ACT UP
ORAL HISTORY PROJECT

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Interviewee: **Rebecca Smith**

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Interviewer: **Sarah Schulman**

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ACT UP Oral History Project
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SARAH SCHULMAN: Okay. I'm eating my final pumpkin seed. Okay, so you look at me, not at the camera.

REBECCA SMITH: I'm not going to look at the camera. I don't like cameras. You're here.

SS: So we start by you just telling us your name, your age, today's date, and where we are.

RS: My name is Rebecca Smith, Rebecca Pringle Smith in ACT UP and on my medical license, and I am fifty-three, I think? I was born in 1962. No, so I'm only fifty-two, fifty-two and a month. We're in my apartment on the Henry Hudson Parkway. And—

SS: Today's date.

RS: Today's date is September 18th, 2014, one of my best friends' birthdays.

SS: Okay, great. So where were you born?

RS: I was born here in New York City, actually, in Harlem at Columbia Presbyterian Hospital.

SS: And where did you grow up?

RS: Well, I grew up mostly in Michigan. So my parents met in New York. And we maintained strong ties. We were in Ann Arbor, which is a college town. I'm really glad I got to grow up in the Midwest, not surrounded by quite so much really difficult sort of symbolism and a thicket of strange things to sort out intellectually.

My parents were—I read a couple of the interviews last night, actually. So you usually ask about what the parents were like. So I made a copy of this for you guys. My mother was a very committed feminist activist, and this is a piece—

SS: Oh, that's *Ms. Magazine.*

RS: This is *Ms. Magazine.* And she wrote this for *Ms.* It's called "Eight Games the System Plays, or How to Psych Out the Bureaucracy." I don't know, she's amazing. And the opening line is, "Having spent much time prodding and poking a bureaucracy to see if it can be induced to move however ponderously in direction of change, I have identified eight major ways the system fights back. By the system, I mean any large bureaucracy, whether a government agency, a university, or a corporation. By fighting back, I mean methods the system uses to resist change, whether change is being demanded by feminists, environmentalists, consumers, or other reform-minded citizens." So you could say I was schooled in this to a certain extent.

SS: Now, were they New Yorkers, your parents?

RS: Yeah, well—

SS: They were both born here?

RS: My father was born on the Lower East Side to an immigrant family, he's the Jewish one, and his father died when he was three months old. He got a scholarship to City College and then tried to take forty credits and work two full-time jobs, and dropped out, went and played pro basketball in Brazil, was the secretary to a writer named Stefan Zweig.

SS: Sure.

RS: Oh, you guys—oh, that's funny. Who knew—that's awesome.

SS: Wow. That's amazing.

RS: Well, it's odd. It's an odd story, and there's layers to it. And then he came back and was part of the founding of the Group Theatre with Clifford Odets and the gang, and he's got a very funny story about why he didn't go to Hollywood, like he realized that he didn't have this kind of talent with a—

SS: Wait a minute. What was he in the Group Theatre? Was he an actor?

RS: He was a writer.

SS: He was a writer.

RS: Yeah, he was a writer, and he wrote plays about social justice. I'd love to—I wish I'd made a copy of one of them for you. I mean, it really is—

SS: But what was his real name?

RS: Aaron Smith.

SS: No, before Smith.

RS: It's been Smith for a couple hundred years. So the pretentiousness on that side of the family goes back a couple centuries.

SS: Oh, wow.

RS: They were in Lviv, and there's a Sephared side and an Ashkenazi side, apparently. My Aunt Billie worked in a sweatshop cutting handkerchiefs. We have an oral history from her.

SS: They were named Smith in Lviv?

RS: Yeah.

SS: That's hysterical.

RS: Well, apparently they had come from England at some point, and we had relatives in Antwerp, I think. So that's some of the Sephardic side. But I don't know a lot more of the history. It's from my Aunt Billie.

00:05:00 Dad was also a big activist. He became a neuropsychologist and looked at patterns of recovery from head injury. But when he was at the University of Michigan during the Vietnam War, he felt strongly about direct action. So he went down on the buses to the protests with his little briefcase and his little pipe, and the students were like, "Wow, man, this is really cool. You're a professor. Here, have a toke."

And he was like, "No. Do you know what that stuff is doing to your brain? Come on. Let's talk about this." And he had a really good time with them.

But this is where I developed a certain suspiciousness of the sentimentality involved in direct action, because my dad would get drunk and teary about all his volunteering and going down there and all this, and I remember saying to him, "You know, Dad, I just saw a TV show. There's people getting arrested for not paying that portion of their taxes that goes to the Vietnam War, so there's other things that people can do."

And he was like, "This is why you're not popular."

SS: Well, you were growing up in Ann Arbor, so there's like John Sinclair and the White Panthers, and there's so much going on.

RS: Yeah. My junior high was where the Black English controversy started, so it was called Clague Junior High, and it was a caldron. I was having a lot of arguments with my dad around that time. He had a heart condition. My mother had been

carted off to boarding school when her parents got divorced, so they sent me to a Quaker boarding school. My mom took on—

SS: In Michigan?

RS: No, no. This was in Pennsylvania, 60 percent Jewish, 20 percent Quaker, but another one of these places with a history of nonviolent activism.

SS: What was it called? Friends—

RS: George School.

SS: George School. Okay. I've heard of that. Right.

RS: Yeah, well, it's like someone showed it to me in the preppy handbook or something. It said, "The students are running around with leaves in their hair. There's a dog running around campus with a bandana tied around his neck. The students have given him drugs."

So it was an interesting place to be. My best friend was the first lesbian I knew well. She came out when we were fourteen. She had her first love at fourteen. I've always bitched at her that I had to wait until I was, like, nineteen. But this was a very, very protective environment, and it was something of a shock then to go to University of Michigan after not getting into one of the Ivy schools or getting wait-listed or whatever happened. It's one of the places that cranks out students to feed the management mills of the country, and suddenly I found myself among 28,000 undergrads, and I was confronted with attitudes and things I had never seen.

SS: Even though it's a very progressive school.

RS: Well, it has everything, so if you're not happy there, it's a reflection on you. You can find progressive people at the University of Michigan. It's very diverse, unusually so, I think, for a large American university in a state.

SS: So you were premed, so you were—

RS: No, no, I was pre-waitressing. I was doing philosophy, psychology, and English, and I don't know what the hell—I think I had wanted perhaps to do medicine or psychology, but I didn't want to be an ignoramus about everything but medicine, and that was how I saw doctors. So I did that, and then when it came time to start psychology graduate school, I got a bit freaked out. I was in the elevator at the University of Michigan, going to a talk, and I was asking the professor something about the talk. He was my age now, like a fifty-something guy. And I remember asking him some question about the talk, and he said, "Well, you know, what I really think would be more helpful is if we could all sit around naked around a hot tub, you know, and look at each other, and know that it's okay to look."

And I looked at him and I said, "You know, it's really not okay for you to think you can say that to me when I'm asking you a serious question about the talk. And it may be what you're thinking about, but I don't know why you think that's okay." And he did think it was okay.

So I had this stupid idea that medicine would be more objective. How naïve. Were we laughing about naiveté earlier? I mean, how naïve is that? So I decided I'd come to New York and do medicine. Another factor in my decision was I was in a dance company, and I was the bad fat one, but I loved it. It's really good to do something

that you'll never be the best at, just because you love it. And the head of the company was named J. Parker Copley. We called him Parker.

SS: What was the name of the company?

RS: It was called the J. Parker Copley company. And he had danced with Martha Graham, and he was an out, gay man, and his boyfriend was named David Smith and was a blond-haired, blue-eyed Smith. And he was the first person I knew who died

00:10:00 of AIDS, and this was, I guess, 1982, '83, sometime then, at University of Michigan, and he was on a transplant ward at the time. I'd seen pictures of what looked like concentration camp victims to me in the news, because this is how people with AIDS were being represented. And he said to me, "The only thing I'm able to do is become a Christian Scientist for my own healing. If you're good at the science stuff, can you do something with this?" And I have his wedding ring still, when he and Parker had a ceremony. I wasn't there at the ceremony, but he gave that to me then.

And it was on a—where other people were getting PCP prophylaxis as a part of work in transplantation, but it didn't occur to people—I don't really know what to think about it. I know what to think about it later. I don't know what to think about it then.

SS: So PCP prophylaxis was preexisting before?

RS: Oh, yeah.

SS: Oh, I didn't know that.

RS: Okay. So this is an important, interesting part of the story, and this comes through me from Joseph Sonnabend, who is also an interesting part of the ACT

UP story, although he will never agree to be interviewed. When he was trying to get me to do it, I was like, "Well, would you do it?"

He was like, "No." But this is Joe Sonnabend.

So in 1977, PCP prophylaxis was discovered with an agent called Bactrim, Trimethoprim/Sulfamethoxazole, all which you guys know all know well, unfortunately. It was initially used in children who'd had organ transplants, so we knew about this for some time. And in—I was just looking at the numbers on this. Let me just—this is odd, because this was actually—my involvement started somewhere between late 1987 and 1989, although when I came to New York, I guess this was '86. I was a GMHC buddy and I was a dancer, so there was a lot—I learned a lot about the closet.

SS: Where were you going to medical school?

RS: Well, I wasn't in medical school yet. I was doing premed at Columbia's postgraduate premedical program, and I was getting it paid for through working as a research assistant at St. Luke's Roosevelt Hospital.

SS: So it was all there. Now, was Carol Vance at Columbia when you were there? No.

RS: I don't know.

SS: Was there anyone doing HIV work inside the school, or was it all—it hadn't reached the academy yet?

RS: Honestly, I don't know, because I was sort of—I was really—I was doing a couple of classes at night and working during the day, and then when ACT UP started to take over my life, I really didn't know. I ventured out only a couple of times. I guess one of them is relevant. I'll have to mention that one of the times I ventured out of

science at Columbia to—I actually asked Edward Said for advice on what to do when you have knowledge that you feel you can't convey. I guess this was 19—must have been, 1991. Yeah.

SS: What did he say?

RS: Well, this is odd. Maybe we should—

SS: No, let's hear. Let's finish this.

RS: Yeah, yeah. So the situation was through ACT UP, through the work of David Kirschenbaum, Iris Long, Jim Eigo, and then Joseph Sonnabend and Michael Callen, those were the main people I knew, I ended up having to go to Washington to talk about HIV stuff and trial design to a bunch of people. And I was very conflicted about doing that, just like I'm conflicted about the interview.

I mean, one of my problems that I'm using your words for with straight people coming in and representing in what is a Gay Liberation Movement, a Gay and Lesbian, LGBTQ Movement, is this is a story that my community—and I guess it's also your community; I don't know where these lines cut—likes to tell, that people like, that gay people are self-hating and they don't have a community and can only be understood through straight women and a straight male lawyer, I guess, in that movie *Philadelphia* or whatever the hell it was. So my point of view was that people with AIDS needed to speak for themselves, so I felt very comfortable behind the scenes, but I ended up having to go into the belly of the beast, and that's not my cup of tea.

SS: So what was Said's advice? That's interesting.

RS: So I ended up with this knowledge that I didn't want, and I saw a parallel with his life. He was an elite Palestinian who ended up with knowledge he didn't

want about the way Arabs were being represented, so he, as you guys, I'm sure, all know,

00:15:00 felt that there were very strongly held ideas about Arabs, about what they believe, about what they do, about what they think, that are held by people who may never have been to the Middle East, who may never have met an Arab, and he sort of articulated a process through which these very strong beliefs come to exist, and his idea was that that process is not innocent, it is not objective, and it exists to serve some interests. And he got so much crap for this.

