

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

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**MIX – THE NEW YORK LESBIAN &
GAY EXPERIMENTAL FILM FESTIVAL**

Interviewee: **Sandy Katz**

Interview Number: **058**

Interviewer: **Part I: Sarah Schulman**
Part II: Jim Hubbard

Date of Interview: **October 15 & 16, 2004**

Tape I
00:05:00

SARAH SCHULMAN: Ready?

Sandy Katz: Oh, so you're gonna film me from two different angles?

SS: Yeah. Look at me.

Jim Hubbard: Look at Sarah.

James Wentzy: The tapes last 40 minutes, so we'll change tapes every 40 minutes.

SS: Okay. So the way we start is you say your name, your age, where we are, and today's date.

SK: Okay. My name is Sandy Katz. And we are at Short Mountain Sanctuary, where I live, which is in Cannon County, Tennessee. I'm 42 years old. What was the –

SS: Today's date.

SK: And today's date is October 15th, 2004.

SS: Okay. And just for the purposes of total revealing the fact that we have a past, we went to high school together, in New York City. And you were the first boy in an all-girls school.

SK: That's true.

SS: That is true. So were you born in Manhattan?

SK: I was born in New York Hospital in Manhattan, but I lived the first four years of my life in Queens. And then I was part of this law school — lawsuit to make Hunter High School, which had been an all-girls school for a hundred and ten years, coed. And my first year there, there were 18 boys and 1200 girls, among them, Sarah Schulman.

SS: Yes. Why did you want to do that? Just out of curiosity.

SK: {sigh} Well, I mean I had gone to Hunter Elementary School, and you know, in a way, you know, like the path of least resistance was to go to Hunter High School, with most of the people I'd gone to elementary school with. And you know, if we hadn't have been able to go to Hunter, then it would have been, sort of figuring out an alternative to what I had been doing for my elementary school education. So you know, I mean, I don't think it was spurred especially by like, you know, a strong ideology. But you know, it was more that I'd been in this amazing elementary school, and I don't know, it seemed like, you know, unfair to not be able to continue with half of my peers at this equally wonderful high school. And you know, the alternative was either to go to the neighborhood junior high school, or to go to a private school. And you know, my, we were exploring both of those alternatives, because we had no idea if we would win this lawsuit. But –

SS: I just ask because most 12-year-olds are not involved in lawsuits. And I was wondering if your family or you had a very strong sense of justice at that time, and if that felt like something that was typical for you to do as a family.

SK: You know, my recollections of how it all started are very, very sketchy. But I, my impression is that for a number of years, there had been sort of like a conversation among the parents of the elementary school, you know, boys, about taking some form of action. Because you know, this was the period when all of the all-boys public schools in the city were being opened up to coeducation. You know, Stuyvesant, Bronx Science, those had all been historically all-male schools. And I think that they were emboldened, somewhat, by the courts' willingness to make those schools

coeducational, and just felt that it just took, it would just take some organizing, and raising money for a lawyer. And we actually ended up using the same lawyer who had gotten Stuyvesant coeducational – Eleanor Jackson Piel.

SS: Okay. So when you were growing up, was there a lot of discussion in your family about justice, making things right, or being proactive, and that kind of thing?

SK: Well, you know, I feel like there was a lot of – you know, admiration for the civil rights movement and the antiwar movement, and you know, definitely – glorification of the idea of citizen action sort of forcing the government to do what’s right.

SS: But your –

SK: But not that my parents were like huge activists or anything. But I feel like their sympathies definitely were with the activist causes of those times.

SS: What did they do for a living?

SK: Let’s see. My mother – my mother had a bunch of different careers.

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When I was a little kid, she was a teacher of English as a second language. Then she got involved in this Saturday theater for children kind of thing. And then she became an administrator at NYU. And then after she split up with my father, and regretted her, like, nonprofit years, she worked in cable television. And my father worked in the knitwear apparel industry.

SS: Okay. So you came into this all-female environment — one of just a few boys — and you were gay. Or maybe you weren’t aware of it at the time. But what was the relationship between those two phenomena for you?

SK: Hmm, that's a good question. Well, I mean for one thing, I'll say, I feel so lucky to have, you know, completely, like, missed the, you know, typical American high school social cultural dynamics that I've seen so much on television and movies. You know, like you know, dating culture; sports culture. You know, it was really lovely to go to an all-girls school, just to, like, avoid all of that. I mean, it wasn't, it didn't really make it any easier for me coming out or anything like that. I mean, while I was still at Hunter, there actually was like a gay rights organization that formed. I remember Donna Minkowitz being a very out figure. And you know, I had a mixture of like admiration for her, you know, and just feeling like appalled that somebody could like self-identify like that. 'Cause I, I was nowhere near ready for that kind of a step in my own life.

I remember being aware of, you know, certain teachers being lesbian or gay. Although I don't really recall any of them explicitly talking about it. I mean, I, I feel like it was just kind of understood. And actually, I recently came across, in a biography of Audre Lorde, that Audre Lorde had been like all in love with Miss Burstein.

SS: That's right, she'd gone to Hunter.

SK: Yeah. So like, you know, her, like, teenage journals were all full of like fantasies about Miriam Burstein. {laughs}

But you know, I mean it made it easy for me to have a lot of friends who were girls, and you know, not have a lot of pressure to be like going out with any of them. But I certainly didn't like come out at that time in my life. It wasn't until later.

SS: Now were you involved in any kind of political organizing while you were a high school student?

SK: Well, you know, one thing that you and I share is that we were both the president of the GO.

SS: That's right. I didn't know that about you, Sandy.

SK: I was the president of the GO a couple of years later. I'm not sure if that qualifies as political organizing, but you know, in its way, it does.

SS: So you were the first male student body president.

SK: I was.

SS: What made you want to do that?

SK: Well, you know, I, I always was interested in politics, you know, in all sorts of politics, definitely in activist street politics; and also in electoral politics. And you know, even before I was at Hunter, I had done electioneering on behalf of candidates, and I had joined my local political Democratic club, Community Free Democrats, as an 11-year-old. You know, sort of instigated by me. My parents sort of thought this was very weird. But they supported me, and like would walk me to the meetings, and stuff like that. But I always was interested in electoral politics. At Hunter, when we had like our little mini-course week, I spent the week with Ted Weiss, who was then a City Council member. I was just always interested in that. So I don't know, it was just sort of when I was in school, and there were like, you know, there was a government, and offices to run for, I just did it.

SS: Okay. It was just your thing.

SK: Yeah.

SS: So you didn't come out, really, till you got to Brown?

SK: Yeah, I was about, like, 20 or 21 when I really came out.

SS: Okay. Thank you.

SK: Yeah, I mean it, it, it took me awhile. You know, in a way, I think, living, I grew up on the Upper West Side of Manhattan. And I was really aware of all of these gay men, in particular. But I just, like, I so strongly did not identify with, like, the characteristics that I could identify in like the typical gay men that I saw on the street, that I, I really, I just felt like, like I wasn't gay, even though I obviously had all this like sexual attraction towards, towards other guys.

Tape I
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And in a way, it took like getting away from New York, and you know, getting away from sort of the clone culture that I could see to sort of, I don't know, feel free to come out a little bit more.

SS: So when you came out, that was what, the early '80s, right?

SK: Um hm.

SS: Now that's right, you know, the beginning of the AIDS crisis.

Was that, were you aware of AIDS as you were coming out?

SK: Yes. Yeah.

SS: Do you remember how you became aware of it?

SK: I, I, I can't remember like, you know, the first references to AIDS or gay cancer, or whatever. I mean, later on, in retrospect, you know, I've read like the early articles that appeared. But I don't specifically remember seeing them. But I mean, I remem-, by the time I started having sex with men, I was definitely aware that there was this like, uh, that there was this, uh, you know, health crisis in, in, in the gay world, and that I, that there were precautions. I mean I think that, I think I was aware of, say, of some basic safe-sex ideas before I was having sex with men.

You know, at the same time, I'll say that sort of because of what I was just describing, of like this idea that I just was so strongly not identified with the men who I could, you know, tell from a block away were, were gay. I did feel sort of weirdly distanced from AIDS in my early sexually active years. I felt like the guys who I was having sex with, like didn't really fit the profile, and you know, I, it, it, I wasn't, I don't think I was really sort of seriously considering the idea that, that they could have HIV.

SS: Well what was the gay culture like when you were at school, in the world that you were part of?

SK: Well, there was a pretty active and large lesbian and gay student alliance — LGSA — Brown University, it was for most a pretty liberal, tolerant environment. You know, although certainly, there were definitely plenty of homophobic incidents that were going on there, especially if we would do proactively gay events, inevitably somebody would have to deface a poster, or have a, like a straight day, or sort of something, just to be contrary.

But it was definitely in that scene, of like the self-identified lesbian and gay students, that I was coming out.

SS: So when or how did AIDS become real to you?

SK: Well, it's kind of interesting. I think that — probably my experience is different from a lot of people in ACT —, probably a lot of people in ACT UP had a friend who died of AIDS, or AIDS came into their life in some way like that, and that's what brought them into ACT UP. But my own route into ACT UP didn't really have to do with personal experience with AIDS. And it was only once I was in ACT UP that I started becoming friends with people who had AIDS, or who knew that they had AIDS.

