

# **A C T U P O R A L H I S T O R Y P R O J E C T**

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Interviewee: **Sam Avrett**

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Interviewer: **Sarah Schulman**

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ACT UP Oral History Project  
Interview of Sam Avrett  
March 12, 2014

**SARAH SCHULMAN: Okay, so look at me.**

SAM AVRETT: Yes.

**SS: Instead of the camera. So just start by telling us your name, your age, today's date, and where we are.**

A: I'm Sam Avrett. I am 49, as of today.

**SS: Happy birthday.**

SA: I'm in our apartment, 193 Second Avenue, East Village, New York.

**SS: And today's date is?**

SA: Is March 12<sup>th</sup> –

**SS: Okay.**

SA: – 19–, no no; 2014. I was born on 1965.

**SS: Right. So where were you born, in 1965?**

SA: Arlington, Massachusetts.

**SS: What kind of town is that?**

SA: I was born in Arlington, which is a suburb of Boston, inner suburb of Boston. And then at age one, we moved up to Andover, North Andover, Massachusetts, which is an outer suburb.

**SS: What did your parents do?**

SA: My dad did, and still teaches, at Harvard. He's a researcher, he's an astrophysicist –

**SS: Okay.**

SA: – at Harvard. My mom and my dad met at a Harvard boarding house, or one of the houses of Harvard. She was the house secretary, and he was the resident advisor. Then she was a reporter, she was assistant to an appraiser, and then she was a personal secretary to a chef.

**SS: Oh, wow.**

SA: Yes.

**SS: So you grew up with a lot of influences.**

SA: Yes.

**SS: So what came first for you; being gay, or being politically and community-oriented?**

SA: I'm not sure. I think they both came to me gradually. So — that's a hard question. Sexuality starts so early, and political awareness starts so early. So let's take one at a time.

**SS: Okay.**

SA: Being gay, sexuality and having sex for the first time, happened before college and during college, the summer before college. I think I came to political, like being proud about being gay probably when I was 20, in my junior year abroad. I had my first boyfriend in my senior year of college, who I stayed with for six years.

Being political: I remember going door to door with my mom when I was a kid, handing out, putting door-knockers on doors for a local candidate. So I had a sense of politics. I volunteered and worked on the Dukakis campaign in 1988.

**SS: Okay.**

SA: So I was involved in politics in that way. And then the politicization related to HIV – happened over time.

**SS: So when did you first hear about AIDS, or how did it first come into your life?**

SA: I don't know. I was trying to remember this. Definitely when I started college, in 1983, I was reading about it in the *New York Times*. Right so, I knew it existed. Memory is tricky. So a guy that my mom worked with, who was an accountant for the same chef that my mom worked with, died, I think, in 1981 or '82. I can't remember whether I knew that he died of AIDS or not.

So I knew that HIV existed. I remember getting tested for the first time in early 1987, when I was a senior in college.

So the test had come out. And so, for some reason — I don't know why I tested.

**SS: Uh huh.**

00:05:00

SA: I remember being freaked out about being tested, and like, oh, you know, is that spot on my leg a KS lesion, have I been at risk, and of course I had been at risk, and going to get your test creates those anxieties.

I remember: I was living in west Philadelphia, because I was going to the University of Pennsylvania. I went down to the gay clinic, in Center City. My memory of it was that the news about Rock Hudson was – I think it was Rock Hudson or Liberace. But they were all carrying on, and like really campy, queeny. I was very freaked out by it – and intrigued by it. It was like this whole world of gay Philadelphia that I wasn't linked into.

**SS: When did it reach someone you knew?**

SA: First time it reached somebody I knew well was somebody who I was having sex with in 1989. Cute, crazy boy; turned out he was manic depressive; had a whole bunch of other stuff going on and he was HIV-positive. His roommate was HIV-positive. There was all this drama between them. And, yes so he was positive. I remember that was the first ACT UP T-shirt that I saw. Like he was wearing an ACT UP T-shirt in 1989, and that was in Washington, D.C.

**SS: So were you involved in any kind of organizations, or anything like that, at that time?**

SA: Yes. So during the Dukakis campaign, I worked in the primaries. And then, after the convention, went back to Washington, D.C., and was unemployed during the summer. I was trying to figure out something interesting to do, looking for jobs, and whatever. I was renting a room in a house. And somebody else in the house said that they volunteered with Whitman Walker clinic to hand bleach kits out, on the street, and it was an interesting thing to do. I thought, that sounds interesting.

So I went over to Whitman Walker, and I volunteered. So they put me onto – I went down to Alexandria, Virginia, and we handed out bleach kits and HIV information down in Alexandria, on weekend nights. And then –

**SS: What was that like? How did people respond?**

SA: A mix. We stood in front of the 7-11 in northern Alexandria. And people were – at three in the morning, in a really poor neighborhood, people were coming to 7-11 to go to 7-11; people were coming to 7-11 because there was drug-dealing going on around. There was — it was chosen as a location because there were a lot of

injection-drug users, supposedly, in that area. Some people said, thank you, and were really appreciative of the information. People did take the bleach kits.

**SS: So did you see that as part of social services, or did you see it as something that was symbolic towards a larger goal? Or how did you understand that action?**

SA: It was something practical to do, and something that engaged me in a world that I didn't know well.

**SS: Right.**

SA: The program was run by a guy named A. Billy S. Jones and Joe Izzo. Joe Izzo is still around; Billy might be. And Joe Izzo and ABilly S. Jones then said to me and a bunch of other people: why don't you – we're going to start a male-sex-industry outreach project. So if you like handing out bleach kits in Alexandria, how about let's go to all the hustler bars, and you hand out condoms and hang out with the hustlers and make sure that they understand about safer sex and talk to clients, and all that stuff.

00:10:00 So then it was like, wow, that's interesting. And I loved that. Because you go to a bar, and you have a role. You have a role there, and there's familiar faces. I liked the role, I liked doing something, and it felt connected with my own personal stuff.

**SS: Had you had experience with hustlers before?**

SA: No.

**SS: So how did you feel about them?**

SA: Intrigued; a little bit, it's – the kids who we interacted with were rough around the edges; usually pretty nice. They were – yes. In general – they were appreciative that we were there. And there was always a boundary. Like I never got to

know any of them well. I knew my outreach workers, the guys I went out with on outreach, really well, and I knew some of the bartenders really well. But it was also just sort of a – it's an interesting thing to do.

