

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

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Interviewee: **Stephen Shapiro**

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Interviewer: **Sarah Schulman &  
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**SARAH SCHULMAN: The way we begin is if you could say your name, your age, today's date, where we are, and where you live.**

A: Okay. Stephen Shapiro. I'm 40. It's the 23<sup>rd</sup> of October 2004. We're at DIVA TV Central. And I live in Coventry, England.

**SS: For the record, I have to say that you have sent us more e-mails about this project than the entirety of ACT UP combined. So you obviously have a lot that you want to say. So why don't you tell me where you want to begin, and let's start there.**

A: Okay. I want to talk about the CD4 campaign. I want to talk about it partly because it's not very well known by a lot of people. But I want to talk about it not because it's particularly special, but because I think it's emblematic of a lot of activity that was going on in ACT UP that's often lost under the shadow of these much larger heroic events, like Day of Desperation. Because I think there were a lot of these types of activities that were going on in ACT UP. So I kind of want to give it as an example of what I consider to be a large body of work that people in ACT UP were doing at the time that oftentimes gets lost as when people look back and they remember the big events.

**SS: Okay. So why don't you explain what CD4 means.**

A: Okay. It came out – I joined ACT UP in '92. And it came up as not exactly an unintended consequence of the CDC revision of AIDS campaign that went on, Centers for Disease Control. Which I consider actually to be the great achievement of ACT UP, and we can come back to why I think that was the great achievement, but –

The, as you know, there was an attempt to expand the definition of AIDS, primarily for women, to gain access to HHS, I think is the agency that offered benefits.

Now the CDC wanted to include a definition that gave you an AIDS, an AIDS definition if your T cells went below 200. Now the reason why the CDC wanted this is because the CDC had always hated the fact that there was not name reporting for HIV-positive. It was a long-term agenda. And the CDC was very committed to naming people, and classifying them. And, partly because the institutional history of the CDC, people at the top level of the CDC have a history of missionary work in Africa. So these values of controlling African populations were carried over.

**SS: You mean the current leadership of the CDC?**

A: The history of the last few decades, the people in elite positions of the CDC, they began their careers, almost uniformly, in missionary work in Africa, often...

**SS: Like who?**

A: The guy who was head, who was a Mormon, who after he resigned, gave an interview to the Mormon paper, indicating he thought AIDS was a, a scourge by God.

**SS: Do you know his name?**

A: I don't.

**SS: Okay.**

A: But I will say that there is an official history of the CDC that was done with their permission that details the relationship of missionary work to the health system that we have in America.

**SS: And where is that available?**

A: Card catalogs. Do, just do a search. I've forgotten. I can find you the name. It's, I've read that many years ago. But we had thought the CDC insisted {phone rings}

**SS: Whoops. Sorry. Okay, so, and you think that this was more than just that Mormon guy. That there were other –**

A: Several. Several. And this, this history indicates this very clearly; that the missionary work was a career trajectory to get into the upper levels of the CDC.

**SS: And for which churches?**

A: Mormon, and I assume, probably, Methodist.

**SS: Okay.**

A: The institutions which had the greatest commitment to foreign missionary work. Those other, there is another aspect on how the CDC relates to the local politics of Atlanta. But that's perhaps not as pertinent. But there's an angle to that: CDC, Coca Cola, Emory University, and real estate development, which has been charted by Clarence Stone. Let me just put that to the side, 'cause that's not really pertinent. We knew that the CDC ultimately wanted names for HIV. So –

**SS: How did you know that?**

A: We knew this because —it was just clear. It was clear in their statements. It was clear that that was in the institutional culture. They didn't like anonymous reporting, and they would claim that they didn't like anonymous reporting because they were committed to this scientific objectivity, because they thought we could just have data out there. And that anonymous reporting prevented them getting from their good data, because people wouldn't be, couldn't be found after the site of testing.

Tape I  
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So we knew that they were very committed to this notion of, in their minds, getting good epidemiological data. 'Cause they're technicians as well. And of course, we were right. In retrospect. We, in fact, now can say, in hindsight, that that in fact was their agenda.

So the CDC CD4 campaign came up, in some ways, as an attempt to prevent a much larger force that we saw coming down the road. It was an attempt of ACT UP to respond to the consequences of a previous campaign – the changing of the AIDS definition. So once that was done, then Karin Timour and Mark Hannay came to the floor and said, well this is, this is the sort of, the consequence of the fact that the CDC was able to put in a numeric classification for CD4. Now of course, a lot of people –

**SS: Wait, slow down. What year is this?**

A: This is –, early '92.

**SS: Wait. Didn't you say you came to ACT UP in '94?**

A: Yeah. No, '92.

**SS: Ninety-two, okay.**

A: I was in ACT UP from '92 to '97.

**SS: Okay, so, and when you say “numeric classification,” can you just be really clear what that means.**

A: They wanted, in other words, because there's no such thing as AIDS, it's a characteristic of symptoms. AIDS is defined by getting one kind of illness, or dysfunction, bodily dysfunction. So in other words, if you have PCP that will put you into an AIDS definition. If you have candidiasis that would put you into an AIDS definition. That's true for, the entire AIDS definition, with the exception of a T-4 cell

count of 200. So in other words, it's a test that gives you that number. That's what I mean by a numeric classification. Now, the problem with that is, of course, that –

**SS: Wait, why is it different? So if you have a below-200 T-cells, you automatically have AIDS? Or you have to have that plus a symptom?**

A: No, you automatically have AIDS.

**SS: Okay, so why is that different than any of the others?**

A: Because, for two reasons. One is that many people have low T-cell counts that have never had any symptoms of AIDS. Still lead perfectly, at that point, {tape glitch} long-term progressors. They had been healthy; they, and of course, there's a psychological distinction of going from being HIV-positive to being classified as a person with AIDS. And –

**SS: It's the only way to have AIDS that's technical, but not experiential.**

A: Yes, that's a good way of putting it.

**SS: Okay.**

A: Yeah. And of course, your T-cell count can get better or worse. So what it meant, in any case, is that once you were on the AIDS list, your name was on the list. And there's no way of getting your name off that list. So for instance, if your T-cells went back up to a thousand, you were on that list. You were permanently on that list.

**SS: And when did naming, when was naming introduced?**

A: I think 1988, 1989. It was after I had moved to England. And the reason why they were able to get naming in is because of the drug cocktail. Because for

many, many years, the CDC couldn't really respond to anonymous testing, because there really wasn't a full-blown therapeutic regime. Once the drug cocktail came in, then they said, well, there's no reason that we shouldn't know your name, that we shouldn't be able to track you for the rest of your life, because if we don't track you, you'll be noncompliant. And there was this fear generated about superbugs, about people who went on drug holidays, noncompliant, that they would somehow genetically morph a kind of Frankenstein virus that would be even much worse than everything else. So there was tremendous, tremendous amounts of pressure placed on people after the drug cocktail.

**SS: So are you saying that today, everyone who tests, there's no such thing as anonymous testing?**

A: I believe that's the case. Truly confidential testing, yeah, I believe that's the case. There was anonymous, there was confidential, and then there was completely non – neither anonymous nor confidential. And I believe that there was no such thing in the U.S. as anonymous testing for HIV.

**SS: And you believe that this happened in 1988.**

A: Nineteen –

**JAMES WENTZY: Ninety-eight.**

**SS: Nineteen –**

A: Nineteen ninety eight, yeah.

**SS: You, oh, 1998.**

A: Yes.

**SS: Okay.**

A: It was definitely after the Vancouver conference. And they were able to use the drug cocktail to remove an entire raft of confidentiality agreements that the general AIDS activist community was able to uphold. And I don't think that was only ACT UP. The notion being is that if people couldn't test anonymously, that they would just go underground; they wouldn't get treatment at all.

**SS: Okay. So now we're back to '92. So there still is anonymous testing.**

A: There still is anonymous testing.

**SS: So KarIn [Timour] and Mark [Hannay] come to the floor and say, there should not be this marker of low T-cells as a definition of AIDS.**

A: Right.

**SS: Okay.**

A: And so there was, they raised the call; who's interesting in coming.

Tape I  
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And a group of us came to an initial meeting at Betty, Betty the Quaker, who was always crying every time she gave a presentation.

**JW: I'll think of it in a minute.**

A: She lives just two streets over. Anyway, you can –

**SS: Yeah, we need, I mean, with the gray hair, and who does all the Haitian work.**

A: The Haitian babies, she adopted Haitian, yeah.

**SS: Yeah.**

A: Anyway, that's where the first meeting was. So it was my first ACT UP meeting; it's a floor-through; it's a whole loft. I'd come to New York imagining this,

this life of fabulous apartments. Of course, I did not find that, and my first ACT UP meeting was at this wonderful floor-through loft.

**SS: Wait, and whose loft was this?**

A: It was Betty's.

**SS: Oh, okay.**

A: Betty's really nice loft. So a working group got set up to do, to fight for CD4 confidentiality. Now –

**SS: Wait, I'm confused again. If there already was anonymous, if anonymity was still in place, how come having low T-cells was not confidential?**

A: Because it had just entered into the AIDS definition. And you couldn't be confident, if there was a law. The CDC, this is how the CDC played it. The CDC does not define federal health regulations. These are done at the state levels. So states have the right to make their own regulations. But the CDC is very influential in determining two things: the disbursement of federal funds for projects — right? It's like a big grant agency. Right? And, it's very important for career advancement, for epidemiologists.

Now you, let's say you're in New York, and you're a progressive epidemiologist, and you get to be a top dog in the New York, the New York system. And the CDC can't do anything to you. You can, you have the protection of New York; you can do good, good policy. But if you want to advance in your career, at a certain point you're going to have to leave New York State; you're going to have to go some other place. And the CDC has this lock on accrediting, on basically saying, yeah, so-and-so's a good epidemiologist. References, access to the institutions. So the CDC would always

say, we don't make the policies; states make policies. What the CDC did have is, they had the right to the honey pot, in terms of funds — financing pilot programs — or the advancement of the individual people's careers. And that's the way, when the CDC wants to make policy, they get states to voluntarily agree to what the CDC wants to do. Okay?

**SS: So then are you saying that New York State voluntarily agreed, in 1992, that if you had below 200 T-cells, you would no longer have anonymity?**

A: Yes, that's my recollection.

**SS: Okay. And that occurred in 1992, is what you're saying?**

A: Yeah, '92, after the change of the —

**SS: Okay, so then —**

A: I think there was a rolling one-year —

**SS: So then Karen and Mark wanted to overturn a New York State policy?**

A: That's right.

**SS: Okay.**

A: With the notion that New York State, because it's in a privileged position, vis a vis the epidemic policy, that if New York could come up with an alternative to restore confidentiality, that this would become a model for the federal system. 'Cause obviously New York's a good place to be for your career, and things like that.

