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P R O J E C T

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Interviewee: **Dudley Saunders**

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Interviewer: **Sarah Schulman**

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ACT UP Oral History Project
Interview of Dudley Saunders
January 18, 2003

DUDLEY SAUNDERS: Dudley Saunders. We are at 5953 1/2 Barton Avenue, in Hollywood, California. What else do you want me to tell you?

SARAH SCHULMAN: How old are you?

DS: I'm 40.

SS: Congratulations.

DS: Thank you. Only two more months, I'm 41.

SS: And what's today's date?

DS: January 18, 2003.

SS: Okay. So my first question is, do you remember the first time you heard the word AIDS.

DS: No, no I don't. I remember being kind of aware of it, but I think at the time I was probably a little pre-occupied with things other than my sexuality, because I was in – that was like '81, wasn't it? So, I was 19.

SS: Where were you?

DS: I was in New York. I think I was in New York by then. No, no, no, you know what? I think I was probably in college when I heard it.

SS: Where was that?

DS: At Northwestern, which is in Evanston, Chicago – just north of Chicago. And, you know, it was there. In a way, I remember, because I was still closeted/confused. You know, not touching anybody. So, it was just another, I think, kind of mixed up with my own kind of confused internalized homophobias, as a thing which made me, you know, worried and uncertain about homosexuality, you know?

SS: So, when was the first time that it – you had a personal experience or encounter with AIDS?

DS: God, that's strange. I didn't for a long time, because I was pretty isolated in the gay community when I first came out.

SS: In what way?

DS: I didn't – well, I never quite connected to most of the gay people I knew – I mean, the ones I met. They seemed like, a little bit like Martians to me. I didn't quite know – I couldn't get their value system. I didn't know what – I couldn't understand why they thought something was important, and since I was very sort of driven. I was a writer, and I was sort of driven. And I was miserable, doing the writing that I wanted to do, so. And, then I had a lot of, you know – I was kind of trying to push through all the emotional problems of my childhood. So, I was kind of – I was always moving really, really fast.

Truthfully, if I really think about it, the moment I really remember was when it directly impacted me, when, probably my – God, I'm trying – it's really hard for me to remember. I mean, I remember when I tested positive, and my then-lover tested positive.

SS: You went together?

DS: Um hmm. Yeah, we went together. And it was just – it was about the end of '87, because we – at the time we talked about it a lot. It was like, well, there's nothing you can do, if you are. You know, so why bother? It was test – you know – for people who've tested positive and fit these parameters, you can try a new drug, which would be for people who have not gotten sick yet. So, we both tested positive, and did not fit the parameters of the study. So, there was nothing we could do about it.

SS: Do you remember why?

DS: I think my T-cells were too high, as I remember. There was no viral load then.

SS: So, did you know other people who had HIV or AIDS, at that point?

DS: No. In fact, when I first came to ACT UP, I actually came because, conceptually, I knew that AIDS was a problem and that it was – there was something disastrous about the way gay people were being treated. I almost came the way a straight liberal would have come to it.

SS: So, you came to ACT UP before you tested positive?

DS: Yeah.

SS: And how did you find out about ACT UP?

DS: Everyone was talking about it. And, I mean, when I came to New York, I mean, I worked on the Gary Hart campaign. Was that '84? I was sitting there desperate to try to – I was just the way I am right now, kind of horrified with the way the world was going. And, oddly enough, my little brother now is exactly the same way I was – you know, very, very politically driven, because we thought the world was going to blow up and that we had a moral obligation to try to make the world a better place, a moral place.

[LAUGHS]

SS: So, what were you doing for a living at that time?

DS: What was I doing? I'm trying to think. I think I was – at that point, I was working in the evening, word processing in law firms – working, I think, the midnight shift.

SS: And what was your real work?

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DS: I was a writer. I started doing performance art in '87, right. Right. Because before then, I'd been writing – doing some fiction. I tried to write plays, but then I realized I didn't like theater. I liked performance art. So, I'd write these things and I would confuse people.

SS: Were you part of a performance community?

DS: Uh uh. I was very isolated. Yeah, I think, like a lot of people in ACT UP, I had some kind of social dysfunction, which is – although, it's funny because a lot of people in ACT UP were people who were socially dysfunctional, but operated at a high level of society, so their dysfunctions would be accepted in a very, very kind of upper-class white boy way. You can be very, you know, socially dysfunctional and not be able to talk to people or carry on a proper conversation, but if you come from a position of power, people treat that as an emblem of your genius. You know. So, if you're horrible to them, they think it's because you're thinking great thoughts, or you've got a great master plan. But, since I didn't really seem to come out of any position – I had no connections. I had no family connections, no money. And I was a little weird. But, I think I left an impression on people, which just irritated them, even more. So, that meant that I came there with my social dysfunctions and it just made people not want to be around me.

SS: That's what you experienced?

DS: That's what I experienced.

SS: Now, were you and your boyfriend together at that time, when you first came to ACT UP?

DS: I think we were broken up. That was a boyfriend, Chris Stewart, who's now dead. We had a tempestuous relationship. We were together, then broken up, then together and broken up.

SS: So, in the interim, before you got back together, you came to ACT UP?

DS: Yeah. I came to ACT UP. I came to ACT UP initially, and I was – I couldn't connect, and I went back there and got everything from the back table – all the flyers and what was going on that week. And I would – it's odd, because, you know, I'm a – I knew he was a smart guy, but I would end up doing the most menial labor.

SS: Like what?

DS: Well, like, you know – I'll organize these, I'll photocopy these things for you. That kind of thing. I didn't have – I didn't feel like I had a way to engage what talents or brainpower, whatever, that I had. I didn't know how to get that engaged with the ACT UP machinery. But, I knew how to be gut-bucket labor, which, I guess is a level of how I thought about myself. It tells you something about that. The only thing I knew how to do was to kind of clean up. And so, I operated that way. And that was that true for a long time.

SS: Before you got tested – if you were in ACT UP before you got tested, where did you do your work? Were you part of a community? Or did you have an affinity group?