**SS: What were the names of some of those clubs? Do you remember?**

SA: No. I remember O Street Southeast, and then I remember – there was some location that I seem to remember being by the post office. But for the life of me, I don't know –

**SS: It's too long ago.**

**JAMES WENTZY: I'm sorry - yes that moved.**

**SS: So from the beginning, you were prevention-oriented.**

SA: Yes. Yes. Yes, I mean, I was HIV-negative, at the time. There was a lot of – there was a lot of stuff to do and to engage in. There were safer-sex workshops, and things like that. So yes, it was prevention-oriented. And then, after the Dukakis campaign, I got a job doing HIV work. So –

**SS: A job – what was that?**

SA: It was a NIDA [National Institute on Drug Abuse] demonstration project, run by a consulting company called R.O.W. Sciences. I was the administrative assistant. I walked in and said, I need a job. What we were doing was, the National Institute of Drug Abuse had funded demonstration projects all around the country to train injection-drug users to, recovered injection-drug users to go out onto the street as outreach workers, to do harm-reduction counseling, and HIV education. So R.O.W. Sciences was the outfit to do the training for those outreach workers.

So we did trainings about relapse prevention, and mapping a community, and how to do outreach, and theories of education, and all that stuff. Through that, I met a whole bunch of people around the country, and that was through 1989.

**SS: So was there needle exchange yet?**

SA: I don't remember – there was needle exchange at that point, but not funded by NIDA, and not that I know of. But definitely the New York groups would probably have been – I don't know the history.

**SS: How come you landed with IV-drug users? How do you understand that?**

SA: I was a drug user when I was in college.

**SS: Oh, okay.**

SA: Not injection-drug use. I have injected. I did in London in — when was it? — 1985, '86. But, yes, I was – tripping, and cocaine, and all of that, and being a drug user was sort of an identity.

**SS: Yes, definitely –**

00:15:00 SA: It wasn't surprising to me. So yes, I did that work. And that was interesting, because I met people around the country, so I knew HIV projects in Tucson and Berkeley – sort of all these random places. The folks I knew the best here were NDRI. And then, I think, Louis Jones, at Stand Up Harlem. But Louie Jeppe was a guy in Brooklyn who I knew well. I don't know whether he's still around. But that was 1989. Then I joined the Peace Corps.

**SS: Okay.**

SA: And then I went to Central Africa to do health education, vaccination programs; again, prevention.

**SS: Okay, so let me just go back to this period before you went to the Peace Corps. How effective do you think those programs were?**

SA: Clearly not very, because we haven't gotten rid of the epidemic.

**SS: But I mean, do you think that they reduced transmission rates, or were they really just a kind of desperate shot in the dark, or whatever?**

SA: Yeah, I think incrementally, they probably did break chains of transmission. My guess — and we could go into the epidemiology and the research — my guess is that prevalence had probably gotten so high among injection-drug users, for a whole bunch of reasons. And the [Robert & Mindy] Fulliloves have documented the dislocation of drug-using networks, and that factored into people mixing, drug-user networks mixing, and that causing the spread of HIV in the late '70s and early '80s. By the time that I was involved, handing bleach kits out — that was 1989. During that time, the surgeon general did the mailing to all American households. So HIV awareness was getting higher — was high. And certainly among people who were at high risk, people were aware of it.

So — yes. I think clean needles are a better strategy than bleach kits.

**SS: Let's just jump ahead to the moment.**

SA: Yes.

**SS: What is the most effective strategy for preventing transmission among drug users? Now.**

SA: A combination — now.

**SS: Yes.**

SA: Okay. So HIV-positive drug users need to be on treatment and undetectable.

**SS: Okay. Well then, that's it, right.**

SA: I mean, that's number one. Secondly, people who are negative — I mean, people who are negative and unknown should be getting tested once every six months, but linked to healthcare, and linked to housing and job training and residential addiction. And that's where our system's falling apart. I think the policy is really — I think consensus is pretty clear about it right now, that those social drivers are part of the package; and that it all has to be brought together in a coherent way.

So if I move to New York City, and I have a history or likelihood of being an injection-drug user; I walk into the emergency room, and for an abscess or for whatever reason; and they test me, and I test negative; what happens? Right? Do you get referred to a prevention cohort and a harm-reduction cohort or a harm-reduction program to help stabilize your life? Do you get preferential access to detox? Do you get access to housing and residential treatment?

Those services fall apart. And when those services happen, it's this person over there is going take care of you, and that person over there is going take care of something else, and that person over there is going take care of someone else. And nobody's saying, I want to make sure that you're healthy next year, and the year after, and the year after.

And I think telling somebody that you care about what happens to them is a really powerful thing. Right?

**SS: So if you could just bring me up to date, because I know everything's changing so quickly. I'm sorry to use you to educate me, but –**

SA: Yes.

**SS: – so if you're undetectable, do you test negative?**

SA: No, no.

**SS: You test positive –**

SA: You test positive –

**SS: You test positive with low –**

SA: – because you've got antibodies.

**SS: Okay. And then you have the undetectable viral load.**

SA: That's right.

**SS: So it's two tests.**

SA: Yes, it's an antibody test and it's a viral-load test.

**SS: Okay. And are they done at the same time?**

00:20:00

SA: Yes. But you don't need to do the antibody test. So I'm positive now, and I go in for regular blood work. They don't need to test me for whether I have an antibody to HIV; they know I have an antibody to HIV. What they're interested in is, are the drugs succeeding and keeping my viral load suppressed.

**SS: And how long would a person have to be off meds to move from undetectable back to detectable?**

SA: I don't know. I think it's pretty fast; a matter of weeks.

**SS: Okay.**

SA: I mean, it depends on, the drugs stay in your body for a little bit of time; and the virus is sitting there in reservoirs, replicating into the bloodstream. So there's probably a – the physics of – or the mathematics of that.

**SS: So since drug users have a higher rate of noncompliance; somebody could be undetectable, and then they're more likely to stray into the detectable range, right?**

SA: Yes, yes –

**SS: So it's a different kind of surveillance is necessary if you want to maintain –**

SA: Right.

**SS: – everyone at undetectable.**

SA: And it's a different surveillance depending on the demographics of the person you're talking about. So a 40-year-old injection-drug user who's been injecting for 20 years or 10 years, who has a stable pattern, or has a stable pattern of instability, of Suboxone sometimes, injection sometimes – but otherwise their social situation, who they're doing drugs with, and who they're potentially exposing is all pretty stable; that's going to be very different than a club kid who's 19, who's couch-surfing, who is from Indianapolis and here in New York because they just met somebody. Right?

So the risk of going — of losing, of not taking treatment, going off treatment, becoming unsuppressed, is different, depending on the person.