And you know, the ways I first came into contact with ACT UP were first through the Gay Pride Parade, the first year of ACT UP, which would be 1987 Gay Pride, when there was like this huge concentration camp float. That made a huge impression on me. You know, just, just, you know, thinking about AIDS in a more political way, even though I wasn't, I didn't have personal exposure to people with AIDS, but I just started thinking about it in a politicized way. And for whatever I lacked in personal experience with AIDS, I mean I definitely did have a political analysis of the world, and it made AIDS more real to sort of see it depicted in a political analysis like that.

And then, in 1987, my mother was battling with cancer, and she ended up dying at the end of 1987. But she was in Sloan Kettering at the time when ACT UP was doing a vigil outside of Sloan Kettering. To, you know, the vigil had something to do with AIDS clinical trials. And getting them speeded up and expanded. But I was visiting my mother in the hospital while the vigil was there. And so I stopped, and I remember talking to Bill Monahan for a long time outside of Sloan Kettering one day. And that was my first kind of direct experience with people with ACT UP, and learning about it.

Tape I
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And then it was really a couple months after my mother died that I started going to ACT UP meetings and demonstrations, and getting involved.

SS: Okay. So at that moment, when you started going to ACT UP, who were you? What were your ambitions for yourself? What kind of life were you imagining for yourself?

SK: Well, let's see. At that time – I had just moved back to New York. I had been living, I had spent a year living in Chicago, being a high school teacher at a small alternative high school in Chicago. And I had been thinking that I would be a

teacher. I was really, I, I feel like I had very kind of idealistic – ideas about teaching, and just wanted to devote myself to that.

And then I was supposed to go back there for a second year, and sort of, in the middle of all that is when it became clear, like just how sick my mother was, and how little time she had left. And I ended up not going back to Chicago for the second year of teaching. And my mother's illness kind of dragged on. And they ended up replacing me at that school. And then meanwhile I found this job, a community organizing, political organizing job. I became the executive director of Westpride, which was sort of organizing on the Upper West Side to stop Donald Trump from building Trump City. So I got this job, doing political organizing against kind of the most appealing monster in New York at that time. And I also-, it also paid twice as much, exactly, as my teaching job had, so I don't know, I just sort of, I let go of my teaching ambition, and so at that point, I had this political organizing job. That was very fun and engaging. It was mostly raising money from wealthy people on the Upper West Side to hire lawyers and keep Donald Trump in court, to prevent him from realizing his ambitions.

SS: Did you succeed?

SK: Well, we succeeded for a while. We succeeded for a while. And then basically, we always had to present ourselves as we're not against all development. We're for rational development, and this is irrational. And so, eventually Donald Trump started scaling down his plans, and involving the organization that I had worked for, and negotiating with them. And they ultimately became partners of his in building what he's still building on the West Side, which is a pretty significantly scaled-down version of

what he'd originally been talking about. But you know, it's still a huge monolith of buildings.

So no, we didn't really succeed. But it was, it was a great job while I was doing it. I definitely enjoyed it, and met all sorts of people. You know, got very plugged into the New York political world. And so, in the middle of doing that, is when I joined ACT UP. And – I don't know, I mean it wa-, I sort of felt like I was leading this double life. 'Cause you know, by day, I was organizing around land-use issues that just felt so small and unimportant to me, compared to the AIDS activism that I was doing by night. And then, and it was all the stuff I was doing at Westpride was all very within the system. You know, it was engaging the system. It was going to meetings with city planners, and deputy mayors, and all those kinds of people. And then at night, after ACT UP meetings, I'd like walk all the way uptown with wheat paste, and be wheat-pasting things. So it gave me a little bit of a feeling of living a double life.

SS: What about the other people in ACT UP? What do you feel that they were doing during the day?

SK: Well, everybody had different day jobs. I mean, one of the things I remember is – the whole Xeroxing system, and how, if you had something that you needed, like, five thousand copies of, there were so many people who were office workers in ACT UP and they were very well organized. And it was just a matter of activating a phone tree, and getting these people originals, and then a few hours later, you come have five thousand copies of whatever you wanted, courtesy of law firms, and whatever other kinds of institutions people were working for.

Tape I
00:25:00

So I mean I feel like I met people in ACT UP who were doing all sorts, I mean a lot of clerical workers. I was always, whenever I went to receptions or things, I was always running into cater waiters that I knew from ACT UP. It seemed like lots of people had various kinds of professional jobs and lives. And then there were also lots of people who were living on benefits at that point, and not working, and having a lot of time to devote to AIDS activism for that reason.

SS: Can you explain to our modern-day audience what a phone tree is? Was?

SK: {laughs} Um, okay. So yeah, before there was e-mail, and you could notify 800 people at once, if you wanted to notify 800 people, you could either have one person call all 800 people, or you could organize a phone tree. Which means, let's say I call 20 people. And each of those 20 people calls 20 people. And maybe even each of those 20 people calls 20 people. And it's just a way of disseminating information, you know, don't forget about the demo tomorrow. Or whatever it was.

SS: And did people do what they said that they would do? Did they call the 20 people?

SK: Well, sometimes it would work out better than other times. The thing about a phone tree is, okay, let's say one person is out of town, if they're near the top of the phone tree, then a whole branch of the phone tree never gets activated. So sometimes it worked; sometimes it didn't.

SS: But I mean, within the culture of ACT UP, would you say people were mostly accountable, and fulfilled their obligations and promises in those terms?

SK: Yeah. That doesn't mean a hundred percent. But I feel like most people did. I mean I, you know really – my feeling at the time was just of total devotion. And I feel like, I feel like a lot of people shared that sense of total devotion.

SS: Can you explain why?

SK: Well, I mean for one thing, it was just like, it was the urgency that, that I felt, and I would say we all felt, or most of us felt, about what we were doing. You know, that it just, it just, it felt like it was life or death. I mean, it was, it was, in certain senses life or death.

And it also felt like what we were doing was powerful and being effective. And if it's life or death, but you're like, you don't feel like you're accomplishing anything, it's hard to stay devoted like that. But it just felt – it felt to me so much of the time like what we were doing was having a real impact.

SS: Can you think of a specific example of something that you saw change, or that you realized, or ACT UP achieved, that you were part of, that gave you that feeling?

SK: {sigh} Well, I mean – uh, you know, I feel like in, in certain cases, it was just about bearing witness to what wasn't happening, and sort of getting that recognized, and – and no, I feel like we were enormously successful in that regard. You know, I can think, in retrospect, of all sorts of things. Needle exchange. I mean needle exchange really gained acceptance through the work that ACT UP started, and then other organizations joined in on. That, to me, is one of the most tangible examples of something changing.

SS: Were you involved in needle exchange?

SK: Hmm, a little bit.

SS: Right.

SK: It was definitely, it was never a – it was never a central focus of mine.

SS: So would you say that if one committee or group achieved something, or succeeded in their goal, that the whole organization felt like it was a victory? Or would you say that the different projects were separate and on their own tracks?

Tape I
00:30:00

SK: Mmm. I feel like for the most part, everybody in ACT UP, I mean I guess that that changed over time. In the time when I first started ACT UP, there was, I feel there was a lot of unity. And then, over the course of several years, things got, part of the reason being that the organization just got bigger, but it also became more disjointed. But I think overall, there was a large sense of all-for-one, one-for-all, and recognition that the issues that were relevant to the project of AIDS activism were many and varied and disparate. It's not to say that there weren't people who maybe had an arrogance that their agenda was the most important one. But I feel like for the most part, the people who I was hanging out with in ACT UP were, could be supportive of agendas that were, that people were pursuing that weren't their central focus. You know, some other thing, I, definitely, some of the treatment activism felt like we had a real tangible impact on getting drugs moved through more quickly, getting the price of certain drugs reduced.

You know, the – New York City–focused activism, focusing on ways in which the city hadn't channeled resources into AIDS. I fell like we had an impact in the

elections in 1989. I don't know what that changed in the long run. But around that time, I just, I was full of a feeling of, you know, ACT UP's collective power and – and I think that that just made me – it just affirmed my devotion to this cause.

SS: Okay. I just have one more general zeitgeist question –

SK: Zeitgeist.

SS: – and then we can get into the precision of everything. Well, it just seems like indifference is sort of the stumbling block of humanity. And yet, ACT UP, there were so many people who did not have AIDS themselves — and at that time, you were negative, or thought that you were negative, right? — who made this commitment to somebody else's life, that human beings almost never make. Why did that happen?

SK: Hmm. Well, I don't know that human beings almost never make that. I mean – I think that looking at the movements that inspired me as a child to just sort of always identify myself as an activist would be primarily the civil rights movement and the antiwar movement. And also the feminist movement. I mean especially growing up in that Hunter environment, I was very much feminist-identified. But I mean all of the movements that seemed important to me never were directly about me. So I don't know –

SS: But you didn't join those movements, did you? Were you an activist before ACT UP?

SK: Well, I mean I was involved in like Central America solidarity work in the early '80s. I definitely, you know, when they first reinstated selective service registration in the late '70s, you know, I was a little bit involved in, I went to some

demonstrations against it. I had been to dozens of demonstrations in Washington, and pro-abortion-rights demonstrations. I mean, I had never gotten as deeply involved in any of those as I did in ACT UP. But I mean, I feel like I had always been drawn to the idea of people demanding change.

