DK: I don't know if I necessarily have an answer for that, because you know about the successes, you don't know about the failures – how many drugs didn't go beyond, because they were totally worthless. I don't have enough information to say what all this involved. We know about the nucleosides. We can talk about Pentamidine. We can talk about, probably, a whole bunch of things, but that doesn't mean there's not a whole lot of drugs that may have been licensed by private companies that do nothing.

SS: I just find it very stark and startling, that you could be sitting in a room with these people, trying to explain to them –

DK: Oh, a lot of it was yelling early on. A lot of it was yelling early on, and giving examples. There was this good friend of mine, John Bowen, who was in the original AZT trial. He was in the placebo group, and he had originally come down with pneumonia. And, he was on Bactrim prophylaxis. To get in the trial, he had to go off

Bactrim prophylaxis. And so then he progressed, and gave them their end point as part of the placebo group. But, he recovered again. Then, tried to get on AZT, as compassionate use, and they wouldn't give it to him because one of his blood values were so fucked up. And at one point, he went to the Montreal AIDS Conference, and there was some session where Ellen Cooper was up there talking, and then he got up and he was talking about, that – hopefully, that's on video somewhere or transcribed, because it was really powerful how he incriminated them, saying, "Here I am, I'm developing pneumonia, and you wouldn't give me any drugs for the pneumonia. You won't give me anything for pain. And, you just let me go on. And then, finally, you wouldn't give me any drugs after the trial, once you reached your end point." And, he's also one of the people – they weren't considering people with low T-cells under 50, and he goes, well, I have like 25 T-cells, and I'm walking around. And it never occurred to any of these people that anyone with such low T-cells could even walk or still be alive. They hadn't even looked at that stuff.

SS: So basically, before ACT UP got involved, people with AIDS were entirely at the mercy of the structures of these trials?

DK: No, I think there were other people out there who were also doing things. It wasn't just ACT UP. I'm very good friends with Dr. [Joseph] Sonnabend, who wrote the original critique of the AZT study that Ellen Cooper used to approve the drug and was very critical. I assume there's lots of other people who are also outside of ACT UP – Martin Delaney, John James, who was doing similar work at other places. I assume there were a lot of people doing different things – I know before ACT UP, there was a group called Lavender Hill Mob, which I was involved with for awhile – and they were formed

before ACT UP and sort of folded into it.

SS: Oh, did you go to that CDC demonstration with Lavender Hill Mob, before ACT UP started?

DK: No. not before ACT UP. I got involved after ACT UP.

SS: We'll get back to that in a second. Now, "compassionate use" – that's an expression you keep using. Where did that concept come from?

DK: It's an official phrase of a release of drugs at the FDA.

SS: So, that was already in place as an idea?

DK: Right.

SS: Okay, so you were using their concept to try to open up their protocols?

DK: Right. I read lots of regs and I had people doing MEDLARS searches on performing – various doctors and who would show up at ACT UP, I would ask them do this and that, because the information was so scattered and no one had computers at home, at the time.

SS: So, why did you and Iris feel that you needed to start Treatment and Data Committee, out of Issues Committee?

DK: Well, she was "Treatment," I was "Data." I did lots of data gathering, and we didn't think we were getting enough time at the Issues Committee – what we needed to look at and talk about. Here's an example, which is a little bitchy – after the meeting with Fauci, with the DHPG, I wanted to announce this at the floor of ACT UP. There are hierarchies in ACT UP, and I'm not the most – I never spoke up very much. I did lots of behind the scenes things, or I gave people information to talk about what I had, because

I'm very bad at public presentations. So anyways, Herb didn't let this information get out right away. And I thought, this is ridiculous.

SS: So, you guys just wanted to have your own forum for developing ideas?

DK: Yes. And, you know, our own air-time.

SS: And so, when you started T&D, was it well received?

DK: Yes.

SS: And who came to work with you guys?

DK: In the early group, there was Michael Cowing –

SS: Michael Callen?

DK: No, Michael Cowing. Richard Elovich. There was Ann Gorewitz, Nancy Adams. It basically became, what later became ATR, which was the *AIDS Treatment Registry*. Basically, we have one meeting with Treatment and Data – we had something that could actually become a not-for-profit, and it was decided that everyone in the room should be on the Board. So, that's what happened. And so, there's John Wagenhauser, Peter Hochschild was part of that, Gary Kleinman, Margaret McCarthy, Bob Huff – I think that's all I can remember.

SS: What year was that, do you remember?

DK: It probably was early '87.

SS: And, what were your treatment priorities at the time?

DK: I'm not sure what you mean.

SS: What were the projects you were working on?

DK: I don't remember specifically, at that time, what we were working on. I

can tell you a whole scope of things we worked on, but I can't tell you specifically, at what time such and such started.

SS: That's fine – tell me the scope.

DK: Well, we got involved with the ACTG program, with NIAID. We got involved with the Food and Drug Administration getting informed consent, because they had bad informed consent on a lot of these trials. Speeding up the drug approval process. We got the Orphan Drug Act, which was something that may have been in the FDA's interest, as a good PR thing.