**SS: So this campaign was aimed at New York State.**

A: It was aimed at New York State. There was not a federal campaign. Exactly right. And the combination, it was a city and state campaign, because there's a kind of crossover: there's city authorities, involving AIDS cases that are specific for New York; and then there's one for the larger state. And of course if New York is important as a state in relationship to the rest of the nation, New York City is important to New York State, 'cause obviously the greater number of caseloads is in New York City. So in some ways, the gamble was that if we could flip New York City policy, that this could be carried out throughout the entire nation. We weren't dictating national policy, but it would set up a strong case.

So what we wanted to do was find a mechanism to restore anonymity for the T-4 cell count. Which ultimately came up with the notion of unique identifiers. Okay, what's a unique identifier? A unique identifier is basically a code that gets attached to a case. That's, would be like double-blinded, so to speak. So it's, there would be, each person would have one code. It would, they would carry that, it's like the Social Security number. You would carry that Social Security number. But there would be provisions to prevent the connection between that number and the person.

And so that's what we were trying to argue. Now, the idea came from people from, associated with ACT UP/Philadelphia, who knew something about –

**SS: Which people?**

A: I don't, can't remember, to be quite honest, and my notes are all in the New York Public Library. But it wasn't a core, they weren't core ACT UP/Philadelphia members. There were, it was an older couple. I think at that point, early fifties? And they, I think one of them had actually worked in the Pennsylvania, the woman, I think,

had worked in the Pennsylvania health system. And they were knowledgeable about cryptography and confidentiality, in ways that we, the people who ultimately ended up working on the campaign, were not. I certainly didn't know much about that information when I joined ACT UP.

So we had this notion that what we wanted to do was have unique identifiers, to allow confidentiality for the tests. So the CDC could get their data — our argument was, the CDC would actually get better data, because people would be more secure in coming to get testing, and/or getting therapies. So they would get the data, but we would get confidentiality. We'd be, we'd protect people's rights.

And so that was the kind of compromise that we were suggesting.

Now, we had the, and we had a couple of strategies. And they were rolling strategies, because when one closed, we tried to go move on to another one. The first strategy was, we protested at the New York AIDS Institute.

**SS: Do you want to explain what that was?**

A: The New York AIDS Institute is the, it's a body that was set up, I think a few years prior, which is responsible for policy and for distribution of New York State monies to various NGOs, like GMHC, or People United of Color. So in other words, they are the kind of local money-holder; they get the state and city tax monies. So they're a leader in making policy.

It was not a political appointment. They had an AIDS Advisory Council. And there were some, the constitution of the AIDS Advisory Council were some people who were there on meritocratic basis, and people who were health professionals. There were some patronage positions, of course. This became more the case after Pataki

regime. And then there were community people as well that were put on the council.

And they were, they, while they did not make the policy, they had a very strong informal guidance toward policy. So –

**SS: Do you remember some of the names of some of these people?**

A: Well Virginia Apuzzo was on. David Hens – she was on because of her, she, at that point she was working for New York, she was a New York bureaucrat. She worked for hiring. If you wanted to get hired in the civil service, your portfolio went across Ginny Apuzzo's desk. She was up in the Bronx, in that postmodern wedding-cake building. David Hensel was on it. At that time, he was working for GMHC. Nick Rango, of course, as ex officio, who was head of the AIDS Institute at that point. And a bunch of others. I can't remember. They also had ethnic representatives. They had people from the Hispanic community. I don't think they had any black Americans at the time. Or I think maybe later on. I did work at that site for several years, so I'm a little hazy as to the – But this would be a matter of record. It shouldn't be hard to find. They were, Sheldon Silver appointed some, from the, later on, it was Silver got some appointments, for the Democratic Party; Pataki got some from the Republican Party, and I think maybe the AIDS Institute proffered some names as well.

So it's kind of complicated. We have lots of informal bodies that are able to make, or strongly determine, formal decision-makings. And of course, the formal, the people who made the formal decisions would always say, we're not really the ones making, we take guidance from this or that. So it's a kind of web, that we were –

**SS: So why did you guys choose them for your action?**

A: We chose them for the action because that would have been the quickest way to get to the solution. The AIDS Institute could have made, could have, well, this is what they would have done. This is what ultimately they tried to do. They would have taken money. They would have advertised it to contractors. They would have said, come up with a unique, system of unique identifiers. See if it works. And if it worked, then they would say, yes, this is a good idea, and then they would come up with more money to institute it throughout New York City and New York State.

So it would have been the simplest direct solution. They could have done it. And we wanted to bring it to their attention. So we did a zap, or a protest at the AIDS Institute. Which was successful. We immediately got a meeting. Nick Rango called the meeting. ACT UP –

**SS: Let me ask you something. We've talked, as you know from reading the transcripts, we've talked about how strategies are constructed. Did you first ask for a meeting, and then do a zap? Or did you do a zap without asking first?**

A: I think we did a zap without asking. I'm embarrassed to say. We knew. Mark Milano was the sort of inside guy, 'cause Nick Rango had hired him. And so I think Mark Milano had the status. I think Mark was hired by Nick to be the wild boy. I don't think he was allowed to really do much policy work. But he was allowed to be the ACT UPper. He was the sort of conduit, so Nick could know what ACT UP was thinking. And I think Mark was the one that encouraged us to do the zap.

**SS: What did you do?**

A: I think we went into the building and protested, back in the days when you could do such things, without having NYPD down your throats. And of course, the AIDS Institute was not a completely hostile body, right? You had people like Nick Rango. I mean, they were sort of relatively friendly officials. So we weren't arrested. The police weren't called. We did the zap, and in fact, the meeting was called the next day. Nick arranged a meeting. ACT UP members came. I think there were five or six of us: Karin Timour was at the meeting; I was at the meeting; Tony Davis; members of the legal, head of the legal affairs, I think that's what it was, at GMHC, came.

**SS: Remember who that was?**

A: It was David Barr. I do indeed. And then, there were about 10 to 12 other people from various NGOs. Now of course, Nick, I think, was interested in this, because Nick, at this point, wanted to shift GMHC's dominance of funds from the AIDS Institute. He wanted to start moving money to, away from GMHC, into these other Harlem institutions, Bronx institutions. So I think for him, logically, this meeting was going to be a good way to stage a kind of confrontation of the tensions that were, had really become very strong at that point, between GMHC, getting the lion's share's of the funds — white downtown organization — and all these sort of other bureaus.

So we went into the meeting. And GMHC destroyed it. GMHC spent the entire time talking about —

**SS: You mean David Barr.**

A: Yes, as GMHC's representative. That's right. He spent the time talking about the need to have PCP prophylaxis — Bactrim? Is that the, yeah, Bactrim. Of course, that's a very important an issue. But it wasn't why we were at the room.

**SS: Bactrim, in 1992?**

A: Yeah. Bactrim had been –

**SS: But why was that an issue?**

A: It was an issue. Bactrim had been around for a long time –

**SS: Right. So why –**

A: But there was very poor, just very poor policies. People who got PCP didn't get Bactrim. This changed, it actually, before the AIDS cocktail, it was the routinization of Bactrim that increased longevity more than anything else. This could have been done years and years –

**SS: Okay, but why was this, so you're saying that he felt that that was more pressing than your issue?**

A: That's right.

**SS: Okay.**

A: That's right. Now of course, no one disagreed with the need for PCP prophylaxis. But that was not why we were there. So the meeting was destroyed, causing a lot of upset by the other committees, who were kind of astonished that GMHC was able to do this; was able to walk in. And right, this was supposed to be their, I mean they didn't necessarily have ACT UP's agenda. But this was also supposed to be their place to enter more at the table. This was completely blown aside.

Now see, what was happening is that GMHC was sending very strong messages that this was not an important issue, and that furthermore, there would not be community support.

**SS: And why was that? Why did they oppose it?**

A: They opposed it because it was not a TAG interest. I mean, this gets into the larger –

**SS: Because David is in TAG, it was –**

A: Because David's in TAG. Do you want me to speak about, that's the hidden story of the CD4 campaign.

**SS: So you're, but your claim is that the reason GMHC opposed this – is because of sectarian ego clash between TAG and ACT UP, and not for any substantial policy reason.**

A: No. There was obviously ego issues. But TAG was pursuing a policy agenda, which they wanted. And they were willing to engage in a scorched-earth policy. Because they had the notion that any policy that was not a TAG policy would therefore remove money and/or interest from what TAG wanted to do. So if it was an idea or policy that came outside of TAG, it had to be suppressed.

**SS: So you are saying that it wasn't for actually, because of the issue of T-cells as a marker. It wasn't about the content of the issue.**

A: Yes, that's right. It wasn't about –

**SS: It was power play. That's what you're saying.**

A: It was a power play.

**SS: Okay.**

A: Exactly right. And that's the sort of hidden story of the CD4 campaign. Now, let me explain why TAG was opposed to this, and it speaks to the wider, sort of post-'92 split of ACT UP and TAG.

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Now, TAG separated from ACT UP. And they didn't just separate from ACT UP and say, okay, you go your way, we go our. Is that TAG on various kinds of fronts, wanted to make sure that ACT UP was not just different, but weakened.

**SS: And you were present in ACT UP for this.**

A: And I was present in ACT UP for this.

**SS: Okay.**

A: And spent three years of a campaign that was ultimately lost because of this. That's partly the story that I want to tell about this.

Now TAG, at that point, was interested in what they called large, simple trials. They wanted to do, this is actually before the drug cocktails come out. That's, at this time, they were, the, the drug that the actions were against were still TAT — it was for the Hoffman-La Roche campaign, to get, this drug which turned out, at least on the clinical trials that were done, to be worthless. I mean, maybe it has some worth, but I don't think there's been any return to TAT as a strategy. And there was a big action at Hoffmann-La Roche. The first agenda was TAT. Now, there were other agenda issue items. And among those other agenda items was to try and get the data about what later became parts of the drug cocktail — these new drugs — which were being held by the companies. But we're not yet at the moment of the drug cocktail. This is even before that.

Now TAG had come away from their experience in ACT UP more or less renouncing their previous positions. They used the split to kind of do a revisionist history of themselves. And they'd come up with the notion of large, simple trials. Now what they wanted to do was they wanted to enroll everyone on a trial that I think lasted five

years, and anyone could take anything they wanted, except there would be one variable. Now that variable would be one of these new, what's the name of the drugs, the classification of drugs, in the cocktail?

**JW: Protease.**

**SS: Protease –**

A: Protease inhibitors, yeah. Except for protease inhibitors. Now what that meant was, if we had this large, simple trial — and “large” meant large; tens of thousands of people — it would be a placebo trial. So, and they wanted, so if you were in this trial, it meant that you would not, there was an excellent chance that you would not actually get the protease inhibitor, right? Which meant that actually would not get what we can now recognize was an absolutely crucial life-prolonging treatment. So there was a lot of resistance to this.

**SS: So you're saying this is their position while they were in ACT UP.**

A: This is their position post–ACT UP.

**SS: Large, simple trials. So you're saying large, simple trials were not**

–

A: Well see, I came into ACT UP after the split. So it's difficult for me to answer those questions.