Tape I
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And I really had been an activist all through the '80s, and I never, you know, there I was in the '80s, sort of always hearing that activism is dead. And it was just never, it was never my experience. You know, when I lived in Providence, I was involved in this collective, left-wing bookstore – the Dorrwar Bookstore. But I, I just, I always have been interested in collectivist institutions, and radical political change. And –

SS: Well did you ever conceptualize of yourself as a potentially future person with AIDS?

SK: Not really. I mean, I really just, I just, you know, I guess I felt like I had enough information, and – you know, was smart enough that I wouldn't, I wouldn't get it. And I never particularly had any anxiety about having been exposed to it. And the times when I got HIV-tested, it was always as a companion to someone who was filled with anxiety about having been exposed, and just wanted a friend to go get tested with. So, and it's kind of interesting. I didn't test positive myself until 1991. But I did start testing inconclusive in 1988. And on two different occasions, it was the same scenario, of a friend who was filled with anxiety. So I went with them to get tested, and got tested, really just thinking I was doing it as support for them. And then, they came back negative. And I came back inconclusive. Which I didn't really interpret as positive. I, I, I sort of constructed all of these elaborate – you know, reasons why I would have a, an

inconclusive blood test. I had had malaria in the late '80s, and some doctor told me, maybe my malaria was making the test read strangely, or. Um. But it, no, it wasn't 'til I actually tested positive in '91 that I, that I really thought about the possibility that I could be positive. I had, I had even had boyfriends who were positive, but I, I just felt like I was being so careful and by-the-book that, uh, that I'd be okay.

SS: So did that change your relationship to ACT UP?

SK: {sigh} Well, you know, I mean my relationship to ACT UP had already changed before that. In a way, it brought me back into ACT UP. Less – less in street action activism, and more in terms of connecting with resources that might just give me more information. In particular, I was interested in learning about alternative treatments. You know, I had done enough screaming about AZT that I wasn't interested in going that route. And Jon Greenberg, in the last year of his life, really ended up being a very major influence on me. And we became good friends.

SS: One of the things we've done in our interviews is everyone we talk to who's positive, we ask them to tell us what medications they take, or what treatments they take.

SK: Um hm.

SS: Do you mind telling us that?

SK: Yeah, no, I've been, uh, well, I mean really, for the first eight years that I was positive, I was very dogmatically opposed to the drugs. And I felt like, I even, for most of that time, I didn't even get my blood work done, because I felt like I would never take those drugs on the basis of a blood test as long as I felt healthy.

And that was a big part of moving here, moving to the country. You know, be – and before I tested positive, I was very career-centric, in sort of, maybe like a classic New York way, or something. But that was really what I had always conceptualized as the center of my life. And somehow, testing positive really – really just pulled the rug out from under that as the organizing concept of my life.

Tape I
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I mean, I was still working in politics at that time. I was working for Ruth Messinger, in her borough-president office. And part of working a situation like that is, I was really sharing Ruth's ambition. Ruth wanted to be mayor, and I wanted Ruth to be mayor. And partly 'cause I thought she was a wonderful person, and would do a better job of that than any of the other people who might do it. And part of that was also that, then I would find myself in a position of greater influence.

And then suddenly, it was really very abrupt. But after I tested positive, I was like, why would I ever want to be the commissioner of a city agency, or something like that? Suddenly, it just seemed like it would be the most burdensome thing I could imagine. And my career ambitions just disappeared. And I don't know, I just started craving some complete change in my life, and I didn't really know what that would be. Until I just accidentally, in New Orleans, at Mardi Gras, met some people who lived at Short Mountain, and they invited me to come visit, and just described this – fairyland in the woods. And it just seemed so different and interesting that I came and visited. And within a year, I moved here.

JAMES WENTZY: We have to change tape.

SS: Change tapes? Okay.

SK: Okay, I need to pee.

Tape II
00:00:00

SS: Okay.

SK: Do you want me to just pick up where I was?

SS: Yeah, I want to know what your treatment –

SK: Okay, so, but anyway, I was telling you all of that, because I really had this idea that good, clean living was gonna keep me healthy. And you know, it did for a while. And I was completely against taking the drugs. And then in 1999, I just, I got really sick. You know, I developed like a persistent nausea. I lost weight. I was having fainting spells. I, I just was kind of on a classic HIV wasting downward spiral. But I didn't recognize it. I just thought I was depressed.

But anyway, eventually I recognized it. And I don't know, I had this whole like internal dialog, where I felt like it's noble to die for your ideas, but I wasn't ready to die for my dogmatic opposition to pharmaceutical drugs. So, since 1999, I have been on Viracept and Combivir. And it's, I've just, it's integrated into my life. I take it twice a day, every day. You know, maybe a couple times a year I miss a dose. But I'm pretty on top of it. And it's working for me, and whatever the side effects are are pretty minimal. I have a lot of, I have a lot of worry about it in terms of long-term toxicity. Like, how long can you really take these drugs? What impact do they have on your liver over the course of years and decades? But I'm really happy to be alive and healthy, and –

SS: Do you think that Jon Greenberg died for the ideological reasons?

SK: Well, he certainly was not, he wasn't ready to take those drugs. You know, I mean the drugs that were available at that time, I think they weren't as sophisticated or as effective as what's available now. And I feel like I can really respect

people who make the choice for themselves to not – not get involved in pharmaceutical medicine; have their lives completely medicalized. So yeah, certainly the choices he made at that time have everything to do with – I will say, if he had decided to take drugs, or had been more pharmaceutical-oriented, it doesn't really guarantee that he'd be alive. I mean, Hush, whose house we're in, was lovers with Stephen Gendin at the point when he died. And he is someone who really embraced the drugs, and as each new drug became available he took it in sort of, in like serial monogamy with the drugs. And developed resistance to all the drugs. So by the time they figured out how to sort of combine them in a more effective way, they weren't, he was resistant to them all.

So I mean, I feel like, in retrospect, my own, my skepticism about the drugs probably served me well. Because if I had started in 1991, taking high-dose AZT that had been recommended to me, then I probably would have developed a resistance, too. And I feel like I owe, well, I mean the idea of not taking AZT didn't originate for me with Jon Greenberg, but it really gave me just a role model of somebody who was, and he wasn't against medicine altogether. I mean he was definitely taking some prophylactic medications.

And you know, his big thing was to try to get proponents of various alternative-treatment modalities to submit their treatment modalities to the same forms of clinical testing that the pharmaceuticals were doing, and try to legitimize things, or really learn what's effective and what's not effective. I think that was a really good idea. Of course, the thing, the problem with that is that it takes tremendous resources to do that kind of testing. And you know, for things that are more generic and don't have the

Tape II
00:05:00

potential to make a huge profit for one specific entity, who's gonna pay for that kind of testing?

SS: Okay. I wanted to talk to you about specifics about ACT UP. And I know it's 15 years ago, but try to remember as precisely as you can, especially who was there and who did what, and that kind of thing. 'Cause one of the things that we're doing is trying to really historicize it; the sequence of events; with a structure; who did what. 'Cause none of this has ever been documented fully.

So can you tell us what, like for example, what committees did you work on in ACT UP?

SK: {sigh} Well, I was pretty regular on the Action Committee. And that was sort of in the early period of ACT UP, there was like this specific committee that was the Action Committee. I think Ron Goldberg was the head of the Action Committee. And you know, as people were developing campaigns and targets for demos and zaps, the Action Committee would try to work out the logistics. We would create clever chants; that was really Ron's specialty. And just figure out who's gonna do what. Like we'd lay out different scenarios. Like if the police let us get to this corner, this is where we want to be. And then scenario B, if the police don't let us be here, then we'll go here. Okay, we're gonna need marshals. How many marshals do we need? Okay, we're gonna recruit people to be marshals. Do we need to special trainings for people? Okay, who's doing the fact sheet? Sometimes we did, some of the actions at ACT UP, I mean I think we did incredible amounts of internal education, just to bring people, bring a large number of people in the group up to speed on the details of particular issues.

So the Action Committee is one place that I remember being part of pretty regularly.

SS: Can you tell us like a specific action that you really are proud of that you worked on, or that you really remember well? Or one that failed miserably?

SK: Well, okay. As you say that, I'm remembering like my first ACT UP action, you know, that I was involved in organizing, which was a kiss-in in front of St. Patrick's Cathedral, some time very early in 1988. It was really small. I remember, I can remember Neal Broome being part of it. You know, I mean I, beyond the generic –

SS: Well –

SK: – crimes of the Catholic Church relating to AIDS education, I mean I don't really remember specifically what sparked it.

SS: But what was the motive of the tactic of a kiss-in? What did that mean to you?

SK: Well, , here was this huge, powerful institution denying homosexuality, and trying to suppress AIDS education, and promote sexual repression and abstinence. And I think it was just like, it was defying that. You know, it was saying, it was just being in your face. Like, look, homosexuality exists. Okay, you don't like it. Well, you can't deny that it exists, because here we are. And you are using the power of your institution to deny the existence of something which does exist, and because it exists and there's this disease that's going on, people are dying because of your denial.