There is also the issue about people who know that they're positive are the safer bet. So people who know that they're positive and are on treatment; it may be the biggest worry is not that those people are going to go off treatment temporarily. That's

an issue. But there's a far bigger issue of people who think that they're negative, haven't tested, haven't tested in the last nine months; and then get infected, and rapidly infect a couple of other people.

**SS: I see.**

SA: So you see those infection bursts that happen. And that's really hard for a lot of policymakers to grasp. That people think about hot spots. Let's like think about hot spots, because it's geographically fixed. But what happens is there are bursts, which change in space and time. And I don't think our systems deal with that really well.

**SS: No.**

SA: You know, it's like boy sleeps with girl sleeps with boy. One person tests positive; the other two test positive. The system sort of handles that well; sort of not. Referral to care; get people onto treatment. And they're not thinking of, okay, there's three 19-year-olds. There's 30 19-year-olds all around them, and who's doing the intervention for that cohort of the 30, to make sure that they're all getting the support – not just HIV education; people are aware of HIV; but it's that interplay.

**SS: Now this rhetoric that circulated awhile back about the danger of being reinfected with a different strain if you're already positive, has that played out to be a realistic concern?**

SA: I don't think so.

**SS: Okay, so that's no longer relevant.**

SA: No.

**SS: Okay.**

SA: I'd rather not say it definitively and tell you –

**SS: Because you don't hear that argument anymore.**

SA: Yes, I saw something in the email LISTSERVs last week about it.

But not that I know of.

**JAMES WENTZY: Drug resistance you can get.**

SA: Yes.

**SS: Yes.**

SA: Yes.

**SS: Okay, thanks for bringing me up to date.**

SA: Yes.

**SS: Okay, so when did you come to ACT UP?**

00:25:00

SA: I came in late. I came after Peace Corps, so I came from Africa to New York, in January 1991.

**SS: Now did you work with HIV in Africa?**

SA: Yes.

**SS: Okay. And so how did that enhance your understanding?**

SA: I was interested in vaccines, which was sort of influential in what I did later; I was interested in prevention; and I also got an appreciation for the fact that it isn't about medicine – I mean, it is about medicine, and it's about medical care, but the administration of healthcare makes a huge difference.

So getting in the place where I was, in the Central African Republic — a town called Bozoum — getting the vaccines to the town in a refrigerated compartment was a challenge. Getting the funding to pay the doctors was a huge challenge. Making sure people didn't steal the money was a huge challenge.

**SS: But what vaccines? Oh, you were testing vaccine?**

SA: No no, we were doing polio –

**SS: Oh, okay.**

SA: – polio, measles, whooping cough.

**SS: Oh, okay.**

SA: All the basic – tetanus.

**SS: And what about – now, I know that this is still vague. But I know that in 2007, there was a realization that men who are not circumcised are more likely to be infected by women than men who are circumcised. And so on this issue of female-to-male transmission — which is a very questionable category in North America — in Africa, is a very significant category.**

SA: Right.

**SS: So what did you have to do there that would be different regarding women from what kinds of thinking people have here?**

SA: Well, at the time that I was there, it was really early, it was 1990.

**SS: Right.**

SA: So all we were doing was education, unfortunately. We were doing education about the routes of transmission.

**SS: Okay.**

SA: So, yes. Just basic HIV 101.

**SS: Okay, it's just too early.**

SA: Yes.

**SS: Okay, so you came back in '91.**

SA: Yes.

**SS: And where did you live?**

SA: Norfolk Street and Houston.

**SS: Oh, right. Okay.**

SA: Yes. So, Drew Beaver was my boyfriend –

**SS: Oh, okay.**

SA: – at the time. And Jay Blotcher – or Alan Klein and Karl Soehnlein were living upstairs.

**SS: Oh, I know that building.**

SA: Yes.

**SS: Yes, okay.**

SA: Yes, yes. Yes.

**SS: Oh, so you were in the epicenter, the ACT UP central –**

SA: Like right there, yes.

**SS: Right. And so did you come to ACT UP at that point?**

SA: Yes, immediately. I don't know – like, it was definitely the first week where I went both to Queer Nation and ACT UP.

**SS: And did you continue in both, or did you stick with ACT UP?**

SA: Yes, I did – I kept going to both.

**SS: So just for the record, could you tell us what the difference was?**

SA: Oh, at that time, Queer Nation was meeting in the LGBT Center; and, god, what was their official line, or slogan? It was around queer visibility and queer

justice issues. ACT UP was about HIV, and the HIV response, and it was meeting in Cooper Union.

**SS: But what was the difference in the cultures of the organizations?**

SA: They were somewhat, well, they were of the same model, I would say, in general. Queer Nation was smaller and much happier, at that time. Early 1991, when I first walked in to ACT UP, there were fights going on that had been going on for a year or two years, three years. And it was a bigger crowd. There were as many as 500 people in that room, as you know.

**SS: And what were the fights about?**

SA: You know better than I do.

**SS: No, I don't.**

SA: I really don't –

**SS: You don't have to know the answer; all I want to know is what you think they were about. Because we've asked a hundred people.**

SA: Oh yes.

**SS: Yes.**

SA: Yes. No – I remember, one of the first meetings — maybe it was a month or two in — where the meeting had temporarily gotten shifted to Minetta Lane Theatre. And at that meeting, the Latino caucus, different parts of the Latino caucus, had a screaming fight with each other. And so it was like a Hispanic AIDS Forum contingent and a Latino Commission contingent, and they were fighting. And it wasn't clear to me what it was about. I remember asking somebody, and they were like, oh, it's a long history.

00:30:00

So, yes. Yes, Queer Nation was fun. Queer Nation was fun. I remember the extended-family vacations, extended-family outings, organized by –

**SS: Oh, Lee Schy?**

SA: Lee Schy.

**SS: Yes.**

SA: And, yes. And I loved those, because it was a real, gave a real sense of community in the group.

**SS: Yes.**

SA: Yes.

**SS: So what did you do in ACT UP?**

SA: Mostly I just went, socialized, and went to demonstrations. I went knowing there's stuff to do, right? And so I went because of, there was this social network, and that's where we went, right? There was this group of people, and it was interesting. And I was completely new to New York City. I was still, in January, I was still trying to figure out what breakfast cereal I wanted to buy – confused about what kind of jeans I was going buy, and settling my life. So I didn't really know how to get involved. So basically, I went, and I listened, and I ended up going to demonstrations just because that was something tangible that I could do.

I remember going to a demonstration in '91 at City Hall. I went to a couple in Midtown, but I can't remember what they were for. And then, because of my earlier work in Washington, where I had learned how to be a grant writer, I went to the Fundraising Committee.