I still don't understand a lot of it, but I felt like he knew or he felt he knew a lot about how this community that had been cast out of its country could organize, that he had things to offer, knowledge to transmit that he couldn't transmit. This is something that I felt. So I stalked him and ended up asking him about this, "What's it like?" Because I felt I had this knowledge about randomization and how to get answers quickly, and I didn't have the—I wasn't articulate enough, I wasn't a good enough writer, I didn't have the political skill, I didn't have the identity, and I felt like Cassandra. I just—so I went to him and said, "You know, how do you handle this?"

And he said, "Are you Palestinian?"

And I said, "That depends how far back you go. I mean, are you Palestinian?" And then he got sort of interested. And, you know, I said, "Look, I know this technology. Clinical trials are just a technology for resolving medical controversy. Because of my queer community that I'm a straight part of, I've got knowledge about how to do that, and I can't transmit it back and I can't stand this. What do you do?"

And I just remember he sort of smiled and looked at me and said, "Oh, I don't have good news for you."

It was a sort of distant acquaintance. I don't think of him as Edward. I met his elevator operator, who's a guy named Vince Passaro, and he calls him Edward all the time. He wasn't ever Edward to me, but he was a fellow traveler in this very strange arena. And just in looking back, it was good to have someone just say, "You know, yeah, I don't have good news for you."

SS: Right. So you were working at St. Luke's.

RS: Right.

SS: And did you have exposure to the AIDS ward there?

RS: Yes.

SS: Were you on that ward?

RS: I had two different kinds of exposure. I volunteered on that AIDS ward.

SS: What years are we talking?

RS: This would be 1986, '87. Yeah, I guess '86, '87, and '88, and then '88, I guess I went to CRI, Community Research Initiative.

SS: Let's start with St. Luke's.

RS: So at St. Luke's I worked in the body composition unit at first, and I volunteered on the AIDS ward. I had had a couple of friends there. They had this thing called the Scrymser Pavilion. It had a lovely view, the nurses were pretty nice, but it was pretty weird, and people—it feels like sort of pornography to start talking very graphically about how people died, so it's a—we're doing this on tape.

SS: Yeah, but you're the 169th person we've interviewed, so we've had a lot of graphic descriptions of people dying. I mean, this is ACT UP. I mean, that's the reality.

RS: Yes, and it's something I'm somewhat critical of. I mean, again, the product of ACT UP, some of these intellectual products, that's why I decided to do this interview, because I have some pretty serious questions about some of them.

SS: Okay.

RS: But this one I will tell you then. Thank you. I saw people dying bathed in quarts of their own excrement, and nobody would touch them. I'm sorry. God, I feel like such a cliché, the straight hospital worker crying about this. It's what happened. And when you witness, you guys all know. I guess I feel better. I've been trying to put this off, this part of it. I was complicit. I'm mean, I'm still complicit. I still work in the medical industrial complex.

So as part of the research that was being done in HIV by Don Kotler, a heterosexual physician but with a very serious interest in the community and a real supporter and someone who really thought about these things, he was looking at how people did and whether there are ways to turn things around. One of the things that happened was a wasting syndrome, and people had this idea that people with AIDS had
00:20:00 immune systems that were just crushed, and that was it and there was nothing you could do. And as Tony Fauci said when Michael Callen met with him to ask for PCP prophylaxis, [imitating Fauci's accent], "No, Michael, you don't understand. HIV is a very strong virus." You know, Joe and I puzzled over this for years. This was in 1987 or something. What does that even mean, that this is going to be able to inactivate all these

medications with known mechanisms of action for preventing opportunistic infections? What the fuck?

But so Don was looking at how people got really thin and looking at ways of feeding them and seeing if we could get weight back on them. And so they'd come, we'd measure what they were losing, and then when they were being re-fed different ways, what they were gaining, whether it was muscle, whether it was fat, whether it was water, did it increase survival.

So that was how I got to know a lot of prominent members of the community, and back then we didn't have HIPPA and stuff like that. A bunch of them were in dance class with me. Michael Hirsch was probably the one that I got the closest to. It's so hard not to sit here and go, "Let's talk about our friends," but I knew Michael. He was the first person to bring me to ACT UP, actually, and he had started the Body Positive, which was an organization for men with HIV to be able to meet and have sex. He was sort of, as Jim Eigo would put it, a pro-pleasure activist in a sense, one of the early ones.

And we used to argue about AIDS, and there were all sorts of people from there, but we used to argue and he would say to me—I remember one day Don Kotler walked by when he was saying to me, "You know, it's a good thing I got AIDS."

And I was like, "I just can't feel that way, you know. Sorry."

Then he just said to me, "Rebecca, without AIDS I just be a nebbishy little faggot."

And Don Kotler said, "Michael, you still are a nebbishly little faggot," and it cracked us up. But humor was important.

But I remember I got identified as someone who could help people understand the mechanisms of clinical trials and things from my time at St. Luke's. The first thing I would explain was all the body composition stuff. Pretty soon people were bringing me consent forms. I knew about Don Kotler's trials and I was interested.

So I'd had really scary conversations with people too. Like I remember asking someone, "How are you doing?" someone with AIDS.

And he said, "Well, not very well, you know."

I said, "What's going on?"

He said, "Well, I've been told I need to choose between my sanity and my life."

And I was like, "What do you mean?"

He said, "Well, I may go blind if I don't get into the study for this drug," that was DHPG, "but I have to go off AZT if I do that, and I have AIDS dementia, and I feel guilty enough about taking AZT." people felt guilty, like, "Oh, I'm doing this. It's betraying the community."

So, these awful conversations about research, and so I was—and people were getting healthcare through these clinical trials. So the toughest conversation I had was with a really nice guy who was very interested in his data being used to help other people. He was not a martyr; he was a fighter. This is a way of fighting. It's not just being a martyr. And he would say, "Are you doing a good job writing down everything I said? You know, my food diary, did you get everything?" And making sure I did a good job overseeing it, which was good.

And he was not eligible for some clinical trial because he had five too few T-cells or something, and he was very upset, and we were looking for another study for him. And he said, "Look, Rebecca, if it really is true that I can't be in the study, I'll lose my healthcare, but I'll feel okay about that if you can really tell me how excluding someone with five too few T-cells will give better data. You know I would do all the work for this. You know you could tell these people I would do all the work. So before I became an artist, I was actually in chemical engineering school. So I want you to walk me through this."

And I was like, "Good question."

He said, "Okay, well, what's the answer?"

And I started to say, "Well, you know, the need for homogeneity," but the hairs on the back of my neck rose, and I went, "You deserve better than I can give you right now. I'm going to go to Don Kotler and ask him."

And as I was saying it, I knew Don Kotler didn't know, and that was the beginning of hell for me. So that was when I started getting more serious with ACT UP, because I realized something's happening here that we all know is happening in medicine and we're not talking about it, and these people are talking about it and they're facing it, and no one's talking about it.

00:25:00 **SS: Was anyone who was in any of those trials with you at St. Luke's, are any of them still alive?**

RS: No.

SS: No, they all died.

RS: Everyone I knew from then.

SS: Right. So in other words, he had a hope that if he was in that trial, he would live, but actually if he had been allowed in that trial, he still would have died.

RS: We got him into another trial.

SS: Okay.

RS: And he didn't die until '91, but, yeah, he did pretty damn well.

And there's characteristics of long-term survivors. My favorite publication ever is still this, Michael Callen's *Surviving and Thriving with AIDS*, and this is the heart of the research I do today, principles of resilience articulated by the gay community about how to take care of yourself.

So one of the things, like the current academic project I'm working on is in people exposed to trauma and disaster. I believe resilience is something you can train for, like a sport. And what are the modifiable resilience factors? Right now I'm looking at perceptions of justice and forgiveness and how they work in people who are exposed to big disasters. And it's a bit flaky, but it's somewhat interesting, as a—it's not important in the way that some of the work we did in AIDS was, but sorting out—I'm what you call a psychiatric nosologist in my research career, so I character the symptom architecture of different illnesses, try to create understandings of wellness and wellness factors as well as illness factors. It's complicated in psychiatry.

But, yeah, it was really, in some sense, as Michael said, it was about being in the moment with that guy. What do you say to somebody? You have have a clean interaction. And so this really changed a lot for me, and so I would go to ACT UP and I ended up with pieces of paper, Xeroxes of all these clinical trials. I had this bag, and it

was really—I had all these people calling me and asking me, and I don't know anything and it was just strange.

Then the head of the body composition lab thought it was really nice the way I worked with the AIDS patients. It was sort of condescending. Oh, I also had a needle-stick injury during that time and got asked to use the patient bathroom and not the staff bathroom after that, and so I had some exposure to some of the wild irrational thinking that goes on.

SS: And did they zap you with a lot of AZT or did they—

RS: This was in 1986, so it was before—no, 1987, so it was before any of that stuff happened, but I wouldn't have done that anyway. The seroconversion rate was very low. But we were all pretty frightened, because twenty-one days after the exposure, I developed severe diarrhea, fever, nausea, vomiting, and a rash, and we were all like—

SS: And do you think that that was emotional?

RS: I have no idea. If I had to say, honestly, I'd say it was coincidence. I was upset, but I wasn't that upset. Some of the ways my family handled it worried me quite a bit, but—

SS: Can you explain for the record what was the conflict between CRI and ACT UP?

RS: I think it was—well, okay. So I mean, when you see this, CRI is representing itself as ACT UP in a sense. So early on—

SS: Oh, that's interesting, yeah.

RS: Yeah, I just want to make that point. Early on, Tom Hannon was the executive director. I'm going to give you guys these, if you care. I don't know. You

probably get loads of pieces of paper from everyone. But Tom Hannon was very pro ACT UP and very pro an activist stance.

And I think the division started to happen, so in 1987, Michael Callen and others met with Tony Fauci to ask him to issue these interim guidelines urging individuals to prophylax for PCP, I guess. By 1989, the numbers, 30,534 people had died of something that we already knew how to prevent. We knew the etiology, we knew the agent, we knew how to prevent it. So Fauci didn't do it in '87, and between '87 and '89, 16,000 more people did.

SS: Now, why didn't he do it?

RS: Well, this is why—bureaucrats. As my mom says, they resist change. They like their jobs. Their digestion is splendid. And I think that I was never comfortable with that whole part of what we did, although I think it's good and I would defend it. I will defend it. But as Michael Callen once said, "Don't assume these people
00:30:00 have your best interests at heart." Not that they're out to get us, but just we don't exist. And I think for Tony Fauci, we became a mechanism through which he related to his work and it became more dramatic and more colorful and more interesting. And he may well care about particular individuals, I don't know, but I'm a different animal, a different breed. Michael was more dabbling in doing the trials, and he was—

SS: Michael Hannon?

RS: Michael Callen.

SS: Michael Callen, okay.

RS: Tom Hannon was a worker bee. So Michael was becoming a celebrity in AIDS and manufacturing an identity, Classic Coke and the love of a good

man, and there's some complexities there, but Michael was a good friend and a complicated person. He got really pissed off with me, actually, because of talking about some CRI trials at ACT UP, the first time I think I got called a murderer.

So by this time I was working with—the lab had tried to donate computers to whatever AIDS organization I wanted, and I was like GMHC doesn't need them, but ACT UP may need them. And I went and I sort of met Iris [Long] and David Kirschenbaum, and David and Garry Kleinman were really, really important friends to me then, and they were in the same situation. Garry was answering letters and dealing with a lot of the same stuff I was. I saw stuff with his handwriting, "Can you answer this?" in one of my boxes that I was looking at. So I was really working a lot with them.