**SS: That's what I just asked you before. I said, were you present during the split? And you said, yes.**

A: Oh no, I'm sorry. I misunderstood you, I think. No.

**SS: Oh, okay.**

A: No, I was not present for the split.

**SS: Okay.**

A: They, they had gone at that point, just a few months prior. Because I remember there was some meeting where Larry was there, and there were still some TAG members, and he said, can't you, everybody get along? And they said, no. We're tired, we're out.

So they had come up with this notion of the LSTs. It was a TAG notion; practically nobody else wanted this, for relatively obvious reasons. Including the scientists. They, and this is one reason why it ultimately didn't take place.

Now, TAG absolutely wanted large, simple trials. And so what they were willing to do was that they were willing to discount anything that they thought might threaten the possibility of a large, simple trial. Now on the larger scale, what this meant was, at the same time, John James, at *AIDS Treatment News*, was trying to advance the notion of the stability of PCR tests, which would be polychrome – PCR. I've forgotten the name. But it's a way of testing viral load. In other words, if you get a very small bit, you can replicate it hundreds of times very quickly. Sort of like what we think of DNA. If you watch CSI, they're always saying, like, can we get a little bit of DNA, they run it through the test. That's more or less the PCR test. Which was new technology that was getting to it was cheaper and easier to do. And John was advancing the notion that we could, that this was a stable test, and that we could use this to test viral load in the bloodstream. Which meant that we would very quickly be able to determine the relative efficacy of a drug.

Now this of course is what happened. This is what we rely on. But see, TAG was opposed to this, because if you used PCR and viral load as an indicator, there

was no reason to have a five-year large simple trial. Right? Because you could get the data very quickly.

**SS: In your view, why did they want this trial?**

A: They wanted this trial because they had become, they had fallen into a cult of scientific objectivity. They had become like the epidemiologists. They thought that good data was the problem.

What happened is that, it was in this moment before we had the theoretical model. What, what was taking place is, people took AZT; and they got better; and then they got worse. And then we had people who never took AZT, and after several years, there wasn't any difference, in that. So in other words, it wasn't clear if you took AZT, or if you didn't take AZT, you more or less ended up in the place. And now we understand why that's true, because we have this model of resistance. At the time, we didn't.

Tape I  
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So TAG thought — we made a mistake. We tried to get parallel track. And we came up with inconclusive data. So they really thought, if we just had good data, we would really be able to get the right drugs. So they had flip-flopped on the position for which they were primarily known in ACT UP, which was the drugs-into-bodies. By the time they left ACT UP, they were like, no, we need good data. So we actually, it's, not everybody can take this stuff. We have to have a placebo trial. And ACT UP's position was opposed to that. And John James's position was here's these new technologies that are coming up, that will serve the community. And as I say, it's John James's position that is the one we rely on today, not Mark Harrington's. Mark

Harrington got the MacArthur grant; John James is relatively unknown. Such is, such is

—

**SS: Let's go back to the CD4 campaign. So you had your first meeting.**

A: Oh, I'm sorry, but there's something very important. Now the reason, I suspect, why TAG was particularly opposed to the CD4 campaign was because its relationship to testing and data. Now we argued that if we had a system of unique identifiers, you would actually get very good data, because you'd get more people implying, enrolling in trials, and you'd get better statistical significance. But of course, this was perceived as a threat to the concept of large, simple trials. So my feeling was, is that the CD4 campaign was conceptualized by TAG as an enemy; that this could not be allowed. And that, this is, it's important to, to recognize the connection. So it wasn't just simply ego. It wasn't just like, we and we alone want to be top dog. I think that it was felt by them — they might disagree — but I think it was felt by them as endangering what they saw as their primary policy agenda at the time.

**SS: Okay. So you had this first meeting. And you felt that it was sabotaged by GMHC. So what did you do next?**

A: Okay. So then we decided, we need to do an end-run around GMHC by forming a national consensus letter. So we spent a lot of time forging a letter of the consensus that we sent out nationally, to all kinds of NGOs and policy groups to sign on, so that we could then say, this is not an ACT UP issue alone, but this is actually representative of the broad stream of AIDS policy activists, AIDS treatment activists.

Which we got. With the exception of two groups. Whitman Walker resisted for a while, I believe; then ultimately, they came on. But the person who wouldn't sign on was GMHC. So –

**SS: And what were some of the groups that did sign on?**

A: You name 'em. A mil-, hundreds. There were hundreds on that list. And I think any substantive group, not only the white ones, also we, there were, it was very, very broad spectrum of groups that signed on. This process took like a year. It was a very long process, of getting this consensus statement.

**SS: Did Mathilde Krim's organization sign on?**

A: I think they did. I think there was some resistance, but I think they ultimately did, yeah. AmFAR, that's Mathilde Krim. But again, it was GMHC that was a problem.

**SS: Okay.**

A: So, what we – two things started taking place. Then there was an attempt to try and get GMHC onboard. We complained about them in meetings. And they called a crisis meeting. It was GMHC and ACT UP. It was held in the basement of GMHC. Because they were increasingly nervous that ACT UP was increasingly breaking the code of silence and saying GMHC is the problem. It was okay if GMHC was the problem. What they didn't want is people saying GMHC was the problem, because they wanted us to feel we can't say anything because it would hurt the community, it would hurt GMHC's funds.

**SS: So who was at this meeting?**

Tape I  
00:35:00

A: This meeting was Mike Swirsky, myself and Tony Davis, for ACT UP. And for GMHC, it was David Hensel, for the legal; David Barr, for, I think, Treatment. I think his post was Treatment. I can't remember. I think I'm confusing who's the lawyer. David Barr for Treatment. And Ruth Finkelstein for Public Relations, I think, or I can't remember her position. Which was mainly an exercise in humiliation by GMHC. They very strongly set out to humiliate all three of us, to sort of get us down, back down. Lots of snide, quasi-abusive comments. David Barr began the meeting by saying, I'm HIV-positive; I don't know about everyone else. Of course, he knew that no one else in the room was HIV-positive. A kind of paradoxical notion, right? We're talking about confidentiality. But he really wanted to sort of silence people's, everyone else in the meeting. So it was a kind of combination of Ruth and David Barr – tag team.

They agreed to hold the meeting. Another meeting. There was a series of meetings. Again, all completely sabotaged by GMHC. They would change the agenda. There was a meeting in which larger community groups were going to be gotten, and then there was supposed to be a group committee. And at the last minute, when Mike Swirsky and I had left, they had gone in and Michelle, who's a black American woman, to represent the issue of unique identifiers.

**SS: What's Michelle's last name?**

A: I can't remember. I'm sorry. I'm tempted to say Michelle Wallace but that's a writer. I don't think it's, it's not Michelle Wallace. And what they had gotten out of the kind of identity issue specs of ACT UP is, they learned how to use these kinds of issues of cultural representation to their advantage. Because they thought, oh, Mike Swirsky and myself, we wouldn't be able to say, actually, we should be on this, because

we've spent the last two and a half years educating ourselves about the issues; we're the ones that brought this. Rather than this black woman from Harlem.

Of course, what happened is she was savvy to what they were trying to do, and she steps aside. But that was this, these kind of games were constantly going on.

That's one side. The other side is, we decided, okay, we've become stymied at the AIDS Advisory Council. We've become stymied at the level of the community, so now we're going to apply pressure on Dinkins, who was mayor at the time.

So we then proceeded to do a series of zaps of Dinkins, where we tried to confront him when he was giving talks. We did two of these. The first one was at a meeting for people who were trying to get Democratic Party club endorsements for judgeships. It was around lots of wannabe judges. And it was at the restaurant at University Place and Eighth. Went in – I went in; we interrupted David Dinkins; I was thrown out; ACT UP was protesting on the sidewalk. Did that. I think a week later, David Dinkins was addressing, there was the ABA, American Bar Association conference, at the Hilton. And Michael Swirsky, who's a practicing lawyer for the city, knew about this. And he read in the advertisements that David Dinkins would be addressing the black lawyers association, or club, or aspect of this, along with Leon Higginbotham.

So we went up to the Hilton, which was completely terrible place to do an action, because of course the public sidewalk is like a hundred meters away from the hotel. So we couldn't actually get close to the hotel. I and Dan, from Action Tours, Dan William-, not Dan Williams. Do you remember his name? Dan [Borden], in Action

Tours, he's an architect. At that time, he worked for the MTA. He was working on the Union [Square] Station reconstruction. Okay. Names?

**JIM HUBBARD: I'll remember.**

A: Well done, I think the reconstruction was a success. So I think he does

—

Anyway, we went in. And we went up to like the fifth floor, of the, of this. And we got in. And we were in street gear, with about a hundred and fifty middle-aged professional black lawyers. So needless to say, we were quickly surrounded by about 20 heavy guards. I mean, so the action, we weren't able to confront him at the speech.

**SS: You were disrupting an event of black lawyers?**

A: David Dinkins's speech — that's right. Or that was, that was the plan.

Now what I, well I remember this very clearly, because it gave us an opport-, 'cause Leon Higginbotham spoke — amazingly eloquent speech about black civil rights and the struggle. I mean, it was a pleasure. I actually, to this day, aside from having heard Mandela, it was one of the most inspiring speeches about civil rights, outside of the lesbian and gay community, I've ever —

David Dinkins got up. And he talked about his tennis backhand, which to me was just anecdotal of the Dinkins regime. Which is to say, even though Dinkins looks good in the history of Giuliani, the point was, he was a machine politician, who just really did not have that kind of commitment to his political base, to political justice.

**JW: Can you hold that thought?**

**SS: We have to change tapes.**

Tape II  
00:00:00

**JH: Michelle Lopez?**

A: Yes.

**SS: Ready?**

X: Rolling.

**SS: We just want to correct some stuff from the first tape. So Michelle's last name.**

A: Is Michelle Lopez, we think.

**SS: Betty.**

A: Is Betty Williams.

**SS: The other organization that refused to sign on.**

A: I believe it was Lambda Legal, also resisted. And should I go on to say why I think this was?

**SS: Well, let's just say that also, James and I recall that the debate about large simple trials actually happened within ACT UP. Yeah.**

A: Okay. So let the record show.

**SS: Okay.**

A: Before my time.

**SS: Okay. Go ahead.**

A: I want to, actually, let me finish the David Dinkins story. But then I want to come back and say something about TAG. What happened is that, so we were completely surrounded. There was, this was not going to take place. And I think both Dan, so both Dan and I, we didn't do it; we didn't do it; there was no interruption. I actually, I think both of us were so entranced by Higginbotham that we sort of

reconsidered. Dinkins exited very quickly, to go to the bathroom. And had gone out on the side. And almost like a football play, we, we were able, amazingly, to elude these 10 security guards, and ran out to intercept him. And what we were intercepting him with was information about the issue, about CD4. We tried to explain it in one or two pages of information. And we were just about to get tackled when Dinkins actually said, let them give it to me. So we gave it to Dinkins. He went on to whatever he was doing. And then we went out. That was the action.