DS: I pretty much kind of worked for whatever seemed – whatever threw – people would come there and say, this is what I'm doing, I need help. And I'd just say, okay, I'd wander in. I didn't stay connected to anything in particular. It

wasn't until much later, when I joined the Treatment & Data Committee, and that's where everything turned around. That actually – you know, I have to say – ACT UP in that sense, really changed my life. It happened – and nothing happens in just one track. At the same time, I moved from trying to write traditional plays, which I was horrible at, to moving to performance art, which was about really confronting who you really are. What are the thoughts that really go through your head? Because if you constantly – you think about what thoughts are supposed to be, how you're supposed to feel and then you look at yourself, and you don't find any of that. I experienced that as a vacancy, an emptiness here. So, with performance I did, what were the voices in my head? What is the way language actually falls out of my mouth, rather than how should language fall out of my mouth. So, by confronting who I actually was – in the shape of own personality and mind – and creating performance art directly out of that, I was able to find out exactly who I was. And, of course, there's a lot of horrible shame involved in that, too. But, by going through that process, you allow yourself to be, you know, obscene, stupid, horrible, you know, just set your feelings about what you're like aside, and just find out what it is. And then, then you can grow from there. A similar – so, I did that with my performance art and became realer to myself. At the same time, in ACT UP, I started to – I joined the Treatment & Data Committee, and I was allowing myself to be stupid. Because at the time, you know, these people just seemed so incredibly smart. And a lot of people in ACT UP were very, you know, intimidated by them. These people can save my life; they're the genius; they can do the talking. And the shock to me – I mean, I

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joined it right after, you know, all the heavy hitters left and formed TAG. So, it was kind of, like, only the weirdoes and freaks were left, for the most part. I joined it, and I started the process of teaching myself the science.

SS: Okay, let me just get the chronology up that point.

DS: Okay.

SS: So, when you and Chris both tested positive –

DS: Right.

SS: How did you decide which – what kind of treatment to pursue?

DS: Well, there was no treatment to pursue. At that point, we were broken up again. And so, I was kind of on my own, and I spent more time at ACT UP, still operating in that sort of menial labor kind of way. By that time, all they said was, you know, try to live healthy – exercise, eat right! And then, wait till you get sick. And then you'll get sick, and then you'll start the chain of drugs, which will fail, make you sicker until you die.

SS: So, when you came to T&D, you were on no medication?

DS: Correct.

SS: And, have you had any symptoms.

DS: No.

SS: And, how was Chris at that point?

DS: Chris was fine. It took Chris – it was a few years later – I didn't realize at the time, but Chris didn't believe he was really positive. And, it was only when he tested again – I think, a year later – and it came out positive, that he believed it, and then moved

out of the city – moved to San Francisco; moved into a basement apartment, isolated himself and began to die.

SS: What year did he die?

DS: I think he died in '92, '92.

SS: So, what year do you think you came to T&D?

DS: God, I'm really bad on the chronology.

SS: Right.

DS: It may have been '90.

SS: So, who? Why did you choose Treatment & Data out of all the committees?

DS: Well, I'd been – before then, I'd been more socially oriented, rather than science oriented because, you know, I understood that it had something to do with my political background, in terms of equal access and making people pay attention. But, I felt like I needed to actually grapple directly with what was going on. I need to actually get the science – the truth of the matter is, when you're fighting about getting a treatment, or getting a study done, you really have to know what you're talking about because people can drop a few terms, like going to the mechanic. You know, I don't the hell what's going on with my car, so you can just – I have to believe whatever you tell me. I knew that couldn't go on.

And the great discovery was that it's not – this is not Chinese. You can, if you will take the time and look up the words as you come across them – you can figure it out. And, if you ask people – even big research scientists, they will explain to you. And, very,

very quickly, I became really conversant and I would shock myself with how much I knew.

SS: So, who were the other people that were in T&D when you came into the committee?

DS: George Carter, remember him? Rick Loftus, who I've – I think he's now in San Francisco. I know he went to medical school up there, anyway. He's a good guy, and he was great. There's Kevin [Frost] – the guy's now at AmFAR – big, tall, blonde Kevin, who's really smart. I'm blanking on his name. And, actually with him, I – we put together a study group to study clinical trial design, which was great. And I think it was Bill Bahlman, who hated Kevin.

And there was always – there was a group of people who kind of were always – it felt like it was the dregs left. You know, people who were there because we had strong political beliefs. And, oftentimes, they were the people who were – they had a fight with science. They didn't want to believe a lot of what science told them. And, I remember having long discussions about, you know, what a clinical trial could tell you. And, a lot of times, there'd be this fight because, as you may know, people do pilot studies, which can tell you that there's something interesting about a treatment, which then you have to do a full clinical trial to tell you whether that's really true or not. And, clinical trial would come out and say, this is crap, it doesn't do anything. But, the pilot study made it sound promising. So, there was a group of people at all times who would try to fight to really, really believe in this treatment that the science told you wasn't any good. Nobody – it's kind of – it was really – talk about wish fulfillment problems. People wanted to believe that there was some kind of magic bullet, and that the scientists just weren't right.

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I remember so many meetings where people would just get up and walk out and storm and – it was a huge waste of energy.

SS: What were some of the specific drugs that you worked on?

DS: I worked on – Oh, God – I remember working on – What did I work on? I worked on – Well, a lot of things I was working on were things about immune modulators. You know, work on IL-2.

SS: What was IL-2?

DS: Interleukin II – that was a cytokine, which now they use sometimes to stimulate CD4, CD8's – it's been so long since I've done this. The idea was that – well, now they use it because it's a way of kind of clearing the drug, clearing infected cells.

SS: When you say, worked on it, what did you do exactly?

DS: Well, what I would do – I would learn about it. And then, I would go to conferences and talk to the scientists and try to find out, you know, where the science was. And, actually, conference – I remember going to an immune – somewhere in North Carolina – a conference on immune reconstitution kind of things. And, actually, you would sit in the meetings, and then, a lot of what I do is get up there and try to re-direct the discussion toward – because very often, research scientists would talk about something which is very, very interesting in a kind of esoteric way. And, I would always kind of pop up and say, Okay, let's talk about the treatment possibilities here. How can we think about this in terms of the patient? And, at that time, a lot of them – they didn't want to get close to that.

SS: How many ACT UP guys would go? Let's say, to this conference in North Carolina?

DS: Maybe six of us, I think.

SS: And you would just – they would let you come in?

DS: Um hmm. Well, we – I think – did we pay? I think we got – no, we got some free stuff there.

SS: So, they allowed you to come?

DS: At that time, they would allow us to come.

SS: And how would they treat you?

DS: Actually, very, very well.

SS: So, they were interested in what you had to offer?

DS: Well, yeah. A lot of them – some of them were esoteric. For the most part, they were all frustrated, because the politics within the research community is just really annoying to them. And, you know, people get – we were constantly finding, you know, research grants, you know, given to people to do studies that didn't need to be done, which were designed to answer a question that had been answered by three other studies before.

SS: Can you remember any examples?

DS: No. I know there's a lot of stuff with AZT. AZT they kept re-studying over and over and over again. And, they were always screaming at Margaret Fischl about that.

SS: She was?

DS: She was AZT queen. She did a lot of work on AZT.

SS: Was she a secretary of – who was she?

DS: No, she was a researcher.

SS: Oh, okay.