And CRI, with Joe Sonnabend and Michael Callen, was a radical organization, and I would argue you could say in some ways it was more radical than ACT UP, because people with AIDS were represented at all levels in the organization: on the board, in the clinical trials, and on the staff. Now, of course, I was getting into trouble because I was bringing up, "Listen, if we're having people with AIDS on the staff, how do we take care of them? People are going to be coming to work when they shouldn't be."

[Cat knocks over plant]

Khaleesi was that you? So the flower falls on my head, I don't know if that's an omen.

SS: That's fine.

RS: Well so. So—yeah

SS: But why were CRI and ACT UP mad at each other?

RS: Well, so what happened was I remember at ACT UP, I brought up—I was trying to talk about the placebo issue and saying, "You know, this monolithic opposition to answers is a mistake. We need access to answers, and in some cases placebo controlled is the way to go, but it depends on the question. And placebo control doesn't mean you take people who think they should be on the drug and you keep them on the placebo till they die. But in some instances, this is a good way to go."

And I remember we were all sitting around talking. I think David was there, and he was not buying it. He was like, "No. Trials are treatment." Jim was there, too, and someone was there who was in the Lentinan study at CRI. And I defended it, and I said "Listen, you know, this is a valid thing."

And this person said, "Well, I think anyone who would do a placebo-controlled trial is a murderer, and anyone who would be in one is a martyr."

And then I went off, and I was like, "Well, you know, I'm not into calling each other murderers here, but suppose there's a drug, a promising new therapy, that's toxic, that kills people. The drug companies are going to say they died of AIDS. They're not going to go with the idea that it was the drug. So maybe in some situations, your point of view, the cost of that can be measured in thousands of lives lost."

At which point, David said, "Okay, murderers. You're both killers. Let's go to dinner. Enough of this already." And so we all went to dinner. And I didn't get anywhere with this point of view about study design. So Michael was furious with me about having—I wasn't authorized to talk about the Lentinan study to ACT UP.

SS: But what was the problem? Why couldn't ACT UP and CRI cooperate?

RS: Well, I still don't know what that was about. When I saw it start to happen was there was this CRI conference and people from ACT UP wanted to be there, and I was like, "Let them in."

And Michael was like, "No. This has to be—." It was the beginning of us getting co-opted, if you ask me, and it was also the beginning of the creation of this myth that there are some people with AIDS who are experts and the rest are just rabble. I really do think, if you ask me, that's part of what was going on.

00:35:00 **SS: Did any trial at CRI produce a treatment?**

RS: Aerosolized pentamidine, yeah.

SS: So CRI did the trial for that?

RS: Well, there were two sites. There was the County Community Consortium in San Francisco, and then there was CRI New York. And at CRI New York, people actually came to a central location and got aerosolized pentamidine, so yeah. But there were loads of problems with the data management. There were loads of problems with follow-up. And Joseph later said — [to cat] Khaleesi you are attacking my papers and the only protocol that ACT UP can be said to have produced. Listen you little pussy, get off of that. Stop obstructing access.

RS: So I really think that it boiled down to that, that it was a conflict of sort of the notion that some of us should do science and the rest of us were rabble, but I don't know a lot about the details of it. It was around then that I got forced to leave CRI.

SS: Why was that?

RS: This is—So I was doing all this work behind the scenes. Like I said, my point of view was people with AIDS deserve a voice and a representation of their

concerns, but in the community, in the boiler room, we can talk about what those are, on the floor of ACT UP. And I was doing all this stuff with them with study design. Now, I didn't have all the ideas. Some ideas came through me, but Jim Eigo and David and other people were involved in a lot of the thinking, and then Joe Sonnabend started to become a big part of the thinking, like all of the stuff about prophylaxis comes from Joe. And Joe is not some community physician; Joe is an immunologist. He worked in Peter Medawar's lab, who's the guy who got the Nobel Prize for discovering the MHC Class 2 receptor, which differentiates self and other. You and I are both interested in otherizing, so it's kind of funny that Joe should have that intellectual heritage. And he was also a clap doctor and an infectious disease doctor, so he's a community doc, but that's almost the least relevant of his qualifications in AIDS. But he came to believe later that clinical trials had its own vocabulary, and that, no, not every doctor or every scientist could run out and do a clinical trial.

So, no, I don't think CRI did produce. The Compound Q issue, I think, was very divisive. I think this was what really broke us all up in a way, CRI and ACT UP.

SS: Why? What were the two positions?

RS: The two positions were—so Compound Q was advertised as a Chinese cucumber extract. It was an abortofacient used in China. There was a corporation that had an interest in developing it here, and they're putting out lots of promising new agent: "It kills HIV in a new way. It goes after infected cells." And I thought the science was crap and—

SS: And Marty Delaney was one of the endorsers.

RS: And Marty Delaney, the late Marty Delaney, who we had a lot of fights with, but who was trying to do the best he could to save his own life and become a consumer of information and help the community in his way. I think he was totally wrong, and I have a joke about—this is one of the statistical things I handed out at ACT UP, "A major activist's contribution to statistical theory about clinical trials is the Delaney Decision Rule: Always reject H_0 [H-naught]. H_0 is a theory that the drug doesn't work."

SS: Oh.

RS: But, you know, he didn't know. We were all learning, and I wish we'd been kinder to each other or more understanding, but we were young and kooky.

So there was a view that some of the nurses at CRI had that if people with AIDS wanted it, we should give them access to it, and I was like, "No. If people with AIDS want it, they can get it, but we need to give them an informed dissent. You don't just go along with it."

And one of the guys who died, Scott Schaffer, who ended up in *The New York Times* in this bizarre caricature, I mean, they had him grunting incoherently into a lamp, looking like some—I mean, he was delirious. It wasn't like he was using drugs or something. It was so bizarre, the representation. But I remember sitting in the hallway at 31 West 26th Street at CRI and giving him what Mark Harrington later called informed dissent and saying, "This is *not* in your best interest. You are *not* helping yourself. This is poison. Do not do this. You're feeling this sense of togetherness because you're going and putting something in. No." And he was crying and holding my hand and telling me

how beautiful I was for caring about him, but that he had to do this for the community. It was like—and so there was a split around that.

So Mark Harrington emerged around then and talked about Scott's death in the media saying, "It was like nothing I had ever seen in AIDS."

And I was like, "Well, I don't know. I've seen people go down pretty fast. What is this?"

00:40:00 So he got told to shut me down by people at amfAR, and that's how we ended up meeting, and he was saying, "This was a bad study. It was poorly conducted."

And I was like, "No, no, no. It was very well conducted. The nurses did a beautiful job of documenting everything. The problem was the study wasn't designed to get an answer. It shouldn't have been called a study. These people were sold a bill of goods. We in the community let our colleagues down by not putting information out there."

And so Mark was like "Oh," and he served me espresso in a bowl. I'll never forget that. I thought that was so East Village and cool, and then later I learned it was because he didn't have another cup. I was like, "Oh, this is so cool."

But that's how we met, and we'd met once before. We'd crossed swords sort of in a T&D meeting. I was suspicious of T&D. I was really into ATR, AIDS Treatment Registry, but T&D, where people were using a lot of acronyms, I wasn't comfortable with that. I was sort of dicey about it. But David Kirschenbaum was there. There were lovely people there. And Larry was—I didn't know who the hell Larry was, you know, and he was just this guy Larry in the back with his dog, and he was like, "Who are you?"

And I was like, "Oh, I'm Rebecca Smith."

And he was like, "Well, we need you here. Come back."

I was like, "Well, I can't come next week. I have a biochemistry test."

He's like, "Well, what's your phone number?" And then I'd get messages from him, "Hi, this is Larry. I'm just calling to wish you luck on your biochemistry test." Then I found out—I saw him on TV giving the speech on, I guess—my friend Rick Shur did this *Closet Case* TV thing. I thing he had a video of Larry talking about—I think he was saying, "What do we need to do to get you people to get your fucking thumbs out your asses?"

And I looked at this guy on the screen, he had a striped shirt, I think, and I said, "This guy looks familiar. Oh, holy crap. That's Larry Kramer." And I went running up to him at the Monday night meeting and said, "I didn't know you were Larry Kramer."

And he said, "Well, yes, who did you think I was?"

And I was like, "I didn't know, but listen, I want to talk to you about this movie you made years ago, *Women in Love*. That's an amazing film."

But it was awkward. And then in the middle of this thing, when I'm sort of bonding with all these guys and we're having these debates, I can't get through to anyone. They're writing their Montreal treatment agenda, and I'm just getting nowhere. I try these different rhetorical positions. "You should be demanding access to placebo-controlled trials as short-term studies where the question is acute toxicity. Toxicity data are vulnerable to unblinding." But we're getting really technical here.

SS: Why is toxicity data vulnerable to unblinding?

RS: So let's use the original AZT trial to talk about this, because this may be part of the AZT story. So the initial AZT trial was begun, I guess, in 1986, enrolled 282 people in AZT versus placebo. And so this was a double-blinded placebo-controlled trial of an agent that had been invented as a cancer chemotherapy to shut down DNA chain terminations. It was discarded as too toxic for use in cancer, but Sam Broder took everything out that had been used in cancer, tried them all against HIV, and presto, this one had some activity. It turns out it's mild antibacterial activity and does other things as well. It certainly wasn't a reverse transcriptase. I mean, it didn't chain-terminate.

So the study, actually, was unblinded, because one of the things that AZT does is it does some funny things to bone marrow, which is one of the most quickly replicating cell forms in the body. A value called your mean corpuscular volume, the amount of volume in each of your little red blood cells, goes way up with AZT. And so anyone in that study—so everyone knew who was getting what, so all you had to do from the minute you got their first lab results, you knew who was on drug and who was on placebo. Also it was so toxic, I think people could tell. Joe Sonnabend thinks this was important because deaths from AIDS were preventable at that time. These were deaths from diseases that we knew how to treat in the setting of organ transplantation when we'd suppress people's immune system. So Joe's view is that if people were known to be on AZT, they were watched more closely and opportunistic infections might have been caught earlier. Now, I'm not sure that really pans out statistically, but it's an interesting question.

SS: That's the argument. They still use that argument. They use that argument for vaccine tests, that if you're in a study, even if the drug isn't going to

help you, that you're going to get more healthcare. This is a thirty-year-old argument.

RS: It's so kooky.

SS: But also at that time weren't the dosages so high that they were producing lymphatic cancer and all kinds of things?

RS: Well, they were producing a lot of different toxicities. I mean, mostly
00:45:00 suppression of bone marrow and severe illness, severe tiredness, wasting, vomiting, nausea, diarrhea, and things like that. I mean, David Byar, one of our colleagues who we'll talk about, couldn't take AZT at the maximum dose.

So, yeah, I mean, I don't think that was a reasonable question. Jim Eigo's point of view, when we were arguing this, that every arm of every trial should represent a legitimate treatment option for people with AIDS, this is not just good medicine; this is good science. If a clinical trial is supposed to be a mechanism for resolving medical controversy, then let's pit things about which there's controversy. Nobody's begging for access to placebos, although I have to tell you Bob Huff once designed a study pitting all the different placebos against each other: IV placebo versus shots of placebo versus oral placebo. And Joe Sonnabend and I wanted to have different flavors of placebo and, you know, different outfits for nurses giving the placebo. And that's actually—it's complicated, it depends on the question, but, no, there was no rational at that time for placebo-controlled trials waiting for death.