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00:10:00

I actually can remember, I was involved in quite a few, you know, AIDS education issues. A lot of stuff with like the Board of Ed and the Board of Regents. I can remember once going out to Middle Village, Queens to distribute condoms and safe-sex information at a middle school. And a lot of the kids were afraid to take the stuff, because the principal was standing there with her arms crossed. But some of the kids were, some of the kids were defiant and, and took the stuff we were distributing.

I remember a huge action, where hundreds of us went to Shea Stadium to do a visibility action. “Men, wear condoms or beat it,” I think that that slogan was from a huge banner that we had at Shea Stadium. And we bought group tickets through the regular group-ticket buying channels, which entitles you to get a message up on the scoreboard. So, periodically during the game, they were flashing safer-sex educational slogans on the scoreboard at Shea Stadium.

SS: What did it mean to go to Shea Stadium?

SK: Well, I think just going into the arena of sports, it's, that's the, you know, the ultimate – site of male bonding and heterosexist male culture, that I think most people in ACT UP felt pretty distant from that. And, in terms of confronting the idea of – men passing HIV to the women who were their partners, Shea Stadium sort of symbolized the site of male heterosexuality and heterosexism. And, it was just, it was very potent and exciting just to go to a place like that as a large group, and just be visible as queers. I mean, some people got all decked out and dressed up, and, people were making out in the bleachers of Shea Stadium. And I think, beyond the specific safe-sex message that we were there to spread, it was a larger sort of queer visibility and – queer, I

don't know, what's the word? It's not like, it's not an invasion, but it's – just confronting this, this institution. You know, sports.

SS: And was that, I mean so that was primarily an action that was geared towards supporting straight women, and asking them to use condoms, right?

SK: Um hm.

SS: Was that, were there other actions that significant, that kind of size and weight inside the organization that were for women, or that addressed heterosexuality?

SK: Well, there were definitely some. Like when I first was coming to ACT UP, a demonstration was being planned that, I was out of town. I wasn't there. But *Cosmopolitan* magazine had just published this story saying that the idea of heterosexual AIDS was a myth. And I remember ACT UP getting very involved in countering that idea, and saying that AIDS was real, and that heterosexuals needed to be aware of it and think about it as well.

SS: Were there straight people in ACT UP?

SK: Oh yeah, definite-, I definitely was, was friends with people who were –

SS: Men?

SK: – who were straight in ACT UP. A few. I, I mean –

SS: Do you remember who they were?

SK: I can remember John Kelly.

SS: That's right.

SK: Um – yeah. Definitely, I can remember more straight women than I can straight men. I mean I had various straight men who would, who would come to ACT UP demonstrations, and would periodically come to a meeting. I think, I think for them, coming to an ACT UP meeting was, they felt outside of it. Um, and they, they felt very supportive of the work that ACT UP was doing. But you know, culturally, they just felt like they weren't part of it.

SS: Well what was it like for a group that was predominantly gay to plan an action that was advocating, that was on the behalf of heterosexuals, or for their benefit?

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00:15:00

SK: Well, I mean as I'm saying, I, I think that the message that we were putting out at Shea Stadium was on the one hand, this informational message for heterosexuals. But, at the same time, I think that the really empowering part of that action for me and I think for a lot of other people, was just to, to go en masse to this most heterosexual of institutions, where maybe our dads had dragged us when we were kids, and we just, we always felt outside of that. And just to sort of go as a large group, and confront that institution, was very thrilling and empowering.

SS: I see that. I think what I'm trying to get at in addition to that is, how did ACT UP see itself in relationship to the global community of people with AIDS, even though it was primarily a gay organization?

SK: Well you know, I mean gay men were kind of the vanguard of AIDS. We were the first group to get it. But it seemed pretty clear –

SS: Well it was the three H's, right? Hemophiliacs, Haitians, and homosexuals, right.

SK: Right. But I, but I mean it seemed pretty clear that it was gonna spread really quickly beyond the confines of those groups. And you know, maybe it was that as the group that was first affected by it we could see that. And it was like, it was part of the witnessing work to just let people know that this was happening, and that this was real, and that living in denial was gonna – have a cost.

SS: Did you ever feel frustrated or disappointed or angry, or anything like that, that straight people, or the families of people with AIDS, were not on the front line in the same numbers as other, gay people?

SK: Um – no. I mean, you know, I felt more – like admiration for those few cases I can think of where the families really were there. Like I ca-, like okay, one thing that just pops into my mind is Frank Smithson. Okay? He, his family was involved in some car business, where he was always like driving cars for them, between New York and somewhere in the Plains or the Midwest or something. And during the 1988 presidential elections, he was just popping up at campaign appearances all over in unpredictable places in the Midwest, just like interrupting 1988. I guess it was George H. W. Bush, and probably the Democratic candidates during the primary. And he would just show up, and zap them. And his mother started doing that with him. And I, I remember him proudly coming, and showing off photos from newspapers of him and his mother, standing up, interrupting whoever those candidates would have been.

So I mean, I just remember more being struck by those like few instances where the families really took the issue seriously, and became part of ACT UP themselves.

SS: Did you ever have friends or acquaintances who were disappointed that they didn't have the support from their families about having AIDS that they wished for or needed?

SK: Oh yeah. No, I mean I definitely feel like I –

SS: Do you remember any specific examples?

SK: Well, you know, Rodger Pettyjohn is someone who I was friends with. Who felt like from his fa-, I remember this one, I mean certainly, I think he felt abandoned by his birth family. But at some point after one of his hospitalizations, he was released into the care of some friend — I don't know who the friend was; it wasn't someone who I knew — and then Rodger felt like the friend was only interested in caring for him as long as he was dying. And then once it became clear that he was gonna be around for a while, suddenly the friend didn't have so much room for him. And he felt, he, he felt abandoned by that friend, or that that the friend could only support him as long as he was in the mode of dying, and not once he was in the mode of recovering and –

SS: So it wasn't a familial relationship –

SK: Yeah.

SS: – in that sense. Yeah.

SK: So that's a specific case that comes to mind. But I feel like a number of friends who died in ACT UP, like their families were conspicuously absent.

SS: Can you still remember who those people were? 'Cause other people have talked about that, too.

SK: Well, I think of Clark — I can't think of Clark's last name. But – I mean I don't know this for a fact, but it seemed like his family was really absent. I went

to a memorial for him at the Quaker Meeting House on 15th Street, and I don't remember any family members being part of that. And I can remember, I can also remember counter-examples. I mean really, the, well this guy who I was in an affinity group with. I was in an affinity group called the Candelabras. We were Liberace's avengers. And we formed for the big FDA action. And there was a fellow in the affinity group named Douglas Byrd, who, he died a couple of weeks later. And our affinity group was really tight for a while. And I remember, we like got together, and wrote this letter, card to his mother. And she wrote, she just wrote us back like the sweetest, sweetest note. I mean not that she had gotten involved in AIDS activism per se. But she – she was so appreciative of it. You know, both of how much it had meant to Douglas in the last period of his life; how much hope it had given him at a time when he was really spiraling down. You know, and just the broader importance of the work that we were doing, it felt like she really appreciated it and recognized it.

SS: Can you talk a little bit about the affinity-group structure? Like how did you come together, and what kinds of things did you do?

SK: Well, okay. Affinity groups are, were different than committees. That affinity group came together specifically for the FDA action. And we got together on a number of occasions, and tried to decide how we as a group would participate in that action. And we came up with the idea of making tombstones. The one that I, that I held — I got a picture of myself in *Newsweek* magazine, so I remember what it said — but it said, I died for the sins of the FDA. And it was all about, it was a hand with red ink. And then the names of drugs that were just stalled somewhere in the FDA's pipeline. So

we all did like this die-in, laying down in front of the FDA, holding our little tombstones, with drug-specific messages on it.

So what the affinity-group structure sort of did was it – we came up with a coherent image that we would all make happen together.

SS: And how did you get into the Candelabras? Were you invited, or?

SK: No, it wasn't real-, uh –

SS: Could anyone just join any affinity group?

SK: I think different affinity groups structured themselves in different ways. I can't remember how we all came together in the first place. I kind of have the idea that it was, it was at a, perhaps there was a meeting of people who weren't already aligned with some existing affinity group, who were looking to create new ones, and the group just sort of split off into different groups of people. I can't remember if it was randomly, or sort of people choosing other people who they already knew or were friendly with. But I feel like in the Candelabras, there were a lot of people I had never met with, met before or interacted with. So it must have, there must have been a certain amount of randomness to it. But you know, we started having meetings at different people's houses. I mean, during that period, when I was really involved with ACT UP, I mean it just seems like most evenings, I was involved in some kind of a meeting. And again, it just gets back to this feeling of incredible devotion. Like it just felt like the most important thing in the world. I couldn't think of anything better to do with my time. And that just became my circle of friends, also. So, it sort of satisfied a lot of my social needs.

SS: What happened to your old friends, the ones who weren't in ACT UP? How did it affect your relationships with them?

SK: Well, I feel like I could have dragged most of my friends into ACT UP in some peripheral way. I was always like calling them, and telling them to come to this demonstration that was like near where they worked, or whatever. So some, certain friends, who like, I'd bring them to the big meetings. They were like, oh my god, this is too much for me to sit through this much processing. But I mean I don't feel like I lost any friends over ACT UP. People who just thought it was like, horrible, disrespectful. You know, most of the people I was friends with were at least sympathetic with ACT UP.