SS: Okay, let's just go through some of things you just mentioned – the ACTG –

DK: AIDS Clinical Trial Group at National Institute of Health – getting a national clinical trials program going.

SS: And what was your involvement with that?

DK: What was my involvement in that? I looked at who they were enrolling. I looked at their protocols. In my Freedom of Information Requests that I referred to earlier, I asked for the copies of all the protocols as they were being developed. And I have a basement full of protocols right now, which I haven't thrown out, but I don't know what to do with because I still have them.

SS: Don't throw them out. Who was supervising from the government side – the ACTG?

DK: Tony Fauci, ultimately, but Jack Killen was running the program.

SS: Okay. So, you were sort of watch-dogging the ACTG?

DK: Yes.

SS: And what were some of the things you discovered?

DK: They weren't enrolling women. In most cities, they weren't enrolling blacks and Latinos, except in Baltimore, at Johns Hopkins – which, AIDS seems to have been a problem, or developing most among black men. So, in that case, it became – that's their patient pool. Some ATGs were sitting on their money for years, without enrolling a patient.

SS: Do you remember any?

DK: Case Western Reserve. The guy who started the ACTG there was homophobic. He was coming from a hemophiliac background and just wasn't enrolling anybody. I found out later he would patient off into Kaiser Insurance. Basically, he'd steer patients into that program somehow, and refused to treat them after awhile.

Tape II
00:00:00

SS: You recorded some of these meetings with the government?

DK: All the government meetings – the early ones – were all recorded on tape, and they exist. I have some. I know Bill Bahlman probably has some, if he's still around – I don't know. Iris has some, and I think all of them were also transcribed.

SS: Okay, well some enterprising historian should come knocking on your door, as soon as they see this. I want to get back to the ACTG – why did they not enroll women?

DK: Often, the government thought women either had more complicated lives, like drug users, or there just weren't enough women that they could get their hands on and maybe women were not being diagnosed properly. Also, they wanted a more homogenous group. I think they were taking the attitude – they wanted to keep it as

narrow a focus as possible, in their patient pool, so they could see differences among their patient pool easier – which, why would you think women are some alien species or blacks or Latinos are a different species than everybody else?

SS: So, you think the reason that the male patients were mostly white was the same reason that there were no women?

DK: Yeah.

SS: And, was there anybody inside the government who was objecting to this?

DK: No.

SS: Not a person? Not even Miss Peggy Hamburger, who's a woman herself – not at all?

DK: No.

SS: Were they any blacks or Latinos working on the government side?

DK: There probably were in the ACTGs and, specifically, when they did a community-based thing, but it was mostly white – not necessarily mostly male, but mostly white.

SS: So, when you would raise these issues of inclusion, what kind of reaction did you get?

DK: Sort of like, where are you coming from? Inclusion wasn't that important to them.

SS: Did ACT UP have an extended debate with the ACTG about enrollment?

DK: Yes.

SS: Can you characterize that a little bit?

DK: I don't know – we'd start getting the statistics on who they were enrolling at each ACTG, and we'd point out, you know, this one had so many women, this had so many blacks, this had so many this and that. And, we'd also look at each trial and see where they were enrolling them, and we'd bring this out, because I don't think anyone was looking at those kinds of statistics.

SS: Were you able to achieve any kind of change?

DK: I think more women, more minorities were getting into the trial.

SS: Can you think of any specific examples?

DK: Generally, it was their large trials that that was happening in.

SS: So, they weren't creating trials for women. They were expanding larger trials to include women?

DK: Yes, but –

SS: Which trials were those, do you recall?

DK: Probably the AZT versus ddI versus ddC – the nucleoside trials were the big trials, which didn't give us much, anyway.

SS: What about in terms of the FDA – what were the issues that you were involved with, in relationship to the FDA?

DK: Speeding up the drug approval process.

SS: What was the process originally, before you guys got involved?

DK: Often, it was a four to seven year process, and we got through things like the Orphan Drug Act, which speeded the process. We got commitments that they would approve AIDS drugs quicker than normal. Was that a good thing or a bad thing? I can't

say, but they could get drugs out there, sooner. Often, drugs got used for populations that may have not needed them yet.

SS: What are you thinking of?

DK: Let's say, like, protease inhibitors and AZT for asymptomatic people with high T-cells – does that actually extend their lives?

Tape II
00:05:00

SS: And you say that that was a direct result of having a faster approval process?

DK: Right. So I don't know if that's a beneficial – we don't know that answer. We still don't know that answer.

SS: What is your assessment?

DK: It's hard to do that kind of work, to get the right answers when people are dying and are scared.

SS: Well the philosophy was to let the patient make the decision.

DK: Yes, that's always been my instinct. But at the same time, we don't know, really, when to start certain medications. Because basically, the patient should be making a decision based on the best information. He doesn't have the best information always.