**SS: Okay. And who was on the Fundraising Committee?**

SA: Eric Nowlin was –

**SS: Hm, don't know him.**

SA: – sweet guy; worked at Macy's? I remember him. Ann Northrop was there; Sean Strub was there; Stephen Gendin. Peter [Staley] probably had been, but he wasn't there by '91. I remember my first meeting – again, like, I was walking into the middle of conversations that had been happening for a while. So the first meeting was at somebody's apartment in Chelsea. And I remember; this guy walked in, with long blond hair, and started acting crazy. And everybody rolled their eyes – like everyone got a little bit tense, and rolled their eyes, but let him go on. And I asked someone who that is. And they said, oh, that's Jim Fouratt – and you know, he's been doing this for, like, a year or two years, or whatever.

So there's dynamics like that.

**SS: It was like a family.**

SA: Yes. Yes.

**SS: And so what projects did you work on for fundraising? Or what was the state of the finances? Do you remember?**

SA: The state was pretty good, I think. It had already peaked. So the workspace was already there. There was a big copy machine there, there were supplies, there was clearly a bank account and a budget, and people raising money for ACT UP.

At some point, money got stolen. And there was a big fight about that. And I can't remember who it was. Was it Dan Williams?

**SS: Dan Williams. We interviewed, Jim [Hubbard] interviewed him.**

SA: Yes. So I remember that happening, and that was – I think that was late '91.

The thing which I got involved in was the Red Hot money. So –

**SS: Can you explain, for people who don't know –**

SA: Yes. So the Red Hot + Blue record, and Red Hot Enterprises; there was a record that was released, Red Hot + Blue, that generated huge amounts of profit. And somebody made a deal to give a portion of the profit, or all the profit, to AIDS. And as I recall — I think Simon Watney was involved in that, in London; and John Carlin and Leigh Blake were involved in New York. And as I recall, the original intention was to give all the money to GMHC. And somebody intervened, and said, no, you've got to give at least half of it to ACT UP.

**JW: Stephen Shapiro, actually.**

00:35:00

SA: Okay, so it was Stephen Shapiro. And so right at that time, then Eric Nowlin and Ann Northrop came to me, and said, you've been wanting to volunteer for something; how about taking this on? And what we need you to do is, the money should not only come to ACT UP New York; it should come to all the ACT UPs. And so we need to reach out to the ACT UP network, and figure out how to share that, in a fair way.

So I said, sure, I'll do that.

So that involved – we had a directory that somebody had, people had created, of all the different ACT UPs around the country, with phone numbers. We sent a letter and called – I called every single phone number of every ACT UP around the country. And I did this with David Evans in San Francisco – in [ACT UP] Golden Gate, there was David Evans and G'dali Braverman. And in Los Angeles, there was Dan Levy

and Mark Kostopoulos. Mark Kostopoulos was lovely; really sweet and really organized.

So Mark and I did a lot of it. But we organized a series of conference calls. And it was open conference calls to anyone from any ACT UP. We had to figure out a formula by which any ACT UP could be eligible for money. It was painful and intense. There were — we had a directory of about a hundred ACT UP chapters. Not all of them were in existence. So we made a lot of phone calls and did a mailing to try to reach somebody. And then the criteria was, we could only fund ACT UPs who had a bank account, or could find a 501(c)3 pass-through, and could provide some demonstration, whether it's a newspaper article, a flyer, minutes of a meeting, that they actually existed as an open participatory organization that was doing actions on HIV.

**SS: Okay.**

SA: And they had to do it by mailing. And so then we did this complicated formula of, every organization got about \$5,000 right off, just for existing.

**SS: How much money did you get, actually? What was the total that we got in?**

SA: I'd say — I think it was half a million dollars.

**SS: Okay.**

SA: New York got \$75,000; Stand Up Harlem got, I think, six or seven thousand; ACT UP Puerto Rico got \$10,000; Golden Gate got about \$20,000; Los Angeles got about \$20,000. So it went to about 40 organizations, in total. So that's — I ran all of that.

**SS: Wow. So what were some of the other ACT UPs – was there anything that stood out for you, of the other ACT UPs?**

SA: There were – well, like the ACT UP Golden Gate / San Francisco split; you know, it's like you had to navigate that.

**SS: Did ACT UP San Francisco get money as well?**

SA: I don't think so.

**SS: Or just Golden Gate? No.**

SA: No. But what fascinated me was there were ACT UPs all over the place. There was an ACT UP Anchorage; there was an ACT UP Shreveport; there was an ACT UP Albany, and an ACT UP Albany youth chapter. There were all the – yes. Yes.

**JW: South Dakota, Kansas City.**

SA: Yes, Kansas City – Kansas City was great. Dallas; Dallas was a great group of people – really big, really strong. Houston; New Orleans; Atlanta – mostly, I think, out of Emory University students – really, really great group of people.

Yes, Madison; Madison, Wisconsin, was Dan Savage.

**SS: Oh, wow.**

SA: Yes. Yes.

**SS: I didn't know that. That's interesting.**

SA: So it's a lot of different — yes, in different stages of formation and different – mostly it was just a small group of people. Los Angeles had a large group.

**SS: Now did Fundraising – did they have any influence on how the money was spent inside ACT UP New York?**

00:40:00 SA: No, not that I recall. The ACT UP money was just a check that went into the ACT UP New York account. So my impression was that fundraising was to fill the coffers, and the floor decided how to spend the money. And there were fights about how to spend the money. People were pissed off about the workspace. And that was a fight that had probably been going on for a long time.

**SS: They thought if it was a waste of money.**

SA: Yes, yes. Like, why are we buying reams of paper?

**SS: What did you feel about that?**

SA: Well – I – I liked going to the workspace, and knowing that it existed. When I went, usually there were people there. I think for movements, it's really good to create an infrastructure. I was working in an office, so I had access to a copy machine and telephone and all of that stuff. So for me, it wasn't needed. It was interesting, when I was first learning about ACT UP, to go to the workspace and have access to the files – because there were files of everything. So I remember reading about, learning about what Phase I, Phase II, Phase III was, by reading through files in the ACT UP workspace.

**JW: Who was the workspace manager at the time?**

SA: I don't know.

**SS: What was the address of the workspace?**

**JW: Twenty –**

SA: Twenty-fourth, 26<sup>th</sup>?

**JW: Twenty-ninth Street.**

SA: Twenty-ninth.

**SS: You don't remember the street address?**

**JW: Between Sixth and Seventh.**

**SS: Great.**

SA: Yes.

**SS: So did you continue with Fundraising after that, or did you move on to other things?**

SA: Moved on to other stuff.