DS: And we made her cry at that point. I remember feeling bad about that. But, I remember specifically – that was in Berlin, where she'd done a study of Zidovudine, as she called it, instead of AZT. And she – the study was designed to answer a question in a certain way. And, you know, clinical trials are very rigid, you know. You set them up to answer this question, and you can't really answer another question. It's only designed to answer, really, one. Well, she got something which was not very positive out of AZT. So, she took her data, juggled them and answered a different question with them. And so, what we had to do was stand up and tell her she was full of shit, that she wasn't – but, at that point, we knew – I knew enough about clinical trial design. We all did, at that point, to say, no, it's not properly powered, answer the question you're setting up.

SS: Well, how did these doctors respond? I mean, they're trained doctors and scientists, and you guys are –

DS: They were great.

SS: Oh.

DS: They were great. They agreed. They would criticize her, too. You know, and she would – she was basically spinning. She was spinning to try to make it look better than it was. I remember looking at her at the time and thinking, I don't, you don't, I don't get a sleazy feeling out of you, you know. Who knows? I got, maybe a true believer feel out of her. Maybe she just really, really believed, like some of the people in ACT UP, that there was some holy grail here. Maybe this really could be the magic bullet that we're all looking for.

SS: So, in those days – 1990 –

DS: Umm hmm.

SS: What were the medications that were available?

DS: God, I can't remember. At that point, they were still chaining the drugs.

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You know, you do AZT, and that would fail. I think you went to ddI, and – was there a ddC? I think there was ddC, which was like death, but –

SS: So, were you all conceptualizing that there would be one pill that person could take and their AIDS would go away?

DS: Well, no. In Treatment&Data, we knew that wasn't going to happen because the group people that I hung out with were doing a lot of studying of the immune system itself and how it worked. And, in fact, one of the things we talked about is we realized, maybe we should call it – instead of Acquired Immune Deficiency, it should be Acquired Immune Deregulation System. And the fact that it's this three-dimensional, multi-pronged system, which is alike an inner connected web. And so, it's not as simple as, you know, kill virus, you're better. And, we knew – understanding that HIV, more than just directly killing cells, had all these side effects, which seemed to tear things apart inside your body, as well. I mean, you know, Fred Bingham was kind of interested because a lot of it was – it increases a lot of – what's the word? Oxidative stress, which is what you take your anti-oxidants for.

SS: Who's Fred Bingham.

DS: Fred Bingham runs DAAIR – Direct AIDS Alternative Information Resources, which is also a buyers club.

SS: So what kind of – tell me some more of the projects that you worked on ...

DS: I got really into mucosal immunity, at the time, and discovering a lot, you know – huge books. I must have looked so strange, sitting – books about the gut, and trying to – which is like the whole mucosal immune system is totally separate. I mean, it's kind of its own little compartment from, like, you know, the rest of the immune system. I'm overstating that a little bit, but it has its own little ecology, which directly impacted – because we had a lot of people who, for some reason, had, you know, constant diarrhea for no reason at all. And so, we were discovering – that was one of the moments where you're dealing with immune system problems, but also quality of life issues and, what are they called? What are those infections? Opportunistic infections.

This was a mysterious opportunistic infection, because, you know, the thing is, if you want to get the virus, but what people are dying of is not the virus. They're dying of these infections, dying of the fact that they can't digest any food, and it just runs through them, undigested, you know. And finding out – that's right, I had a big push on that – to try to get people to address what was going on. I mean, have you really flattened out all the villae in your gut? Are you unable to absorb anything? And sometimes yes, sometimes no. What's really happening. The odd thing is that we really approached a lot of these issues directly, and I would try to get people to talk about it. But the funny thing was, ultimately, it was the triple combos, with just lowered virus that made a lot of this issue go away. The truth is, if you did get the virus down, a lot immune constitution would come back; your gut would heal.

SS: But that wasn't yet known.

DS: No, it wasn't known then.

SS: So, were you mostly –

DS: I can't remember anything. It's like, I can't remember anything I did at all.

SS: Now, were you guys in contact mostly with scientists or with pharmaceutical companies?

DS: I dealt mostly with scientists.

SS: And where were they based?

DS: They were all over the country. I mean, I'd usually run into them – I mean, it would be at the conferences.

SS: Would they be working out of universities? Or, are they working for pharmaceutical companies?

DS: Some of them were, I think. Well, whether they were working directly for a pharmaceutical company wasn't – it's neither here nor there, because they were usually funded by a pharmaceutical company.

SS: So, was there a struggle about which drugs should be funded and which studies should be funded and which ones not?

DS: Yeah, it was the same problem that we kept running into, that they're – I mean, you – the number of studies that were about AZT, which at that time, we knew, was just a waste of time. We knew enough about it. We weren't going to discover anything new. They kept funding more studies of it.

SS: Why?

DS: Because – Well, a) there's a lag time on getting your grant proposal together, and often – I mean, frequently, through no one's fault at all, by the time they got something approved, so much time had gone by that the question was answered. But, what are you going to do, throw away the money? No. They would do it, actually, a lot of times, because they needed to eat, which is pathetic. And we were always going in there fight like no, cancel it, you know, which was going to be really bad for them. But, the other scientists fully agreed with us.

SS: But, wasn't there an issue about consumer base? That certain drugs, if they had a potentially large market would receive more money for research?

DS: Well, at that time – I mean, anything HIV-based was going to have a large market, that was clear. And, in fact, there were times we tried to mention that. I remember this coming up in meetings – trying to get this across to companies – that, you could make a lot of money here. There was some argument about people were uncomfortable about bringing that up. You know, there was sort of feeling like, should be talking about their profit motive? And, should people be making, you know, money off of other people's sickness. There was a lot of, you know, moral discomfort there. But there's a lot of moral discomfort in AIDS because, you know, in spite of all the government funding that went in, went to the research, probably, there's a real question, would we have the drugs we have today, if there wasn't a profit motive? It's like – but, it's a profit motive that has to be regulated by activism because God knows, the government wouldn't do it.

SS: Well, what was T&D's attitude about AZT?

DS: Which part of Treatment&Data?

SS: Well, if there was a split, tell me.

DS: There was a split. I mean, there were people who believed – true believers, it was just poison, keep away from it. There were people who believed, kind of in the middle – and then, nobody believed it was good. In fact, you’d have these big fights. We’d have to preface it – again, I don’t like – it’s a terrible drug, it’s a terrible drug, but, it can have its uses. Whereas, other people were still haunted by the fact that they’d seen people wither and die on it.

And I remember, oh clearly, the date – I can’t remember what the study was – but it was a very, very big study – long-term study, which totally changed everything about AZT. As I remember, there were two lines in the study – they had a group who did it&Didn’t do it. I think it was early versus late AZT. That was what it was.