SS: So, in order to speed up the drug approval process, did ACT UP have to literally construct a better process and then present it to the government? Or, did ACT UP simply lobby for the government to create a faster process?

DK: We got Jim involved in that process with the FDA, early on. Somehow, we got him on a committee. That's Jim Eigo, who was brilliant, very articulate, and quite wonderful at voicing our concerns at that time.

SS: So, he was actually sitting there with government people –

DK: Officials, on a regular basis, working out these various programs.

SS: And what else were you involved with, FDA?

DK: We got them to fund a national database of clinical trials, of all the trials available. Iris and I went down and testified and things on that, and it did happen. And then also, the state created funding for the AIDS Treatment Registry, which would give a local directory for everything that was happening in the tri-state area.

SS: So, basically, you achieved 100% turnaround from withholding information to funding and publishing it.

DK: Yes.

SS: Okay, congratulations. What was it like to just sit there and take on the government face-to-face in that way?

DK: It was exciting, if that's what you're asking. What was it like? I'm not sure.

SS: Did you ever worry that maybe you were arguing for things that may not actually be right?

DK: Sometimes. Some of that more came out later – thinking back on things, that they might not have been right.

SS: Can you give me some examples?

DK: When to start drugs – that specifically. When do you start the process? We don't know. A lot of stuff has been found out after the fact the drug has been on the market. Originally, the approval for AZT was 1200 milligrams a day and just through talking to doctors and then communicating that back to the NIH – well, people are doing fine with 300 milligrams a day, so why are you giving them all this drug so that they have

these toxic reactions? Often, the philosophy was getting the maximum tolerated dose, not the minimum effective dose – that’s a lot of what the research was based on.

SS: Can you sort of take apart the mentality of over-medicating? What do you think was behind that?

DK: I have to think a minute. I can’t –

SS: You got so close to these people, and you had the personal experience

–

DK: Some of this has to do with cancer therapy, I believe, where you want to hit the patient with everything you can, to get rid of the cancer. And as long as they don’t die, there’s some benefit. I know of one trial that happened at Sloan-Kettering, that had to do with Kaposi’s Sarcoma. So, they gave these patients full dose chemotherapy, and they all died. So, then they cut the dose in half and they didn’t die so quickly, and some of them actually lived. So, what did they do with those remaining patients – they upped their dose, and so then they died.

Tape II
00:10:00

SS: Why did they up the dose?

DK: To see if they could treat it better. But meanwhile, the treatment that they were trying to do probably didn’t do anything anyway, it just didn’t kill off the patients so quickly.

SS: The picture that you’re painting is people who are sort of inhuman in their view of medicine, and I’m wondering what attracted them to their fields – or, if you have any insight into their psychologies?

DK: I couldn’t say. I know like, Ellen Cooper for the longest period of time would be perceived as being very cold, but eventually, she became very warm and she

quit the FDA and became on the AmFAR payroll.

SS: So, you watched these people have personal transformations?

DK: Yeah.

SS: What about Fauci?

DK: I couldn't say on him if he ever had a transformation or not. Again, I don't know if him including us was for his benefit or ours.

SS: What about when Peggy Hamburg became Health Commissioner in New York City – did her relationship with ACT UP help? Was that helpful in the way she carried out her policies?

DK: She didn't buck too many points in the system in New York. She didn't cause major havoc. She was pretty much just there. She wasn't out in the news. She didn't want to close the STD clinics, which they were trying to do at that time, to save funding. I don't even know if that happened later on, but she stopped that. But mostly, she was not in the forefront of anything. She was a quiet Health Commissioner – unlike previous ones, like Steven Joseph, who was out in the media all the time.

SS: Doing damage.

DK: Yes.

SS: Now, the FDA action – what was the name of the action?

JIM HUBBARD: Seize Control of the FDA.

SS: Seize Control of the FDA. Was that around an agenda developed by T&D?

DK: Yeah, I would think so.

SS: Do you remember what the demands were?

DK: No. But, I probably have the handbook downstairs.

SS: Do you remember why you felt that you needed to seize control of the FDA?

DK: Speeding up the approval process – basically, getting drugs into bodies. Because at the time, AZT was the only thing approved.

SS: So basically, you had presented this agenda to the FDA repeatedly and you were not getting any progress.

DK: Right.

SS: So, was that the reason why this action took place?

DK: Yes, among others. I think a lot of times our actions were to bring media attention to the problem, not just us talking, but to try to draw a larger group into it.

SS: So, just to reveal, a little bit, about how ACT UP worked internally. So here you guys are, you're a small group, you have a lot of information and you're meeting directly with the FDA. How does that translate into ACT UP deciding to do an action of such epic proportions?

DK: Information gets disseminated, and people decide at what point this sounds like a good idea.

SS: Did you guys propose the action, or did it come from somebody else?

DK: I'm not sure who proposed it. I actually don't. I don't have a clue. I know the State actions – when we did the three actions on the State – basically were developed at one of my bridge games with Mike Frisch. We'd talk about these things at my bridge games, and Mike was playing bridge with us. And so, we worked out, we should do this, this and that – and that's what we did.