**SS: Where did you go?**

SA: In '92, I got a job at Gay Men's Health Crisis.

**SS: What were you doing for them?**

SA: Fundraising.

**SS: Okay.**

SA: Development. So I was first managing the Ryan White contracts, the first Ryan White contracts, and doing sort of government contract proposals, and reports.

**SS: Let me ask you a question.**

SA: Yes.

**SS: I mean, historians see this huge difference between ACT UP and GMHC. But there were so many ACT UPpers employed by GMHC.**

SA: Yes.

**SS: Is that difference a little bit of an illusion?**

SA: There was a different, there was an overlap, but it was different. So –

**SS: So it was the same people acting differently, based on what building they were in? Or –**

SA: No, no –

**SS: No.**

SA: – no, no. No, but GMHC was a service organization, and it was very much about the buddy program, and about meals, and about all the services that were being offered. And it was a formal structure and a hierarchy. And increasingly a hierarchy, that was increasingly professionalized and bureaucratized and resistance to that. So there was a lot of overlap, but they had different purposes.

It was a — I'll give you a really personal example, which is, I moved to New York in 1991. And within the first three weeks, I walked in to the Center, I walked in to GMHC, and I walked in to ACT UP. And in fact, ACT UP was a place where you could walk in and plug in, no matter who you were. Right? You didn't have to go to the volunteer coordinator. You didn't have to go through a two-weekend training before you could be considered to be a volunteer. There was no barrier.

So GMHC was different in that way.

**SS: Okay. So when you went to work for GMHC, were you still part of ACT UP?**

SA: Yes.

**SS: And so what were you doing in ACT UP?**

SA: I started gravitating toward the T&D treatment folks. So I started going to the TAG meetings. And – yes.

**SS: Now were you looking to make treatment decisions for yourself? Do you think that that's what brought you to T&D, or –**

SA: No no, I didn't seroconvert till 2000.

**SS: Oh, okay.**

SA: Yes.

**SS: So what brought you to T&D?**

SA: David [Barr].

**SS: Oh, okay.**

00:45:00 SA: Yes. So David and I started dating in 1992. And so, yes. So then – so he was living here; I was living on East Fifth Street, and then I moved over to Mercer Street. But yes, we were hanging out all the time. And so through him, Gregg – David was living here with Gregg Gonsalves. So I was hanging out with Gregg. And then Peter and Mark [Harrington] and that whole crowd. And I liked that crowd. They're smart. It felt like a crowd that I – I came to New York already reading *The Economist* cover to cover. And here was a crowd that – Mark, the first time I met Mark, he was quoting – being really authoritative about something. And I thought, I know where you read that.

So it was like a common group.

**SS: Right. So what was going on in T&D when you came in there?**

**What were some of the issues that you were involved in there?**

SA: Mostly I just listened – at T&D. It was – the meetings – I went to – a couple of meetings that were at the Center, upstairs somewhere at the Center. And then, I remember, it moved to Marvin Shulman's apartment. And I went there. And there was always sort of the body language of those meetings. There was the coffee table and the couches, and sort of the core of people sitting there. And that usually was Gregg and Mark and Garance [Franke-Ruta] and David and whoever else — Michael Marco, Derek Link — whoever was involved in the work, whatever they were doing. They were deeply

involved in their various projects having to do with the NIH and Countdown 16 Months, or 18 Months –

**SS: Countdown 16 Mo-, oh yes, 18 Months, yes.**

SA: – in that world.

**SS: Because this is the ddi era, right? Isn't this –**

SA: Yes.

**SS: Right.**

SA: Yes. That was ddi, d4T. So what I eventually did was – I was intrigued by that group; and I couldn't really figure out a way to latch into it. I remember the warnings that the — I can't remember who was doing it; it was the women's group — the warnings on Gyne-Lotrimin to say, if you have a persistent yeast infection, and it was to put the warning, to say, if you have persistent yeast infection, you could be at risk for HIV; contact your doctor. And I remember being really intrigued by that, because I was like, wow, that's prevention, and it's science, and it's something that those boys aren't focusing on, and it's something maybe I could get involved in. But then there was a group of people already working on that.

So I got interested in vaccines. Because I was HIV-negative; it seemed like the model of, okay, take your personal experience, and the politics, and combine it, and see what ultimate truth there is. The truth, for me, was, I was negative; I had an HIV-positive partner; behavior change, condom use was working well for me, sort of, maybe. But the immediacy and the truth really was that safer sex isn't the answer. And if we had required control of polio by telling people to wash their hands and do behavioral interventions in polio, we'd be nowhere.

So –

**SS: So this biomedical versus social solution is a longstanding debate –**

SA: Yes.

**SS: – in AIDS, yes.**

SA: Yes. Yes.

**SS: Okay.**

SA: And so I asked the folks in that group what they knew about vaccines and vaccine research. At that time, in '91, there had been this big blowup about a gp120 trial. And Donald McNeil and the military had tried to push ahead with a gp120 –

**SS: What's gp120?**

SA: GP120 is a protein –

**SS: Oh, okay.**

SA: – of HIV.

**SS: Okay.**

SA: And the idea was to use – it's a classic approach that's used for vaccines. Which is, you take the virus — whatever virus it is — you take the presenting protein; you chop it up so that it's harmless, but it's still the protein; and you inject it into somebody to get their immune system to recognize that protein, to generate an antibody response –

**SS: Okay.**

SA: – to the virus. So there were a lot of old-school vaccine researchers and vaccine experts, all the way back to polio days, who said: it worked for all these other viruses, it'll work for HIV, let's go ahead.

There was, I think, concern — and I'd have to go back — but in 1990, '91, there was concern to say, well, actually, it may not work that well. And from the activist perspective, it was, you're going spend hundreds of millions of dollars on a trial to prevent infection, and you're spending nothing on treatments and opportunistic infections; and that's an outrage. So we're opposed to this, because it's shoddy science; and we're opposed to it because it's not where the money should go.

So then, and that's background, so I come in, go, oh, what's there to do about vaccines? And a number of people said: vaccines are bad. You know, no, we're against them. And David Gold said, oh, well, you know — David Gold had just organized a conference on vaccine research up at Columbia University, bringing in the NIH and activists to talk about what was needed. So David said, oh, you know, there's a lot of issues. There's ethics. There's this, there's this, there's this. Write a paper, and we'll put something into Treatment Issues, at GMHC.

So I — David, that wasn't the first time David got me involved in doing something.