And the people who took it early – their health got markedly better, and they began to decline, until they died. The other group didn’t take it and they were crappy, crappy, crappy. The group that didn’t take it early ended up surviving slightly longer than the people who took it early, and had a better quality of life. That rocked everybody’s world. And, some people were still emotional about the fact that they had seen people – sorry – in the short term do better. And they could not let go of the fact that some people took AZT&Did better. Other people were caught up in the fact that they had been horribly betrayed by AZT and it had murdered them. And, in fact, the people they had seen turn into skeletons – it wasn’t HIV, it was murderous AZT.

SS: But, you decided not to take AZT. You were asymptomatic.

DS: Well, I was lucky. At that point we knew there was no reason to take it early. And I had seen, I'd seen people around, mainly at meetings. That was probably where I was first came in contact with people really suffering with AIDS.

SS: Now, within T&D, were your agendas – was the committee's agenda determined by the personal medical needs of the members of T&D?

DS: Sometimes.

SS: Can you think of an example?

DS: But, not much, really. Often it was – I think, often didn't know why. Sometimes, it's more the people they've known.

SS: Would you guys discuss your meds or your treatments in a personal way?

DS: Yeah, probably at that time, mostly we would talk about the other things we were doing. I mean, George Carter was always talking about the oxidative stress. And so, most of us – well, about half of us were taking a lot of vitamins, and there were some people who didn't want to hear about it.

SS: Now, were there any of these scientists who were gay, themselves? That you knew of?

DS: A few. I remember –

SS: Did any of them have AIDS that you knew of?

DS: No, I didn't know about that.

SS: And the ones who are gay, did they relate to you in a different way?

DS: I'm trying to think. I'm having a picture. I'm remembering one guy in my mind.

SS: Do you remember his name?

DS: No. It's – you know, I don't know if they did. They were the friendly scientists. I had many scientists tell me that – I remember at one conference saying, oh, God, you know, I – part of me wishes that I can just go and do what you're doing. And, somebody says, no, you're far more useful here, you know. It's only when you're doing what you're doing that I can do what I do.

SS: Do you remember the names of the scientists who were particularly cooperative and ones who were particularly difficult?

DS: No.

SS: You don't remember any of their names?

DS: We – I mean, I came in contact with them, I talked to them. Sometimes they gave me their cards. But, really, it was all situational.

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SS: So, if you read a study that was really exciting, would you tell that doctor?

DS: Some people in mucosal immunity. I can't remember who they were.

SS: What I'm not understanding is the nuts and bolts of how the relationships were built between you guys and the doctors. How did you –

DS: We didn't – ACT UP had the relationship with them. That was my experience of it.

SS: And who was ACT UP?

DS: ACT UP was an organization –

SS: No, who were the people in ACT UP who had –

DS: No, no, no, I mean the fact of ACT UP. At that point, a lot of the scientists knew about ACT UP and they agreed with what ACT UP was doing. So, you could walk into a room and say, Hi, I'm from ACT UP, and they'd go, oh.

SS: So, by the time you came in, in 1990, all these relationships were set.

DS: ACT UP was a good guy to them. We were there. We were going to be able to scream about the study that was getting funded that shouldn't have been funded; about the study that deserved to be funded, that wasn't going to get funded. And, we didn't have to worry about stepping on someone's toes, and hurting a scientist's chances down the road, because, you know, we were activists, we were outsiders. So, they could say, it's not my fault.

SS: Now, before you – you said that before you came in – a lot of people had left T&D.

DS: Right, and I actually joined TAG, as well.

SS: Can you say who those people were and why they left?

DS: People like Peter Staley, Mark –

SS: Harrington –

DS: Harrington, thank you. Gregg Gonsalves – I forgot, he actually stayed around a little bit with us in T&D. Did he? I'm trying to remember. We tried to maintain a friendly relationship with TAG.

SS: So, the old Treatment & Data Committee formed TAG –

DS: Treatment Action Group.

SS: And left ACT UP completely?

DS: Yeah.

SS: Why did they do that?

DS: Because they were frustrated by – because basically they wanted to do strictly science-related activism.

SS: And why could they not do that in the context of ACT UP?

DS: Well, because there were a lot of other – there were a lot of social issues dealt with in ACT UP; things including access, you know, access – also, letting – the things that made ACT UP work, which was that, you know, people to define for themselves what their issues were, and then they made everybody else deal with them. I think probably the thing that most – I know what probably drove most of those people out was when – it was actually when Max – I think it was when Maxine said she wanted to stop all discussions with pharmaceutical companies – do a moratorium on it.

SS: And so, they left?

DS: They said, that's it. We can't operate like this.

SS: So, why did you decide to work in both TAG and T&D.

DS: Hmm. I was not a major part of TAG. TAG, I just worked with, as I could. I was going broke at that time. But, I don't think I felt good enough to be in TAG, initially.

SS: In terms of your knowledge?

DS: My knowledge, you know. I wasn't smart. I wasn't savvy enough. I have a terrible self-image.

SS: What were they doing that was different than what T&D was doing?

DS: Not that much, really, except our focus was a little broader. I mean, I, you know – I kind of nosed around and found what was interesting to me. I guess the sense I

had, maybe, was that TAG had bigger and broader agendas, which they were hitting, which may have been more fundamental. I guess in ACT UP, you ran into the part of the epidemic that ran into you, you know? If people were shitting their guts out, I'd focus on mucosal immunity, which, in a way, is kind of like, you responded to what was happening at the grassroots level.

SS: When did you start to have symptoms?

DS: I never really did.

SS: When did you start taking medication?

DS: What year was that?

SS: You've had no hospitalizations?

DS: No. I was extremely lucky. Now – and the funny thing is – and now, as we – as people are living longer with the virus, there are questions about the health problems that aren't specifically opportunistic infections. You know, people have weaknesses, pain, strange things that happen to them. Suddenly, you're getting warts when you shouldn't – never got warts before. There are a lot of things – that's the great mystery, still, about HIV, you know? What are the health problems you have that you wouldn't have without HIV, even when you're healthy?

SS: When did you start taking medication?

DS: I started taking it the summer after the triple combo was verified – at whatever AIDS conference that was. And, I'd been thinking about it for a number of months, because I got a call. I can't remember what year that was – was it six years ago? I got a call from the Community Research Initiative on AIDS saying, we're doing, recording a roundtable discussion with some scientists. Do you think they can eradicate

the virus? And, I need a scientist, I need an activist to be mean. And so, I started to scream on the phone saying, what kind of crap – they were always doing that. They were always getting excited and telling us something, and I was going to go – and I knew how to – what all the holes in those arguments were. And so, I got on the line, and we had this conference. And it was published. You can still find it – I think – on the Internet. And, it was Marty Markowitz, Aaron Diamond –

SS: Yeah.

