

# ACT UP ORAL HISTORY PROJECT

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Interviewee: Linda Meredith

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Interviewer: **Sarah Schulman**

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**SARAH SCHULMAN: Why do you have the Koran? Just out of curiosity.**

Linda Meredith: The what on?

**SS: The Koran.**

LM: Because I went to Istanbul. And because I spent a couple of weeks there. And because they were giving them away in front of many of the mosques and because I was fascinated to have one and read some, so I took it.

**SS: Oh cool. We just went to a mosque in Abu Dhabi, I had to wear an abaya.**

LM: Yes.

**SS: But Jim didn't have to.**

**JH: No I didn't.**

LM: In Italy, you have to cover your shoulders and men can go in in wife beaters. Right.

**JH: I would have.**

LM: Do you ask the same questions to everyone?

**SS: No. It's different questions because we're expanding our coverage areas. So you start out by telling us your name, your age, today's date, and where we are.**

LM: My name is Linda Meredith. I'm fifty-seven years old. It's March 10<sup>th</sup>, 2013, and we're in my apartment in the West Village in New York City.

00:05:00

**SS: You were born in Georgia.**

LM: I was born in Georgia.

**SS: Now, was your family in any way community oriented or politically aware or involved?**

LM: My family was aware in the following sense, that they were avid and dedicated proselytizing members of the Southern Baptist Church. And so I grew up with the church being the center of my very small community in northeast Georgia — northwest Georgia, and all things emanated from there.

**SS: What was the name of the town you grew up in?**

LM: Rome, Georgia. It's about halfway between Atlanta and Chattanooga, Tennessee.

**SS: So there is a value there about being accountable to other people in your community. I mean, church communities are all about that, right?**

LM: Church communities are all about that — except not so much this community. This community, to use today's analogy, probably is more like the Westboro Baptist Church, where the accountability was for the members of my parents' church to go out into the community and let folks know that if they didn't change their way, that they were going to go to hell.

**SS: And when did you start questioning that?**

LM: I started questioning that when I was about nine or ten.

**SS: And why?**

LM: Why? It didn't feel right. I don't know how to explain it any more than that. My parents never went to college. We were very lower middle-class. I very quickly figured out that my ticket out of that environment — because I definitely wanted out — was my brain, so I became an avid reader of all sorts of things. I'm adopted, so I always felt like I was kind of a displaced person anyway. It didn't make sense to me. What they were saying didn't make sense to me. We didn't have the opportunity to travel, which is another way I was able to, in my own adulthood, reinforce the fact that none of that made any sense. But it was through books that I first started to question what I was told — the dogma.

**SS: Do you remember what some of those important books were to you?**

LM: Honestly? When I was a kid, Nancy Drew.

**SS: Definitely.**

LM: Yes.

**SS: Bess and George were the best couple going.**

LM: That's right. But there were no models, for example, of lesbian in the town that I grew up in. I remember walking down the street with my mother, and I would stare at women, and she would smack me on the back and say, "Stop staring. It's not polite to stare." But I had no connection between that and my own sexuality until I was twenty-five.

**SS: When did you become aware of the political world? We're the same age, and that was quite a generation to grow up in. Everything was on television.**

LM: Right. So I guess the political — it's one thing, I think, for me to understand it intellectually, and then it is another thing to see how it impacted me. I would answer that question in two parts:

The first part would be that I was very aware of the political world through the Vietnam War, and through — I remember being transfixed when Kennedy was shot — that kind of stuff I thought about. But in terms of how the political world impacted me as a person, I would say not till I was much older. It was very removed from me, or I was very removed from it, until probably 1986, So when I was in my early thirties.

**SS: Now, was Rome segregated, legally segregated?**

LM: Rome was legally segregated until I was a junior in high school. In town we had separate water fountains at the department store, and they were labeled "white" and "colored." There were two white high schools, East Rome and West Rome, and I went to West Rome. Then there was an all-black high school called Main High. When I was a junior in high school they closed Main High and — depending on where you lived — they just sent the students from Main High to either West Rome or East Rome, and that's how we were integrated.

**SS: So were you privy to discussion? There must have been enormous amount of —**

LM: There was a ton of discussion. I heard it through a very racist lens, because that's the world I lived in.

**SS: Right. Of course.**

LM: I get angry now when people talk about the South being racist and that's the only place there's racism. So, I'm trying to figure out how to say this, because I don't mean that.