**SS: Okay.**

A: So then we got a call from Ron Johnson, to have a meeting down at City Hall, or somewhere in the City Hall complex — I don't think it was City Hall per se — but down by that complex. So we had a meeting. Now it was ironic that we actually got a call from Ron Johnson, because the one time that actually had a direct encounter with Larry Kramer was he was at one of our meetings, and we were explaining the issue. And Larry said, well why are you doing all this? Why don't you just talk to Ron Johnson? And actually, at that point, in my one kind of iconic reference, I said, well, David Dinkins is the pressure point. We want to focus on Dinkins because he's an elected official, rather than do this kind of like back door —

**SS: And who's Ron Johnson?**

A: Ron Johnson — I think Ron Johnson's position was the mayor's liaison to the gay community. Is that right?

**SS: Under Dinkins? No.**

**JH: He wasn't the head of the Health Department then?**

A: Ron Johnson wasn't —

**JW: Under Giuliani, he was AIDS. But – and then later, GMHC.**

**SS: Under Dinkins the liaison was that black woman. What was her name?**

**JH: Marjorie Hill.**

A: May-, yeah. Maybe it was, he was liaison for the, for AIDS. So we had a meeting with Ron Johnson [City Coordinator for AIDS Policy under Dinkins. Citywide Coordinator for AIDS Policy in the Office of the Mayor and City Co-Chair of the HIV Health and Human Services Planning Council under Giuliani and Associate Executive Director of GMHC]. He was incredulous. We explained the issue to him. He got it. He understood what it was about. The meeting ended, however, with him saying, make it an issue. In other words, they, he understood the issue; he understood the need for it; but unless there was a political payoff for the Dinkins administration in the media, they weren't going to do anything.

**SS: Why is going to the liaison going behind, what did you say you didn't want to do? Go behind the scenes? Why is that going behind the scenes?**

A: Because we wanted to, because we didn't want this to be seen as ACT UP getting a deal for ACT UP. We thought it was important that it take place, as it were, in the public arena.

**SS: But if you see a liaison, why is that not the public arena?**

A: Because it would have weakened the notion that public officials should, could be held responsible in the public.

**SS: Okay. I'm not clear about – all right, let's keep going.**

Tape II  
00:05:00

A: Okay. Anyway, the meeting ended by saying, essentially, unless there's a, basically, Ron Johnson said, make a disturbance, and then we can be seen as responding to the disturbance. Which, perfectly understandable, but nonetheless, somewhat frustrating that they understood the need for it, but they weren't willing to do anything. That to me is again, to me, that's very symptomatic of the Dinkins administration. In other words, they got it, but they just really weren't willing to do this.

Now of course, ironically, years later, Ron Johnson, when he was at GMHC, was calling for unique identifiers. He knew about unique identifiers because we, he had had the meetings with us years before. He knew conceptually what they were, 'cause we had all laid it out. By that time, it was too late; the moment had been lost. The moment was years prior. So that was yet another –

**SS: So you guys gave up after that?**

A: No. We didn't give up. At that point, we were close to giving up. But we didn't give up. I still want to say something about TAG –

**SS: Okay.**

A: – I can push that on later. At that point, Ginny Apuzzo gave us a call. And Ginny Apuzzo, I'm not sure – we had written to Ginny Apuzzo. We had actually, we had informed her about it. And she immediately responded. She said, come up to the Bronx and have a meeting. And we explained the issue to her. And she said, yes, this should be done; this is right. And she said, I encourage you to come back to the AIDS Advisory Council and, where we can get GMHC to fall in line, and that we can then go back and get this position taken care of.

So it was Ginny Apuzzo, her aide, Pat Siconalfi, and another aide, Bruce, and I don't remember Bruce's last name at all – that was taking place.

So we then, after maybe a year and a half, went back to the AIDS Advisory Council. Because we'd gotten sort of renewed encouragement. And I think this is we, this is when I started going to the meetings. Bought a laptop; started recording what was going on. This made them very nervous. They didn't like records. James came with a camera – made them even more nervous. They didn't want public records on this.

But the AIDS Institute, with some of the policy people, were not terrible people. They were trying to do good things. I don't consider them – at this point, Nick, I think, had passed away. And I can't exactly recall the name of who replaced him. A lot of meetings went by; a lot of time went by. But ultimately, they came around to the notion. They didn't, see, they didn't think it was possible. They didn't think a unique identifier system could be done. So they had given up the resistance. And we had had meetings; I'd actually talked with New York State epidemiologists, these guys, these wonks. And, who had no contact. But they, since I had a science degree — my first degree was in chemistry — I could talk a little bit with these guys. And they had actually gotten over their initial resistance to the idea, and had moved on to what was for them a technical problem: can this actually be done? Right? And see, they didn't think it could be done.

So what we did is, at that point, we got in contact with Phil Zimmerman. Now Phil Zimmerman is the inventor of something called PGP — Pretty Good Privacy — which is the gold standard of cryptography, for e-mail. And he's a sort of god in the

Internet world. Phil Zimmerman was from Boulder, Colorado. And he was, he had come out of the disarmament campaign. He had this history in progressivism, he comes – as a matter of fact, he came to New York once to speak about privacy rights. But he was really invested in this older tradition, and he understood the issue. And he agreed to work with ACT UP, to show that this system of unique identifiers could be done; that these were possible. And so I took a copy of PGP to a meeting, and I said — on a little floppy disk — and I held it up, and I said, here it is. This is possible. Not only can you do it, you can do it for free. Because he had invented this system of cryptography and made it freely available to the Internet. It was this old model, before the Internet was for corporate privileges. So he had done this as his own bit of activism.

So a lot of phone calls took place, oftentimes at four or five in the morning. It's great talking to net heads, because they don't think it's at all strange that you call them at five in the morning, 'cause they're on their own completely different schedules.

And so we, we said, it's possible, and we have leading experts who say it's possible, who are committed to this. So what the AIDS Advisory Cou – AIDS Institute did was they advertised. They did what I said in the first place; they advertised to contractors, asking for people who would conduct a pilot program for a unique identifier system. Right?

It was this close; this close. We're really come, years had gone on; we're this close to getting it. Unfortunately, it was a few months before the campaign, the election, the Cuomo, Cuomo lost to Pataki, right?

Tape II  
00:10:00

It was Cuomo v. Pataki. And contractors were worried. Because they, at that point, they didn't believe, they didn't have confidence that Cuomo would win. So they weren't going to commit to a project that they thought they, that it would be profitable for them, 'cause they have profit interests. So what happened is that we didn't get any responses. No contractor would step up to the plate. But nonetheless, the AIDS Institute, at that point, was committed, they had signed an, I think an MOU – a memorandum of understanding – which is coming close to a contract. They were committed to re-advertising for a pilot program for a unique identifier system. So we're talking, we're just months, just months away, from getting the system tested and locked into the system. And then Pataki won.

Pataki immediately put a freeze on all new pilot programs. He set about dismantling the current regime of the AIDS Institute, either through directly firing people, or making people's lives so miserable they left on their own. And he started instituting Republican antagonism – sort of heavies, Republican heavies on the AIDS Advisory Council. The environment completely changed, and that was the end of the CD4 campaign.

We lost it by a space of a few months. To this day, had we not, in my opinion, spent so much time trying to overcome the resistance to various kinds of institutions that were staffed by TAG members, we would have gone in, in my opinion, to the point of advertisement well before the felt demise of the Cuomo system. Had we gotten an advertisement even three months before, it would have been in the system, and safe from Pataki's hands. It was a, really just, we lost time; and that time was absolutely crucial.

**SS: Now when you started telling this story, you introduced it in this very particular way, which I can't exactly remember. But you felt that this was very, very important and emblematic. Do you remember how you introduced it at the top?**

A: Yeah, that I thought it was emblematic of a lot of activity that was going on in ACT UP at that point.

**SS: Oh, okay. Okay.**

A: Do you want why I feel that –

**SS: Sure, go ahead.**

A: Well, I feel it because even though if you looked at the service level, I take your point, did we ask so-and-so for a meeting, or do we just have a, did we just have a zap. And I think maybe we had, or maybe we hadn't. But the point is, a lot of times, you will only remember it through this events through zaps or actions. And it's very important to realize that for every one of these actions, the actions were only tips of the iceberg. And behind that, there were a lot of work on all different kinds of strategies: political strategies, legislative strategies, policy strategies. There was a lot of different things that we were trying to put together, sometimes in a rational fashion, and sometimes in a somewhat awkward fashion, because we weren't aware of the matrix of how power worked at the city or state level, so there had to be an educational process. So we made mistakes, mistakes that we probably could have avoided had we been more knowledgeable about how the system worked. But nonetheless, there was a lot of these things going on. And in my opinion, that was true of a lot of other kinds of things in ACT UP. There were lots, I believe that there were lots of these small things, that never

really got the attention or the celebrity — for instance, never got newspaper articles — but there were, a large bulk of ACT UP's activity was this kind of work, that was not sporadic, not spontaneous, not irrational, but was trying to pursue a long-term objective, picking up the tools that were available to us at the time; when we were stymied at one point, moving on to the other. It wasn't just simply a case of giving up. Until, at, until it absolutely became nowhere to go.

**SS: But what about — I'm very troubled by the whole way you're characterizing this, I have to say. I mean, ACT UP was a different, was a less effective organization by 1993.**

A: I think it was less effective than it had been in previous years, but it was still, it was not ineffective.

**SS: No, I understand that. But I mean, you're saying, you're characterizing it in this very kind of heroic stance. That we, they were doing all this stuff, and it wasn't recognized, blah blah blah. But actually, just that ACT UP was less functional. And so it was unable to achieve things it was able to achieve before.**

Tape II  
00:15:00

A: Possibly that would have been the case. But other things were achieved with very small groups of people.

**SS: Right. That's true, too.**

A: Stadtlanders action is a good example of that. Four people –

**SS: Yeah, no, I'm not saying that that's not so.**

A: So I don't think I quite understand.

**SS: Well I don't unders-, I mean you're making this claim; you're taking this position that ACT UP was in this heroic stance, and it just didn't get enough credit for what it did. But it was actually less effective at that point.**

A: I don't think I'm arguing that ACT UP was either heroic, or that it didn't get credit. What I'm arguing is that ACT UP was doing quite a bit of things that oftentimes is made invisible by the record, because of these other large-scale heroic activities. And it's very important to understand that ACT UP was not simply five or six actions over a few years, but many, many actions, done by, oftentimes, smaller groups of people, sometimes medium-size groups of people. There was a lot more that was constantly going on in ACT UP, than Day of Desperation or Stop the Church, or Seize the NIH, or whatever the name of it –

**SS: All right. Well, we'll just have to disagree.**

A: Okay.

**SS: Okay.**

JW: Can you hold on just for a second?

**SS: Yes.**

JW: Hold that question.

**SS: Yeah.**

JW: I want to change here. Your sweater – {Mic adjustment} Thanks.