DS: Marty Markowitz – I think it was him that day. And they started going on, and so I would jump in and do my little attack. And, they'd answer me. And, at the end of the discussion, I hung up and I was with somebody else and I turned and said, did I forget something? I must have forgotten something. This can't really work. And we couldn't think of anything. But, we didn't do anything. Then, we waited, and then the conference came and the data came out and we thought, Jesus, maybe it will.

I had had pneumonia that winter. It wasn't PCP, but it did – and my T-cells were coming down. I was, like, 320 or something. And, you have to understand that at that time what that meant – what I knew I had to look forward to – what I was not fearing was death. I was fearing the moment when my life became about staying alive, managing illness. And, I knew that the minute I would take my first AZT or what have you, it would be the beginning of the end. What this meant to me was the possibility – well, maybe there could be an extended future. Maybe the scenario I had written for myself all this time wasn't going to be true. And so, I took them – we finally decided to take them, once the data came out, and try it.

SS: What did you start with?

DS: What did I start with? I started, I think, with Crixivan – I think it was Crixivan, d4T and 3TC. The funny thing is, now I talk to people – younger people, and I'll talk about d4T – like, what, what is that? Well, Zerit – they know it as Zerit, 3TC you know, is Epivir. Nobody knows the old way we used to call them anymore.

SS: So, what was the effect of the drugs on you?

DS: They worked.

SS: Your T-cells —

DS: They went up, and I went to zero viral load, which – I'd never had a viral load until then. But, I didn't believe it for almost a year, and it was finally – almost a year later I thought, you know, maybe I'm going to have a future. And, you know, I pretty much, from the age of my early '20's believed that I could die on a moment's notice. So, I guess it really wasn't until my mid-30's that I thought I might be alive long enough to do something. And that was true of everyone in ACT UP, you know, the people who were positive, anyway. Things were very episodic. You had to do something right now, while you could. And you didn't have time to find out whether it was the most important thing. And you hoped. And it was a horror, you know. What if I'm studying this drug? What if, you know – a lot of people believed, maybe, that all HIV – the answer to AIDS was going to be a mucosal immunity – people really, really believed that. But, what if you worked on it up to your death's door and found out that you were wrong. And a lot of people were. All the crap – what was that stuff, albumin – wait – the stuff from eggs, stuff from eggs that we all believe –

SS: AL721.

DS: AL721, yeah. All the things that were going to save us. And then, I remember, DNCB, the photo chemical. In fact, ACT UP San Francisco – years later, when they really devolved, they became DNCB Now – believed that was the cure, and you put these inflammations on your body and it would save you. It's hard to admit that you'd gone down a blind alley.

Tape II
00:00:00

DS: What I was going to say is that, I don't remember us really spending a lot of time working on individual drugs. In fact, that's what I found TAG was doing a lot of. Individual drugs were sort of big picture. They were like the big guns. Most importantly – because at that point, they weren't working. And, why should one drug work better than another. I mean, all you can do is really learn what's a better – how to manage it better. But, again, you start your AZT and then you keep chaining them until you die. And no one really had any reason to believe that it was going to be any different. At the time, I really was started in Treatment & Data, there was a belief that we've got to do something different. We've got to look in a different way. So, we were pulling back and approaching it, you know, from, you know, from looking at the immune system directly; looking at other – other things that we could do to approach this. Maybe we're looking at it in the wrong way. Maybe looking at the virus is not the right thing to do. So, we were kind of casting a wider net. In fact, TAG seemed to be the one that was dealing directly with pharmaceutical companies.

SS: And – so, you guys were doing basic science.

DS: It was a big push to do a lot of basic science, because a lot of the basic science had fallen apart.

SS: Now, is that because – how was the outside – the outside of ACT UP, in the pharmaceutical community, in the science community, how was research coordinated? Did people know what each other were doing? Was it – did anyone have a big picture?

DS: Sometimes. No, they didn't really like to share too much. We were always pushing to share. Sometimes – I mean, I remember, I remember going into meetings at conferences and saying, well, what about this study that said that? And they said, I've never heard of it. And so, I'd be handing them copies of studies they'd never heard of. That was actually – I remember, because I actually, like, brought two scientists together at one point. I think it was in Berlin – see, have you talked to each other? And leave them talking to each other.

SS: Was there a central organization that was tracking all of the AIDS research?

DS: No. Not as far as I knew; not as far as they knew.

SS: And who organizes international AIDS conferences?

DS: Different groups – I remember, there was, like, an immunological society that did some. Some drug companies would do it, occasionally. I, honestly, didn't even really know, sometimes. I just knew that they were there and I had to go there because the scientists would come.

SS: So, when you decided to take the triple –

DS: The plunge.

SS: The triple cocktail.

DS: Yeah.

SS: Did you discuss it with other people in TAG and T&D?

DS: No, because I'd kind of drifted away from it, at that point. I'd had one horrible experience, which left me horribly frustrated.

SS: What was that?

DS: I'd been trying to remember exactly what the issue was – but, basically, the split – there was an emotional split that took place when the people from TAG moved out of ACT UP, and, you know, there was this kind of false thing between the people who wanted to do treatment activism and people who wanted to do social activism. And the people who wanted to do treatment activism, you know, didn't care if, you know, you know, people of color died in the streets, as long as white boys were getting it. And, the social people were, like, we want access for everyone, not just for white boys. It was sort of mutual demonization going on, which was an enormous waste of time.

SS: Why did that happen?

DS: Well, it happened because – as I was saying, a lot of those people – if you're a privileged white guy, you've got the – it's easy for you to focus on just making the science happen; just making a drug a cure, because you know you're going to get it. And, of course, you believe that everyone should have access to it, but you're not going to think about that right now. You'll make sure you write in, access to people of color, and women and children. You'll throw that in every time, and, you know, God bless you. But, there was an enormous amount of distrust. And, you know, I mean –

SS: So, what was the bad experience you had?

DS: There was – I can't even remember what the fight was about, but I think someone in TAG had done something. Basically, everybody – the huge split – everyone

hated each other, on some subject, which was, going to, really, basically stop all our action for a while. We couldn't work together. We were all fighting each other, instead of fighting the drug companies and the government. So, I got the idea, okay, I know – we have a lot of the issues we do agree on, you know. We do agree on certain elements. So, I decided, I'm going to get a consensus statement together. I'm going take it back and forth – do we agree on this? Do we agree on that? So, I spent this time fighting with people and getting them to fight – calming them down. I spent, like, two months on this, and finally, at the end of it, I got a consensus statement. I pushed it through. I was so proud. Everyone signed off on it. Nobody cared.

Tape II
00:05:00

SS: It didn't end the fighting.