**SS: We know that.**

LM: Okay. I'm defending the South.

**SS: No, but it's just that you were living in a highly politicized situation that was —**

LM: That's correct. And my aunt lived in Birmingham, and I would go and spend some time in the summers in Birmingham, and there were all sorts of things going on around the Civil Rights Movement in Birmingham.

But for me, personally — when my school was integrated, the first thing that occurred to me — I was in band, and that was a big deal for me. I played the tenor sax. When my high school was integrated then we had a bigger band, and we were rehearsing for a competition that we were going to go to. And there had been a lot of discussions and forums in my high school about how the election process for various

00:10:00 things was skewed towards white people always being the ones that got elected. The people who had come from Main High were demanding that there be a different way, so they could be represented on a lot of the committees and the Student Council.

We were on the marching band field one day, and, of course, unbeknownst to me because I wasn't privy to it, there was a walkout. A third of my band colleagues just put their instruments down on the field and left, and we didn't go to the competition. That walkout lasted for about five days.

There was a group of us who were asked to be a student committee with teacher supervision to figure out how to change the elections and to see how it would work best now that integration had happened in our high school. So that was the first time I figured out that there were other people with whom I needed to share.

**SS: And you weren't going to church at this point or were you still —**

LM: By then I had left the church.

**SS: What was your career goal at the time?**

LM: To get out of Rome, Georgia.

**SS: So how did you get out?**

LM: Well, first, I got married to a man.

**SS: In high school?**

LM: No. When I was a junior in college, I got married to a man who was in the army, and we stayed married for five years. I had a child with him, and we lived in Hawaii for three years. In my world at that time, what I had heard was my two career

opportunities were school teacher or nurse — and I don't mean professor. I mean school teacher or nurse, or I could married. Honestly, I didn't want to be a school teacher or a nurse, and so I got married.

**SS: Did you finish college?**

LM: I went back to college after we got divorced, yes.

**SS: So I didn't know you had a child.**

LM: I do. I have a child whose name is Brian. He's thirty-four.

**SS: Where is he?**

LM: Well, right now he's probably in his apartment in Brooklyn.

**SS: Oh, he's in New York.**

LM: Or he might be walking around.

**SS: So he lives in New York.**

LM: Yes.

**SS: Do you have grandchildren?**

LM: No. He's not married. He has a live-in girlfriend, but he's not married.

**SS: So that's for the future, perhaps. Okay. So you got divorced, you went back to college, and what did you decide to study?**

LM: Well, I studied immunology. Brian was two years old when I got divorced, and I hadn't finished my degree, so I went back to school to finish my degree. I

was working full-time and I had a very small child, and I was going to school at the same time. After I finished my undergraduate degree, I worked in a lab for a couple of years, and then I went back to school and got a graduate degree in immunology — all in that very compressed five-year time frame after I came back to Georgia.

**SS: So is that when you started to come out? Was that in that time?**

LM: Yes. Pretty soon after — actually before my ex-husband and I, Jim, were officially divorced, I met in work and school what turned out to be the first lesbian I ever knew personally. I couldn't figure it out. I just loved her, and we had so much fun and we studied together, and on the weekends she would disappear. I was like, "Wait a minute. How come Harriet and I can only be friends during the week?"

So we took boards together, and when we got the boards back she called me and said, "I'm picking you up on Saturday. We're going out." And I don't know what came over her but she just drove me to the only lesbian bar in Augusta, Georgia, and I walked in and thought, "Oh, my god. Yahoo."

**SS: What was the bar called?**

LM: I don't remember what the name of the bar was but it was near the military base, because Fort Stewart — Fort Gordon, I'm sorry — Fort Gordon is in Augusta, Georgia. So there were all these women from the base, plus some women that Harriet knew from the town, and it was fantastic.

**SS: What was the community like at the time? What year are we talking now, seventy —**

LM: Seventy or '79, '80.

**SS: What was the community like at the time?**

LM: Well, it was another small town in Georgia, right, so it was very much centered around bars or the softball field. There were no politics that I knew of in the community at that time, except somebody wanted to play left field and they got relegated to right field or something. That was the only political thing that went on.

The other thing that stuck with me was that there was this uniform for the dykes in Augusta, Georgia, at the time, to go out on the weekend: Timberlands, 501s, and a flannel shirt. So what did I know? I'm twenty-five, twenty-six years old, and now I've found my place, but I don't know anything about it, and I desperately wanted to fit in. So every Saturday I would get dressed in 501s and Timberlands and a flannel shirt and just be in the mirror like — "This isn't me. I don't fit here either." But that was just the community. It was a very partying community and there with little cliques of people.