SS: Okay, now you have to start from the top and tell us what the three actions were.

DK: One was, we went to the State of the State Address, and we interrupted Cuomo's speech in Albany.

SS: How many of you went?

DK: I think there were eight of us, but it might have been 12, and the only one that got in was Gedali Braverman, but Mathilda Cuomo had to step over me, and they ripped my suit to shreds and we all got hauled off to jail.

SS: What did you do, tell us what happened?

DK: We blocked the entrance.

SS: Before he spoke?

DK: Before he spoke, and Gedali was actually in there while he spoke, and interrupted the speech.

SS: What did he say?

DK: I don't remember, but there was a lot of budgetary games going on with the State. Often they would – there were lots of State issues – I don't know what he said.

SS: What was your demand?

DK: There's a whole series of things. I had started going to the AIDS Advisory Council meetings with Iris. Every month, or every other month, they'd have a meeting.

SS: What was that, the AIDS Advisory Council?

DK: It was an AIDS Advisory Council to the AIDS Institute, which was some politicians, some healthcare workers sitting in a room and talking about what were the

problems, going on about AIDS.

SS: Was that a government organization?

DK: Yes. They funded the AIDS Advisory Panel – like any other advisory panel to whatever government agency.

SS: So, when you went up in your suit, were you arrested?

DK: Yeah.

SS: What happened?

DK: They put us in jail. We went in front of a judge. I'm not sure if we got charged fines that time. I know the next time we did. The second one was – we took over one of the offices in the Budget Office.

SS: It was the same group?

DK: Yeah, plus a few more.

SS: Did you guys have a name for your group?

DK: No.

SS: It was just a bunch of people.

DK: It wasn't an affinity group action. And, we got arrested again. They knew we were coming and for some stupid reason, they didn't figure out how to stop us.

SS: How did they know you were coming?

DK: There had been – I assume there's talk from meetings that went out. We weren't doing anything in secrecy.

SS: Do you think that there were people from the government at ACT UP meetings?

DK: Sometimes yes, sometimes no, probably. I mean, yeah, I would say – but,

some of them were there because they were actually concerned.

SS: No, but I mean for someone to give information about an action that's coming up – do you think they were informers?

DK: Probably, yes.

SS: Do you have any evidence of that?

DK: No. I know during – here would be the evidence – that, I think before we did the Albany action – I mean, my name would be published in the newsletter, and I was getting calls at home from people in the government, asking us to stop it.

SS: Well then, they saw your name in the newsletter. That's not an informer, necessarily.

DK: No – as a contact person, not necessarily for T&D.

SS: Oh.

DK: Okay – from our contact list.

SS: Who called you from home, do you remember?

DK: Ginny Apuzzo.

SS: And she asked you – what was her official position at the time?

DK: She was one of Cuomo's assistants. I'm not sure what, exactly, it was.

SS: And, she called you at home and asked you not to do the action?

DK: Yes.

SS: And what did you say?

DK: No, of course not. There was another person who was going up to Albany who met with the governor and also, at that time – there's things.

SS: So, what was the second action? You took over –

DK: We took over the Budget Office.

SS: And, what happened then?

DK: We got arrested again. We chained ourselves to the desk. They took us away. And then, the third one was the big action.

SS: Right, how many people would you say were at that big Albany action?

DK: A couple of thousand.

SS: And you got arrested there, too?

DK: No, I didn't, because it was supposedly major jail time.

SS: It would have been your third.

DK: Yeah, that was – the judge wasn't looking kindly on those previously arrested.

SS: Now, what was the name of the big Albany demonstration? Do you remember?

DK: No.

SS: Do you remember what the demands were?

DK: I don't know specifically what the demands were. I could say what some of the issues were, but I can't tell you – I don't remember what the –

SS: That's fine, what were some of the issues?

DK: Give me a minute. One of the things that was going was they would claim in the budget that they would allocate so much money for certain AIDS activities or services, and then they would never award that money. So, that would probably be the big ticket item – the state just didn't fund it. At one point, Axelrod wanted to break

anonymous testing of pregnant women, prior – but I don't think that was one of those issues.

SS: Who was Axelrod?

DK: He was the State Health Commissioner.

SS: What was his first name? David?

DK: David Axelrod. And, I would follow him around the city whenever he came, and scream at him.

SS: Oh, he was your personal object?

DK: Yes.

SS: Why?

DK: He wanted break the anonymous testing of pregnant women, which I thought would lead to anonymous testing of everybody – or, mandatory testing of everybody.

SS: And, why was he focused on pregnant women?

DK: They had the information, because women were being tested anonymously, after they gave birth – for some study or something that had gotten approved in the legislature.

SS: What was the ideology that allowed him to single out pregnant women?

DK: They had the data, they didn't have a vocal advocate, and I would assume to protect the innocent children. But, after the fact that they'd given birth already, it's too late in fact, and then they refuse to treat these children, because they weren't offering them healthcare.