**SS: Okay. So let's move on.**

A: Okay.

**SS: What else would you like to talk about?**

A: Well, I just actually wanted to say something about how it was that TAG was able to be so powerful a force in the city. And it has to do with how NGOs, that are often financed on a combination of public and private donations, about the fear that motivates institutions. Granting institutions are primarily organized on the principle of fear. They're terribly scared that they will seem to, on one hand, that they will be too leading the edge, or too out there. They're worried about being considered sort of crazy or irrational. They're very concerned about appearing stable. So, which makes them very vulnerable to people who can then provide solutions, or an air of stability to the or-, to these institutions.

**SS: Which organization are you characterizing –?**

A: I'm talking about institutions in general. Granting institutions in general operate on principles of fear.

**SS: Oh, foundations.**

A: Foundations –

**SS: Okay.**

A: So in essence, if you, the best way to get a grant is not to be good, but to have gotten another grant, from other institutions. They work like packs. If so-and-so says this person is safe, then it's okay for us. It's very hard for an institution to say, to give that first initial grant. There are some — the MacArthur, for instance — but in general, granting institutions and money disbursements are kind of constantly watching each other to make sure that they don't seem too, too beyond the pale. So they're constantly waiting for, as it were, part of the system to sort of say, okay, this is, this person's good, or this idea is good, this is safe. And that makes them very vulnerable.

Which is odd to think, because we think, oh, they've got all this money; they're stable institutions. But they're actually, they can be extremely fragile, because even though NGOs were set up, they were given this non-tax-profit status to create social change, institutionally, they're actually very reluctant to do social change. And it's probably, again, for molecular levels of careers and things like that.

Now the reason why TAG, even though it was a very small group, was able to be so powerful is because they were able to get their members in policy positions among this network of institutions, whether it be GMHC, or whether it be AmFAR, or Lambda Legal, that they were, what they were able to do was that each time one of these positions came up, they were able to, as it were, speak not as TAG members, but as their institutional positions. So in other words, in their guise as institutional positions, like jobholders, let's say as policy director of X, they were then able to say, yeah, so-and-so is really, he's the person you really need to know; very smart; not crazy like ACT UP; they really can do it. And so what they were able to do in the mid-'90s is they were able to actually get this kind of like lock-hold on a series of these institutions. And then, it was very unclear as to when people spoke for TAG, or TAG issues, or when they spoke for these institutions. So oftentimes, it would seem as though you were in opposition to these major institutions, when in fact, it was oftentimes a TAG policy position that was then being mediated or amplified by the relative position that they had. And that's what made them so formidable a presence all throughout the mid-'90s.

Tape II  
00:20:00

**SS: Well what about all the work those people did? Wasn't that part of their credibility?**

A: It was part of the credibility, but there were also other people who also did good work, and were just as knowledgeable. I mean, the example of John James is an

–

**SS: Right. But he wasn't in ACT UP.**

A: No, he wasn't in ACT UP, but he was very closely associated with ACT UP/San Francisco, I think, at that point. And there were other kinds of positions. It also meant that there was very few, there was very little people who came into New York. In other words, the talent pool of New York was, remained at a New York level, instead of sort of the national level, if that makes sense.

**SS: Okay. Let's move on.**

A: Okay. Well that's really the main thing that I wanted to talk about. I wanted to give that chart of the CD 4 count –

**SS: You said you wanted to talk about Ron Medley?**

A: Oh, just very, very peripherally: that Ron Medley mentioned that I was involved with 076. And he's confused, because that took place before I joined ACT UP.

**SS: Okay.**

A: I think the point of confusion is that I knew Anna Bloom. And Anna Bloom was the one who came to the floor to give the reports in which she was arguing in favor of 076. So I think this is the point of confusion.

**SS: In favor of 076.**

A: Yes. Anna gave the report that said that ACT UP was wrong to oppose it.

**SS: Okay.**

A: Because she believed that it prevented transmission. And I know many of the other tran-, you've had debate in many of the other interviews about 076. So I'm, I don't have much to add about that, except to say I think, I knew Anna when we were both in graduate school, and I just think Ron got confused about that.

**SS: Okay. And you wanted to say something about Scott Sawyer?**

A: Not specifically about Scott Sawyer. I think, I mean, did you want to talk about the financial troubles of ACT UP?

**SS: Whatever you want. Go right ahead.**

A: Well, I mean it has to do, I mean if, if we're going to talk about what I thought was the relative, not failures, but problems that I think led to ACT UP being less effective, as time goes on. So –

**SS: Go ahead. Yeah.**

A: Well, I would just say this: I consider the great achievement of ACT UP to have been the CDC change in AIDS definition. Though oftentimes people say that is not the great achievement, it was parallel track. The reason why, and actually, it's Tony Davis who, this is Tony Davis's take on it, and I agree complete with Tony Davis. The point about the, about parallel track, and increased access to drugs is that that was not only an ACT UP initiative. There were a lot of the players who were in favor of that. Deregulation, so for instance, Republicans. Republicans are generally in favor of deregulation. Now I'm not saying that they drove that issue. But what it meant was is that there were a lot of, as it were, players who weren't going to be opposed to that. That still was a great achievement. But I don't consider it a sole ACT UP achievement, even if ACT UP, members in ACT UP drove that definition.

Now for me, the CDC campaign was solely an ACT UP initiative. It was really, I think our really great achievement in policy. And it was even our own in uniquely to other AIDS organizations. So I thought the campaign, the campaign to change the AIDS definition, really was ACT UP at its savviest, its smartest, its links to groups outside of ACT UP; things like that.

**SS: Okay.**

**JH: Wait, so were you involved in that?**

A: No –

**SS: No, this is before he joined.**

A: But in general, if I had to think what I really think was emblematic of the great success of ACT UP, it's actually not parallel track, or better access to drugs. Because there were a lot, lots of people were in favor of that. It wasn't, there wasn't the kind of resistance to that, even if that was, it was a great achievement of ACT UP, it wasn't, to me, as solely an ACT UP achievement. That entered into a relatively amenable environment. And I don't think that was the case with the CDC. It was a hostile environment, from all rounds. And the way the CDC campaign, the kind of activism that went into the CDC campaign, I think really was the shining moment of ACT UP.

Tape II  
00:25:00

**SS: Okay. And now, is there anything else you wanted to talk about?**

A: Yeah. I wanted to go back to the question on why I think ACT UP became less effective. I don't think ACT UP had any failures. I don't think – there may have been missteps, but short period of time, you do, it's in some ways, ACT UP should have more craziness. There was, I have, I don't have anything like that; I don't want to

speak against Stop the Church, or for whatever reasons. But I do think there was a situation around '92 that decreased the efficacy of ACT UP. And I don't think it was simply the split with TAG, although I think that was a problem, partly because donations to ACT UP were siphoned off. And so this led to this sort of decreased funding of ACT UP, which increasingly became a problem.

But I do think that there were some things that changed in ACT UP, that sort of led to its, to it getting smaller and smaller and smaller. So I'll just talk briefly about that.

**SS: Okay.**

A: The first was the loss of the educational structure. ACT UP was this great university of educating people about the issues. So when treatment actions came up, there was a lot of teach-ins, a lot of self-education went on. And as time went on, there was increasingly less of that. I think there was, people got more impatient about the learning process. It was more of like, just tell us what to do, and we'll go do it. And it was this kind of loss of that educational structure which hurt. It hurt because it was important to have these teach-ins because the people who would go into the meetings need practice explaining them. But it also hurt because it meant that we weren't training replacements. For instance, treatment replacements. A lot of times, if you're giving a training, there could be there's the people in the back, or whatever, this sort of generation. And see, they never heard a lot of the educational, that these kind of materials. So when the point came that there may have been replacements, we didn't have them. And that, it was that kind of like lack, or the sort of increasing erosion, of the alternative educational mechanisms in ACT UP which I think did hurt it as years went on.

It hurt it because people became less good at how to speak to the issues; and, which was a tremendous achievement in early ACT UP. And it also meant that potential replacements weren't trained how to become potential replacements. And that process kind of increased as the years went on.

I also think that by '92, there had become a kind of entitlement in ACT UP regarding direct action. So in other words, there was an increasing notion that if you did an action, you would get arrested. You'd be in and out of the system within a few hours. It was a kind of privilege, I think, that people – now in the Giuliani, and that was relatively true in the Dinkins regime. A lot of people have talked about the fact that the police were more amenable, and things like that. When the Giuliani administration came in, that ended. And I think that a lot of the anger at the Giuliani administration is, is that ACT UP members had actually, at that point, internalized a notion that they were something of the direct action elite, that they could go in, do their action, get put through the system quickly, and then get put out. And that when that stopped, people started getting increasingly frustrated. And I think the problem with that is, is that as time went on, people took the kind of Martin Luther King preparation, internal preparation and dedication to an action, less and less and less. It almost became, almost became something like you would purchase, we're going to, people would talk about, how many arrests they had in arrest-a-ramas. And then suddenly, when they were put back into, when we were put back into a position where we actually, people did have to spend time in arrests, there was a tremendous amount of frustration, and I think a bit of fatigue. And

Tape II  
00:30:00

I think there was a problem, in some ways, the Dinkins regime was also bad for ACT UP, because things started to get easy, easier, as time got on. And I think at a certain point,

we had forgotten the dedication that we, we really had to address for every single action. We had to think through, we had to be clear why we were doing things, and be prepared to take that action.

And so what it meant was that I think after, from '92 to '97, is that people would get arrested a couple of times, and then get burnt out far more quickly than they had in '87 to '92. Where people got burnt out, but often got burnt out because of personal issues, or the sort of the dynamism of the period.

So I think we, it was all this kind of combined together: the educational part decreased, which meant that people thought less about why they were doing it; then they got sort of tired – we started then some actions got very serious. So for instance, the Clinton Pledge campaign ended with Jim Aquino and James Learned getting arrested. And it was a federal arrest. It was a federal arrest. So they were told they couldn't leave the state. And it was an entirely new dimension. Which we were sort of unprepared about.

I think another example of this thing about the educational issue: it has to do, I think, with why Maxine thinks the move to Cooper Union was bad – that we were out of sight of the community. And increasingly, I think, one of the problems is that because we didn't do this kind of educational self-awareness, and we didn't kind of make dedications to it, some of the actions, increasingly, got done more for the arrest aspect of it, or the confrontational aspect of it. So for instance, the Clinton Pledge campaign, which was a notion that whenever Clinton would come to town, he would be confronted. But the key aspect of the Clinton Pledge campaign is, you had to pledge to get arrested within a period of 24 hours for, and not know why. Not know where or why. You just

basically had to commit yourself to being arrested. Clearly, this, that, this campaign vanished very quickly.

But it was that kind of gesture, where people increasingly, they weren't asked to be smart, to be savvy, that I think hurt the organization. Or increasingly, some actions were done because people just wanted to get the action in before the police got there.