**SS: Were you concerned about Jim finding out? Were you worried about custody?**

00:15:00 LM: Jim did find out. He found out. I was at work one Sunday in the lab, and he was back living in the same town again. He was keeping Brian, and I was at work, and I went over to his house to pick Brian up. It seemed that no one was home, which seemed weird. I went around to the back of the house, and his car was back there.

I was pounding on the door, and he finally opened up; Brian wasn't there, and he wouldn't tell me where he was. And I called my parents, hysterical, and they wouldn't tell me where he was either. They pretended they didn't know where he was — let's put it that way.

So I went back to my apartment, and I don't know why, but all of a sudden I just thought, "My parents have him."

So the next morning, I went to the JAG Office, which is like the police on the military base where he was stationed. I had custody of Brian, and I told them that an officer that was stationed on their base was in violation of a court order for custody. Literally, in five minutes, my parents called and told me to come and pick him up.

**SS: And that was that?**

LM: And that was that.

**SS: Wow. That was lucky. Good move.**

LM: That was lucky. I haven't thought about that in a little while.

**SS: So you're working in the lab, you're going out on the weekends to Augusta.**

LM: I'm living in Augusta and going out there, yes.

**SS: Did that lead to any kind of further exposure within the lesbian community or feminism or —**

LM: No. When I moved to Atlanta. Pretty soon, after I came out, I moved to Atlanta, which is where — at that time at least — all small-town gay and lesbian people ended up going. So I went to Atlanta too.

**SS: Little Five Points, or whatever. Yes.**

LM: Mm-hmm. And that's when I started to be more politicized. I'm blanking on the name of the feminist bookstore. Blue Stocking? No.

**SS: Charis.**

LM: Yes, Charis Books and More, right. That's it. So I started hanging around there and gradually — well, not gradually — pretty expeditiously, I became politicized. I was still in the closet at work. I would neutralize the gender pronouns. And now I began to disappear on weekends.

**SS: When you say "politicized," did you get active in anything?**

LM: In 1986, I got active in the Lesbian and Gay Democratic Club in Atlanta, and we figured out how delegates got elected to the Democratic National Convention — because it was coming — in '88. It was one of the Al Gore running years. We organized the community and shepherded people to the various districts where the elections were going to happen at seven o'clock in the morning on a Saturday, and we block-voted our candidates in. It was the first time an out lesbian or gay person had been elected to a Democratic anything in Atlanta. So that was kind of my first organizing.

**SS: Now, did you become aware of AIDS through your work as an immunologist or through your presence in the gay community?**

LM: Through my presence in the gay community, and then through my work as an immunologist. So the first person I was friends with who died of AIDS is a guy named Perry Pittman, who was a dear friend and an architect who lived in Atlanta. He moved to San Francisco, and he died in 1985. Actually, his quilt panel is in the very first section of how they number the quilt. And I went to visit him, and he hadn't told me that he was sick. I went to lunch at his apartment, and his entire face was covered in KS lesions. That was the first person I ever saw that I knew — that I loved — who had HIV, then AIDS.

**SS: Why didn't he tell you?**

LM: Why didn't he tell me?

**SS: Yes.**

LM: A lot of people told me at the time, because for some reason I think because I worked in immunology, they thought I — there was such a desperation that they thought that somehow I could help them.

00:20:00

Then my lab got a grant from the CDC — now I'm in Atlanta, and I'm working in a lab — to try to screen the blood supply with surrogate markers before there was an HIV antibody test. There was a prototype test before it was approved — the HIV antibody test — and we did some studies to match what we had found to be surrogate markers to see how the sensitivity and specificity correlated with this new HIV antibody test that was coming. I didn't think this through very well. A few of my friends asked

me if I would run their blood samples in our study, blind, and so I did. A few of them turned out to be positive. And that's where I hadn't thought it through, in terms of now I had information that they couldn't get anywhere else, and it was up to me to tell them what I had found.

**SS: This is before HIV?**

LM: Yes. This was when people just presented with AIDS.

**SS: What were the markers?**

LM: Well, back then you called it T-helper and T-suppressor — before there was CD4 or CD8. Absolute T-cell counts and lymph cells and certain kinds of IgG antibodies that were nonspecific for other things if they were elevated.