SS: So, what do you think they really were after?

DK: Isolating people.

SS: Why would they want to break down anonymous testing?

DK: Probably to discourage these women from having children. I don't know the answer.

SS: I'm just going to ask you a pediatrics questions, because I wrote an article about this for the *Voice*, when this was all happening way back then and it was about the issue of placebo. You were involved in that, right?

DK: For children?

SS: Yeah, placebo in pediatric AIDS.

DK: I don't remember.

SS: That wasn't you?

DK: I probably was involved, but I don't remember enough about it to say anything.

SS: Okay. Let's go back to informed consent. Can you explain what the issues were for informed consent?

DK: A lot of people were enrolled in trials because they didn't have access to healthcare. Sometimes I think ACT UP made the mistake that clinical trials were healthcare and these researchers didn't think of it that way and only we thought of it that way. Supposedly, you go into a clinical trial, you get state of the art care, and that wasn't the case, but that's historical looking back on it. But, you at least get access to doctors. What was the question?

SS: What were the issues around informed consent?

DK: One is, people should have care. People should be told of the side effects that are going on in these trials, that they often were not. I know in the trial for pregnant women with AZT, they weren't informed that several of the patients came up with extra digits. I think that turned out to be a fluke, but I don't know any of the statistics since then, that have come out. But in reading the development of the protocol, it's there. What else can I say about informed consent? What other options people have. Researchers want people in their trials so they get money and they don't always tell everyone all the options that they have -- that they could get healthcare this way.

SS: Were you able to achieve any kind of change in informed consent?

DK: I don't know.

SS: Were you involved in the 076 at all?

DK: I founded the 076. [LAUGHS]

SS: Well David, we're going to have to talk about this.

DK: I discovered the 076, and I was pivotal in fighting everyone in 076. That's when I left ACT UP.

SS: 076 is like, the demise of ACT UP – it's all around 076.

DK: It's all around me.

SS: It's all around you.

DK: So we're gonna get to the dirt of the matter?

SS: I'd like us to take a little break and stretch and then we'll all come back and get the story.

DK: Why?

SS: The dirt of the matter. So David, try to tell us, in as much detail as

you can, the history of 076.

DK: The history of 076. With 076, there had been talk about a lot at NIAID, and we were having trouble getting hold of the protocol. And finally, ATR got a copy of the protocol, and then I had a big fight with some people at ATR about obtaining a copy myself.

SS: Why didn't they want you to have a copy?

DK: Specifically, Mark Milano didn't want me to have a copy of it.

SS: Why?

DK: Because he thought it would compromise his information gathering for the directory. And I always thought that ATR – part of it was to also find information for us, to use to help people in other ways than just getting them into trials. So, he was basically the person gathering the information at ATR. I eventually did get it through ATR – through the executive director there, and through the Board, as well, which I was a member of. And then, Margaret McCarthy and myself analyzed it and we brought it to ACT UP.

SS: Now what did you discover when you read – can you detail what you remember about the protocol?

DK: It didn't tell women about defects –

SS: Explain, first of all, what it was.

DK: It was AZT for pregnant women. All the specifics about the protocol are hard to remember -- of what the critiques were.

SS: But, in general?

DK: It didn't tell them that women in New York who were getting cesarean

sections cut down the risk of transmission significantly than not. That's a big issue. Why do you need necessarily to be on a drug that may be harmful to you and your child?

Because nucleoside analogs do affect DNA. Why give women who may not have children who may be exposed to the virus on a drug which they may not need, if they could reduce the chance of infection by just giving them cesarean sections? And it's still not practiced today, I don't think. But, without cesarean sections, I think there was a 20% transmission rate and I think, with cesarean sections, women were getting 8% transmission rates.

SS: How do you understand that biologically?

DK: What?

SS: Why would cesarean have a lower transmission rate?

DK: Evidently, in the birthing process, blood – the virus doesn't transmit through the placenta regularly, but it's during the birthing process that the virus is transmitted.

SS: Where in the birthing? How?

DK: I don't know if that's known. I assume that there's lots of blood involved in the birthing process, and evidentially, they're able to control the amount of blood with cesarean.

SS: What was the government's goal with 076?

DK: What was their goal? Probably, ultimately, preventing more children with HIV, which is a worthwhile goal. I don't think it was necessarily an evil goal. I mean going back with ACT UP, some of the people who worked on that with us – their goal was just to set down the protocol. Mine, personally, was to give women information, so

they could make their own choice, just as often – we talk about people having choice of what they can take or not at certain points in their infection.

SS: Let me ask you two questions about moral issues and 076. Do you think it's ethical for people to give birth to HIV-positive children?

DK: Yes.

SS: Why?

DK: Because, well in retrospect, some of them are still around 20 some years later and they're leading – maybe not perfectly normal lives, but they're living quality lives. So, why not?

SS: My second question is, do you think it's ethical to use women as a vector of treatment for children who are not yet –

DK: Not yet out?