**SS: Um hm.**

SA: So I wrote something. And that turned into, then David recommended me for taking a job at the New York Blood Center to run a vaccine-preparedness cohort study; and then also put me in touch with Bill Snow and Garance. And so Bill Snow, Garance, and David Gold, and Chris Collins out in San Francisco, were all trying to figure out how to create an activist group around vaccine research and development. And so I was part of that group of five who created what turned into AIDS Vaccine Advocacy Coalition.

**SS: And what went wrong?**

SA: HIV is trickier than we thought. The immune system is more complicated than we thought. And, and it takes a long, long time to unpack all of the scientific questions, all along the way. So at this point we don't have a vaccine; we won't have a vaccine for another 10 years, at least. They're really in basic science and animal studies, and some safety studies or some approaches. But ultimately, treatments have done an end run around vaccines.

**SS: Yes. So could there conceivably be like a long-term implant of PrEP [Pre-Exposure Prophylaxis], or something like that?**

SA: Right. So that was the –

**SS: Yes.**

SA: – that was the information out of CROI [Conference on Retroviruses and Opportunistic Infections].

**SS: Okay.**

SA: So, last week, in Boston, at the conference on retroviruses, there was news that in monkeys, a long-term injection worked to protect against infection for a long period of time.

**SS: And how long?**

SA: I don't know. I think it was three months, but I'm not sure.

**SS: So there's like a three-month vaccine on the monkey level right now.**

SA: In a monkey model, yes.

**SS: Yes.**

SA: Monkey models are very different. In some ways, they'll be much easier.

**SS: So this is a completely different strategic direction than what's being developed.**

SA: Yes. So potentially – the, the concept is there; and the technology is there. So, so maybe it's a matter of time, where you could have a once-every-six-month injection.

**SS: That maybe you could self-administer, even.**

SA: Yes, but you'd want to link people in with healthcare anyway.

**SS: Right.**

SA: So everyone who's extremely high-risk should be coming in and getting tested every six months anyway.

**SS: Well that is one of the benefits of the vaccine studies, right? That they show that even though the vaccines didn't work, people, by getting the attention of the healthcare –**

SA: Right.

**SS: – right – did not –**

SA: Yes.

**SS: – seroconvert at the same rate.**

00:55:00 SA: Yes, and that was the most interesting thing about New York Blood Center and doing that cohort, for me; was, in '94, it was pretty clear we weren't going to have a vaccine for awhile. There was debate about whether it was cost-effective to create these preparedness cohorts. But for me, the idea of, we enrolled 600 gay men at Union

Square; 600 gay men in downtown Brooklyn; and 600 high-risk women in the South Bronx. And we followed them for two, and in some cases, three years, with regular HIV testing and counseling.

And it goes back to that thing, of, it's a really powerful thing to tell people that you care about them.

So the idea of putting out an ad – we did posters, we did movie screenings, we did everything we could to get the message out, to say, if you come in to downtown Brooklyn, you'll be assigned to a gay HIV counselor who will be your counselor for two years. And you can call them at any time, to answer questions, get linked to healthcare, and all that stuff. And that felt like a – it's a very expensive social organizing method. But the NIH was paying for it, and it felt like, oh, here's a program that could yield – it feels like the right thing to do.

**SS: Can I have two factual questions. I'm treating you like my teacher today, but thank you.**

SA: I get to act like an expert.

**SS: Oh! So who owns the patent for PrEP? Who owns – it's Truvada. Who owns Truvada?**

SA: Gilead.

**SS: Gilead. So they're going be the richest people that ever lived in the history of the planet, right? Because –**

SA: They have huge profits –

**JW: And hepatitis C.**

SA: – I imagine. And, yes. But let's talk about hepatitis C, which is even bigger.

**SS: And is there going to be the same problem with them, in terms of countries not being able to afford to buy these –**

SA: Yes.

**SS: – same, exactly.**

SA: Yes. Same exact – same exact and the same battles. Not exactly the same battles. Let's see. So – I mean, hepatitis, hepatitis is going through that battle right now, and is going to go through that battle. We've got new drugs coming out that are highly effective, low side effects, badly needed; being priced at \$60,000 per course, or \$80,000 per course. Crazy, crazy.

The companies did actually learn a lesson from the 1990s, in that they realized that there is a big market out there; and working with activists, you can create funding streams to pay for all those drugs. So there is – some cooperation is a useful thing. And I think the HIV and hepatitis activists have also learned that lesson from the '90s, of saying: it's not just a fight; it's working to increase access to the most people. And sometimes you're enemies and sometimes you're friends. And, and it's not going to come easy.

**SS: Jim and I were just in Russia, with our film.**

SA: Oh yes.

**SS: And we just kept hearing that all over the place.**

SA: Yes.

**SS: About hep C.**

SA: Yes.

**SS: Yes.**

SA: Yes.

**SS: And how come women have lower viral loads than men?**

SA: I have no idea.

**SS: You have no idea. Okay. I've been trying to find that information, and I can't find it.**

**JW: Vaccine research isn't done in the United States anymore, is it? Isn't it farmed out?**

SA: No no. There is – I'm pretty sure vaccine – well, no. But definitely, basic science research and Phase I clinical trials are done in the United States, as well as internationally. There aren't a lot of Phase III efficacy studies, those big studies that enroll lots of people. There are not a lot of those studies out there. They don't have candidates to run. So if there's been a reduced number of people enrolled in vaccine trials in the United States, it's just because, I think, there's a reduced number of people enrolled in Phase III trials in general. And I'm on the board of AIDS Vaccine Advocacy Coalition, and I should really know that, and I don't.

01:00:00

**SS: Okay. I'm assuming you left ACT UP with TAG. Is that accurate?**

SA: By association; yes. I mean, not by politics. Not by politics, at all. I think that – I started – you were talking about a difference between ACT UP and GMHC. When I started working at GMHC, I suddenly had an infrastructure for being involved. So literally, I was in an office where you got the weekly news clips about HIV. And you

got information about all sorts of stuff that was happening. And so the need to be at ACT UP to know what was going on was diminished. So I still went to meetings, and there was definitely a time where I was going to TAG meetings and ACT UP meetings, both – even at a point where those two groups were not regularly meeting together.

**SS: So – I mean, you're like the hundred-and-fiftieth person I've asked this. But to what do you attribute the split between TAG and ACT UP?**

SA: Different – different framing, in terms of what people were after; and a difference level of tolerance about process.

**SS: What were they after? What were the two factions after?**

SA: So I think that ACT UP was a very powerful meeting place of a whole bunch of overlapping interests: people living with HIV, trying to survive; people who were interested in that goal, and addressing HIV as a social-justice issue, and who brought in tons of skills and tons of interests, around housing, around harm reduction, around women's equality and women's health; around a reform of the healthcare system, and the reform of government, and holding government accountable, and so forth.