SS: So just jumping way ahead, that concept that every aspect of the trial should be a path of treatment, how does that apply to 076?

RS: I have no idea. I mean, I don't understand where that actually—I don't understand. They were doing so many trials of AZT, I guess it was just because the money was coming from the drug company. I mean, I don't think it makes any sense.

SS: All right. Then let's go back. I just want to talk about the transition from the David Kirschenbaum, Iris Long, Jim Eigo T&D to the Mark, etc., T&D.

RS: Yeah. Yeah.

SS: So can you articulate what was the ideological difference between these two formations?

RS: Well, I mean, my particular path in that was I got called out on my one vacation day and sent down to the Statistical Working Group meeting after people with HIV had been down there already to talk to the government bureaucrats, and we had an agreement I was never going to have to do that. And I was just like, "I don't do this, and I'm a straight woman. This is not—no."

SS: So was Iris Long a straight woman. I mean, why was that different for you?

RS: Iris Long was not out there talking about holding researchers accountable for clinical trial design, so this is—

SS: Okay.

RS: I was directly involved in the healthcare. I have no problem with meeting with people about testing or things like that, but when it comes to trials, I felt like I had learned from the trial participants. They had the wisdom. My wisdom came through them, and it was sort of a misrepresentation for me to go.

But what David Kirschenbaum or someone told me was that when the guys had been down there, the statistician looked at them and said, "Listen, you guys don't know anything about this stuff, and we need the person who does. This is serious. People are dying."

And they're like, "Okay." So their own rhetoric was used on them.

So I had to go down on a Saturday to this meeting of the Statistical Working Group, and I got these phone calls from these people at amfAR, and I was not an amfAR fan. I remember I'd met them at the CRI conference when they weren't letting ACT UPpers in. And I remember David Corkery actually saying—trying to bond with me, and I was like, "Look, we have no reason to ever talk. I don't know why you guys are in the mix. This was supposed to be about study design. You guys are about movie stars and raising money for whatever. I'm not part of this. Have a nice day."

But I got sent down, and I got called and told that the head of this meeting had AIDS, by one of the people at the meeting, and I was just like, "How can you do that to this guy? We are opposition, you don't like us, and you're calling? What do you think this will—do you think this will make us be easy? What the hell is going on here?"

So I said to her, Susan Ellenberg—and she never forgot this—"You can consider him under our protection against you guys, and this is now a further bone of contention."

SS: And this is the government guy?

RS: Yeah.

SS: Who was it?

RS: So his name was David Peary Byar and he was a statistician, a closeted statistician.

SS: Oh, yes, many people have mentioned him, but not said his name.

RS: That's right. And Jim actually thought he was closeted. I was freaking out at this. I was like, "Fucking, Jim, this is one of the most important things that happened for me personally in ACT UP was David learning that he had a powerful, beautiful heritage." That's something ACT UP gave David. This is him. So he was the chief of the biometry branch at the National Cancer Institute, and he was beloved there. And he thought he was in the closet, but everybody knew, and when he got PCP in his
00:50:00 fifties—and he was this very attractive, charismatic guy—he decided to come out. And people were like, "Yeah, like you think we didn't know? But it's nice that you're comfortable enough to tell us."

So he was taking AZT, and he didn't know they had told, and I didn't know who he was. But I got to the meeting, and all I had was like my little Laura Ashley dress or something, featuring these bizarre heterosexual signifiers, as I am today with my *I Dream of Jeannie* hairdo or whatever. And he was like, "Oh, we'd like the coffee service set up in the corner."

And I was like, "No. I'm the ACT UP rep."

SS: Oh, no.

RS: And he just looked at me, like wig flip, you know. I looked at him and I went, "Oh, my god, this guy has AIDS and it's pretty advanced," because he had the skin and the teeth, and I was like, "Holy hell, this isn't just somebody with HIV." And it shocked me that one of *them* was really ill. But I think this was a much more

important part of why the statisticians were so open to us. I think it's much less a product of our brilliant intellectual critique. One of them was sick, okay, and I think that matters. I think there was a community of statisticians and that mattered, much more than this.

So in this process whereby very strongly held ideas get concocted about who's who and what's what, the brilliance of TAG is why the statisticians were brought to the table. People piously intone this, people who know better. I mean, Susan Ellenberg talks about how they really educated themselves about secondary analysis. No. David Byar educated me and I educated them. But I didn't want to be. I wanted to be like singing *Kumbaya* to people with AIDS, or as John Ingbretson in ACT UP used to say—he was the guy who held up the sign in his affinity group, "I got the placebo." And he was like, "Yeah, you want to be on the corner handing out toothbrushes to the homeless. You know, that's you."

SS: What year was this meeting?

RS: This was in 1989, early 1989. And I came back and I gave a report to the floor, because I felt stabilized by the floor. It was really the place where the conversations that mattered the most took place, and ATR was also a home. T&D became sort of a home, but always very conflicted because by the time I got there it was all about what Brad Gooch calls the HIVIPs, you know, and the intellectual products.

So I was like, "Well, so what do *we* want? Here are the issues." I mean, I did this complicated report. Oh, and I had this fight on the floor of ACT UP, like, you know, I did not talk about my views about placebos, because we have not agreed on this, and I am not going back down there until we talk about this more seriously. And some people are happy, some people aren't, about that, you know. But I felt that I wasn't there

to represent my brilliant study design views. No one cared about them. I was there to further this process.

And what ACT UP brought was a focus, and I channeled Tom Hannon and all the big queens, and Rollerena, I channeled them at that meeting, because I didn't have anything to bring to the table. But David Byar started the meeting saying, "So we begin this meeting with how is HIV different from other diseases and how should clinical trials be designed differently from the way they are in other diseases? Victor Dugatrolla has prepared this agenda," another gay, out statistician.

No one said anything, and I said, "Well, this'll be very nice. I'll just read the question, give my opinion, and it will go down in history as the opinion of this august group." So I got my cig – and I said, "Uh-huh, I thought that's the way you guys did things. Well, one of the things that's different is we're here and we're watching, so you don't get to do things the way you usually do."

And then somebody—we talked about the noncompliance issue, and I gave Jim's line about how every arm of every trial needs to be a legitimate treatment option, and this guy said, "Well, you know, we don't think placebo controls are that big a deal, actually, because we're looking at the noncompliance data in these studies of AZT." They were called 016 and 019, early AZT. "So, you know, we don't really need to do things differently because there wasn't much noncompliance."

And I said, "Really? So you think that's fine? Well, if that's what you guys think, then I have more important things to do than to talk to you, like go home and clean my apartment in New York. So I'm leaving."

And David Byar was like, "You sit back down."

SS: What was his investment in pretending that there was compliance?

RS: Well, in 016 and 019, apparently, because you could look at MCV levels, there was. Apparently there were compliant martyrs in that study. I mean, I don't know their story. I did see some of those data, actually. Knowledge translation is this very strange thing. Bob Huff was with me at this meeting, and he really bummed me out, because he said to them—the first thing he said was, "You guys are the people that can really do things, you know."

And I was like, "No, you know, we're supposed to be here to tell them that we have to do things in a different way."

00:55:00 **SS: What was the difference in ideology between the early group and the later group?**

RS: I think it happened in one day, which was the day we let the media into T&D, and it wasn't DIVA. It would be different if it was our TV, a TV that had been invented to keep people safe during demos, to record what happened.

My favorite picture from ACT UP is Miss [Alexis] Danzig and the photo of her smiling, you know, just very comfortably at the camera, being safe because the camera's there.

Jim Eigo and I were the only people in the room who didn't want the media in the room.

SS: Do you remember what media it was?

RS: It was not the *New York Native*, which I think would have been better, more comfortable. It was, I think, it might even have been Laurie Garrett or something,

but someone important that wanted to come to T&D meetings. And Jim said, "If this happens, we'll stop talking to each other and we'll start talking to media." And to me, that was the beginning of the end, that and the debate around Stop the Church, you know, the—

SS: Explain. In what way?

RS: There was this big fight. I mean, I just remember a couple of Latino people very concerned about this, and David Barr talking, too, about how they were trying to build consensus, and so they had to have a really clear agreement beforehand about what was going to be done. And they did agree that they weren't going to go in, and then they went in.

SS: No. They agreed that they would go in in silence.

RS: Yes, yes, yes. I'm sorry. I meant they—I can't believe I made that. That's a really odd mistake to make.

SS: That's okay.

RS: No. It's interesting. These sorts of things are interesting. Yeah.

When I see it, I think it was the right thing to have done, you know, just like maybe the Community Constituency Group was the right thing to have done. I saw it as co-optation in action, but I don't have a better alternative. I don't know how these things should be done. But I think that was the moment at which the old ideology started to die.

David Kirschenbaum, who I had dinner with, I guess a few months ago, and talked about this, he said that it was when Iris—we got this grant from the state to look at clinical trial enrollment in New York, and she got really on David's case about—

they started fighting. Maybe it was just the emergence of ego, like the celebrity, the star-maker machinery behind the popular song. I mean, I think that's what happened is that the floor of ACT UP became the star maker or felt like the star-maker machinery behind the popular song.

SS: So your claim is that exterior forces transformed people, not that people arrived with different ideologies?

RS: I don't know. I don't know what my claim is. But that would certainly be one possibility. I mean, you know, at one of the shelters I work, there was some violence recently and someone was seriously harmed, and I was concerned about the safety procedures. And one of the program assistants said, "You're just beginning to see things for what they are." And I was like—so maybe people had different ideologies. Maybe I was idealizing people, but the floor was this place that I trusted. Even though it was scary at times and freaky, conversations could happen there, they couldn't happen anywhere else, and it transformed me. It gave me, as David Robinson once said, "I had a visa to travel in the queer community. She's here, she's not queer, and she's not leaving." You know, I mean, it was just—

SS: But there were a lot of straight people in ACT UP.

RS: Absolutely. But the meaning of straight people in ACT UP is an important issue, and I—

SS: What is the meaning?

RS: I don't know, but I'm worried about the public product. I don't want it to be a whole bunch of straight nurses—

SS: You know, I've asked a lot of straight people what was it like to be a straight person in ACT UP, there were so few, and most of them just like, "I don't know." It's not even like a concept, because they couldn't understand the possibility of *not* being in ACT UP. So why all these other straight people were not in ACT UP was not anything that they could understand.

RS: I also feel that way, but I felt that and the whole issue of—I mean, Jim and I used to talk about being negative and what that meant, and being seropositive versus AIDS. I mean, Michael Callen would say that ACT UP and CRI fell apart because ACT UP was pro AZT and drugs into bodies and pro HIV equals AIDS, and CRI wasn't. But I don't know what the—

SS: Okay. I'd like to discuss that. ACT UP never took a position on AZT.

RS: Yeah.

01:00:00 **SS: Do you think that CRI's anti-AZT position was appropriate?**

RS: I don't know that CRI ever took a position. I know Joseph had a position, and I think there's a lot of confusion and intermixing about who was speaking for whom and at what period and why.

SS: Fair enough. Do you think that AZT did anything positive for anybody?

RS: That's a very interesting question. I mean, I guess I would go with the randomized evidence on this.

SS: Which is what?

RS: Which says that if there is a difference that AZT makes, it's too small to have been detected by any of the studies that were done. It does have a mild antimicrobial effect, so it might well be that it worked as a weak antibiotic. But—

SS: So you're saying that all those trials on AZT, none of them produced a positive result?