**SS: So there was a test where people could tell before HIV —**

LM: If you looked like this display or array of things, then it was pretty likely that you were infected. But there was no test directly for — there was no anti-HIV test at that time.

**SS: When you told these people that they have it, there's nothing for them to do anyway.**

LM: That's correct. That's why I said I didn't think it through very well. I just wanted to help.

**SS: How did you get involved with AIDS organizing?**

LM: In 1988, the Democratic National Convention came to Georgia, so I put my name on the list to provide housing for people who were coming from out of

town; I ended up with Maria Maggenti, Maxine Wolfe, and Amy Wolfe at my apartment. I was doing work during that convention for the Lesbian/Gay Political Club.

They had a designated free-speech site, so anybody that wanted to say something about politics had to go into this fenced-in area, have their rally, or give their speeches, or whatever. Our club hosted a lesbian and gay rally, political speeches. Perry Watkins and Alan Simpson spoke. Yes, this was a long time ago.

Then I found out that it's — what do I know from tradition about gay and lesbian clubs around the country for politics? So, I find out that there's this tradition that the vice president of the host club and the president of the host club are supposed to speak. I'd never made a speech in my life. There's several thousand people standing in this penned-in area, and it's my turn to speak. This was not so many years after the story I just told you, about Brian. Several other dykes in the community, who had been married to men and then divorced, had a lot of trouble with custody and threatened to have their children taken away. Mostly what I spoke about was about parental rights for lesbians, because I knew about that.

The next day on CNN and for the full twenty-four hour cycle, did they show Perry Watkins or Alan Simpson? No. They showed me going, "As a lesbian mother," "As a lesbian mother," over and over and over again.

My boss at work was a dyke. This huge — fifteen, twenty years older than me at the time — but she was in the closet. She had always been my mentor. So, when people started seeing that coverage on CNN, she really distanced herself from me.

And she called me a couple of times into her office to threaten to get me fired, because she was terrified that her mentorship would out her. It was this transference thing.

So here are these three women from New York, who came down from ACT UP, that are staying with me. This is my life, and then they're staying there. Every day, we're just staying up till three o'clock in the morning, talking about everything.

**SS: And smoking. Let me guess. Smoking.**

00:25:00

LM: Smoking our faces off, yes.

**SS: That's right.**

LM: I went to a kiss-in, and I participated in the kiss-in. For me, it was like walking into that dyke bar in Augusta. I saw the reaction of the people on the street, and I understood what had been happening to me, personally. I had the benefit of a tiny bit of mentorship from people who were already politicized. I just never looked back. And that's kind of how it happened.

**SS: So the absolute number one kick-ass recruitment team was beamed into your living room.**

LM: That's correct. I know. How fortuitous.

**SS: Yes. So what did they have you doing immediately? How did you plug into ACT UP?**

LM: Well, boohoo, they left to go home to New York pretty quickly after that. Primarily Maxine and I stayed in very close contact. Literally, we talked on the phone every day. And I helped start an ACT UP Atlanta.

**SS: With your girlfriend, right?**

LM: With my then-girlfriend Melinda.

**SS: Melinda, that's right. That's right.**

LM: And a couple of the men that I had run those blood samples on, who ended up, themselves, getting connected to folks in ACT UP New York. Several of those men are now dead. The first thing I did was help start an ACT UP chapter in Atlanta. That was 1988, the end of 1988.

**SS: So our focus is on ACT UP New York, and I know that you cooperated enormously with ACT UP.**

LM: We did.

**SS: So can you tell us some of the projects that you worked on with ACT UP?**

LM: Absolutely. I think the first thing that we did jointly — sometimes the timelines get a little messy for me, so I might be wrong about the order. Two Days, Two Ways to Fight for Your Life. So, day one was an anti-sodomy-law demonstration around *Hardwick v. Bowers*, and day two was the first of a campaign series protest kickoff from the CDC to change the definition. We worked very closely together on that, and I came to New York and I —

**SS: That was the first CDC demonstration.**

LM: That was the first CDC demonstration. That's right. Then we collaborated on a demonstration in Columbia, South Carolina.

**SS: Let's go back to the first one you did. So you came to New York and you reported to the core organizing team for that.**

LM: That's right.