SS: But how did it change your life to be spending so much time in one environment?

SK: Well, I mean I loved it. You know, I mean I had a real, I think it really – it answered like a craving that I had unfulfilled, you know, for kind of a coherent sense of community. You know, I think up until then, I had sort of random, disparate friends. But it, you know, sort of suddenly, I had this sort of like circle that I was friends with. And you know, there were specific people within ACT UP that I became more intimately connected with. But I mean I do remember just this feeling of this like really big circle that I was in with, and I liked that.

SS: Now who were the other Candelabras? Do you remember?

SK: I remember some. Let's see. I can remember Zoe Leonard was –

SS: Um hm.

SK: – in the Candelabras. Sharon Tramutola was in the Candelabras. Michael Young was in the Candelabras. David Leavitt, briefly was in the Candelabras. Those are the names that are coming to me right now.

SS: I want to ask you a little bit about the culture of illness inside of ACT UP. Were you aware of the people who knew, which ones were positive and which ones were negative? And were you ever involved in care groups for people inside ACT UP?

SK: Um, you know, just, I was a, I'll say that I was aware of the people that I was aware of. I mean, I can remember the first person who I ever explicitly knew was HIV-positive was Michael Petrelis. And you know, at the time, at the time that he first said that on the floor of ACT UP, and I became aware of that, it just filled me with admiration for him, just for the bravery of being so open about that. I was never involved in a structured care group. But I feel like I spent a lot of time in hospitals just visiting people who I'd become friends with who, when they were ill.

SS: Do you think people were open about being HIV-positive inside the group?

SK: Um, I think many people were. I mean I feel like there were a lot of people who openly identified themselves in the group as HIV-positive. But I'm sure that there were plenty of people who didn't. Yeah, and I think that there were plenty of people who only found out at some point after they were associated with ACT UP that they were positive. But I feel like generally it was a very supportive environment that was pretty easy to be open about HIV status within it.

SS: Do you –

SK: I mean, I don't really specifically know of anybody who was HIV-positive there and felt like they needed to hide that.

SS: Did people in ACT UP have safe sex?

SK: Um, I did. Although, you know, not nearly as much of it as I would have, might have liked. But yeah, no, I mean I think people were – I think people were, generally well informed. I think that the people in ACT UP faced the same struggles that all people do around safe sex, which is, first of all, most real-life sexual encounters aren't just black and white, like this sex act, that sex act. But there's like, you know, there's a lot of gray area and a lot of sort of touching and groping, and fingers in assholes, and cum all over bodies, and I don't know, like it's not, it doesn't really all fit the textbook scenarios of like anal sex, oral sex. You know, I think a lot of sex happens when people are inebriated in some ways. That's when people have the, seem to have the easiest time hooking up. And when people have the least chance of making really smart decisions.

So I think that those factors are, were in play for people who were in ACT UP, just as they are for anyone else.

SS: Let's talk about the fun social side of ACT UP. Where, what part of it were you at? I know that there were certain clubs and bars that ACT UP people went to. There were certain parties. How did you, what was your circle?

SK: Well, I, other than the ACT UP period, I never have spent any time in clubs or bars. And it really only made it fun to go to clubs and bars, like going to places where I'd walk in, and I'd already know half of the people who were there. So it was like going to, it was going to somebody's party, a friend's party, and there'd be all these

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friends. I actually just, I just recently was like, when I was in New York, I was at this community garden that was across the street from where the World used to be.

SS: Oh, Jack [Waters] and Peter [Cramer]'s garden.

SK: Yes, yes, yes, exactly. The Versailles garden. [Le Petit Versailles]

SS: Yeah.

SK: Yeah. And you know, we were just talkin' about the World. And I mean I was just like so not a club kid at all. But I had gone to a bunch of parties at the World because they had been benefits for ACT UP. And I had so much fun going out to the big clubs when there were all these people who I knew from ACT UP at them.

Also, you know, The Bar; the now-departed Ba-, The Bar. T-H-E Bar, on Second Avenue and Fourth Street. That was another big ACT UP hangout, where I would often go and just run into people I knew.

SS: Did you live in the East Village? I can't remember –

SK: I didn't. I moved to the East Village, I just moved there like maybe 1992.

SS: Okay.

SK: Like my last year in New York I lived there. But I had mostly lived on the Upper West Side.

SS: Now, you mentioned earlier that at a certain point, you started to change your relationship to ACT UP, or your feelings started to change. Can you go into that a little bit?

SK: Yeah. Well, I'll tell you. In 1990, I started working for, I started working for Ruth Messinger as the borough president; well, she was the borough

president. I was an aide. And I kind of – it wasn't really my intention when I started working for her, and I really, the first year that I was working for her, my job had nothing to do with AIDS. My job had to do with land-use planning stuff. But I just sort of got involved as an intermediary. Like, trying to – trying to get her to be more proactive on AIDS issues, and go out more on a limb on AIDS issues, and also trying to give people in ACT UP more access to her.

But I ended up, it ended up putting me in this sort of intermediary position, where over time, I just started feeling like a mixed allegiance, that just made me start feeling a little bit more outside of ACT UP. You know, because I mean I was sort of trying to help her navigate, where she could find her place, that wasn't necessarily taking ACT UP's position, but moving towards it. And I don't know, it just, becoming in that – putting myself in that position, finding myself in that position, just made me feel a little bit more outside of ACT UP. Like I was mediating between ACT UP and this political figure.

And it was sort of at the same time that ACT UP was just getting much bigger. And I was feeling less part of a cohesive community of people. And it also coincided with one action that I was involved with which I think was particularly divisive and kind of scary for me personally, which was the Stop the Church action. You know, I had, I had kind of halfheartedly decided to be inside the church. But you know, in something that I understood to be like a silent act of defiance. 'Cause you know, I just feel like I would never – I would never personally presume to get in the way of somebody's spiritual or religious practice. And the sort of sensational events of that day, which included sort of shouting down the cardinal, and somebody spitting out the body of

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Christ; and then the president and the mayor and everybody in between talking about what we had done. Well, I, I mean I got very scared. You know, that we were really going to do some time for that. And I felt really, I didn't feel good about having been part of sort of shouting down a religious service. You know, it was something like I didn't really feel –that I would have done. But you know, there I was, part of a group where it happened.

So you know, that sort of happened at the same time that I was having these other experiences that were making me just feel a little bit more distant from ACT UP. And I don't feel like there was like a moment when I stopped considering myself a part of ACT UP. I mean I kept on supporting ACT UP, and being part of demonstrations, and stayed friends with a lot of the people who I had gotten to know through ACT UP. But I just, I really just slowly and gradually ceased to identify myself with ACT UP in the same way. And I started having, I stopped having that feeling that I've been describing, of just being totally devoted to this movement.

SS: Okay. I only have one last question, unless there's something you feel that we haven't covered.

SK: Okay, what's your last question?

SS: Oh, okay. Looking back, what would you say was ACT UP's greatest achievement?

SK: {sigh} {long pause} Hmm, it's hard to know where to start answering that question. Well, for one thing, I mean I'll say that, I mean I think that for myself and for a lot of people who were involved in ACT UP, it was such a – it was just such like a watershed experience to be involved in something, to be involved in a group,

just like raising so much power, and – just challenging this like, this silence that was in the government, in the media, around AIDS. And you know, I feel like in the early years, ACT UP really succeeded just in shattering that silence, and forcing people to acknowledge that this was going on.

Now, in retrospect, just sheer numbers that have evolved over time, I mean I guess that would have happened anyway. But you know, I feel we, we did, in a very tangible way break that silence. Not that I feel like we resolved the crisis, or solved the problems. And you know, but I don't think that diminishes at all the success that we had in just forcing the powers that be to acknowledge that there was a crisis, and there was a problem.

I don't know, you know. I was, I think, in that time, I just felt much more hopeful and optimistic. And you know, for me, that was the biggest, and that was the power of ACT UP, is it, like it made me believe that a better world was possible, and that we could have, we could play a major role in bringing that to be.

You know, and I really feel it was like, it was like a revolutionary moment, or something, that I was, that I feel really privileged to have been able to be a part of. You know, and I don't feel filled with that kind of optimism at this point in my life. I mean I, a year ago, I participated in an ACT UP action that was initiated by ACT UP Philadelphia that was at Senator [Bill] Frist's office. And he's the majority leader of the Senate, and he's the –

SS: We're out?

JIM WENTZY: That's a good place –

Tape III
00:00:00

SS: In the break, we realized that actually we have more to talk about. What I want to say is that, you know, on some level, ACT UP saved your life, on some level. And the lives of a lot of our friends. So when you say, we had hope, that was one of the hopes. And the fact that we're sitting here is a consequence of that. Of course, we all have our worldviews, too, that didn't come to be.

SK: Yeah, no, I think that's, I mean that's important and that's good, yes. No, I mean I, I can definitely appreciate that I, in preparation for this, I just sort of went through some of the papers that I've saved from ACT UP. And, particularly some of the stuff around treatment activism like at that 5th International AIDS Conference, in Montreal. ACT UP really took the bull by the horns, and –

SS: Were you there?

SK: I was there. And I just read through the treatment agenda that we put out there. But I think that, in this vacuum of leadership that existed in the federal bureaucracy, ACT UP filled that vacuum, and kind of provided a research agenda that at least for a time, the Maryland and Washington bureaucrats were using. So you know, when you say that I'm alive because of that, I think in some regard, that's true.