RS: Oh, no, no, no. I'm saying something much worse, much worse. I'm saying that all of those trials were designed in such a way that if AZT had a positive effect, we'd have been in no danger of reliably detecting it. That's what I'm saying. And that the knowledge for this has existed since 1969.

SS: Okay, wait. I don't understand what you're saying. Are you saying that pharma designed the trials to produce a positive outcome?

RS: Pharma and government designed trials. The problem is doctors are in charge of studies, but there are gross misperceptions about sources of precision in clinical trials, gross misperceptions. And because doctors are in charge and statisticians work for them, or as David Byar said, "We're their bitches," that conversation wasn't happening. So the studies were too small and too complicated to reliably detect an effect. So what would happen is one study would be grossly positive probably due to the play of chance, the next study would be negative probably due to the play of chance. So you'd have, "AZT works." "AZT doesn't work." "AZT works except for in blacks." And what happened there is really statistical sleaziness.

SS: What study was that?

RS: This was the VA study, actually, and it was published in the *New England Journal*. It was too small, again, to reliably detect an effect. So what you do

when you've just done a huge clinical trial, huge meaning three hundred people and you've just spent god knows how much money and measured all this crap, you start analyzing, dividing into smaller and smaller subgroups until you find something that's controversial, and then you put that out there and you say, "Well, this is a preliminary analysis," caveat, caveat, "but there's a suggestion that this drug doesn't work in black people." So that gets picked up by the media.

SS: And you're saying that actually it just didn't work in anybody.

RS: Well, I'm saying that there wasn't—it wasn't a cure. It wasn't as good as it was initially touted to be. Whether it had a moderate effect, we'll never know, and I don't think it's an important question now since we have stuff—

SS: But it is an important question.

RS: No, no, I meant for us to resolve with clinical trials.

SS: Oh, right.

RS: It's an important question to look at it. My statistical point of view is that if there was an effect, it has to have been less than 30 percent.

SS: Historically, who were the number0one advocates for AZT?

RS: Oh, Burroughs Wellcome, and Margaret Fischl was the poster girl for AZT, but she got used by it. I mean, she's responsible, but she got used. I mean, she's some doctor, she's flown here, she's flown there. They write papers for her. I mean, those of us who were more skeptical from the beginning wouldn't have ended up in that situation. This happens to lots of people. There's this guy named Kent Woods, who's the poster boy for magnesium and heart attack.

SS: So in other words, someone could make a movie starring George Clooney about the scandal of AZT.

RS: Absolutely. Yeah. If there were a David France of statisticians, you know, this could be made into a very compelling story starring—we could have another episode of *Let Us Now Praise Famous Men*.

SS: Now, just another question. Now, Iris had worked on AZT as a cancer drug.

RS: I don't think so.

SS: No? What did she—no?

RS: She was a chemist, but she hadn't actually worked on AZT.

SS: What is it, Jim? Did Iris work on AZT?

JH: Now I'm trying to remember, was it AZT or was it interferon?

RS: She worked on interferon.

SS: Oh, interferon, okay.

RS: Yeah, another story there.

JH: And that's how she knew Sonnabend?

RS: No, she met Sonnabend through the whole—

SS: That's how she came to ACT UP, because she was following interferon. She worked on it for cancer, right?

JH: Yeah.

SS: Okay. So I want to get back to the thing you raised about HIV. So Sonnabend had this cofactorial theory. Now, to this day, many of us assume there is some other factor besides HIV, but nobody knows what it is. It could be genetic

predisposition. It's unclear. But somehow this question has been completely dropped.

RS: Yes.

SS: Why is that?

RS: Because there's no money in it. So I think we can make the statement even starker and say that we do know very definitely some of the things. I mean, social
01:05:00 support, what we provided for each other in ACT UP, nutrition, exercise, a place to sleep, I mean, these are things we know are cofactors. In Africa, the disease looks very different. That suggests there are infectious cofactors and, I think, empowerment cofactors as well. I mean, there's all sorts of theories, but, yeah, these are not studied, and in the current environment there's no danger, they're going to be studied properly. There's a few of us doing little studies on resilience.

SS: But when Sonnabend said cofactor, he didn't mean nutrition. He meant like poppers or repeat exposure or whatever the theories were at the time.

RS: Well, so Joseph had seen before viruses that were completely sort of innocuous, some Virus C, I can't remember what it was, that was implicated in breast cancer, and then it was found to be ubiquitous. CMV. There's all sorts of viruses that exist, and because of the way the medical field likes—the medical industrial complex likes a single agent, you know, we attack a single agent with a bevy of drugs, that's simpler than the idea that there are either fifty-seven cofactors or fifty-seven protective factors.

So Joe had a bunch of notions about possible cofactors, and Joe still feels—so he and I respectfully disagree. I think that HIV has now been conclusively

shown to be causally related to AIDS, and Joe can go there, but where we do agree is that the paradigm for how this happens has not been sufficiently studied, and that's certainly true.

SS: Now, how do you understand the HIV denialists?

RS: David Byar used to read the *New York Native*. I think it was a legitimate suspicion for a long time.

SS: When you say the *Native*, you mean Duesberg.

RS: Well, the person that he and and I were obsessed with was Neenya Ostrom.

SS: That's right, Neenya Ostrom, whoever the hell that was. That's right. I remember her.

RS: Yeah. We tried to find her. We really wanted to meet her.

SS: Is that a real person?

RS: Well, we thought—we decided that it was an acronym, and so we came up with—what do you call those things when you change your name? So I was Eccareb Thism and he was Avdid Eyerb. And then there became this side theory that I had a statistical degree from Abyssinia, and I got asked about this over and over. "Why are you so ashamed to present your credentials?" And I was like—

SS: So you think it was who? Do you think it was Duesberg? Or do you think it was Charles Ortleb? You don't know?

RS: I don't know. Or maybe we just couldn't find her. I have no idea.

SS: That's so interesting. Okay. But HIV denialism was beyond the *New York Native*. There was HEAL. There was ACT UP San Francisco. I mean, what is the psychology behind HIV denialism?

RS: I mean, I think at the time—you know, I spent a lot of time listening about this, a lot of time listening to people, and my experience was often that people just needed to be heard about it, but I couldn't ever quite get a coherent narrative. Early on, I think it was totally legit. I mean, it was a fact that we didn't have—and once HIV was discovered, the idea that it was a strong virus, and so we weren't testing any prophylaxes, that's just ludicrous.

So there were cofactors that produced death in HIV. That has been proven. So to a certain extent, I think we need to acknowledge that the HIV denialists were correct, at least when it comes to mortality. So it wasn't completely off the wall.

SS: Although they died.

RS: Although they died.

SS: The HIV denialists.

RS: Yeah, yeah. I mean, the only one I know who's still left is Joe. But I wasn't—I was sort of a grind worker, you know, getting people access to trials, toothbrushes for the homeless. But I did do serious work making sure that if Treatment & Data—so I got stuck with the account as it got put, of clinical trials design, and Mark Harrington made it fun for me. So one thing people didn't know about him was that he was really silly and fun. When they forced me to go to amfAR—so David Byar said to me, "Okay. You guys have done a critique. Now, which of you is going to sit at the table and help us figure out how to do this?"

And I was like, "I'm taking premed courses. I can't do this. Someone needs a job."

And Mark was like, "I'm not going to do it." It's like that Life cereal commercial, you know. "You try it." "I'm not going to try it. You try it." "Let's get Mikey to try it. He'll try anything. Hey, Mikey." You know, and I was Mikey.

So it became interesting. Mark helped make it interesting. David helped make it interesting. But I made sure people in T&D were literate, and I did do a lot of—I taught them what the intention to cheat analysis was.

SS: What is it?

RS: Well, so this is the analysis that was used on the VA study of AZT,
01:10:00 which is you take a clinical trial that's too small to detect an effect, and then you start dividing it up into smaller and smaller groups, and just by the play of chance, some of them will come up negative and some will come up positive.

The best illustration of this, which I brought to T&D in 1990, was a wonderful study, the ISIS-2 study. I came out with SISI as our study. So this is ISIS. SISI is Studies of Immune System Intervention. I think somebody in—I don't know who mocked this up for me. But ISIS was International Studies of Infarct Survival, and we flipped it as Studies of Immune System Intervention, but I wanted it to reflect where it came from.

And that was, by the way, supposed to be one version of the parallel track, for people who wanted it. So our version of informed consent and inclusion criteria was, if someone's sure they want the drug, and their doctor and they feel it's best, then it's unethical not to give it to them. If someone's sure that they don't want the drug, then it's

not ethical for them to be in the trial. But for people where there is substantial uncertainty who want to participate, they should be allowed to participate. They should be allowed access. And that's called the uncertainty principle. It was formulated by Professor Sir Richard Peto for the—and I think it gets us around a lot of these goofy issues because it lets the uncertainty in the community drive who gets randomized. And Ralph Alsader and I tried to work this out with PCP prophylaxis with the government, and they wouldn't let us. They insisted, "No, you cannot allow people not to be prophylaxed below 200 T-cells, and you can't prophylax them above." And she was like, "But we don't know when people are at risk." We introduced this number of 200 in.

So back to the intention to cheat analysis. So in ISIS-2, there was a finding that the drug worked if you were forty to fifty, fifty to sixty, sixty to seventy, but not seventy to eighty, but eighty to ninety. Well, why doesn't it work in that subgroup? Well, it's because once you start subdividing, you get weird things. So Richard Peto was refusing to publish that, and *The Lancet* said, "Well, we won't take it without the subgroups." And we were like, "Yeah, don't. That's so cool. Don't give them the subgroups."

So he did give them the subgroups, but he also did an analysis by astrological sign, and guess what? The drug doesn't work if you're a Libra or a Gemini. P is less than .05. So that gets his point across about the intention to cheat analysis.

SS: I see.

RS: And I'm not saying these people are out to cheat, but there are incentives, you know. I mean, I remember the first time I ran correlation. I ran two thousand correlations one night looking at what predicted survival back when I was a lab

assistant, and in AIDS it turned out elbow breadth, the width of your elbow. Mark Harrington later said it sounded like an insult, "Oh, shut up, elbow breath," you know.

But I thought, well, why would this produce a survival advantage? Well, it's an index of frame size, so maybe people with larger frames have more muscle mass to begin with and they're heartier and they can live longer. Then I realized I've done two thousand correlations, and so I've just explained one. What if this was just chance? So, you know.

SS: Right.

RS: And the play of chance is much more dastardly at producing answers than anyone realized. So these positions were articulated, and for ACT UP, Jim Eigo, Joe Sonnabend, and Mark Harrington made me go to amfAR, the belly of the beast, and I was just like, "Do not make me go there."

SS: What was amfAR really about?

RS: Well, it was another one of—so initially amfAR was started as the AIDS Medical Foundation to—

SS: Mathilde Krim

RS: —Joe Sonnabend, by Mathilde Krim, who was a very interesting, controversial, complicated history, too, but basically she could have just had parties, and she tried to do something. But, you know, I'm not sure. I mean, Joe was ejected when one of the people there, Terry Beirn, who had gotten paid to cover Woodstock back in the day and was an empowered gay man who had AIDS and who died of AIDS while at amfAR, but he really wanted this to be big news, and so he was trying to distort some of

the science, and he wanted to put out stuff saying heterosexual men are at major risk. And Joe said, "There's no evidence for this."