**SS: Can you tell us who else was on it and what you guys had to do to prepare for that demo?**

LM: Well, at the same time there was a group of us who knew some physicians in New York City primarily who were seeing a lot of women who had AIDS. Some of us, like Risa Denenberg and myself and I'm blanking on some of the people. I'm sorry.

**SS: That's okay.**

LM: So we would go to Kathy Anastos's practice and we would go to other clinicians in New York, primarily, and we would blind look through the records with a little tick-mark thing: Extrapulmonary TB; invasive cervical cancer. Check, check, check, check. We were documenting what women with AIDS were sick with and dying from at the time in a very un-placebo-controlled way. We could tell very quickly that the list of opportunistic infections that were in the current CDC definition had no relation to the things that were making women so sick. So we did a lot of teach-ins and education around that for the group.

At the same time, Terry McGovern was preparing some legal stuff from her work on the same thing. I think a lot of it when I came to New York was educating people — helping with a group of women to educate about what the issues were.

**SS: Who were the HIV-positive women who were working with you?**

LM: Keri Duran.

00:30:00

**SS: Yes. Can you tell us about her?**

LM: Fierce, awesome dyke from Wooster, Mass., who was mostly part of ACT UP Boston. She is dead. She was one of the first women who was HIV-positive who had AIDS that I knew that publicly disclosed for the purpose of activism, like ACT UP kind of activism. There were a few people, like Kimberly Bergalis, or Amy Sloan — she went on Oprah, because Ryan White bailed. This was a different kind of partner for me in the fight, and we became very close.

Right before she died, Maxine and I took her on a trip to Key West, just to get her out of Boston. It was a brutal winter, and she was very sick. So the three of us went to stay in one of those little B&Bs in Key West just to warm up and hang out and, essentially, say goodbye. We got kicked out of the B&B because they saw Keri's meds on the dresser.

**SS: No people with AIDS in Key West?**

LM: No people with AIDS in Key West. At first they tried to tell us they were kicking us out because we had left the air conditioner on in our rooms when we had gone for a walk. So I got in the guy's face and I started yelling at him. And then he said, "You people." That was kind of it. That was a big scene; we got kicked out.

Maxine took Keri and they sat on the curb and cried, and I went and told the guy I was going to call my credit card company and not pay for the rooms. I think Keri died, probably about six months later.

Katrina Haslip.

**SS: Yes. Tell us.**

LM: Bedford Hills. She was an organizer for women with AIDS in the Bedford Hills Prison. She was very involved in the CDC campaign, as was Iris de la Cruz — other women that Katrina brought to the fight from Bedford Hills. So there was a fantastic mix of women who weren't HIV-positive and women who were, that all bonded to do this activist political work around issues of women with AIDS. I don't know what else to talk about about that.

**SS: So you guys would meet and make decisions about — so how did you decide to do the demonstration at the CDC?**

LM: We brought it to the floor of ACT UP. There was a demonstration before the CDC demonstration, actually, which was at the Social Security Administration in Washington, D.C. Do you know about this?

**SS: No. Go ahead, tell me.**

LM: It was basically just a street picket on the sidewalk, but because the CDC took so long to change the definition, our strategy was to go to the Social Security Administration and try to press them — in the absence of a changed definition — to allow women who were incredibly sick and dying and had no way to live financially, to

be able to get SSI and SSDI. Because the way that that was given is if you fit the CDC definition. It was this whole chicken-and-egg thing; if you didn't fit the definition, you couldn't get the money. And so women were in bad shape. We thought maybe the Social Security Administration would do something, and that's why we went there — simultaneous but with a different thing — because that was about real people's lives, right then. And then there was counting women — because that was the source of recognition and study and funding.

**SS: Now what I want to ask you about is direct contact with institutions. So who from the CDC organizing committee was the person who communicated with the powers that be at CDC or at any of these institutions?**

LM: All of us.

**SS: What did you do? Did you call them up?**

LM: We called them. We had fax zaps. We had letter-writing campaigns.

**SS: So who did you talk to? Who were the people you were asking to change?**

LM: The people on the HIV surveillance project.

**SS: And who were they?**

00:35:00

LM: Jim Curran primarily.

**SS: And what was it like dealing with him?**

LM: Well, you know, he was super obstreperous and he was a sexist pig. He tried to argue with us about the science, because he thought he could shut us down if

he said more about the pure nature of epidemiology than he thought we knew. But we knew a ton. And actually, unlike a lot of the other campaigns that I worked on, the CDC was very much behind those walls in that brick building. There was no public face of the CDC. We would fax stuff to him, we would call him, we would bomb him with letters. We would see them at public health conferences and interrupt them and all of that — but there were not meetings. Essentially you didn't know who they were, right, except you did know who they were.