SS: Let's talk about Montreal.

SK: Okay.

SS: Can you explain what that conference was, and the preplanning before you all got there?

SK: Well, the conference was an international, mostly medical conference. But it was an international AIDS conference that was medical people, researchers, AIDS educators, you know, from all around the world. It was huge. And

ACT UP bussed up hundreds of people. And some people, I actually, I had bought credentials. You could just register for the conference and buy credentials. But the ACT UP graphic artist geniuses just figured out how to copy the credentials. And so, on the first, in the opening session, there were hundreds of people from ACT UP who got inside. And from the opening moment of that conference, we just really would not let the conference proceed on its planned agenda. And you know, sort of forced our agenda to be the center of it.

SS: But how did you do it? No, literally. How did you force them?

SK: Um, we just –

SS: They always say you can't –

SK: – we shouted, we just interrupted the opening plenary session. It was really, it was really beautiful. I mean, I can't remember the specific individual who was talking. But just hundreds of people from ACT UP started chanting, and interrupting him. And get, and I, and then we ended up just going up on the stage, and taking over the stage. And shutting down that plenary session, and demanding that people with AIDS, people who were patients, in the medical system have a voice in this conference, and in setting the agenda.

And then, you know, it wasn't just about interrupting the session. You know, people had put together this tremendously detailed research agenda to try to sell to the federal government, and to try to get people who were medical researchers all around the country and all around the world to support this agenda. And you know, I think that that conference was pretty major in getting a lot of support amongst the medical community for a more aggressive research agenda that ACT UP was promoting.

SS: Do you remember any of the details of what those demands were?

SK: Yeah. I mean it basically had to do with expanding access to drugs, it was what in ACT UP was the drugs into bodies agenda, of trying to get more access to drugs on a compassionate-use basis. So that somebody who was really sick wouldn't have to get into a double-blinded trial where they wouldn't know if they were getting the promising drug or not. It was for specific steps for expediting the approval process, so that it wouldn't take years and years to get approval for a drug. It was, it was basically people who had really studied what the approval system was, what the bureaucracy of that consisted of. And I was not one of those people who had studied that, and was well educated about it. But there was a large circle of people who had become really well informed about that. And you know, they were proposing very specific changes in the approval process. You know, which I think ultimately, the Food and Drug Administration adopted.

SS: Now how are these logistics done? How were hundreds of people bussed to Montreal? Who paid for it? And where did they stay, and who paid for that, and where did that money come from?

SK: We chartered busses. Whenever ACT UP went anywhere, we would charter fleets of busses. And you know, we would figure out what that cost per person. And people who had jobs and felt like they could afford it paid their way, or subsidized the people who couldn't. I mean, there was a moment when ACT UP had a ton of money. Among the papers I found was the Auction for Action. And I mean, I remember, at that point, ACT UP raised a million dollars or something in a night, auctioning all of these paintings and other artworks. And I actually remember going to Atlanta, for two

actions. One was CD at the CDC. And then the other, it was right after the *Hardwick* decision. So the other one was just a kiss-in to promote queer visibility in the state where that case had come from.

But I, in that case, we flew down. That was the only, that was the only action I can remember where a huge group of people flew somewhere. But that was, ACT UP, just at that moment, had a ton of money, and could afford to fly. I mean, there were over a hundred of us on one airplane. It was like one of the most fun experiences of my life, was like being on an airplane with a hundred people from ACT UP. You know, we were just so rowdy.

SS: What was the CD at the CDC?

SK: Um, okay. The CDC is the Centers for Disease Control. And I mean, the issue at that time was the CDC isn't involved in approval of drugs or anything like that. But they're this, it's the statistical wing of the government that keeps track of epidemiological records: how many people have AIDS? And that's, that was a hugely politicized question. You know, what is AIDS? What are the defining characteristics of an AIDS diagnosis? And depending on how you defined it, you could have a larger group of people; a smaller group of people; a group that included more women; a group that included less women.

So I mean, at that time, there, there were issues relating to the CDC's tracking of AIDS cases. And then we had a similar set of issues in New York City, with the New York City Department of Health, but ACT UP was basically involved in expanding the case definition of AIDS. And specifically, there were opportunistic infections that women with AIDS were prone to, that the original group of people who

Tape III
00:10:00

were identified as AIDS — gay men — weren't prone to. And ACT UP was trying to get the case definition expanded so that the larger number of people — and in particular, the larger number of women who were HIV-infected — would be recognized in the statistics.

So anyway, so getting to Montreal, I mean some of the logistics that ACT UP pulled off were just, were amazing. I mean, just involved moving tremendous numbers of people, figuring out housing. In Montreal, there was it was some dormitory of some educational institution or religious institution or something that people were camped out in. And I think some people had hotel rooms also. It definitely wasn't everybody in one place. In Atlanta, we all stayed in one motel, I remember. That was very fun. But in Montreal it was more people, and we were more spread out around the city. There were actions happening every day. I don't think it was clear beforehand that we would be able to get huge numbers of people inside. But you know, I think a relatively large number of people had registered themselves. But then once we were there, it became clear that everybody could get in. And we did that.

SS: Were you ever involved in something that completely did not work?

SK: I can't remember anything that was like that. I mean — definitely sometimes we ended up on the plan C scenario, where we'd be on the far corner, over there. And you know, sometimes it just felt like we were, it felt like we were wasting our time shouting at a building. But I can't remember ever feeling like an action that I was involved with was a total failure. No.

SS: What a great feeling.

SK: Yeah. Yeah. And I mean, a lot of them are really memorable.

SS: Well let's end there.

SK: What's that?

SS: Let's end there.

SK: Okay.

SS: Thank you. Great. Thank you so much.

Part II

[Jim Hubbard interviews Sandy Katz while he is milking the goats.]

Tape IV
00:00:00

SANDY KATZ: I can turn a light on if that helps.

JIM HUBBARD: Okay.

SK: Well there. I suppose there aren't too many ACT UP alums who are milking goats.

JH: Probably not.

SK: But, uh, but I love doing it. And I definitely have come to subscribe to the theory that live milk is tremendously beneficial to health. And have, stupid laws about mandatory pasteurization have made it hard for most people to access.

JH: Is it hard to learn how to do it?

SK: Um, you know, it takes some hand strength. You know, definitely there's a learning curve for it. But there's about a dozen of us who share responsibility for the goats. And none of us grew up milking goats, and we all learned how to do it. I think some really small people have a hard time just sort of feeling like they can control the goats. You know, the goats can be a little bit aggressive where they push you around, as you're about to see. This is – Lentil is an incredibly fast feeder.

JH: Uh huh.

SK: One, one of the other goats, Linnie, we call her the macrobiotic goat, 'cause she chews everything a hundred times before she swallows. But Lentil pretty much inhales it.

JH: Oh look, there are chickens.

SK: There are chickens, too.

JH: Do you, uh...

SK: Well, I'll tell you. You know, chickens harbor some avian diseases that immune-compromised people like myself could potentially be prone to. So me and most of the other people here who are HIV-positive, you know, pretty much don't get too involved in tending the chickens. But we do have chickens down there, and fresh eggs are a lovely thing.

JH: It's nice that someone else gathers.

SK: Yeah, yeah. So like, on my days to milk, I find someone else to, come on, come on, come on. Come on, Lentil. Oh, I just have to open the gate. Lentil, if you want to be, if you want to be in the video, you say, ACT UP. Fight AIDS. Sylvia, up, up.

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JH: Is it toxoplasmosis they have?

SK: Yeah, yeah, yeah. That, that, that is, that is definitely the most, the most specific concern is toxo. You know, it seems like the risk is pretty small, but I would just feel so stupid to get toxoplasmosis just from cleaning out the chicken coop or whatever. So I pretty much stay out.

JH: Farmer Sandy.

SK: Yep.

JH: Reestablishing the old tradition of Jewish farmers.

SK: Come on Sylvia, what's up? What's up? Are you gonna try and not let me milk you? Come on, aha. Sometimes you have to lock them in.

JH: Ooh! Jesus!

SK: You okay?

JH: Yeah. Yeah, I just slipped. So you're gonna tell me more ACT UP stories.

SK: Yeah yeah yeah. Sure.

JH: What is it we forgot the other day?

SK: Well, you know, getting to hear, getting to hear different people's memories has triggered a lot of different memories for me. Both of like, you know, people I was friends with who are gone. I don't know, I just started thinking yesterday about this really sweet guy, Rod Sorge, who'd been in, in ACT UP. And died a few years back. And he's a great loss.

JH: Do you remember anything in particular about Rod?

SK: Well, I do remember that he was in that, you know, earliest, well, my most specific memories of him are on the ACT UP actions in Atlanta. We were, we were in the same hotel room, and we were hanging out a lot together, and having a good time. I remember we went to the, the High Art Museum in Atlanta together. And you know, the actions that I most specifically associate him with are the needle exchange actions. He was part of that affinity group that just was distributing needles, and then went through with a political trial over that. And he was just amazingly articulate about all that. And you know, the real tragedy for me is that, you know, then he got involved in shooting up drugs, and – you know, that was –

JH: So he wasn't shooting up before that?