DS: It didn't end the fighting. People just sort of got – basically, they just sort of drifted away from it and then, you know, would start fighting again a little bit down the road.

SS: What was the consensus that everyone agreed on?

DS: I can't even remember. And it was one of those things where – you know, the truth is, maybe the smarter thing would be just to wait for it to end – rather than to try to fight it. But, because I was trying to directly fight this problem and just lower the temperature, let's move forward together. I think at that point, people didn't want to move forward together anymore. Things had changed. At that time, there was mostly an enormous amount of despair. Here, ACT UP had all these incredible successes so quickly. New York still has the best insurance laws in America. It's incredible, the things we got done. I mean, you know – but we'd won all these battles, but the war – we were all still dying. There really was no hope. It was horrible. And there was this kind

of panic that had set in – this mixture of panic and despair. And people began to drift away from ACT UP – partly in despair, and partly because they couldn't take the fighting. But, it just wasn't working.

SS: And is that when you left?

DS: I left and began to work at TAG because I knew at least – I mean, I was really, really broke then. I'd, you know – I was in such horrible debt from all those years. And, I knew that, at least, if I worked at TAG, I knew I could actually get something done, and I wouldn't spend two months trying to get a consensus statement that no one would care about. And that was two months that were lost from the fight.

SS: So, what did you work on at TAG ?

DS: Not very much. I worked on the immune system stuff, but in short – well, there was a period of time where I was – it almost went a different way, my life almost completely changed because I was up for a job as associate editor at Treatment Issues, at GMHC, and, it was a big moment for me, because I thought, oh, this is doing everything that I loved, and I should have – I never mentioned this, but, the great thing about ACT UP, when I started working in Treatment&Data, is that I've – it was the most exhilarating thing that I've ever done in my life.

I remember being at the Berlin conference, and just racing down a hall and almost giggling, because I was so thrilled by everything I was doing. I was so effective. I was learning so much at all times; I was making things happen, and I couldn't believe I was able to do this. And sometimes, I would be horrified because I would – you know, someone from ABC News came up to me and was about to wildly mis-report something – no, no, no, no, no – come here, talk to this person, and just stopped it in its tracks. And

I thought, what if I hadn't been there? What if I hadn't been in front of this guy? It would just – it gave you an incredible sense of responsibility, which was – it was amazing. And so, when I had the chance to work at GMHC and, basically be paid to do what I was doing for free all the time, but not have to worry about going and making a living by working all night – word processing documents for South Africa, you know. It was like heaven, but it also meant that I would stop being an artist, and probably what freaked me out is that I was, I would have been happy to do it. And, I never could have said that before about anything. But, as it happened, another insider GMHC got the job and I was in such horrible debt, I became very peripheral at that point.

SS: Now, when you got to TAG, were they doing different treatments than you were doing?

DS: The people?

SS: Yeah.

DS: Umm. Some. I remember Mark Harrington had just done – he just had his lymph node removed. They were looking at the follicular dendritic cells and, I think, some people were on treatment, some people weren't. Some people were holding off.

SS: What are you taking now? Do you mind telling us?

DS: I'm taking, I'm taking Viramune – a non-nucleoside reverse transcriptase inhibitor; 3TC; Epivir and, what is the other one? Oh yeah, ddI – good old ddI – once a day formulation.

SS: So, how many pills a day are you taking?

DS: Two, four – basically five.

SS: And at the height, how many were you taking?

DS: Oh, 20-some. I think I had to take Crixivan – what was it, six tablets three times a day? I think that was it. I can't remember, exactly.

Tape II
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SS: And how have you felt about the way it's changed your body?

DS: Well, I look a lot older. It just sort of speeded things up a little bit. But, it just made me look the way I feel, you know. I do walk through the world feeling like, you know, like an old hippie might have felt in 1980. I feel like someone who came out of a wartime that nobody remembers; nobody even knows it occurred. So, the fact that I walk in looking like a scary daddy, just sort of fits.

SS: So, let's talk about some of the fun stuff about ACT UP.

DS: Okay.

SS: You said, when you first came in, you were sort of anti-social and you couldn't click with people.

DS: I wasn't anti-social, I couldn't click. But, it was okay, because nobody seemed to be clicking, in a way. There were the people who were clicking, but they were clicking at this kind of miserable level.

SS: What was that?

DS: Well, they would have these really dysfunctional connections, where they would kind of hate each other at the same they were hanging out together all the time. Or, they would get – it was like this sort of joyless cliquery.

SS: When did you start making friends?

DS: Well, I – I guess it was really with Treatment & Data is when I began making really, really strong connections.

SS: And, did you to ACT UP parties?

DS: I went to the big ones. I go-go danced for ACT UP at Mars one time. I remember that. [LAUGHS]

SS: And what about socializing and sex and flirting?

DS: Well, of course, you always went there and you wanted to flirt, because there some very sexy guys there. And there were guys that were sexy because they were so driven and uninterested in you, which made them seem wonderfully unattainable. But, I actually never really saw it really connect – in fact, there were usually people who would kind of avoid you – avoid me, sexually, because I was in ACT UP with them.

SS: Oh really?

DS: Um hmm.

SS: What do you think that was about?

DS: Too close, you know.

SS: So, if you went out –

DS: Later, I would run into a lot of people in sex clubs. There came a point in my life where it dawned on me that if I was going out to a bar and trying to talk someone up and pick them up – when I was just horny, I didn't really want to get to know them at all. It was a huge waste – it was like a mis-direct, you know. This is not – if I'm – So, it was much cleaner – like, to do sexual fast food in some kind of sex club; get it over with quick and get home, and then if you want to date, you date.

SS: And what were the clubs that the ACT UP people tended to frequent?

DS: I remember going to Club 82? Bijou 82 – remember that? On 4th Street and 2nd Avenue.

SS: So, how would it be if you went to a sex club and there were guys –

DS: Well, there'd be, like, a crowd of guys and sometimes – I remember Mark Milano was there – Oh, yeah, another crazy one. [LAUGHS]. Yeah, uh, who, at that time was kind of sexy – wouldn't even look at me.

SS: So, when ACT UP guys would see each other in your experience in a sex club –

DS: Or, you could be – if it was sort of down period between, you know, orgiastic moments, you know, you might talk or you nodded and moved on.

SS: It was like you were related or something?

DS: Yeah, a little bit.

SS: Do you think that people in ACT UP had safe sex?

DS: Um – at all times, at that time. That's the funny thing about the difference between now and then. At that time, safe sex was the easiest thing in the world, because we were – it was just what you did. We were all in this together. It was just – I never had to think about it. It was so simple. In fact, safe sex was a problem before I got into ACT UP, because I was, you know, which we've now seen in studies – before, the more disconnected you are from the gay community, the more likely you are, you know, to have unsafe sex. And, uh, once I got connected, it was fine. It was just kind of understood. There was no embarrassment about condoms. It was just matter of fact. But, then, AIDS was a part of our lives, where AIDS isn't really a part of people's lives now.