SS: I don't want to say that. [LAUGHS] Is it appropriate to give adult women medication that may be detrimental to them, in order to reach, in order to do fetal treatment?

DK: I would say, probably not.

SS: Why is that?

DK: Everyone hit – it's a choice they should be able to make, whether they want to be there for their children or not. And the question is whether it is harmful to them was not part of their protocol. It was about transmission. It was not about women, it was about transmission.

SS: So, women who were enrolled did not really understand how AZT could hurt them?

DK: Yes. I would say, specifically.

SS: And who was in this protocol, and how were they enrolled? Who was in the trial, and how were they enrolled?

DK: I have no idea. I was trying to negotiate the protocol, and I stopped. I have no idea of any information. I know at some of the meetings that we had with the government, certain people were supposed to bring some women who were HIV-infected, and that did not happen.

SS: Which certain people?

DK: Tracy [Morgan].

SS: Oh, ACT UP people.

DK: ACT UP people were supposed to have contact with HIV-infected women, and they were supposed to bring them to meetings that we were having with government officials and that did not happen.

SS: But if the governments were in the protocol, don't they have the contacts?

DK: Not necessarily. They think in isolation. As has happened – let's say, as I said with my friend John Bowen – they had never thought that anyone could be alive in certain circumstance. They're thinking detached – as pure scientists, not as scientists with people. They're thinking several steps away.

SS: Well, who was the person who was running this protocol? Who was talking to the people who were the patients?

DK: This protocol was very widespread all across America. New York did not enroll, to the last point that I was watching, that many people into this protocol. They

were enrolled outside of New York. So, people in New York had more information, I would say, than people in the rest of the country.

SS: Can you approximate how many women were enrolled nationally?

DK: I think it was 700 people.

SS: Seven hundred people and the government could not produce one of them?

DK: The government wasn't asked to produce one of them. But, we were going to bring some to our meetings with the government to talk about issues.

SS: So, when it came to women with AIDS, in a protocol like this, ACT UP really had no contacts either?

DK: No.

SS: So, ACT UP had no contacts. The government didn't know who these people were. The people who were running the protocol were not involved in this conversation, so it was all substitution. How did that happen?

DK: I'm not sure what you mean, how did what –

SS: Well, it seems like, of all the things we've talked about –

DK: On a personal note, I tried to talk to people and get them involved in what we were doing. I did a lot of pediatric issues until I could find a mother with a child with AIDS, who could pick up a lot of the staff, and that was Joey DePalma's [DiPaolo] mother. And I got her –

SS: He's still alive.

DK: Yeah, he's still alive. And, I sat with her and gave her information, and she became involved with the ACTGs, and became a major person in all of this – and that

is a better person than me, who's a white, gay man talking about pediatric issues.

SS: But it just seems so strange that everything else we've discussed – the constituent body was represented in ACT UP, but when it comes to this issue – I remember women, there were plenty of women with AIDS in ACT UP.

DK: They weren't involved with this specific –

SS: They weren't pregnant.

DK: And they weren't pregnant.

SS: And they didn't get involved in 076?

DK: I don't think so.

SS: Mary Lucey, from LA, wasn't she involved in this?

DK: I don't think so. There were only a handful of people that went to this thing.

SS: How did ACT UP respond to this debate?

DK: Well, a group of women thought it was their issue. I specifically was told at one meeting that maybe I should find another organization to work in.

SS: Okay, you need to back up a lot.

DK: It was really ugly at moments.

SS: You got this protocol from Mark Milano – you and Margaret analyzed it –

DK: Wrote up the original points on it.

SS: You critiqued it.

DK: We critiqued it.

SS: You were opposed to it.

DK: Yes.

SS: You brought it to the floor, and what happened?

DK: And a group of women got very interested.

SS: Who were they?

DK: The ones that mostly come to mind are Tracy and Heidi.

SS: Tracy Morgan and Heidi Dorow.

DK: Who, I think were a couple at that time. I don't know if they still are.

And, there's a couple of other women – who I don't remember their names. I know my friend Ann Otto was involved. She's in London. There's probably eight to 10 women.

SS: And what was their position?

DK: We need to stop the trial, period – which wasn't my position.

SS: What was your position?

DK: Women should have informed consent. Women should be knowing what they're getting into, which generally, I think, has been a position – I thought that was – generally, the general position is, people should have information on what they're doing in this disease. And also, I think, it became a point where they could gain visibility within ACT UP. They could use this as a stepping stone to whatever they were trying to do, because often, there's a conflict that these women didn't think enough attention was being given to them or their points. And also, they discounted anyone who was working in T&D who happened to be a woman, that they even existed.

SS: You mean, like Margaret or Iris?

DK: Or Garance. They just didn't exist, because they weren't friends with them.

SS: So, what do you think their motives were?

DK: I think for themselves, higher visibility.

SS: Do you think they had an ideological motive?

DK: No.

SS: So, what did they proceed to do?