SK: I, I, I, I don't really, I, I don't really know that. I don't really know that.

JH: Yeah.

SK: Then the other action, another action that I was thinking about, which was just really fun, was a bunch of us went, took a boat to Liberty Island, on Labor Day, 1988. It was the kickoff of the post-primary and convention presidential campaign. And Dan Quayle was kicking it off at Liberty Island. And you know, we did what ACT UP used to call Republican drag, where we just tried to look respectable – wear suits and ties and dresses and whatever we imagined Republicans would be dressing as. And we went over to Liberty Island.

And you know, we interrupted the, we interrupted Quayle during his speech. And you know, we were a huge presence there. We were over a hundred people. And then we all got like a – they didn't arrest us. They just sort of cordoned us off near the ferry terminal and made us wait for the next ferry that was coming through. And while we were waiting for the ferry, you know, the specific image that, like, will always be with me is Al D'Amato, who at that time was the U.S. Senator from New York, and just this notorious corrupt arch-conservative figure, but he just sort of got into this homophobic mockery of us. And he was doing this little dance, like this, with limp wrists, and moving his hips around. Really in plain view of us. I think, in a way, for our entertainment, or perhaps meant to offend us. But you know, it was just the most absurd thing, to see this U.S. Senator doing this little sort of gay-mockery dance.

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And then we took the ferry back to the city. And you know, at this point, it was only 10 in the morning. And I remember a bunch of us going out to Odessa or Kiev or one of those restaurants and having breakfast. And then we changed into our glamour drag, and went across the street to Tompkins Square Park to Wigstock.

So that was a very memorable action. And you know, just interrupting, this just ridiculous vice presidential candidate, Dan Quayle was very satisfying. I have to tend to –

JH: You're feeding them. But don't they eat grass?

SK: They do. The, yeah, yeah. These, these goats graze freely. Rather than fencing them into a small area, we fence them out of our central living areas, where we have gardens and things that we don't want them to eat. So they, they wander about a quarter of a mile in any direction. They don't really, they're not grazers on grass, the way cows are. They are, they're called browsers. And they eat off of trees, and they eat leaves, primarily. They also eat lichen off the bark of the tree. So they eat a lot. But that's part of the routine of milking them and giving them a reason to come into this room and step up onto these stalls to make it easy for us to milk them, is that they get food.

JH: So it's not true that goats eat everything.

SK: Goats eat an awful lot.

JH: But you know, all those cartoons of them eating shoes, and –

SK: Yeah, they don't eat everything. And as a matter of fact, they're kind of picky about what they eat. Like if we, like sometimes the farmers' coop where we buy the grain that we feed them will like change brands. And they can be incredibly picky. They're real creatures of habit. And you know, the word "capricious," which is based on goats, really does apply very well to them. Okay, Sylvia, thank you.

JH: Okay, next.

SK: Thank you, Sylvia. Thank you, Sylvia. Okay. So now we got to two at once.

JH: Oh, how fun.

SK: Because Love Goat isn't milking. Love Goat's just eating. And so, you know, I can multitask. I can milk another goat while she's just eating.

JH: Why is Love Goat not milking?

SK: Well, okay. If a goat hasn't had a baby, it's not lactating. So Love Goat is a year-and-a-half old now. And she hasn't had a baby. She, we will be introducing her to the buck shortly, and she will, this winter, she'll be having her first pregnancy experience.

JH: So they have to have one every year to keep them milking, or –

SK: Not necessarily every year. Like if not every year, then every second year.

JH: Uh huh.

SK: You know, the euphemism that we use to describe this is freshening, you know, the supply of milk. I'm milking today, and I've been away. So I haven't milked for about six weeks. And they have a lot less milk now than they did six weeks ago.

JH: Hunh.

SK: So you know, just in the normal course of things, the amount of milk that they supply just goes down over time.

JH: So do you get to a certain point where they'll have no milk?

SK: No. I mean, you definitely, you can keep each goat going for more than a year. Like close to two years. I mean, you'll get a reduction in the quantity over the course of that time. But you can, the milk will keep flowing. So what we do is try to

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overlap them, and so we get roughly half of the herd pregnant each year. And then typically, each goat will have an average of two babies. Sometimes they end up having three. And you know, most years we'll keep one of the babies. So we kept Love Goat. You know, generally we'll keep a baby of the goats that are the biggest milk producers or the easiest to milk. 'Cause you know, each goat is a little bit different, just in the shape of their teats and the ease of milking them.

JH: And what happens to the other – kids? Kids, right?

SK: Yeah, we're pretty, we're pretty plugged in in the neighborhood, and we generally, depending on who it is, sell them or give them to neighbors, or friends of neighbors. You know, there's all sort of whole network of goat people around here. And some people use them as brush goats. Some years we've slaughtered, you know, slaughtered one for meat. The person who used to actually do the slaughtering is no longer living here. And I think, none of us are, none of us feel the calling to actually, to actually do the killing. So we've been avoiding that by giving them to other people.

JH: So how many are there?

SK: Seven. I just wanna look a, I did actually – I made some notes for myself on a piece of paper yesterday.

JH: Wait, so this is four –

SK: This is Persephone.

JH: Persephone.

JH: This is Persephone. And this is Love Goat. Love Goat was born during a gathering. Somebody put together a dinner that was, the theme was Love Boat. You know, the cheesy television show from the '70s. So the goat, and they all follow a

lineage. Like there's an L line and an S line and a P line. So Love Goat was part of the L line.

JH: Oh, Sylvia.

SK: Sylvia, Sylvia is the daughter of Sassy. You'll meet Sassy in a minute. Sassy's got a big personality. Maybe Sassy's, maybe you've already met Sassy, 'cause she's the one who butted you.

JH: Oh, yeah.

SK: Okay, y'all. Are you done? Yes. Love Goat never wants to leave the stanchion. Come on, Love Goat. Come on, Love Goat. Thank you, Love Goat. Thank you, Love Goat. Thank you, Love Goat.

Okay, Persephone. Thank you, Persephone. Thank you, Persephone.
Okay, Luna. Come on in.

JH: You have Luna in there already?

SK: I've got Luna in now.

JH: Oh, okay.

SK: Yeah, they – they move quickly.

JH: So you have another ACT UP story?

SK: Yeah, sure. You know, I feel like – organized actions were really only – were only one part of ACT UP. But it was also, {sigh} I feel like each of us sort of became an action waiting to happen, should we stumble upon the right situation. And you know, one day, I was, when I was in graduate school at the New School, I walked onto 5th Avenue. And there's like a crowd of people. And I look. And stepping out of a limousine, towards the Forbes Building, was Ronald Reagan, in his, post-, post-

presidential period. I guess going to, going to a little tryst with Malcolm Forbes or something. And there's just a crowd of people, looking awestruck. And I just, almost without thinking about it, I just started screaming, "Murderer!"

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Oh my god, a couple of the people who were in that crowd just sort of turned, and started screaming at me, and then Ronald Reagan was gone. But, but it was still exciting to have a direct confrontation with, with Ronald Reagan, who was, uh, just like the – you know, single most potent symbol of the government negligence during the early years of AIDS.

And you know, it's funny, 'cause in, in general, I had a lot of, I had a lot of reservations about – about shouting that word at people – calling people a murderer. But like I, and I always had a lot of ambivalence, when we would shout it at various minor government officials. But I had no ambivalence about shouting that at Ronald Reagan.

Okay, I gotta let Luna out. Okay, who's next? Come on, Linnie. No, you've already had some. Come on, Linnie. Come on.

Okay. Okay, I'll be right back with you. Lydia. Lydia.

JH: Lydia, Lydia the Encyclopedia.

SK: Lydia's our injured goat.

JH: Oh.

SK: Who got, who was attacked by a dog some years ago. Oh, there she is.

JH: Oh, yeah. Huh.

SK: So she's our three-legged goat. And she doesn't get milked. But she kind of, she generally waits for a personal invitation. Come on. Come on. Come on. You can do it. Aren't you hungry? Come on. Okay, well I'm not gonna force you. Come on.

JH: Why did the dog attack her?

SK: Um. It was a dog who was visiting. I mean, we generally – ask people to not bring their pets. And this, it was someone who was staying with us for a long time. And mostly, he was keeping his dog up at the top of the driveway. But you know, as the summer got quieter, and the dog spent more time here, we just sort of accepted the dog being around. And one day, the goats broke out of the fence. And I guess just the dog was territorial enough that he recognized that they were out of their territory. And he just went for them, and she's the one that the dog got.

And we were milking her at the time. And she had – she, she had bites on her udder and on her leg. And the bite on her udder, because it was dripping milk, just, just freaked us out more. So we really paid much more attention to the wound on the udder. But as it turned out, the wound on the leg was the much more serious one.

Okay, you're almost there. Come on! Come on. Don't you want some food? Oh, you're gettin' a little, little pellet action on the film.

JH: Yeah.

SK: Come on. Come on, Lydia. If you want some food, come on up here. Lydia. Come on. Okay.

JH: Look. She's coming up here.

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SK: Lydia, do you want to come in? This is your opportunity. Come on. Come on. Please. No, you already were in there. Okay. I don't think so.