**SS: You said they weren't asked. Asked by who?**

A: The Clinton Pledge required you to pledge to show up and be arrested, with no knowledge whatsoever of the action; various plannings of the action; and the specifics of the action; what was being demanded at that point. It was a pledge to be arrested. Which I thought was almost completely antithetical to the –

**SS: So you raised that on the floor?**

A: I didn't raise it. That Pledge campaign essentially collapsed. It didn't, have to be –

**SS: Was there a discussion when it was proposed?**

A: There was a discussion. But it was, at that point, it was kind of a confrontational discussion. People, I thought, were almost chastised for why they wouldn't participate in the Pledge campaign. Now of course, the reason why no one would have this discussion, or the reason why it was difficult to have this discussion, it was because there was a group of people who had come together in ACT UP that had a lot of high status in the organization. So it was very, very difficult to say, we don't think this is such a great idea, when you had this group of high-status people in the

organization that it became, in a certain sense, difficult to question what went on in ACT UP.

**JH: Who were those people?**

A: Well, it was a lot of the moderators. It was a lot of people who had done a lot of hard work, good work. Scott Sawyer was one; James Learned was another; Esther Kaplan was another; BC Craig was another. I mean, they're people who had had high-profile positions in the organization, and people who had led successful campaigns, as well. So it's very, it's very difficult to say to somebody who's done a lot of hard work, and has done, has had tremendous success — the Guantanamo campaign — tremendous, tremendous success —

**SS: Well, I'm really confused, I have to say. Because my experience of ACT UP — and I was in ACT UP for seven years — is that there was a high level of debate about everything. But there were very difficult conversations between all kinds of people, for a very long time.**

A: That's right. And I'm arguing — that in the period from '92 to '97, that decreased. That it —

**SS: So you're saying that you yourself did not raise questions in an active way about policies that you personally disagreed with.**

A: That's right. That's right.

**SS: And why did you not do that?**

A: I did not do that because I was very low status in the organization. I was just rank and file. I —

**SS: And when did the moment come when someone —**

A: Wait wait wait. Hold it.

**SS: Okay –**

A: Because I had been part of group actions that had been shot down by many of these high-status members. For instance, the campaign against Christine Gebbie was –

Tape II  
00:35:00

**SS: Okay, wait a second. So if what you're arguing is that at this point in the history of ACT UP, if someone made a rigorous, intelligent, committed argument against policy, they were not taken seriously. Then at that point, it's not a really very functional organization, is it?**

A: And that's what I'm arguing; that it became decreasingly, I'm trying to give a scansion on why I think it was, over the period of –

**SS: But you're, okay, so your explanation for why that happened is because people had status, and other people didn't? I think it's more complicated than that.**

A: And why do you think it is? What's your explanation for it?

**SS: For why ACT UP changed?**

A: Yeah.

**SS: Well, it's very, very complicated. I mean, many, many things occurred. One is the extremely high death rate and the consequences of that alone are almost unquantifiable.**

A: I agree. That was the very s-

**SS: The split – deprived the organization of a lot of functional personalities. And also alienated a lot of people from the whole experience.**

A: Yes, but it also deprived the organization of a lot of dysfunctional personalities, that in some ways had created an opportunity for reconstruction of ACT UP.

**SS: Okay, so then how come it didn't work out?**

A: It didn't work out because, I think that some of the legacies of the previous period, I think, were, by '92, there was an increased internalization of the safety and ease of doing actions. Those conditions changed with the change of administration. And the Clinton effect, which was a strong sense that when Clinton came in, that he was not such a bad person. It was a kind of indecision that descended, I think not just on ACT UP, but I think this is the story of the left in general in those periods: that Clinton would do the right things. And of course, as we know –

**SS: And so you're arguing that Esther Kaplan believed that Clinton would do the right things? So she wouldn't tolerate dynamic – conversation in the organization?**

A: – There was a campaign proposed by 10 people against Christine Gebbie, who was Clinton's appointment to AIDS czar, who was not tremendously competent; who was uninformed about the issues. And ACT UP wanted to do a campaign pursuing her. I mean, not stalking her, but confronting her in terms of policies, demanding that she do more. And yes, this was voted down by the floor after several high-status members had spoken against this policy, and then we were told not to do this because we had to give Gebbie a chance.

**SS: Well, then it's not, it's no longer a functional organization.**

A: It's in the process of becoming less functional. It's not as though it stopped in one day. I'm talking about a period of several years. It's not as though it just, one line would be, TAG left and ACT UP died. That's not at all the case. There were phases. I'm arguing that over a period of years, these liabilities became more and more a problem. Now they didn't necessarily have to be a problem; but they became one, over years. So I don't think it's as easy to say it's a, it's not a functional organization. It was a functional organization. It was just functioning, over time, less effectively. And then this functioning less effectively created ultimately other problems, such as the financial crisis.

**SS: Now what about the people we've interviewed who were late members, like Ron Medley, like Richard Deagle. What was your feeling, response, to their testimony?**

A: What do you mean? More specifically.

**SS: Well, as they were detailing and chronicling ongoing campaigns that they were involved in in ACT UP, within this time period in which you were involved. 'Cause they paint a very different picture than you do.**

A: No, I don't think they did. I think you have to listen to the, what I was trying to say about CD4. It's not an either-or situation. The ACT UP, what I'm trying to say is, I'm trying to paint a picture for what I think, a process that went over years that ultimately led ACT UP to be less effective. It didn't just suddenly stop being effective. It was tremendously effective. So, it's a complex picture. ACT UP is still doing lots of things, is still very active. What I'm trying to present is what I think is ultimately factors

that led, over a period of time, to ACT UP being a much less effective institution by the time that I left in '97, '98. It's not simply this or that.

**SS: Okay.**

A: So when I read Ron Medley, and Ron's transcript, or Richard's transcripts, I think they're exactly right. I don't see what I've just said as in any way contradicting what they have argued.

**SS: Okay. I don't have anything else. Do you guys?**

**JH: Yeah, I actually do.**

**SS: Okay, go ahead.**

**JW: We have to change the tape.**

**SS: All right, let's change tapes.**

**JH: So why don't you add what you wanted to add.**

**SARAH SCHULMAN: Okay.**

A: The first of the two. Yeah. Just two more things that I wanted to add.

I also think that what happened as time went on is there was a loss of community feeling.

A lot of times, people kept on saying, we need the affinity groups to come back. The affinity groups are the structure. But as the years went on, some of the affinity groups,

they became more and more enclosed. They weren't sort of reintegrated into a lot of groups. So people would, they would just come in for like, I think it was, what, what

happened is, if people in Cooper Union, as people have talked about, if they sort of

stayed by the side, or whatever, the week, there was a sense of sort of these little groups.

I think by the time when we went back to the Center, this notion that we would have a

meeting, but there'd be little groups, increasingly, these groups would now only come for

Tape III  
00:00:00

20 minutes. They'd only come for their action; then they would leave. And that was a process that I also think started accelerating. So that people almost felt as though they had – they took their cue from TAG. It's almost as though they felt more identification with the group, rather than the, with their affinity group, or quasi-affinity group — I'm thinking of City AIDS Action as a primary example — rather than ACT UP. And this, I think, further increased this kind of disaggregation of the group. So I think, I mean I do think there was a loss of the sense of community that many, many people talk about, as really holding the glue, the solvent. There was, there was a –

But also, a lot of this has to do with the period, again. I mean, you had talked about the increased number of deaths. And clearly that was true, and clearly, we started having the period when people who really were very beloved and respected started passing away, and it started the political funerals — Aldyn [McKean], Bob Rafsky — that was going on.

But I think there was also, what also can't be discounted is the post-Berlin, pre-Vancouver era of desperation. And what I mean by that is, after the AIDS conference in Berlin, after the Concorde trials, which showed that there really wasn't, over the long term, there really wasn't any benefit to taking AZT or not taking AZT. Right? This is before the theoretical –

**SS: But were you, was this something you experienced?**

A: Yeah.

**SS: This is before you came, or after you came?**

A: No, this is after I came.

**SS: Okay.**

A: Berlin was '93.

**SS: 'Cause did you know Bob Rafsky and those guys? Aldyn McKean? That's before you came.**

A: No, I mean I didn't know them, I didn't socialize with them, but I knew them, yeah. No, Bob was still in the organization – for about a year. Aldyn was in the organization for – I mean, I had a couple of conversations with Aldyn. I wasn't very close to Aldyn, but –

**SS: Okay, I'm sorry.**

A: I mean, now, one of the first meetings that I came, that I remember was the members coming back from, I think, Tim Bailey's political funeral? Where they had carried the corpse to the Republican headquarters? Was that Tim Bailey? Yeah. I very clearly –

**JW: Mark Lowe Fisher.**

A: Mark Lowe Fisher. I very clearly remember that as my third or fourth meeting.

**SS: I see.**

A: People returning from that. Returning from that campaign.

**SS: Okay. So in that, Berlin, you were saying.**

A: Yeah. After Berlin, people came back. And you have to remember, there wasn't that theoretical model that could explain why AZT alone, over long periods of time, was insufficient. And there weren't, there was not really anything in the pipeline. The protease inhibitors were seen, the information was very difficult to get out of the drug companies. There had been a large investment in this, TAT, as I mentioned,

which was the last really large-scale treatment action, done with TAG and ACT UP.

They did, we did actually come together for that. But that quickly went nowhere.

So there was this sense of – and then of course, the Vancouver was the introduction of the drug cocktail, which of course meant, for many people — and I think myself would be included — marks the sort of breathing space, now people seem to be living longer. This is the moment. But in, there's that period between Berlin and Vancouver, which is a very bleak period, as well.

Tape III  
00:05:00

And I think it's not simply the deaths, although the deaths are very important. But it was the general sense that we don't have cards anymore. It's not, it wasn't as clear to say, if we can get access to drugs, then we'll be okay. All those kinds of agendas or interests between '92 and '96 is Vancouver? It wasn't clear exactly what the treatment agendas would be. And I think to their, if you are going to make a defense of TAG, I think this is the defense of TAG, is that large simple trials were their effort to respond to that.

All the, a lot of times there's a lot of discussion about the split between social issues in ACT UP, and the treatment issues, as though one was at the advantage of the other. And I don't think that's true, and I particularly don't think it's true in this period between '92 and '96. It wasn't as though there were clear treatment actions of the scale that had been done between '87 and '92. When in that sense of desperation, it meant Bob Rafsky, very, one of the last times I heard Bob Rafsky, I think he said, I respect the people who are activists, and I respect the people who are going to Fire Island, just trying to have a good time with the, trying to enjoy themselves with the time they

have. He said, but what I don't like is the people who come to meetings only waiting out their time, so they could go to Sugar Babies.