DK: Well, I'd set up a meeting with Fauci and a whole bunch of people from NIAID to meet in Newark Airport, I believe, at a hotel room. And, we were going to talk about the protocol, talk about our issues – that was the first step in all of this. And, we got to the meeting. Basically, they closed down the meeting, just started yelling and ranting and walked out.

SS: Tracy and Heidi?

DK: And the rest of the people who were there. And I was like, what's going here? I mean, it was just screaming. No points were discussed, nothing. No actual input was put into whatever they were doing, and it just became like a yelling match.

SS: So, then what happened?

DK: I was really disturbed. I wanted to – and I think I brought it back to the floor, eventually. It didn't come back immediately.

SS: And so, how did the floor respond?

DK: How I felt was, I didn't feel the floor responded well, and I eventually left.

SS: You quit ACT UP?

DK: I quit.

SS: Because these eight people –

DK: I didn't feel I was being supported. I wasn't being supported by the T&D

side, by people I was working with, either.

SS: Why not?

DK: I think T&D was about to split off as well.

Tape III
00:00:00

SS: OK, so just to recap. So, you feel that Tracy and Heidi disrupted this really just out of ego, or do you think that they were actually trying to disrupt?

DK: I think, often, people who were getting media attention were resented by some people who were not getting the attention that they wanted.

SS: Okay, so it was sort of an ego issue?

DK: Yes.

SS: Now, why was T&D unable to support you?

DK: Because, first of all, 076 sort of got taken out of T&D, into this affinity group. So, they weren't working on it, as such. And some of it was, you know, they knew these women, specifically and they thought they were okay, that they should work it out. And also, I think there was a group in T&D who wanted to break off, for whatever reasons they wanted.

SS: The original personnel of T&D, when you first started it – by the time we're at this moment, T&D has had a whole new influx of people.

DK: It's completely different. Because the first group all became ATR and they stopped going to T&D.

SS: So, who took over T&D?

DK: Take over is not a proper word.

SS: Okay, what's the right word?

DK: Take over means, sort of a coup, I don't think it's a coup d'etat or something.

SS: Who assumed the responsibilities of T&D?

DK: T&D was always quite large. Charlie Franchino became the facilitator, and I thought he was actually a good facilitator, unlike some – as I referring to, with Herb – I don't think Herb was a good facilitator. And basically, everything got on the table with Charlie.

SS: So, who were the leaders?

DK: The people who were doing a lot of work – by the time I was done, Jim Eigo had pretty much stopped. Mark Harrington was doing a lot. But, to point at Mark Harrington, and not a whole lot of people – there were a lot of people in the room. It became like, 40 people at a meeting, and on a regular basis there were 40 people doing work on T&D. There's Garance. I don't remember everyone's names – there was David Samuels. There was John Hendy. I think by the time I stopped, also, Gary had stopped. Gary had continued with the Issues Committee.

SS: Was there an ideological shift within T&D at this point?

DK: What do you mean?

SS: Was their relationship to the government different than your relationship had been in the early group?

DK: That's very pointed, in what you're saying. Some members were on a lot of committees. Is that a bad thing, or not? I wouldn't make a comment on. I'd like to discuss it further if you want to –

SS: I really just want to know what you think.

DK: I didn't think it was bad that people were on government committees.

SS: **Is there anything that you would say –**

Tape III
00:05:00

DK: I think we should work all angles, whether inside, outside – and I don't think just because you're on the inside, you can't scream on the outside.

SS: **The thing about the story that you're telling and the thing that I'm not understanding is, here you are, you started this committee, you were fundamental in getting the government to pay attention to really important issues that have changed AIDS. Suddenly, this group of disruptive people with, not your kind of history and legitimacy are opposing you and your own committee is not supporting you, and I don't really understand what changed in that committee that would create that outcome.**

DK: Some of the people who I was working closely with stopped working in it. Some of the people, specifically in the committee of T&D, let's say were not particularly friends of mine, as I would say. Some of them were. And I think, I don't know, people were working on lots of things.

SS: **So, you didn't have the personal relationships that –**

DK: Some of it was personal relationships. I'm not sure, I'm not sure where to go with this.

SS: **Okay, it's just that it seems unfortunate that you felt you had to leave ACT UP at that time because a small group of people were harassing you on some level or disrupting your work.**

DK: Yeah, I didn't think I could be effective any more.

SS: **So, you just stopped going?**

DK: I just stopped going.

SS: And what was that like?

DK: It was hard. Because I thought I'd given a lot and I enjoyed it a lot.

SS: And you had been there for how many years?

DK: Five years.

**SS: And how many days a week of those five years were you spending on
ACT UP?**

DK: Probably, at least five.

**SS: Were most of your important friendships inside ACT UP at that
point?**

DK: A major portion of it, yeah.

SS: So, did you just have to walk away from your life?

DK: Some of it.

SS: What was that like?

DK: Hard.

SS: But you felt like you had no choice?

DK: Yes.