SS: Why is that?

DS: Because AIDS is a problem that people with AIDS have. People with HIV have this problem. And, you know, I got to say, in a horrible way, at the time, it was

really politically incorrect or, it was shameful to avoid people who had HIV sexually. It was just an outrage. Now, I have to say, it's kind of – for the most part, it's the opposite, and I'm glad.

SS: Why is that?

Tape II
00:15:00

DS: Well, at the time, also we figured that more – we thought more people were positive than were – a higher percentage. At this point in my life, and in the lives of a lot of people with HIV, I don't want to be in a position where it's even possible for me to infect somebody, because I just don't want to be – and, even though, I'm, we're looking at people who are regularly taking enormous risks, who are just, they're just time away from sero-conversion, I don't want it to be my virus. I just don't want that responsibility. And I resent it. I resent putting me in a position to infect you.

SS: Well, socially, inside ACT UP, was there any division between people who were HIV negative and positive?

DS: Not too much. Although, being positive was almost a badge of honor, and you knew if you were positive and doing this work, that you were serious. And so, you were – people believed that you were going to stay with it. And there was always a bit of a feeling that if you were negative, um, maybe you're going to be out of here.

SS: You think that the division – and I know you said that you thought this was a false division, but, ... the way it's been constructed between treatment activism and the access question, the social question. Do you think that that came down, based on who was positive and who was negative?

DS: Well, to some degree, because – the thing I remember about this organization is that it was not – it really wasn't that altruistic. It was an emergency. I

mean, it was a matter – I wonder if I can stay alive? I wonder if I can keep George from going blind? Right this second, because he's going blind right now; he's dying right now; he's got PCP right now, and I know how to stop it and I got to get something right now and I'm going to do whatever the fuck it takes right now. And so, I didn't have time to really think about, you know, the larger repercussions. And, if there hadn't been that sense of emergency, you know, I mean, would a lot of the more privileged people shown up? You know, I don't know. I don't think so. It was wonderful – it concentrated the mind wonderfully – to be in a state of real emergency. I think people kind of, don't quite understand this, when they think about ACT UP right now. You know, crisis – we use the word crisis so often that it stopped meaning anything. It was emergency. It was right-this-second scary. And, you kind of felt like, I'm doing this – but I'm – you're like in some movie and you've got to get the gun, you know. Get there before the bullet gets there. You can't possibly do it, but maybe we'll be like the hero in the movie, who does the miraculous thing.

And that we pulled off a couple of things; we managed to keep – I think that was the horror around the AZT study – about, you know, early intervention with AZT – we discovered that this great, you know – this thing we'd done, which had given people a brief good quality of life, had actually worsened the problem. It was horribly disheartening. It was a dose of reality that I don't think many of us could take. Wait, what were we talking about? I'm sorry, I lost –

SS: That's okay. I was going to ask you a little bit about the leadership, because you used to go to Monday night meetings, right?

DS: Um hmm.

SS: Who were the people who you found very powerful in a positive way and who were the people who you found –

DS: Negative?

SS: Or, that, you know, not as constructive as they could have been.

DS: [LAUGHS]. Well –

SS: In terms of leadership.

DS: Oh, leadership. Well, it depends on how you define leadership. I mean, certainly the most destructive person was Jim Fouratt.

SS: Why do you say that?

DS: There were times he would kind of come in – he would sort of show up, say things to stir up hysteria and then step out, and not really take responsibility for it – not take a leadership role, but just kind of be obstructionist.

SS: Can you think of anything particular?

DS: I remember him coming in at the last minute on a benefit. We'd gotten Grace Jones – remember that? We got Grace Jones to appear and do this benefit for us, which was hugely successful and made a lot of money. At the last minute he said, Oh, didn't she do something in South Africa – like, at the last minute. A legitimate question, but, it's like – you know, it's really too late to pull out right now.

SS: Well, this was when there was an artists' boycott of South Africa.

DS: I think it was more like, she went to visit her husband who was making a movie there, I think is what it came down to, you know. And it was a legitimate – I mean, it was a legitimate question, but, I remember, we all looked at him, like – you waited until now, on purpose. I know you did. And again, everything stopped cold for,

like, a week. Work stopped cold for this to happen, and a lot of us were really just disgusted.

SS: And what about positive leadership? Who were some of the people you remember?

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DS: I don't remember anyone not being positive, as far as leadership goes, because it was kind of a parade of people getting up there to talk about what they were doing, what they needed work with. I mean, I remember a lot of constant applause, you know. You had – the quiet applause. I'd actually thinking about when we moved over to Cooper Union for awhile because we had gotten so huge – this was just after Stop the Church – I guess – there were so many turning points in ACT UP, I'm realizing.

SS: Do you think that the membership grew after Stop the Church?

DS: Oh, hugely. I mean, we were – suddenly we went from, you know, a few hundred – I think we topped out at around four or five hundred at the Center. We were having the meetings there, and we doubled. We doubled.

SS: Why do you think Stop the Church attracted so many people?

DS: Because it was so exciting. It was so big. It was so angry. It was the very thing that drove so many people away from us. It was so bold. And, there's a lot of Catholic anger. It's funny because it was one of those moments, which, I think touched a wellspring of really deep anger. You know, the thing is – the thing that's amazing about ACT UP is that most people did not believe they had the right to be angry, and to – didn't Mao talk about, like, the forbidden emotion in China was anger? I think he said that, and so, if you can tap into a forbidden emotion, you can unleash enormous amounts of power. And, I think for a lot of gay men, there was such shame around being gay. And then, to

have gotten yourself infected – even if you’d done it before you knew anything. You’d done this dirty thing, and gotten this dirty disease, just as, you know, you deserved to get. You had nothing to be angry about. And, somehow, we did these things that – it tapped into this rage that people didn’t know they had – didn’t know they could have. I think people were surprised by it. Now, living in a state of rage, also makes you crazy. And so, the very – maybe it touched into a wellspring of anger, and drew people to it who really couldn’t handle the anger, once they had it out. And the people who came were a lot younger, for the most part.

And so it was exciting. But like, as with a lot of young people – you know the old thing, don’t trust anyone under, over 30 – well, in fact, you can’t trust anyone under 30, because there’s this period that is kind of post – adolescent and post-adolescent period, where you’re more willing to do anything. You’re willing to be rebellious. You’re going to be more interesting then, then you will ever be in the rest of your life, because you haven’t done the retreat back to your true self. And so a lot of people who were drawn there, would shortly be, you know, returned to their suburban roots, you know. They want to move to suburbs and, you know, have some test-tube babies. That’s all they all they really want. This was, you know, a fondly remember time of when they were an activist. It’s not part of their lives, really. So, and, the people that it did bring there who were truly angry – there were a lot of crazy people. And so, it just became destructive.