And Terry said to him, "Look, Joe, I've got a virus in me and it's pointed straight at my brain, and we are saying this."

So Joe said, "then I'm leaving."

SS: Because he thought if people thought that, then they would do something.

RS: Right. Right.

SS: Well, that was a strategy of a lot of people.

RS: Right.

SS: And it backfired because it never manifested.

RS: Right. Right. And you know, in general, it's probably a mistake to play fast and loose with the evidence. I mean, I believe that at their best, clinical trials are a form of activism, you know, that if every arm is really, really a legitimate treatment option and you're coming at this from different points of view. So this study that I feel
01:15:00 ACT UP designed, I feel this was the first—I still say that there was this idea that's out there that all these people are—I mean, it was in Maxine's interview that I read, that what these people in TAG did is went to AIDS clinical trials group and designed protocols. There's no one in TAG that has designed any protocol ever. Okay. The only protocol that's ever come out of ACT UP—and by protocol I mean a study that is designed and enters patients, that is produced independently of the pharmaceuticals industry — that my kitty is now trying to deny access to.

RS: It is called COMPACT, Community Partnership and AIDS Clinical Trials. It was funded by amfAR, but it was produced by me and Donald Abrams and Paul Meyer in the honor of David Byar. Where the hell is it? I don't know.

SS: Why does Maxine think that TAG designed protocols?

RS: This was the intellectual product. This was how this got talked about, the—

SS: Was that her misperception, or was that put out that they—

RS: I think that was put out. I think that there was this, you know, "We're coming in there and we're *Buckaroo Banzai Across the 8th Dimension*." I don't know if you guys ever saw that movie about a rock-star neuroscientist who, in the middle of a rock concert, would stop everything and say, "Wait, there's someone crying in the audience," and with magical perceptual powers. And this was sort of a trope that got created in ACT UP, that there were these super smart men and they were going down and telling—

SS: And Garance.

RS: And Garance, yes, and Garance, beautiful Garance. And they were going out and showing them how to do this stuff. And it's interesting when you actually look at the evidence, what is it? I mean, I can characterize one instance when I know at the ACTG that there was a representation of a person with AIDS concern affecting the design of a clinical trial, but it didn't happen at the ACTG; it happened at the Studies of Ocular Complications for AIDS.

David Barr actually talked about a meeting that had been had with Curt Meinert. They couldn't enroll this trial that they had been trying to enroll, looking at

DHPG and CMV retinitis. And the question was, they wanted to look at randomizing people with sight-threatening versus non-sight-threatening CMV retinitis, but nobody would enroll. So they met with people with AIDS, and people with AIDS told them, "To us, once you have CMV retinitis, there's no such thing as non-sight-threatening CMV retinitis."

SS: Right.

RS: And they got it instantly. So when those conversations could take place, that is one instance where it did happen. The other instances, I think, were David Byar's work, you know. David Byar, we had—and Jim. Jim and David and Iris had articulated, "We want broader inclusion criteria for clinical trials." I was trying to get in there, there should be an option to randomize at least doses. Joe Sonnabend used to argue with me about that saying low doses are a virtual placebo. There's something to that. But these requests were reasonable, and David Byar wrote an article published in the *New England Journal* that validated, you know, that got the statisticians behind a lot of these ideas, and said randomization is not necessary in all cases. Obviously it isn't.

SS: What's your definition of randomization?

RS: Well, so randomization is a method of allocation of people to different treatments, and what randomization is, is a sequence of random numbers that determine assignment and the definition. It's actually very hard to generate a sequence of random numbers. You and I couldn't do it. What a random sequence is, is when you know one number, that gives you no basis for predicting what the next number will be.

Now, why does this matter? It controls bias, and it produces a situation in which unknown patterns of error behave just like random error. But it's not necessary in

something like DHPG where you have some CMV retinitis, CMV colitis. It's going to kill people quick. You know how to find it. You know what it does. You have something you think is a cure, and you have pretty good reason to think it's a cure. Why randomize?

SS: Right.

RS: I mean, it depends on the question. So a lot of David Byar's stuff kind of got appropriated, and David didn't mind that, but it is odd, in retrospect. And then this idea that Spencer [Cox] designed the study that got done by—what was it, Merck? I mean, this is SISI-1, which was adding drug versus placebo on top of whatever people are currently taking, but mine had the caveat for people who believe that this is ethical and if you want access to drugs, you should get it.

SS: So you're saying Spencer never designed.

RS: Well, I'm saying he put out a design that has been used for forty, fifty years, that had been enunciated and put out in Treatment & Data, that he knew about,

01:20:00 and, I don't know, I never—I didn't worry about it too much until last week.

SS: Because what happened last week?

RS: So I was trying to get ready for this, because I decided I needed to do it, and I was looking at this beautiful eulogy that Gregg Gonsalves had written about Paul Meyer, and it had meant a lot to me at the time. So Paul Meyer was a statistician of some renown, and he was on the inside of statistics saying, "We need larger access. We need broader entry criteria."

And Ellen Cooper was telling him, "The activists won't let us do it."

And we would say to her, "We've got to have broader entry criteria. Heterogeneity can be a scientific strange thing."

"That old guy, Paul Meyer, won't let us do it." And I think she probably thought that she was representing correctly. I have no idea, you know, sort of how that actually worked out.

So Paul was another ally. So Gregg wrote this beautiful eulogy, and he talked about how statisticians like Richard Peto and Paul Meyer had taught him so much and had taught them so much about how to do trials. But Paul Meyer never actually met him, and I was the one who worked with him, because nobody wanted to do the sort of grind stuff. I was happy with people with doing that part of it, and having Jim and other people—you know, there was a lot of cross-fertilization.

SS: Is Gregg lying?

RS: Well, when I wrote him, I said, "You know, it would really help me to know right now what time you spent with statisticians and how it helped you," especially those particular ones, because I didn't know about it. And I'm learning a lot of things. Like I learned, for example, that Jim Eigo thought David Byar was in the closet.

And he wrote backing saying, "Well, I actually never spent time with any of them, but I did spend time with people who were really concerned about answers." And he used a phrase that was mine, was the phrase I used from 1987, which was, "We need to demand access to answers." And this has become a product of TAG now, as of large simple trials. And so this is odd.

And I wrote back, "Do you remember having any conversations with me about trying to understand randomized evidence in trial design?" I said, "It was a long

time ago, and it might not have mattered to you in the ways that I thought it did at the time."

And we wrote a piece. I wrote a piece and put him and Spencer on it for the treatment directory to try to get them clear on what these things were. And he said, "Yes, we wrote a piece with Richard Peto and all these people." Well, Richard Peto wasn't on it. And it got to the point where I couldn't get any feedback from him or Spencer, and I said to Paul, "Is this wrong for me to put their names on it?"

And he said, "No, we'll do a conference call and we'll get some edits. We'll at least make sure they know what's in it."

But so this process, where the statisticians I knew and worked with as part of ACT UP, not part of TAG, are somehow appropriated as part of the people who Gregg was bonding with. I have no doubt that he didn't talk with really important, interesting statisticians, but not the ones he names in Paul Meyer's obituary. Those were specifically the ones who taught me.

SS: So what's the history of the large simple trial claim that you just referred to?

RS: So, large simple trials. So when Jim was first—when Jim wrote that letter about the parallel track, which is really a rearticulation of something called compassionate use, but much more powerful formulation, I think. It's just my little opinion. And this was the end result of a lot of discussions with a lot of people. But Jim had thought of it for something like fluconazole. You know, we weren't thinking. And he was not buying my, "Let's at least have some dimension of it randomized. That way

we can get information, and people shouldn't participate if they don't want to. But if people want to be randomized, they should be allowed to."

So then ddI comes, and we were like, "Oh, they're going to do this?" Jim's and my main concern was they're going to make the forms too burdensome for anyone to enroll, and the forms looked like fuckin' encyclopedias, and it was ridiculous. I think it was deliberately disincentive, and yet I don't know how many thousand—22,000 got access through that?

SS: I don't know.

RS: So the hope, my hope was that there could be large-scale randomizations. Now, why large scale? Because if there is a moderate effect, the larger the number, the smaller the error and the more clearly you can see the effect. Now, for a lot of things, it doesn't matter. But for some things like—so a good story is aspirin. So Richard Peto did the large simple trials, and Charley Hennekens' looking at aspirin as a treatment for heart attack. No one had a financial interest in it.

So Richard Peto's a red-diaper baby. His parents were communists, you know. He did acid. The person who dealt acid to him is in his clinical trials group at Oxford. There was sort of a goofy group. And I remember when he met his mentor's
01:25:00 wife, Sir Richard Doll's wife, Lady Joan, who was also a communist, and she said, "So what do you want to do?"

And he said, "Well, I don't know if I want to *do* anything. I think I might just want to *be*." And we used to make fun of him about that all the time.

So he did the large-scale randomizations that showed that if you're having a heart attack and you take an aspirin, you can reduce your risk of dying over the next

five weeks of that acute heart attack by 50 percent. Now, that's from a relative risk of about 13 percent to a relative risk of about 6 percent, so it's a 50 percent reduction, but in a relatively small risk. But I think this is relevant for people who are about to have a heart attack, and I think people with AIDS, if they wanted to know that level of difference, they should have had the right. They should have the right.

And Jim came to agree and TAG came to agree, so we developed a large simple trial to deal with this AZT question. Okay. So I didn't know what to think about any of the antiretrovirals. Let me state for the record, one of my favorite times I was ever wrong was I thought the protease inhibitors wouldn't work, and I *love* being wrong about that. It's a delight. I also thought that there would be more attacks after 9/11, you know, right after. If these people had had a brain, they would have sent three suicide bombers out to malls in America, and that would have shut the economy down.

By the way, Sarah, thank you for talking about how the sentimentality about 9/11 is so weird for those of us who went through AIDS here in New York City. I mean, I worked down at Ground Zero, too, and that's another set of weird intellectual products. I love John Weir so much for getting on TV and saying, "Fight AIDS, not Arabs. AIDS is news."

SS: But so how did TAG make a claim that—

RS: I don't know. Let me show you the protocol. It's called COMPACT, Community Partnership in AIDS Clinical Trials. It was designed and people were randomized into it, but I went off to medical school. Donald Abrams was the principal investigator. This is a product of ACT UP and me. Was it my idea? No. I have the protocol. Didn't I just take it away from my cat? Oh, here's the protocol. Community

Partnership in AIDS Clinical Trials. This was an iteration that got written in November of 1993, but this study first started to pilot in '91. I guess that was before TAG even formed, and this had been in formation for a couple of years.

So this is a study of immediate versus deferred antiretroviral therapy. This was designed, I guess, what is it, twenty years ago now? So there's two policies that you can test this AZT question, and I'm still interested overall in antiviral versus not, the question of when to begin.

So if you're Peter Staley or a lot of TAG and you want to hit that virus hard with pills, then start immediately. There's a very good rationale for it, and may I say the rationale has gotten better. On the other hand, there is such a thing as resistance, there's such a thing as side effects, and it could be that waiting to initiate treatment until there's some reasonable sign that disease progression has emerged would be a better strategy. And for people who are sure that they want to do that one, it would be unethical to be randomized. For people who are sure they want to hit hard, unethical to randomize. But for people where there's substantial uncertainty, they could agree to be randomized between immediate versus deferred antiretroviral therapy, all cause.