**SS: So how did you adjust? Did you stay involved in AIDS on any front
after that?**

DK: I became really close with Joe Sonnabend. I attempted to do a couple of research projects with him. But other than that, no.

**SS: So, what would say was the consequence in your life of that sudden,
abrupt –**

DK: I went on with a career. I started a career in architecture. That is, whatever, it's a real career versus what I was doing before wasn't really a real career.

SS: **Right, so you put a lot of that energy into taking care of your life.**

And, have you maintained friendships with some of those people from ACT UP?

DK: Yes.

SS: **Who are you still friends with?**

DK: I would say Peter Hochschild, Margaret, who I talk with occasionally, who's in Ithaca. Gary I see every month or so.

SS: **So, some of those are friends for life, really.**

DK: Yeah, probably.

SS: **I'm sort of coming to the end here, unless you feel there's something that we haven't really gotten into.**

DK: I don't know, there's lots of stuff.

SS: **Like what, what do you think we should be talking about?**

DK: I don't know – there are city issues, there are state issues. I don't know – maybe it's not necessary.

SS: **The thing is, you've made such a fundamental contribution and looking back on the work that you did, what would say is the thing that you're most proud of?**

DK: The things that were most effective were expanding ADAP.

SS: **We should talk about that.**

DK: On smaller levels, I know of a person who had pneumonia, had not responded to Pentamidine and Bactrim, so the hospital said they couldn't treat the patient

Tape III
00:10:00

with any other drugs, and we had done the research and said, look, you've used this drug before, you can use it again. And they did, and the patient lived longer. I don't know how much longer. I didn't know the patient.

SS: But, so you got to see real consequences of your work, in real people's human lives. Let's talk about ADAP – that's a really important project. Can you explain, just for history's sake, exactly what it was/is?

DK: It's the AIDS Drugs Assistance Program.

SS: And how did that get originated?

DK: I'm not sure how it was originated. The federal government gives the state a certain amount of money to take care, to distribute drugs to people with AIDS. They can use that money or produce that money through their simple Medicare/Medicaid programs that the states had or they can create a separate drug program, which is what New York did, which was basically for middle-income people.

SS: So, what was the threat on ADAP?

DK: Well, ADAP didn't cover that many drugs. There's always funding issues with ADAP. ADAP was not getting to a lot of the communities that were affected. It was primarily being used by gay white men in Chelsea and in the Village. And, I did research on trying to find out who was using it where in the state. I cross-referenced that with the AIDS statistics by zip code in the state, which I had gotten from the state, and to see who had AIDS, where. And then, I also got the statistics on who was using ADAP by zip code. So where there was need, I organized, basically, advertising in those neighborhoods where we'd wheat paste signs saying, "Call this number, get AIDS drugs." I tried to get a subway ad campaign, which eventually did happen. I tried to get

it through AmFAR, I tried to get it through the state. I had gotten Don Moffett to design a poster, which we presented to the state. The state didn't like that poster. We tried to get AmFAR to fund it, and they didn't fund it, either, but they eventually did do it like a subway ad campaign.

SS: What was the image?

DK: It was "Free drugs." It was a psychedelic background, [LAUGHS] which I thought was very catchy, and it was about getting free AIDS drugs.

SS: Right, but they said no.

DK: They said no. It was too catchy.

SS: Right, they just said no. Are you involved in any kind of political work now?

DK: No.

SS: Or any kind of gay community organizing?

DK: No.

SS: Do you think you ever will be again?

DK: Maybe, I can't tell you.

SS: Let me just ask you, looking back overall on ACT UP, what would you say was ACT UP's greatest achievement, and what would you say was its biggest disappointment?

DK: Greatest achievement?

SS: Or its biggest impact. What was the great thing that ACT UP achieved?

DK: Well, it created community, which had been sort of falling apart. From

my understanding, it created something like the Gay Activists Alliance, way back when, which was a major political thing in New York. So, it was a political force to be dealt with. And, anything that would get George Bush to say, you know, you weren't good, blah, blah, blah, publicly, is a good thing. That's George Bush, the first.

SS: Where do you think ACT UP was weakest? Or, what was most disappointing looking back?

DK: Too many personal egos got in the way for personal motives. ACT UP was best when it was anonymous, and it wasn't always anonymous after a certain point. For a large part, in the beginning of T&D – specifically T&D – no one took credit for things. It was all, someone from T&D gave a report. It wasn't this person is giving a report. And so, I thought it was strongest when everyone was empowered within ACT UP to be spokespeople and instead of individual spokespeople – “designated” spokespeople, which is I think a phrase that Michael Signorile came up with.

Tape III
00:15:00

SS: Oh, was that a creation of the Media Committee?

DK: I think so.

SS: The Designated Spokesperson. Was there a debate about that at the time?

DK: No.

SS: This is looking back, you're seeing that as a turning point?

DK: Yeah.

SS: Okay, thank you David.

DK: Okay. Did I give you enough dish?

SS: You gave me a lot of information – really appreciate it. You did a lot

of work.

[END OF INTERVIEW]