**SS: Who were some of the really inspirational people that you remember?
Just some names?**

DS: Some of them were actually people who I don't even know about. Oh, it was Karen – oh, God, I can't remember anybody's name – Karen, who worked at Body Positive, as well, and I worked with her on insurance issues.

SS: Timour?

DS: Karen Timour, thank you. Wonderful gal. I remember having to protect her when she was being assaulted by this other – well, verbally assaulted by this other woman. Karen Timour was extremely ... that way.

I think he dealt with housing issues – what was the – Richard Elovich. I remember when I had to come to kind of announce that Ethyl Eichelberger had killed himself – and, he was one of those people who didn't talk directly to me. He sort of wall-eyed, looked around me, but in that moment, he connected with me.

Everyone seemed to be pretty inspirational, because they all they came up, and they were working really hard and what they'd done – they kind of present what they'd been spending all this time working on. It was always very impressive to me. Kevin blank – I hear him on the radio every now and then when they interview him for AmFAR. Kevin, I apologize. I've forgotten your last name. You know, again, you know, really driven and could actually manage to break down – oh, God, what was the science – the lady doctor who started T&D?

SS: Iris Long?

DS: Iris Long. I remember Iris Long coming in from a conference, and Iris Long could not put two sentences together and so she came to a meeting and gave this, you know, incoherent ramble, and then Kevin says, any questions? Kevin stood up and said, I just want to make sure people really understand, you know, the importance of what

she said, and then – because the whole audience was just kind of listening – yeah, yeah, yeah, Iris. And he succinctly stated everything she couldn't get across, and whole place went dead quiet. Oh, we get it, something important happened. You know? Iris was great. Iris trained, you know, T&D, initially. She taught them the science they didn't know. And then, I think – I don't know exactly how they ended, but she was not happy with them. She didn't like what they'd done.

But, Kevin could take something and he could explain it to anybody. He did not – he had the understanding that science was something that could be understood by anybody. And that there was not this – you know, as Doctor/Patient, in a relationship, which, I hope are more fundamentally altered. I think, in some respects, that really altered health care in this country – the idea that, you know, that your doctor is a partner. And, also, your doctor doesn't know as much as you think. We came in contact with one study which showed, I think, that, even when a clinical trial proved without a doubt that a new drug was infinitely better than an old drug, it would take them at least five years before they'd prescribe it. And, even though today we've got all these commercials, you know, touting drugs – ask your doctor – there's a positive to side to that, because you're doctor wouldn't have given it to you. Talk about it. Make him explain why he won't give it to you, you know. God knows, there's a downside to it, but that really changed things. At the same time, you can talk to a scientist – as, and certain members of T&D occasionally would do, when they get ... from the floor, and they'd throw around a few terms, which would just make people – okay, whatever you're talking about, I believe you.

I remember trying to fight, saying, no, no, let's really listen, let's really all understand this. It's not brain surgery. This stuff really can be understood – or, maybe brain surgery can be understood, that's the point. You know, yeah, you don't have to get into the minutia of, you know, how this epitope fits with that epitope.

The fact is, this epitope – an epitope exists, which will connect. See, like two keys – they fit together, and then you can do something. That's all you need to understand, you know. Kevin could explain that. He knew how to get it down to the essential elements.

SS: We only have one more question. Thinking back, what would you say was ACT UP's greatest achievement, and ACT UP's greatest disappointment – in terms of its legacy?

DS: Oh, God. Well, in the larger scheme, ACT UP certainly permanently altered the relationship of the patient community to the medical community. It will never be the same again. That's why other, you know, groups of the afflicted, now have a different relationship. They have more access. They know they're allowed to fight for treatment, instead – it used to be this kind of, you know, begging – this supplicant kind of quality, you know – help me out. I know that breast cancer – they already – they picked up on the ACT UP model, you know – very quickly. And, I think that that is permanently altered.

SS: What enabled ACT UP to change that?

DS: Because, because most of the people who came into ACT UP – or, the most immediately effective were people of privilege, who felt they had the right to everything. The trouble is, that so many of the people who came into ACT UP did not

think they had a right to anything. So, a lot of times, the more socially minded people, came in with an expectation of failure. They came in with an expectation that they would protest, but probably not get anything. And so, there was a kind of futility in a lot of what they would do – a feeling of futility, which is why – because if you know – if you sort of implicitly know you're not going to get what you want, then you can deal – you can bring in the whole world's political setting, you know, and bring that along with you. Everyone's agenda is on board for a train that's going nowhere. But, I think one thing it did teach people is that maybe they did have a right to expect better treatment. They had a right to expect real lives. They had a right to expect attention and to be responded to. They had a right to expect to have power. And, I think it did – it changed it for a lot of people. People who didn't have a sense of power, got a sense of power. I don't know if I'm really answering your questions very well, but that, I think, was a fundamental – it's the sense of privilege made it possible.

Tape II
00:30:00

SS: What would you say that ACT UP's – in terms of its legacy – the thing that it was least able to achieve?

DS: Well, it was unable to achieve a real legacy [LAUGHS]. It's funny, I remember – you know, it was odd within a few years after I left ACT UP, I was so angry at having to be embarrassed by a lot of what had happened to it, when I was watching people from ACT UP San Francisco, kicking people with AIDS down a staircase. And suddenly, it was like, you know, what used to be, you know, a mis-characterization of what we were like, was now becoming the truth.

SS: But, that wasn't you?

DS: That wasn't me. But, that was the public perception. So, if I said, ACT UP, they'd go, oh, God, you're the scary people.

I don't really think there really was a failure, because it was implicitly, a crazily democratic organization. It was an organization of emergency. It wasn't really an organization. I mean, it was designed – it was a response, not an organization. And, once it had gotten to a certain – it could only go as far as it could go. This is not the NAACP we're talking about here, you know. As the epidemic changed, so the organization had to change, so the fight had to change. And, in a sense, people – there were some people who wanted to keep operating in the same way they'd always operated. It kind of wasn't democratic enough, at that point. Because people aren't that democratic. People get attached.

I guess I'm saying, the failures of it are the failures of anyone operating in an emergency. They can only do what they can do. The thing is, they did, they– we – we did an absurd about. I don't think it's possible to appreciate – I mean, most activist organizations will go 50 years, if they're lucky if they get one thing done, you know. We got dozens of things done – so many that we don't even notice it.

SS: Thank you, Dudley.

DS: Well, I'll spend the next few days thinking about everything I didn't tell you.