And this was a formulation—I think the idea was Richard Peto's. It's widely attributed to me, but I think it came out of this little soup, you know, of people, and I was only there because of people with AIDS. It wasn't because I was like Little Miss Brilliant. So this has been appropriated by TAG, and it became TAG's large simple trial, and, you know, I just wasn't all that comfortable with TAG. I mean, I care about the people, and I wouldn't go on the record unless I felt they were financially stable, because I think TAC [Treatment Action Campaign], some of the stuff they're doing to

promote treatment activism worldwide is really valuable. But I'm very uncomfortable with—I mean, I didn't realize until Gregg wrote me that, that this was quite as conscious a process. I thought maybe I was just difficult.

SS: It's branding, is what you're saying.

RS: It's a little bit worse than that. I mean, he's comfortable writing me saying, "I didn't know those people."

SS: Well, when I was in London last year, Joe Sonnabend came to my talk, and I know you know about this, but I want us to just revisit this discussion.

RS: Oh, I can't wait. Sarah, can I just tell you?

SS: Yes.

RS: I'm trying to get over it, because it's totally unfair on my part. I was so pissed with you. I was like, "How can she think that?" I get it now after a few minutes of thinking about it, but I—

SS: But let's say it for the record so that the world out there knows what we're talking about after we're dead.

RS: Yes.

SS: So Joe came to my talk and he stood up and said, "How do you

01:30:00 **know that ACT UP impacted on science, and how do you know that ACT UP impacted on the government and how they proceeded?"**

So I said, "Well, you know, you have Jim Eigo designing parallel track, and then we go and do a demonstration at the FDA, and then we get parallel track. So, to me, that shows that there's a cause and effect."

And he goes, "I'm a scientist, and that's not enough proof."

RS: Oh, I didn't know this. I love hearing this. You put it up in a much more neutral way. Bless your heart.

SS: So do you think that ACT UP affected how science and the government proceeded on AIDS?

RS: Yes, and you know what? Joe thinks that.

SS: In what ways, though? In what ways did ACT UP do that?

RS: Well, let me give the other side first, the evil side that I believe. So another way of looking at this is that the pharmaceuticals industry looked at these people who wanted to deregulate the drug industry because they wanted drugs into bodies and, "You have no right. The government is bad. Small government. Government get out of my life." Sound familiar? Republican refrain.

So the deregulationists were like, "Great. Fine. Let's dismantle the FDA. Let the drug companies sell whatever crap they want." So Joe's theory is that AIDS made bedfellows out of AIDS activists and deregulationist Republicans.

SS: Yeah, but that's not new. I mean, Garance said it in her interview as well.

RS: She got it from Joe. I mean, it is important to give some of the—I mean, this doesn't just spring into the head of a nineteen-year-old, you know.

SS: No, but I mean when we interviewed her as an adult.

RS: Yeah, yeah, yeah, yeah, yeah.

SS: Okay, but, I mean, yes, it's true, deregulation is Reaganism. We understand that. The whole world is paying the price of deregulation right now.

RS: That's right.

SS: However, we had to change the FDA's policies.

RS: And we did. Or the people who got arrested did. I mean, when I look back at ACT UP, yes, I mean, for the first time the notion of—and it all flows together for me, not an AIDS victim, a person with AIDS, a person living with AIDS, people having a voice and a representation of their own concerns, and the concept that this can affect beneficially the way science is done, the articulation that every arm of every clinical trial needs to be a viable treatment option, that is the most refined statement of the science that I can imagine, another great statement, scientifically speaking as an epidemiologist.

Women don't get AIDS; they just die from it. Okay? So this is a very powerful way in which women, mostly HIV-negative lesbian women in ACT UP, advocated for a change in the way that HIV and AIDS were articulated for women. So Joe, if he were here, he'd go pour us all a glass of wine, but he would never—he would never take me on about this.

SS: Do you think there's a relationship between ACT UP and the development of protease inhibitors?

RS: Oh, no. This is where I went nuts. So the protease inhibitors had been in development since the eighties, okay, because what people did was look at what's different between HIV and the human body, because viruses are different from germs. Germs come from the outside, they take over your body, they're built differently from us, but viruses go into our cells, hijack our cells, and then produce themselves. So they're more difficult to get at, so you have to find something they have that we don't have. Otherwise, it's going to be really toxic. It was pretty clear pretty quickly what HIV had,

and it was this protease that cleave two proteins, but it looks a lot like something that we make naturally in our body called renin. So what I think you had said is that ACT UP forced the pharmaceuticals industry to re-conceptualize its approach to HIV, and—

SS: You believe that's false.

RS: Yes, yes, I mean based on knowing how long the protease inhibitors had been in development. But, you know, the thing I really think needs to happen is—

SS: But if they were in development for so long, why did we have all this bullshit like ddI and ddC and all of that?

RS: Oh, I mean, it takes so long to get a drug from—I mean, I haven't been able to get good information from—we weren't able to get this—this is the one thing David Kirschenbaum couldn't get us, information about drug companies about how long the process takes. But they have to develop the chemical and then patent the process, test it in animals—

SS: So you don't think the process was speeded up because of activism?

RS: The process of access, the access was definitely speeded up. Access was definitely speeded up.

SS: So drugs into bodies. So getting people protease inhibitors, that process was affected by ACT UP.

RS: Absolutely. And Joe, he would not disagree with that. But more

01:35:00 importantly, I mean, we were in this together and we will be stuck in it for the rest of our lives or whatever. No, I'm not going to say that I'm certain of that. I would like us, out of mutual respect, our process in ACT UP was that we would research it, you know, so

maybe it bears a second look. I mean, I do know that they were in development, so the answer is yes and no about that.

SS: Okay. It's unknown.

RS: Well, they were in development, so it wasn't like they came up with protease inhibitors because we forced them to reconceptualize—.

SS: No, but there were a lot of things in development, and certain things got developed and other things didn't.

RS: Right.

SS: There was a research, an activist research agenda that was established that emphasized certain things and not others.

RS: Right. But protease inhibitors, we learned about them from the drug companies.

SS: Right.

RS: So that's where I think the discourse falls apart.

SS: I have three big things I want to discuss with you, and, like, everything's taking so long.

RS: I'm sorry.

SS: That's okay. So let me just try to focus. So the first thing is the NIH action. What was the demand of that action?

RS: I don't—I mean, I was talking to David Kirschenbaum about this, and other people, but Risa Denenberg felt that we really got something out of that action.

SS: What did we get?

RS: I don't know.

SS: You don't know.

RS: I mean, to me, this was when things had—the brilliant, as Fauci said to Mark, he said, [imitating Fauci's accent], "Listen, Mark, it's just that the investigators don't want some gay guy from the Village with an earring telling them how to do research." So the product was, in Fauci's words, gay guys from the Village with an earring telling them how to do research. Fauci created the product and it was sold.

And I didn't know what the community constituency process was really for. I saw it as co-optation, but I wasn't going to oppose it. I didn't have a better plan. Community research based on these small single sites wasn't panning out, apart from aerosolized pentamidine and maybe providing access to people who didn't live near tertiary medical centers, which is a laudable goal, but not a research goal. So I don't really know what it got us. I think we were trying to stay united and trying to stay together in our efforts to prod this massive bureaucracy that on some level was indifferent, but in—

SS: Okay. So, next topic. What happened between you and the Women's Committee?

RS: Oh, god.

SS: Or what is that?

RS: It's so kooky. I mean, you know, honestly, I owe so much to the Women's Committee. I mean, Risa Denenberg was the person who explained to me what a colposcopy was. And I felt that I benefited greatly from their work.

SS: But what happened there?

RS: We were—I remember there started to be personal friction. I started to get some resistance. Like I remember coming to somebody with this concern I had that's probably wacky, but about what is vaginal candidiasis? Is it itchy labia or is it actually vaginal candidiasis, and should we be—when do people need a systemic drug and when do they need something topical, and maybe the idea isn't that people—and they were just like, "That's just—you're just male-identified."

And I was like, "What the fuck?"

SS: So the conflicts started around the CDC campaign.

RS: Well, I was feeling the tension earlier. I think it was as a result of my being identified with the product of these brilliant people who were on the inside, you know, and I think that's a legitimate gripe.

SS: So you don't think it was a substantive ideological difference. You think it was like a weird ego?

RS: It is a failing of ACT UP if it actually is an ideological difference, and as you're saying this, I'm sort of cringing inside, because we should have hashed that out on the damn floor. I don't know why we couldn't do that. I don't know. I think the product thing got in the way. But I think there was. I mean, there's this drugs into bodies, let us in and we'll do the research, and you people just go demonstrate in the streets. I mean, I think that is a real ideologic difference. You have to have unity between the troops in the streets and the people inside, and the people inside have to be accountable, and when the people inside aren't accountable, that's when—

SS: But were you involved in a conflict over 076?

RS: Well, so early on, David Kirschenbaum brought this to me, and he said, "You know, this is treating women as fetus receptacles."

And I said, "Well, you know, let's talk to women with AIDS about it. I mean, I've heard that this is a concern." But, I mean, I was worried about that it would cause birth defects. I was like, why the hell—if women with AIDS are worried about whether they will give it to their babies, don't give them something that's going to cause birth defects. And that's where I felt I was on the same page with them, and that's where I felt like the cofactors thing needed to come up more. There was a really good teach-in
01:40:00 that the women did, and men, and, I don't know, I still identify with that. So I think, yeah, there was a—

SS: Did you read Tracy Morgan's interview?

RS: No, not yet.

SS: I can't remember who, someone—I can't remember whether it was Marion Banzhaf. I can't remember who discussed—there was some confrontation with you.

RS: Oh, there was a bunch. Oh, there was weird things that happened. God, I mean, it's going back a ways. There's all sort of weird things that happened.

SS: In Washington, possibly.

RS: Oh, yeah.

SS: Okay, what was that?

RS: Okay. Oh, yeah, now, this is awful. Yeah. There was a conference on Women with HIV that was being planned, and I was asked to give a talk on whatever I wanted, and I said, "Mechanisms for incorporating community input into clinical trials,"

and I couldn't get any feedback on my talk. And people were like, "We don't care about that," and there was clashes going on. And I think I was too sensitive, in retrospect. So stuff was under way.

So David Byar and Mark had wanted to meet Fauci to talk to him about large simple trials, and my view was, "This guy doesn't know—he can't spell clinical trial, you know. But if they want to do it, fine."

So whenever the conference was planned, we planned to get together with them if David was still alive, and we had no coordination with the women, you know. And I don't know how to cast this, but so this got—and the way this played out—and I'm indifferent to Tony Fauci. Like Jesus—Tony Fauci is Jesus to me—I'm indifferent. But you know, he was talking to the guys. He wasn't talking to me, but I was involved in there, and there were other people. There was a wonderful woman named Michelle Roland, who was involved. I mean, there were other visible females who were involved with this, not just Garance, although Garance was also there.

So they were talking to Fauci. I had thought we should have a meeting together about what the tactics were going to be. And this is going to sound really bad, but I really feel that we should have coordinated, and that this view got put out that the men were nice and the women weren't, and Fauci liked the men better because they were nice, and the women weren't, and I think that's such crap. But the men and me bear responsibility for not fighting it out with the women beforehand about, "Look, if you want to talk to a fucking bureaucrat, don't waste it by just screaming at him. He doesn't have any decision-making power anyway. Figure out what you want out of him and get it." And we should have fought that out, but we didn't.

And so this got cast as me and Mark and Tony Fauci undermining the women, you know, and I can see it being cast that way and I'm willing to be accountable and talk to anybody about it, but I also think that the women are accountable and that this gross rejection of everything T&D did, and of me, as being completely male-identified, I remember saying to—I think it was Tracy Morgan, I said, "You can't even spell male-identified, and you know nothing about me. What are you doing?"