The Treatment and Data group, writ large, and then the TAG group within that — so there's – there's a difference — were, I think, characterized by being very interested in the science, and how to push NIH and the FDA — particular institutions — forward, on particular drugs and scientific questions. And they felt like that was going to have the biggest impact – just as Housing Works was working on their issues, and working on their particular set of topics. There was a centrifugal force that was happening with all of the different subgroups in ACT UP, and that was just one of the groups that was spinning off.

The reason they started meeting apart — and, I think, had closed meetings — it was because they felt like there were folks who were crazy that they didn't want disrupting their meetings, and they got tired of the interpersonal and got tired of the politics.

**SS: Okay. So that's a fair assessment of how it felt back then.**

SA: Yes.

**SS: Now we're decades later, and we see that there's a profound crisis of access.**

SA: Yes.

**SS: Profound.**

SA: Yes.

**SS: Okay. So now, knowing that, with hindsight, how do you evaluate those divisions?**

SA: It means that all those strains need to keep reintegrating and need to keep coming together.

**SS: Because when we interviewed Garance, she made a very interesting point that we had never thought of before. Which is that the reason we were able to be so successful with the FDA, for example, was because actually, it benefitted pharma in the long run to have less regulation on drugs being released.**

SA: Yes.

**SS: And so this action that felt like something that had to do with access actually has this other meaning. Okay, but now, we're talking about global**

**access, and the issue at stake is industrial profit. Right? That's the problem. And similarly with domestic healthcare. So how do you transcend this?**

SA: Okay. So I'd challenge, and unpack –

**SS: Okay.**

SA: – some of that stuff. So what was powerful about the FDA action was not just that it was a very clear ask and a very clear and unique target and very good media. It was a big coalition of people who showed up. And as I understand it, that demonstration was going to be at the Capitol, and it got shifted to the FDA.

**SS: Not that I know of. Do you know that, Jim?**

SA: That's the story –

**JIM HUBBARD: I think very early on, there was a suggestion. But it quickly – people quickly realized —**

SA: Yes. The story that I had heard was, all the ACT UPs were coming together for a demonstration in Washington, D.C. So there was a plan for a demonstration in Washington, D.C., and it was going to be at the Capitol, and then they shifted it to the FDA. And that's important because there are a lot of people being part of that coalition who weren't treatment experts, who weren't experts on FDA, who were unified in that demonstration. And bringing that today – there needs to be that same coalition across multiple purposes. We see it a little bit in advocacy about the Global Fund, and, I think, about North Carolina and Moral Mondays, which is a great coalition.

But there's still all that fragmentation. You have the state LGBT equality campaigns; you have a state harm-reduction coalition; and you've got the state HIV activism coalition. And usually, these are three different organizations. And they're

overlapping. But where are the places where they come together, and are working, and are led by activists for the NAACP and Planned Parenthood, and pushing on a common agenda.

So –

**SS: Well, they have different ideologies now, because Gay Inc. wants to push away anything to do with AIDS.**

SA: Not necessarily. That's the accusation. And I think Gay Inc. has heard that accusation loud and clear.

**SS: I'm just in the process of finishing a big journalistic investigative piece on HIV criminalization in Canada, which is a very interesting, super interesting –**

SA: So you're talking to Richard Elliott a lot.

**SS: No. Uh-uh.**

SA: No? Oh, okay.

**SS: But one of the issues there is that they're more advanced in gay rights than we are in the U.S. Right? They have gay marriage, gay adoption; they have anti-discrimination, they have everything. And so in a weird way, straight people do look at gay marriage as an approximation of straight marriage, and they project onto it a certain kind of control of gay male sexual culture. And so it becomes antithetical to AIDS in their minds. In a way, gay marriage has been sold as a kind of antidote to AIDS. Because you never see the poster boys for gay marriage saying, I'm HIV-positive.**

SA: Right.

**SS: So in a way, it helps allow a nation like Canada to get behind HIV criminalization. Because now they have the good queers and the bad ones, even though most of the people are straight that are being prosecuted.**

SA: Right. And within the gay and lesbian movement, there are profoundly conservative elements who – I am waiting for abstinence until marriage, and when that is going to become an issue. But also, I think that there is something interesting, where there are organizations to tackle LGBT homelessness. And there is a constituency, there's a large constituency to help the homeless teen; but not to help the homeless teen deal with the fact that they're schizophrenic, or that they're using heroin, or that they're HIV-positive.

So there's a constituency for rights that doesn't necessarily want to embrace pathology, dysfunction, or services.

**SS: But who are you talking about when you say – who is fighting for homeless teens that's not focused on consequences of poverty?**  
01:10:00

SA: I think there's — I'm thinking about donors. I'm thinking about individual –

**SS: Okay.**

SA: – contributions.

**SS: I see.**

**JW: But it's still not a line item in the New York City budget, so every year, they have to fight for funding.**

**SS: I see. I see what you're saying. Okay. So –**

SA: Yes. But I think it's a key issue around HIV right now, is criminalization. And Sero has done a good job of raising it. And there is a danger that use of criminal law to control our sexuality. If I'm positive, and I have sex with somebody, and I don't disclose that I'm HIV-positive, and then I'm criminally liable, in a lot of states –

**SS: But if you're in a country where you have a national healthcare system and your goal is for everyone to be undetectable; you can puppet-master everything in a way that you can't do here, where you don't have the healthcare.**

SA: Yes.

**SS: Okay, so here's a totally weird question.**

SA: Okay.

**SS: If we're at the dawn of the time when many, many people can be undetectable; and if we ever get a coherent healthcare system, most people can be undetectable; how bad is it to be HIV-positive, honestly?**

SA: It –

**SS: It's a drag. But –**

SA: Yes. I mean, for me, I take pills every night. I don't have many symptoms. The treatments are working for me. I have a normal life expectancy.

**SS: So why the stigma persisting? It's not only not a death sentence; it might be something that you would never be symptomatic in your life. So with criminalization, what is the obsession?**

SA: Because of the history; it's because of the history of it.

**SS: Because it's associated with anal sex? Is that what it's all about?**

SA: No, because it's an infectious disease, too. People freak out about fatal infectious diseases. Okay?

**SS: Smoking is still legal.**

SA: I know, but that's a behavior – lung cancer, it's different, because it's behavioral. I'm trying to think of – I mean, hepatitis – even –

**SS: But they're not mandating that everybody gets a permanent patch put on them, against their will, to stop smoking.**

SA: Right.