But nonetheless, there was that kind of dynamic. It was not clear what to do. I mean, it was just a tremendously depressed time. And I think that's different from saying that increased deaths. Because actually, after Clinton, after the sort of routine health care got better under Clinton. And mortality and longevity rates went up under Clinton, before the protease inhibitors. Right? Protease inhibitors increased it. But the trend was already starting to go up, and it was starting to go up because PC prophylaxis, and better treatments, did come in. That was one of the things that Clinton did. But it wasn't clear what else you could do, at that point. So there was this kind of like freeze. That was one of the factors of the freeze that went out.

The other thing that I think made ACT UP a less effective organization is its cultural success. And what I mean by that is in the periods between '92 and '95, there was a tremendous renaissance in lesbian and gay civil society in New York. Magazines started to come back. Admittedly party magazines, but nonetheless, magazines. Many social clubs. People were in the academy. Many clubs. There was this, it was the sort of great blossoming, again, of clubs that took place. And so what it meant is that if people may have come into ACT UP not only because of, as a personal response to lovers and friends dying, but because it was this tremendously vibrant place of lesbian and gay civil society. By '92, and for this period, '92 to '95, well, I think of *Out* magazine, that would be one example. There were lots of competitive sources. So lots of people felt that they didn't have to go to ACT UP. I'm thinking of *Sex Panic*, for instance. None of the members in *Sex Panic* felt that they had to make any connection with ACT UP,

whatsoever. And so that too meant that, and it wasn't simply groups like WAC — we lost, losing members to WAC, or losing members to Lesbian Avengers — you could argue that. But it's not, it's simply that there were lots and lots and lots of different things that arose because of ACT UP's success, that created, ACT UP created this cultural revolution. And one of the consequences of that is that after five years, ACT UP no longer had to be the primary reference point. So which meant, is that when people came in, and wanted to be active, ACT UP was not primarily the first place that they went. And that meant that we were losing the staff members, or the personnel, that would have helped rejuvenate the organization. And I think there's — it's this weird dynamic of being at the same time, a period of increased desperation, but also a period of vitalization, but not in activist circles. And those, all these factors, I think, sort of combine to, leading to '97. It's not simply one factor, but they all, they form this kind of general environment.

**SS: Okay. Jim, did you want to —**

**JH: Yes. You started to talk about the financial aspects of ACT UP, and then you didn't go into it. So I wonder if you could talk about that.**

A: Well, of course, the other thing that really hurt ACT UP was the prolonged financial crisis, where suddenly, the monies that supported ACT UP vanished. The treasurer at the time, Scott Sawyer, came in, and said, we have \$40,000 less than what we had. And one of the consequences of that is that we lost the work space. Which meant that we no longer had a stable base. Which also was a real, that really was one of the weakenings of ACT UP, is that we lost, as it were, our mode of production, our means of production. It meant we couldn't Xerox to get information out to people. It

means that we didn't have phones. I mean, all, meetings couldn't be organized; posters were increasingly more difficult to make.

So the lack of the finances and the crisis about what was happening to the money also helped dissolve the glue that kept ACT UP together. Because the structures that we had had for ACT UP — namely, having two treasurers, so there could be a check and balance — that failed. One of the treasurers left, was not replaced. And so then we were left with a single treasurer, who, as it came out, was the source of the problem. And we never really were able to investigate it quickly.

Now in retrospect, what we ought to have done is that the minute there was a financial crisis, an ad hoc committee ought to have been established, of five or six members. We didn't do that. And what it meant was, over a long, painful period of two years, we sort of burnt ourselves out on yet another strand, leading ourselves to a certain point not doing any actions at all because of the lack of money. And again, it was a self-defeating, it was a cycle, a vicious cycle. Because the less actions we did, the less publicly we were seen, which meant the less reasons there was for people to give money to ACT UP, which meant that we could have less actions. And we sort of, we ended up in this decreasing cycle.

**JH: Do you know what happened to the money?**

A: Well, I suspect that the treasurer took quite a large amount.

**SS: Is that general consensus?**

A: It is general consensus. There was a paper that was given by Bob Lederer and Bob Lederer's boyfriend, whose name is —

**JW: John Riley.**

A: – John Riley. They brought a paper to the floor detailing this. And it was, it was talked about. And then it was a discussion about whether to pursue this legally. And there was a general vote that we would not pursue it legally.

**SS: And did Scott resign?**

A: Scott disappeared, to my knowledge. Never to be seen again.

**SS: And it was \$40,000?**

A: No, we'll never know. I think I have the more pessimistic view. I think it could be much more than \$40,000. The difficulty is that one of the things that we discovered is that Scott had set up, because there were no longer two treasurers, Scott had set up, we discovered one bank account that he had set up, which he was the only signator. Now, we discovered one. That doesn't mean that there were not others. The problem with ACT UP is that it was a 1001 4C organization, not a 1001 3C.

**JH: 501.**

A: 501, yes. The distinction is, is that people could donate money to ACT UP, but it wasn't tax deductible. Now, in a tax, 501(c)3 organization, both the donor and the donee have to have records of these funds. Now, in a 5014c, or 3c –

**JW: Four.**

A: – (c)4, there, this, dual records do not have to be kept. So the thing is, money may have come in to ACT UP of which we never, we will never be able to find. So it's very, we, there's, you can't say 40,000. It's simply not possible.

**SS: At least 40,000.**

A: At least 40,000, maybe at least 10,000, maybe at least a hundred thousand. There's just no way of knowing, because records did not have to be kept,

legally. And that was, I mean the, we didn't want to have it, we didn't want to be a 501(c)3, is that the name of it? Because it would have prevented us from doing certain kinds of political activities. Which is, which was right. But the consequence of it is that when the group started to become distressed, there was no way, there was no sort of safeguards. And so what it meant was there was this tremen-, it's the saying, how did you, what's it? *The Sun Also Rises*. How did you become broke, all at once and suddenly. And what it meant was, over a long period of time, and then suddenly. And then so, there was a period where week after week, tens of thousands sud – there'd be ten thousand, it was almost like the roller coaster: oh, this week, we only have two thousand; this week, we only have zero.

And so we had to leave the workspace in a period of, I think, two weeks. It wasn't even a matter that we could properly, properly leave it.

Now of course, this tied directly into the acquisition of the New York, of the, of why New York Public Library has the ACT UP archives, and the debate about that. Now the debate in the organization was whether it should go to the Center, as a lesbian and gay organization, or the New York Public Library. And there was a debate about that. But the point — well, I shouldn't say the point — but these debates had to be done in extremely compressed fashion, because if we did not have a decision within literally a period of 10 days, the papers would have been completely lost. Or probably would have been likely, I mean, in retrospect, I think, why didn't we just get a storage space. But that, the concept of the storage space wasn't something around. We could have saved them. But there was very much a sense that 10 days, and everything ACT UP had would be on the street, and/or lost or destroyed.

Tape III  
00:15:00

So what it meant was, in these periods, is that a lot of energy was spent on emergency provisions. And that, that had its impact as well. But of course, there was a lot of bad feeling about that, too. People left because they felt alienated by the fact this situation had taken place. I mean, City AIDS Action left almost immediately after the loss of the workspace. I think they left a week after we left the work space. The two events are sort of relatively synchronized.

**JH: So what was the debate about the New York Public Library versus the Center?**

A: The debate was whether, if I can characterize it, one side felt that the papers should be in a lesbian and gay-controlled organization; that heterosexuals, or straight society, wouldn't understand the materials, and wouldn't protect them, and that we should sort of build up community organizations. And so that, I think that was the Center, the Center side.

On the other side was an argument that ACT UP was New York history and American history. And that we had a right to be seen as such. That if they were in the New York Public Library, preservation materials would be held at a much, they'd been, the papers would be preserved much better, for the long term, than they would be at the Community Center. Stuff at the Community Center is held in basements. If there was a fire, there was no fire –

**SS: Who wanted it in the Community Center?**

A: Maxine wanted it in the Community Center. Bill Dobbs wanted it in the Community Center. Ann Northrop wanted it in the Community Center. Alexis

Danzig wanted it in the Community Center, and others. I mean it wasn't just those four. It was definitely a wing of ACT UP that wanted it in the Community Center.

Now for me, I was very nervous about this, because if there was a fire, the things would have gone up. And of course, that's not such a crazy thing to say, because the first Center was burnt out, and it was in a firehouse. Right? There was, it was a firehouse, there was a fire, and we lost it.

And of course, the second thing is, is that, which was the unsaid secret before the reconstruction of the Center, is it was a public school; Community Health Project was there; the place was falling apart, and which meant it was asbestos-ridden. It was actually an unsafe, now of course, nobody really wanted to say that, because nobody wanted to criticize the Center. But all throughout the city, there's massive amounts of money to get asbestos out of public schools. But the Center was not part of that system. So I also thought there was important health considerations for not having it in damp, underground, asbestos, friable conditions. I mean, that was why I, one of the reasons why I wanted it in New York Public Library.

I also thought that it, as I say, and others thought, that it was, that we sh-, that in 50 years, there's going to be an ACT UP stamp. It's, they're going to incorporate it into the mainstream narrative history, which will be bad and good. But in other words, but we, we deserve to be there.

And we also wanted it in the New York Public Library for a specific reason. And the reason had to do with staff dedication. Now if we had it at the Center, the Center operates on volunteer staff. Which means that you could only access it by the goodwill of staff volunteers, oftentimes in the evening, or whatever. Now if we had it in

New York Public Library, it meant there would be 9 to 5, or 9 to 6. They would make a financial commitment to it, which they, which you have to have, because when an institution like New York Public Library is they actually have to invest in keeping that, that space there. Because it's to their, it's professionally embarrassing if they're not taking care of the resources. It's like a big, the cardinal sin of access.

So we knew that actually, when we're looking at ACT UP, and instead of 300 people coming to an ACT UP meeting, as I recalled in '92, when we're at 30 people, in '97, and you think, okay, in 2027, how many ACT UP members are there going to be? How many Community Center members are there going to be for this, versus – and the answer is, we don't really know. And versus that the New York Public Library, well, we do know. They might have budget cuts. But they're going to have a rare archive. They had just made this massive commitment to building subterranean levels. It was going to be there for –

And the reality is, is that after we got it in the Center, and we, there was, there's two significant things about the ACT UP archive which made NYPL history. The first is, it was it a public domain grant, which means, nobody has copyright over that material. They had never had a public domain grant. It took them three months, the lawyers had to spend an extra three months to figure out how to accept material under which no one held copyright provisions. And there, no one held private property. They were also stunned by the fact that we put no time restrictions on the material. They had just got in the One, I think it's the One archives, there was a 25-year ban on that material, before anyone could even open up those boxes. And we wanted an oral history, as it were – to come out, and we wanted people to wait 25 years for an oral history; think of

all the difficulties, think of all the people who can't be here to speak this. Now add 25 years. So we wanted contact sheets and information in there; we wanted people to know about that. They were stunned by that.