SS: What was it really about?

RS: The product. I mean, for all intense and purposes—

SS: It was resentment or was it about that they were being marginalized?

RS: I think it was worse than that. I think they *were* being marginalized. I think it's legitimate. I don't think this is bullshit. I think it's a process problem.

Bob Huff cast this as the smart people left and the dumb people were pissed. No. You know, the best epidemiologic slogan to come out of ACT UP is, "Women don't get AIDS; they just die from it." Pure science. Okay, so, you know, but I don't know, somehow between ATR and the rest of it, I felt lost, and I don't—

SS: Okay. I want to move on to something else.

RS: Sure, sure.

JH: Before we do, I just want to be clear about it. So this meeting with Fauci, this is the dinner that people talk—

RS: Yeah, yeah.

JH: Okay. And so you and who was at this dinner?

RS: So David Byar had said, "When you come down for this meeting," and this was like months before, "can we have dinner with Fauci?"

And I said, "You know, you and Mark should have dinner with Fauci. I'll just be a distraction."

But they were like, "No, no, we want you to come," so I came. And I mean, I learned that from Fauci's standpoint, they had no power, and they just had to do whatever the pharmaceutical industry did, that the ACTG was the pharmaceutical industry's bitch, and we got nowhere with the large simple trials agenda.

But I had assumed somehow that we would talk before this, and we didn't.

01:45:00 So it plays out badly. But like I said, if I had it to do over, I would be in the—I mean, but we were yelling at each other. I mean, it wasn't like we weren't trying to talk. I don't know what the hell was going on. But I don't feel I think this discourse is bullshit, that, oh, the men were nice and the women weren't, and the men divided the women. No, the women should have gotten their fucking act together, talked to the men. "How do you guys do this? We don't want to do it that way." Like there should be some negotiation beforehand, and I don't know why there wasn't. I don't know.

SS: You don't have a theory as a psychiatrist or as—

RS: Well, because it was me personally, I mean, I think it was pure sexism, okay? But I'm censoring myself somewhat, because I don't want to go on the record as saying really destructive things about colleagues and friends and—

SS: Right. But there's phenomena, I mean.

RS: Yeah. I mean, I think it is—

SS: Should I posit something and you say yes or no?

RS: Yeah, yeah, yeah.

JAMES WENTZY: Stop?

SS: Yes? I said I want to posit something.

JW: Oh, posit.

SS: It's your age, James.

RS: It's the pause that you are seeing.

SS: Okay. So back to the posit.

JW: So you're still going. Okay.

SS: So let's say that these people had different credentials.

RS: What were the different credentials?

SS: Mark had gone to Harvard.

RS: Risa was a women's—she performed fucking women's health at the CHP.

SS: But was she the person in conflict?

RS: I don't know, but she was a very important part of that agenda to me.

SS: All right. Let me say my theory, and then you tell me what you think. I think that when there was no inside, certain people were able to be effective, to be popular, to be influential, because they knew how to do certain kinds of things, and when there was an inside, the value of those things was diminished.

RS: Yes.

SS: And so they were being sent to pasture.

RS: Yes. That is *exactly* what happened. That is exactly what happened. And oddly enough, that was my experience too. I mean, I felt, I mean, sometime, I guess

when the community constituency group thing started and there was a formal process, I'm like, "I'm outta here. What the fuck am I doing here?"

SS: Okay. So let's move on to something else.

JH: Wait. I just want to get this clear. So at the dinner, is it true that you walked out of the dinner and it was raining and there was a women's demonstration?

RS: No!

JH: Okay. Because people said that.

RS: No!

SS: Do you remember where the dinner was?

RS: No, I don't, but I mean, there wasn't a—

SS: Really, you don't remember? Think. Where was it? Where was that dinner?

RS: I could find out. I mean, I have diaries.

SS: Okay. Okay. All right. Let's move on.

RS: No, but the thing is, you know, no, if there'd been a fucking demo, I would have known about it, and we never would have—no, it never would have happened. But there wasn't coordination, you know.

SS: Okay. I understand. I want to go into a whole new arena now. So now we have Quad and people are undetectable, undetectable viral loads, and we're seeing that women are responding differently to these drugs than men and that it's more difficult to have viral suppression in women. Is that because these drugs, after all that crap, were never tested on women significantly?

RS: I think the fact that we don't know is because they were never tested in women, and we haven't gotten the evidence on women, and so the demands—this was an early demand of ACT UP. It's in everything Jim wrote. It's in every—you know. But it became—it did become marginalized. Despite being in the writing, it was just maybe a concession. The women have not been studied in Africa, other places. There was this division, like, "Oh, it happens to them in Africa."

"No, it happens here."

"Oh, it's just IV-drug users."

"No, it's not just IV drug users." HIV behaves differently in women, and we don't know why because women haven't been studied. There's only a couple of cohorts even now, and, you know, in the rest of the world, HIV is a huge women's issue. I mean, feminists in India – I remember there was this — I was really interested in prostitutes and prostitute-to-prostitute, PONY [Prostitutes of New York]. Remember? There was this big thing in ACT UP?

SS: Right. Iris De La Cruz was part of that.

RS: Yeah, yeah, Iris De La Cruz, yeah. I just remember hearing through my iPhone that the reason you guys didn't interview her was because she was dead and that the women were all dead and that this is—

SS: There's one person who's alive, Marina Alvarez, but she doesn't want to be interviewed now.

RS: I mean, people may change over time. I'm so glad that one of us is still alive. But this is really important.

SS: Yeah.

01:50:00 RS: So some of the powerful achievements of ACT UP in some ways were in India. Prostitutes in—Bengali women have an empowerment tradition. They unionized in Calcutta, okay, the safe-sex message, and this came through women, through women's health. I got pulled into this. They unionized and they said, "No glove, no love," in Bengali. I tried to learn how to say it. I never learned. But, you know, there's a powerful women's movement internationally, and this all came out of feminism, *Our Bodies, Ourselves*. So the way the split happened is just really weird, you know.

SS: But I'm just interested that—I mean, like the very first thing I ever wrote for the *Voice* about AIDS was called "Women Excluded from Experimental Drug Trials." And here we are with the—

RS: Same problem.

SS: Yes. And how come there's not like some huge headline in *The New York Times* saying, "Protease inhibitors were never adequately tested on women and are producing different results based on gender"? Why is that not like a big, big scandal?

RS: It's amazing. It's amazing. And you know, it's like, I mean, it brings me back to my first experience in street psychiatry, back when I was trying to figure out my social justice work, saying to a man, "Why are you guys being so horrible to me? I'm just trying to give you sandwiches with a phone number that you can call."

And he was an African American man out of jail, and he said, "Ma'am, don't take this wrong, but we can get to feeling pretty low sometimes, but there's one thing that is always lower than us, and that's a bitch. Forgive me." And I think that's

where this started and where it still is, and how bizarre that we haven't moved substantively past that.

SS: But isn't it weird, though, that we got a place at the table, that we're at the ACTGs, that we're on every fucking committee that there is, and women are still not being studied for basic treatments?

RS: Well, what use is it, having us on all those committees?

SS: Right. So what went wrong is what I'm asking you.

RS: Well, you know, there was a power to ACT UP. I totally buy your theory that before there was an inside, we spoke to each other, and Jim's and my version that Jim articulated, but that once we let the media in, we started speaking to them and not to each other, and I think—

SS: Well, you're saying it's the media.

RS: No, no, no. I mean, just anyone who makes us feel important, that it was about being made to feel important by interests who were creating products around what we do that are not necessarily in our best interests. But, yeah. No, I think that is what happened.

SS: Okay. So is there anything else that you want to discuss?

RS: I guess there's the whole statisticians thing, I mean, so just one tiny thing.

SS: Go ahead.

RS: Which is David Byar was a closeted statistician in Washington and he was in psychoanalysis for trying to de-gay himself for twenty years, and ACT UP helped him. I remember he didn't care about T&D. Once we were really close, I was just like,

"Look, I go because it's my friends, you know, but I don't know what it is really anymore."

And he said, "Well, I really want to go to the floor. Take me to the floor." And I introduced him to David Kirschenbaum, and we had dinner with Larry Kramer and Joe Sonnabend and Mark, and he came home with me that night and he said, "Rebecca, this is the first time I've ever felt proud to be gay." And that's a product of ACT UP.

SS: That is pathetic. Yeah. That's tragic. Yeah.

RS: Yeah. But it's something that ACT UP provided that is part of his story, you know. And why he is excluded from the discussion is strange, too, in favor of TAG. I don't understand the story, but it's not innocent. I mean, I guess now that I've heard your version of things, you know, my thinking has changed a lot. I sure wish I had handled things differently.

SS: Well, we all do.

RS: After Steve Gumm died, I sort of went out to lunch. I mean, I said to Jim, "I feel like putting on my machine."

SS: Who's Steve Gumm?

RS: He was a physician at CRI, and he was a close friend of mine, and he died of AIDS working as a doctor at CRI, and I was all about this whole thing of if we're going to have people with AIDS on the staff, we have to find ways to take care of them, and people are thinking they have to show up all the time. Yeah, that was a mess.

SS: So here's my final question. So looking back, what would say was ACT UP's greatest achievement and what do you feel is its biggest disappointment?

RS: There is one answer to both of those questions, and that answer is the stories that it allows us to tell. Its greatest success is the stories it allows us to tell. Its
01:55:00 greatest failing is the stories it allows us to tell. But over time, you know, the arc bends toward justice, and it makes me feel better.

I was looking at some interviews with people in South Africa that my mom conducted about the Truth and Reconciliation process in Operation Mayibuye, which was their sabotage operation, and Mandela, and how he was seriously about sabotage, and he got sanitized into this friendly, smiley guy, but he was a fierce activist early on.

And I heard one of the guys say, "You know, we still don't agree on what happened and what we should have done." And that made me feel like this is a common problem in liberation movements, and the problem of co-optation and when is it a good thing and when is it a bad thing. I mean, David Byar said, "You want them to steal your ideas. Make them steal your ideas." But what happens to the group as a result?

My personal failing, I wish I had stayed more rooted in group process, but, honestly, I was just too fried.

Jim had a message on his machine, "Hi, this is Jim. I'm out to lunch." Remember Vito's message?

SS: Yes. "I wish I was here."

RS: "I'm sorry I'm not here."

SS: "I'm sorry I'm not here." That's right.

RS: You know, he was very kind. I wasn't a friend. It's not like I hung out with Vito. But he was really nice to me after one of these very heated interactions,

and he said to me, "You know, you do have use here." And he gave me this movie—I still have it; it's in a VHS form—called *Metropolis*. And there's this woman in it who's like sitting there like Florence Nightingale. And I was like, "What the fuck?"

And he was like, "Look, I know it's not what you want to be, but there's images."

And another artist person who helped me was Douglas Crimp. I was so stupid. I got all twirled up about these—remember when George Bush said a thousand points of light? Someone made a thousand Molotov cocktails, and I was like, "No, we can't use violence! It's not a valid. We're confusing tactics and strategy."

And he just sat me down and he said, "Listen. Sometimes just an image can have power, and people who are saying that, they're not serious. It's posturing." And he was so nice to just sort of walk me through that. And those sorts of exchanges could happen.

SS: Great. Thank you.

RS: Thank you, guys.

SS: Cool. That was a fantastic interview.