**SS: There's something about HIV that's out of proportion to what it actually is in this historic moment.**

SA: Yes.

**SS: And I'm just trying to get you to tell me what that is. What is that something?**

SA: I don't know. I don't know.

**JW: Typhoid Marys?**

SA: You know, and it –

**SS: Is it homophobia? Is it that AIDS has been queered –**

SA: No.

**SS: – even though it doesn't –**

SA: No. It's not about homophobia.

**SS: Okay.**

SA: I mean, I can tell you; I'm a volunteer in an ambulance corps. Right? So universal precautions are universal precautions. So those rules are those rules. You

wear gloves. If it's icky and sticky and not yours, don't touch it. You know, like, really simple lessons. So people in the healthcare setting understand HIV, hepatitis – whatever. You're HIV-positive; that's the same as everything else.

But it doesn't feel the same. It doesn't feel the same.

**SS: Right. But what –**

SA: And I don't know. And I can tell you; the way I reveal – I'm publicly positive. And I've done newspaper articles saying I'm a person living with HIV.

Anyone can Google Sam HIV, and I'm there. So I'm open. But I'm guarded about – yes, I'm guarded about who I reveal being positive to on the ambulance corps, in a way that I wouldn't – I mean – we talk – I mean, I have to use reading glasses in order to fill out somebody's chart. You know, it's like we all have health issues and disabilities. So –

**SS: But I think if we can understand that thing, we can unlock the criminalization obsession. Because it doesn't make any sense; it's only ideological.**

01:15:00

SA: Right.

**JW: Wasn't there a proscription against donating blood if you're gay?**

**SS: Yes, that still is true.**

SA: Yes.

**SS: So is there anything that we haven't covered that – I only have one more question for you.**

SA: No. I think — I had two observations when we were scheduling this interview. One was my ambivalence about it. Because I felt like ACT UP was incredibly

important to me; but I wasn't quite sure how important I was to ACT UP. And so that was confusing, because, yes, I want to do this interview, because it was a really important part of my life. And, oh my god; how do I talk about it? Because it was 23 years ago, and I can't remember half the people who were important to me then, and memories. And besides, I went to some actions; but the more important stuff, for me, happened after I was in ACT UP.

So that was confusing.

And then the other thing was: just that observation about what's happened to everyone. Because it – it's a really interesting study. And you've done that study, because you've talked with over 550 people.

**SS: A hundred and sixty eight.**

SA: Or a hundred and sixty eight, or however many.

**SS: Yes, yes.**

**JW: It feels like —**

SA: Yes. But – the – I guess if you take any cohort of people who are in their teens to their thirties, and watch what happens over 20 years, you're going to get the same prevalence of – you know, everybody's got lower-back pain; everybody's got depression. Some people spiral into substance use and craziness; some people's lives get upended. Some people don't have any introspection. And this was a self-selected group of people, who had a proclivity for — not arrogance; some arrogance — audacity. Right? It's a self-selected group of people who are self-selected for audacity, who liked it. And some people didn't have a lot of introspection, and have kept marching on, in absolute certainty, of what is right, and sort of their cause. And it's just – it's just

interesting. I think the people who I've stayed in contact with, and the people I like the most; and what I consider a success for myself, is to bounce between those extremes. I think there's relatively few people who have managed to do that.

**SS: Well, one thing is that we certainly found a great deal to talk about – in this interview, right?**

SA: Yes.

**SS: So you did have a lot to contribute.**

SA: Yes.

**SS: I mean, having talked to all of these people — and I would say Jim and I probably have more cumulative knowledge about ACT UP than anybody, at this point — it's a very interesting group of people.**

SA: Yes.

**SS: Almost no – people do not say the same things. You know, we still have not reached a critical mass. They don't repeat each other; they don't use the same phrases. With very few exceptions, it's overwhelmingly individual thinkers.**

SA: Yes.

**SS: Because I think the – the way I understand what all these people have in common is that it's characterological. It's a certain kind of person, regardless of what their experience was, or class background, anything; they could not sit still in the middle of a historic cataclysm, and do nothing.**

SA: Right.

**SS: And that's what links them. But nothing else links them.**

SA: Nothing else –

**SS: Yes.**

SA: Yes.

**SS: So here's my final question...**

**JIM HUBBARD: Oh wait, I have a couple of questions.**

**SS: Go ahead.**

**JH: I want to go back to T&D.**

SA: Yes.

**JH: So did you continue going to T&D meetings after TAG split off?**

SA: Yes.

**JH: And how would you characterize T&D after as opposed to before?**

01:20:00 SA: I don't really know. It was so much an overlapping set of the same people. And it was always focused on specific projects that people were working on; people clustered around particular issues and reports that they were working on, and whatever they were obsessed by at the moment. And that didn't change. So I would say it sort of stayed the same.

**JH: Did you join TAG?**

SA: I wasn't – so when TAG got created as an organization; no, I was – at that point – Peter was the first executive director; Gregg and Mark were the first employees, and then Peter got hired. I was – it was all sitting here, in this room. So I was witness to all of that. But I had a job elsewhere. When we created AIDS Vaccine Advocacy Coalition, I worked with Gregg to coauthor a report, and I did a lot of work with TAG. But I was never part of TAG, officially.

**JH: Okay. And what's always confused me is how Treatment Action Guerillas morphed into Treatment Action Group.**

SA: I never heard of Treatment Action Guerillas.

**JW: It started that way.**

**SS: They're the ones who did the condom on Jesse Helms's house.**

SA: Oh, okay.

**JW: I think it was more of a grant thing.**

SA: Yes.

**SS: Yes.**

SA: Yes.

**SS: Okay, so my final question is just thinking back, what do you consider to be ACT UP's greatest achievement, and what do you see as its biggest disappointment?**

SA: Its biggest achievement is that it was an open door for people to walk in and get involved; and to teach a method, and to teach audacity. So, to teach Robert's Rules of Order; to teach how to marshal an event; to organize a demonstration; and that a small group of people could organize. I think there were methods that got disseminated, and there was a culture that got disseminated. So beyond specific achievements, I think that's the biggest achievement.

**SS: And what about disappointment?**

SA: That the coalition doesn't exist with that amount of energy – the coalition's gotten more diffuse.

**SS: Okay.**

SA: That it's not all in one room together.

**SS: And what are you doing for your birthday?**

SA: Going home, and David's cooking me dinner.

**SS: Okay, great.**

SA: Yes.

**SS: All right, well, thank you for coming in for the interview.**

SA: Yes.

**JW: It was always called Roberta's Rules of Order.**

**SS: Great, thank you. See that was great.**