And lastly, that information can be made, can be seen by high school students. It's the only material in the New York Public Library Rare Book Archives which is accessible to people under the age of 18. And the reason why we wanted to do that, because a lot of the material was YELL [Youth Education Life Line]. Cardinal O'Connor was on the board of the NYPL, and people have said very s-, I, somebody said, a very smart interview, about how after Stop the Church, people took O'Connor much less seriously. But we didn't want any kind of interference, so that it was information that had been made by teenagers, non-researchers, and we wanted high school students to be, to have that resource. Now maybe it's a little utopian to think that a 16-year-old is going to go into the Center. But a couple have, actually. That's also unique. There's no other material in that library, in the Rare Books access, to which a non-college student can attend. Of course, that took time, to sort of negotiate.

Now what happened is, we put that information in the archive. And within a period of six months, it became the most frequently asked for material in all of the NYPL catalog. We're not talking about the Shelley letters. We're not talking about the Wordsworth letters. ACT UP's material is the information which people want to see the most, and more frequently. The tr-, in other words, the resource was there, and as it were, the people came. And if, had they been at the Center, we would not have had that kind of, that kind of access. It just wouldn't have taken place.

So maybe people very knowledgeable about New York City, like yourself, would have been able to gain access. But people who were out of those loops, never would have been able to find that information.

**SS: Okay.**

A: So there was that. There was, that was this debate that, that took place.

**SS: Go ahead.**

**JH: You named four or five high-status individuals who were against it. How did you win this argument?**

A: Uhhh.

**SS: “High status” in quotes.**

JH: Yes. That’s his term.

**SS: That’s your term.**

A: Well, yeah, but also people who actually I respected very, I mean it was people who actually, who I respected practically more than anyone else in the group. I don’t know. It’s one of the mysteries to me. I have no idea why the floor voted for it to go to NYPL.

**SS: Is there anything else that you want to talk about?**

A: Yeah, just two –

**SS: All right, let’s hear it.**

A: – two other things. Actually, it had to do with – it actually is kind of my response to reading some of the transcripts. And I kind of just want to sort of offer my gloss on this. I don’t think ACT UP was so special because there was a set group of, like a 10 percent that was just like politically dedicated for activity in their life. I think

that may be true. But I think what made ACT UP special was that it took people who were not lifelong activists, and empowered them to do activism, maybe for just a brief phase of their life. But it was that ability to, as it were, to take people who ran the whole spectrum of relationship from being not on the left to being sort of peripherally on the left, or left in spirit. It was, it, what made ACT UP amazing was its ability to empower lots and lots and lots of different groups together. And I don't think, if the oral history will, for me, if it has a tremendous achievement, it will be to the ability to which it's able to tap this, outside of some of the more well-known names and figures. Because without the kind of broad rank and file that became empowered to do kinds of activities, maybe for the year and a half to three years which was the average tenancy of people in ACT UP, the people who had long histories in political activism would not have been able to accomplish the things that's done. I mean, oftentimes the model is, is that people who had a history of political activism met men with resources. And I think that's true. But it's also true that that meeting would have not come to any great achievements had it not been for the sort of the broad activity of memberships. The way ACT UP was really able to sort of educate people into a kind of cultural activism for the life. To me, that's the great success of ACT UP, not – the skill of a specific group of individuals. I also think it's true that there are class issues in ACT UP. I think this was very, very true. And I do think that there was this gender split that maps onto class. But it's also interesting that a lot of the women who've been interviewed have been professionals, and relatively highly educated as well. And I think that's something kind of interesting to think about as well; that they're, it's, they also came with professional managerial skills. I don't think it's so easy a split as to say the men were in these positions, and the women were not. The

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women brought in a history of political activism. If you look at a lot of the women, the women also, a lot of women came in with relatively secure positions as well, maybe not as much money as a stockbroker. But also come in with, I think, more security. And I think there's, that's also something interesting to think about, that the binary is not as sort of clear-cut or straightforward on that.

And two last things. I think ACT UP's visual history is important. But I, again, I think that the achievement of ACT UP does not lie in its relation to people who were professional artists or writers. Though the poetry and the images of ACT UP come from the sort of, the rank and file. People were provided with that. I think it's, it's, it would give a not-completely-correct view to think of ACT UP as the action of aesthetic elites. There's lots of people who had very little relationship, did not get involved in the arts or graphics or rhetorical issues of ACT UP, that provided that, that to me is the strength of ACT UP. It was these groups.

Again, it's a situation of the people who were skilled wouldn't have been able to do anything without the sort of creativity of the broad population of the rank and file; the people who come in, oftentimes who didn't take, quote unquote, leadership positions, but really were the heart and soul of ACT UP, despite the fact that ACT UP had many, many, many amazing individuals, who were able to speak eloquently, who were able to formulate policy decisions far more clearly than government officials whose job it was to deal with it. But none of that would have really come to anything had it not been for the sort of broad masses, the hundreds of people coming to meetings, coming to actions. That's the, sort of the lifeblood of the organization.

And it, and that's much trickier to get, to recognize, because they don't leave the kinds of records or traces. But nonetheless, that's what I, to me, that's the real, the heart and soul. And ACT UP's achievement was its ability to sort of create this kind of culture of political activism among broad sections of people, who maybe neither had financial resources nor long experience with ways of representing themselves, or long experiences with political groups.

I think oftentimes, in the interviews, there's a sense that ACT UP was betrayed by the already-existing left. Right? That the, in other words, ACT UP wasn't taken up as an issue for the, let's say *The Nation*, the left of *The Nation*, or the left of these institutions. But in some ways, what makes ACT UP great is that it moves beyond this model of these old left institutions, which at that point had become, I think, a sort of elite, standing elite. ACT UP breaks away from that, and that's why it was able to have the power that it does, and that's why it was it was able to, as it were, as the book collection argues — *From ACT UP to the WTO* — ACT UP provides much more of an inspiration to antiglobalization movements, anti-sweatshop movements than these older left, sort of New Left, or post-New Left organizations that did that.

ACT UP might not have been supported by *The Nation* and the *Village Voice* for a long time, but that I don't think weakened ACT UP. If anything, it empowered ACT UP, because it allowed to, as it were, empowered these new populations, these new people out there, which these older magazines had failed to do. I don't think you could say that *The Nation* or the *Village Voice*, or even some of these old, even like the ACLU or whatever, by the 1980s, by the early 1980s, they were no longer capable of creating the social movement. ACT UP was. And if it's true that we might

not have had the resources or the support of these organizations, but I think actually, in retrospect, that was a benefit. That, that was a freeing, not a disabling motion. So I'm not that bothered by the fact that the sort of, the quote unquote, broad left of the 1980s, as it were, failed to come out. Because basically, that was the left that was in crisis, not ACT UP. ACT UP was responding to a crisis. These older left institutions were, more or less, far less functional than the ACT UP of '97; even the ACT UP of '97 was a far more functioning organization than these.

So I, we might not have gotten help. But it's, I, for me, this is not really a case of betrayal. And I think that's, what makes ACT UP special is that it breaks from that model. It's a break in the left tradition. And that's a good thing. And I think that will be the, sort of the legacy of ACT UP beyond the lesbian and gay community, and beyond health issues.

**SS: Okay. Let's end on that.**

A: Yeah.

**SS: Thank you.**

A: Thanks.

[Long Pause]

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00:30:00

**JH: I wonder if you could talk a little bit about T&D [Treatment and Data Committee] after TAG left. What it was like –**

A: Yeah, I can. Do you mind?

**SS: No, go ahead. You know what? I just want to –**

A: Do you want to split?

**SS: I just feel like I need to go away. Can you just undo this [microphone]?**

**JH: Yeah.**

**SS: Thank you. Okay. Go ahead.**

A: Okay, thanks a lot, Sarah.

**SS: Okay.**

A: Do you want to take a pause, or do you just want me to go on?

**JH: No, go ahead.**

A: Okay. T&D. I was in T&D for a year. Or I attended meetings in T&D for a year, in my first year. T&D, generally, what I think happened to T&D is that T&D, I think there were two problems with T&D. The first problem was that T&D became increasingly unwilling to bring actions to the floor. There was a lot of debate and a lot of discussions in T&D; but they wouldn't bring them to the floor. They wouldn't bring any actionable things to the floor. So it became more and more enclosed.

The second aspect is, is that my opinion is that there was a rump of TAG members who stayed behind to ensure that T&D did not bring actions to the floor, that actually stayed behind to contain T&D. I don't think it was the case of just T&D not doing any things. I think there was, there was active pressure to scramble T&D.

**JH: Could you be more specific about that? Talk about any particular issues, or persons who did something?**

A: Well, there were a lot of issues. I think Kevin Frost was remarkably unhelpful in this regard. He's a very voluble person. I can remember Bill Bahlmann being screamed at by Kevin, on various kinds of actions. Andy Vélez and Kevin Frost,

of course, loathed Mark Milano. So what that meant was that the AIDS Cure Project, of course, was always going to be cut off from T&D. So there was kinds of snaps. The CD4 campaign, actually, CD4 was shouted down. I don't think I've ever been shouted at in the way, when I came to T&D and talked about that.

But it was systemic. I just think, it, it's not simply just one thing. It just happened for like a year and a half. I honestly believe that a few TAG members stayed behind to ensure that T&D wasn't, was, would not be effective. So much to the point that one of the last things that Bob Rafsky did on the floor was he chastised Kevin Frost for Kevin's arrogance and refusal to trust the floor with actions. And that's really an incredible thing. The fact that Bob Rafsky said this on the floor. He begged Kevin to have more faith in the floor and to bring more actions to the floor and not to split off from the group. So I think that that's, in some sense, that's the case of what the problem with T&D that went on. If that speaks to what you were what you were arguing.

**JH: Did they continue to try to do science in T&D?**

A: Yeah, they did. They were. I forget the name that they did. People would track a particular drug. I know Rick Loftus did this. Theo Smart was doing this. And others. So they would do that. There would be discussions about that. There was a lot of discussions about TAT, people who had a lot of faith in it, and others who were cautious about investing so much energy into it, considering the long, that it would just be another in the long list of things that turned out not to work, like egg yolks or shark cartilage, or whatever. There was also a renewed attempt — very, highly frustrating — there was a renewed attempt to teach basic science to T&D members. They actually, which is how I learned a lot of it. They put together the ABCs, I think, of AIDS, or

whatever. They would educate themselves. But the information never got to the floor. Just never came to the floor.

So there was that kind of activity that went on. It was, they were still doing things, but increasingly, just a few people. And they just, the bridge was broken, just I think after the Hoffman-La Roche action, no actions came from T&D, with the exception of, I think, Ocular Ganciclovir. Would that be right, James? And a treatment through eye drops. But after that, no, to my recollection, no treatment actions came from T&D to the floor. The treatment actions came from the AIDS Cure Project at that point. But T&D became increasingly less of a presence. Sort of almost invisible to the organization. So that vital link, that vital link of treatment to direct activism also increasingly was less active in ACT UP.

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**JH: Okay. Anything else?**

A: Let me just – one second. Sorry. Just let me –

Just one second. I just want to think about –No. I don't think so. Thank you.

**JIM HUBBARD: Thank you.**