JH: Okay –

SK: So here, okay, now I have another, so this is, this is a, this is Linnie. She's actually the oldest goat of these. And I couldn't tell you exactly how old she is, but she's maybe seven years old, something like that. She's the macrobiotic one, so.

JH: What does that mean?

SK: She chews a lot. And –

JH: Oh right.

SK: She's a slow eater. Another thing I was involved with in ACT UP was I was a trainer for, for civil disobedience. Like you know, trying to work with people who had never engaged in civil disobedience before, just in sort of basic principles of nonviolent civil disobedience. And giving people an idea of what to expect from the police or sort of playing out different possible scenarios and just getting them to think them through, and just like anticipate some of the possibilities of what might, what might happen as a result of their actions. And that was really very interesting and satisfying work to do, training people in all of that.

JH: How often did you do that?

SK: I probably did it a half a dozen different times, over the course of a year. I did, I mean I was trained by some of the really experienced people, some of whom were from Quaker backgrounds. Like I remember Mike Frisch being involved in that, and he was from a Quaker background. I remember Amy Bauer being involved in that. And I wasn't super-experienced, but just because ACT UP was doing these things

in such extraordinary numbers, there was just a need to have more people to disseminate the basic information.

And I mean, there was just, there was a ton of internal education that we did. I mean, I just remember everybody being so well-versed in all of these obscure acronyms of government bureaucracy, and we just threw them around because everybody learned what they were: ACTGs – because I was working in the city government, I got very involved in teaching people about the city bureaucracy as we were preparing for the Target City Hall demonstration, which was early in 1989, I guess. And it was – I really enjoyed being able to turn my arcane knowledge of the New York City municipal bureaucracy into useful information for people in ACT UP trying to figure out agencies and officials to target in actions.

JH: In particular, Target City Hall, what happened there?

SK: {sigh} Well, I mean that was sort of in the final years of the Koch administration. We had these huge conflicts with Stephen Joseph, who was Koch's health commissioner, who, it appeared, was changing the statistics of projected AIDS cases to sort of suit budgetary projections. And, and it was an election year. And I think that, that, that made Ed Koch a – a vulnerable figure. Because he, he was facing reelection. Sorry, I'm multitasking. Okay.

JH: That's the last one, right?

SK: No, there's nine. I have to get Sassy. Sassy is, like the, she's the alpha goat. She's the queen of the herd. And typically, she's the first one in. Like, she's just waiting at the door. And she makes everyone else wait for her. But sometimes she

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plays this sort of like passive-aggressive game, where she won't come in until I come and get her. Like now.

JH: Oh. She's in the –

SK: She, yeah, see, she's sitting down here. She's like the queen, sitting in her throne. Hello Sassy darling. Come on. Do you want some milk? Do you want to eat? Do you want to eat? Come on. Come on. Come on. You don't have to come. I mean, I'm not gonna milk you. I'm just gonna feed you. You'll be happy with food. Okay. I guess not.

JH: Oh, you don't milk Sassy?

SK: She's, no, she's not milking right now. So you know, the ones that aren't being milked, I mean we, we generally give them some food anyway. But if they don't want to come in and eat, they're not gonna starve. Oh, look. Sylvia's eating your bag.

JH: Yes. Get away. Go on.

SK: But Target City Hall was a great action. For one thing, it was just, it was massive, you know. Some of our other big actions like going to the FDA, I mean, that was massive, too. But that was only as many people as were committed enough to get on a bus and go down to suburban Maryland and spend at least one night there. Whereas Target City Hall was much more of a mass action, because a lot more people who were more casually involved could participate in it, 'cause it just meant taking a subway down to City Hall. And yeah, I think that there were several thousand people there.

And – I was with some group that hung a banner off of a building a few blocks from City Hall. You know, out of some artist's loft. And I remember doing reconnaissance work, checking into the access of some, the roofs of some buildings around City Hall. And I got arrested that day. Actually, I think I got arrested with Tom Duane, who was already running for office. I don't think he'd been arrested, uh, I don't think he'd been elected to anything yet. I imagine now that he's an elected official, he wouldn't be so free to be doing civil disobedience. But he got arrested at City Hall.

JH: He still does occasionally.

SK: Oh good.

JH: Yeah. Yeah. So anything else?

SK: No. Yeah. Thanks for –

JH: That was good.

SK: – thanks for comin', checkin' out the goats.

JH: Yeah, no. I'm really happy. So are any of them ready to get laid?

SK: Well, okay, so, so we just brought this, we don't really keep a male goat here. For a number of reasons. One is that you need to have more secure fencing to really keep a male goat in. They have a much more kind of aggressive energy to them. And the other thing is that a male goat makes the milk of the female goats that are around them taste different. The male goat somehow engenders the release of pheromones that change the flavor of the milk. And the flavor that people could identify as goaty comes from those pheromones. So if there's no male around, then the milk has a milder flavor.

So we just have borrowed a neighbor's buck. Because this is the time of year, in the fall, when we want to get, the goats that we want to get pregnant, this is the

time to do it, and then they'll have babies in the spring, which is the, well, it's the time when, the babies born in the spring have the highest survival rate of the year. If they're born in the summer, they're more prone to various diseases. You don't want to have them born right before the weather's getting cold, because then they're just vulnerable to the cold. So the spring is just the best time to have the babies.

JH: So are the goats ready?

SK: Oh, are they, are they in heat?

JH: Yeah. They don't seem to be.

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SK: Yeah. I don't think that they are yet. I mean really, like it's, it's, like they keep their tails in the air. Maybe Sylvia's in heat? No, they, they keep their tails in the air. And they release a little bit of a vaginal discharge. You know, and their voices become a little bit different. And I haven't really noticed any of the classic signs.

So here, I, actually, I have one more thing to say.

JH: Oh, okay.

SK: It's like, it's in relation to living with AIDS, more than it is specifically to do with, it's in relation to living with AIDS, and sort of my current project in the world, which has been, I wrote this book about fermentation, called *Wild Fermentation*. But you know, I feel like eating live culture foods — live culture foods are foods like yogurt; a lot of dairy products are live culture; sauerkraut; miso; but I feel like as a complement to the drugs that I'm taking, live culture foods have really helped keep my digestive system strong and good and have saved me from a lot of the side effects of the drugs that I'm on that most of the people who take them experience. So I just want to, I just want to suggest that people taking a lot of meds, people suffering from

immune compromised systems and anybody can benefit by eating live culture foods. So that was a little plug I wanted to make.

JH: And where can they get your book?

SK: Anywhere. I have a website: wildfermentation.com. You can get it directly from me. Maybe you could find it at Barnes & Noble or Borders. Who knows? But it's out there. Check on my website.

JH: So how long have you been into the live culture stuff?

SK: Well, I'll tell you: as a kid growing up in New York, I always loved pickles more than anything else. Like you know, sour pickles. And it wasn't really until I moved to Tennessee and discovered that what the rest of the country calls pickles is something completely different, that's just drenched in vinegar, that I started thinking about, well what's the difference between those pickles I loved in delicatessens in New York and the pickles that the rest of America eats? But it's that the delicatessen-style pickles are brined. And you know, vegetables that are brined develop a bacteria called lactobacilli. And acidophilus turns out to be the most famous member of the lactobacilli family, but it's a huge family. And sauerkraut and kim chee. Most sour-flavored fermented foods are sour from the lactic acid that's produced by lactobacilli. Oh, the goats are so affectionate this morning.

So it was really when I moved here that I started, well, that I started learning how to make my own fermented foods, because I could no longer go to Zabar's or Gus's Pickles to get pickles. So I learned how to make pickles, and one thing led to another.

JH: I miss my grandmother's pickles.

SK: Mmm.

JH: She always made pickles.

SK: Was she an immigrant?

JH: No. She was born on East 9th Street.

SK: But she probably was carrying on a tradition from her immigrant –

JH: Yeah. Um hm.

SK: – parents, grandparents. Yeah, I mean it's until a couple of generations ago, fermentation was part of every family's practice and every community's practice. It was the primary way that people had to preserve food from abundant seasons into the seasons when there was less abundant fresh food. And you know, every cuisine has fermented foods as elements in them. You know, certainly every tradition that involved dairy animals. Think about, without a refrigerator, the milk does not stay fresh very long. But luckily, raw milk sours, and it separates into yogurt, sour cream, kefir, cheese – all sorts of foods that are even more delicious than milk. And you know, that's how cultures that domesticated animals used the milk.

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And I don't know, I feel very lucky to – to be part of raising and milking these goats. And I feel like if I was on my own, I never, in a million years, would do this. It requires a tremendous amount of commitment. But you know, being part of a collective taking responsibility for them, it means I can have my relationship with the goats, and milk them and still be a little bit of a dilettante about it, and just milk them once a week, and go away when I need to, and know that they'll still be taken care of.

JH: So can we drink, have a little taste of the goat milk?

SK: Yeah yeah yeah, definitely, definitely.

JH: I actually don't like milk. I only like dairy products.

SK: Uh huh.

JH: But – I want to try this.

SK: Well, cool. We could, typically, we filter it first, just because there tends to be hair and other like particulate matter just falling off of their udders into the milk. So we typically filter it before we drink it.

JH: So should we do that?

SK: But if you're, if you're dying for some instant gratification, you know

–

JH: No no – let's go filter the –

SK: Okay. Cool.

JH: I just want to get a quick shot of the chickens.