**SS: What was their argument, that these symptoms were not related to HIV?**

LM: That's correct. Lots of people who had been former IV-drug users, for example, had extrapulmonary tuberculosis; so that was a function of their lack of access to healthcare and their socioeconomic class, and their injection drug use, or their homelessness — or their whatever he wanted to say for the day — and not as a function of the fact that they were immunosuppressed.

**SS: What was his investment in that?**

LM: I've never understood the CDC. They have that classic stodgy epidemiologist mentality, which is test and quarantine. That's all they want to do. And I think, honestly, his investment in that was that he had characterized the disease in such a way that it was only men, and he had created a whole program around that. There was this whole surveillance. He made his career out of the HIV Surveillance Report, which came to be the HIV and AIDS Surveillance Report. He just didn't want to change it. He

couldn't see women. He didn't know that anybody had a vagina or cervix. And he just didn't want to see it, because it would have to make him rethink the way he constructed his entire department.

**SS: So, a true bureaucrat.**

LM: A true bureaucrat, yes.

**SS: Can we close that window? Did the window open?**

LM: It did. Just yank it really, really so

**SS: Some of the HIV-positive women who worked on this really took positions of leadership.**

LM: That's correct.

**SS: So how was that? That was a cultural change for ACT UP.**

LM: Yes.

**SS: And what was that like?**

LM: I don't remember that many of the women that were working on this who actually had AIDS came to the ACT UP meetings. That's my recollection of it. Keri, yes, but not like Iris [De La Cruz] and Katrina. Not on a regular basis.

**SS: But when you would say, "Okay, we're going to have this demo, and Phyllis Sharpe is going to be the speaker," how was that decided?**

LM: In small working groups. These women just wanted a voice. They wanted to speak, and they knew the stuff, and they were dying to get their story out, because — talk about the invisible of the invisible. They could have a megaphone, a

bullhorn in their hand, and say what was happening. I think in certain ways without a definition and without drugs, it kept them alive. And they just wanted to.

**SS: So ACT UP paid all the expenses?**

LM: That's right.

**SS: So they brought everybody in, they put them up.**

LM: Yes.

**SS: What kind of small working groups? Where were they? Were they in Boston? I know Mary Lucey was involved from L.A.**

LM: Yes.

**SS: So were they on location, these small working groups, or were they over the phone?**

00:40:00

LM: A lot over the phone. I think there were a few people from Boston, a few people from L.A., a few people from Atlanta, and then from D.C. Then there was the mother ship in New York. We all spoke to each other on the phone all the time. We had a phone tree with each other. We would speak about — We would fax each other fact sheets that we were working on. People would bring them to the floor of their own thing to try to get an endorsement. But really the hub, the mother ship, was in New York City.

**SS: Now, none of these people survived except Marina Alvarez.**

LM: Well, Mary's alive.

**SS: Mary?**

LM: Mary's alive.

**SS: Okay. What's her last name?**

LM: Lucey.

**SS: Oh, Mary. Yes but I meant that were involved in New York.**

LM: Oh, that. Yes, that's correct. That's correct.

**SS: And what is your understanding about why that is?**

LM: A bunch of reasons. I think socioeconomic, and lack of access to healthcare. A lot of these women were way sicker and not diagnosed until it was essentially too late. Many of them had an aversion to swallowing the early medications because they hadn't been tested on them, and they didn't know what the dose would be, and it made them sick. I know AZT made a lot of people sick. So, lots of reasons like that. And isolation, I think.

**SS: That's what I'm interested in, because it seems like of all the HIV-positive women who got involved in this, none of them got on the conveyor belt towards the right trials, the new meds. It just didn't happen for them.**

LM: Well, no, it didn't. It's very difficult for a woman — still — to participate in a clinical drug trial of any medication, despite what the FDA says. Especially for the drugs that are available even now — but certainly for the first couple of waves of protease inhibitors. You can tell how many people were in those trials by looking at the package insert by demographic. Very small numbers of women were in those studies, because the way the pharmaceutical industry takes care of a potential lawsuit for teratogenicity is to keep the women out.

**SS: So the drugs people use now, Atripla or Quad or whatever, how are women doing on these drugs?**

LM: Well, I think it's a little early for Quad. I actually just talked to Mary the other day. She finally went on meds. So in a one-dog study, right. She started with Atripla, and she lost sixty pounds, and she couldn't sleep, and she was having nightmares, and she changed her medication.

**SS: From Sustiva?**

LM: If you look at the Sustiva package insert, it's really only about 12 percent of the people in the pivotal studies that led to the approval of Sustiva who were female. The way that works is this would never happen if it weren't women. But they do an analysis to say — they run down the side effects, and then they look at the overall population and say, "Yep, no difference."

Now, if that was men, they would say, "Well, we can't make that judgment because we don't have the statistical power to do that." But for women, it's always been okay to just make a cursory look and check a box and say, "Done."

**SS: So of the 12 percent of women that Sustiva has been tested on, do they show a different level of reaction?**

LM: They don't, but you have to have enough women to be able to see it.

**SS: So you don't know what that 12 percent means. You don't know what that number is.**

00:45:00

LM: That's correct. And they don't split anything else out by that number. They don't split it out by co-infection or baseline CD4 count or hemo. They don't split out any of that. They just tell you how many people were female, how many people were male, how many people were white, how many people were black, how many people were Latina. Then, they move on to the rest of the stuff in the aggregate: how many people had anemia; how many people had fatigue; how many people had nightmares are not split out that way.

**SS: Okay. So we don't really know if the holy savior compound meds work for women.**

LM: No. That's correct. That's what I personally tried to work on for — besides the CDC definition, that was pretty much the work I did in ACT UP — for seven years.

**SS: Now, let me just ask you one more thing on this, and then I want to get into that. The mortality rates, we know that 1,600 people died of AIDS in New York City last year. Fifty percent were diagnosed in the emergency room. Is there a gender breakdown?**

LM: No. The CDC Surveillance Report just came out, and you can't look at it that way. That's the other thing that's frustrating about the CDC. Every question I've ever had when I would bury my nose in one of their surveillance reports was never answered. And it's not just for women.

**SS: So that could have been 80 percent of women.**

LM: That's correct. That's correct.

**SS: So we don't have mortality rates for women from AIDS in the U.S. right now.**

LM: We have some, but not in the way that would be beneficial to ask some questions about establishing a research and treatment agenda for women.

**SS: Right, because there's two questions. One is how many women with HIV are not getting any care?**

LM: Right.

**SS: And then how are women with HIV responding to the standard of care?**

LM: That's right. That's right. Then there's another thing now, which is people who die of HIV die of certain things. People who die of AIDS die of things that are in the now CDC definition, and those are now two different things. For a lot of men, for example — don't ask me the statistics, because I don't know — but for a lot of men, for example, when they die of HIV now, they die of things like premature aging and cardiovascular disease —

**SS: Like heart attacks.**

LM: Yes. And there are such small numbers of women that fit into that category because they're all dying of AIDS, still. The big conversation around treatment now in this country, in terms of treatment as prevention, which just sends chills up my spine, is ludicrous. You can see how selective a model of the person with HIV is they're

thinking of. You should start meds when you have 750 or 650 CD4 cells; the majority of people who are newly diagnosed have 100 CD4 cells at diagnosis. How is that going to help them? What is that about?

**SS: Right. And that's because we don't have healthcare, so they're not diagnosed.**

LM: That's right. They're not diagnosed until they're deathly ill and they come crawling in to the emergency room — still.

**SS: Now, when we interviewed Kevin Frost at amfAR, he said that of the 1.2 million infections in the U.S. right now, the first group that's getting infected is white gay men, and the second group is black women, but I know that their infection rate is down 21 percent.**

LM: That's right.

**SS: Now, what do you attribute that drop to?**

LM: For women, you mean?

**SS: Yes.**

LM: No idea. No idea.

**SS: Because Linda Villarosa thinks that it's because that using needles is not as much —**

LM: Well, I was going to say that, but I don't want to say it that way.

Here's why. There's a lot of heterosexual transmission that occurs for women, and I don't

understand — maybe the drop is about needle exchange, but I guess I was thinking about needle exchange plus heterosexual transmission.

**SS: It's not needle exchange. It's that people aren't using needles.**

**They're using other drugs.**

LM: Well, I don't know if that's true. That's not what I hear. But that's not my bailiwick.

**SS: So you're saying heterosexual transmission. I guess basically we don't know. We don't know what we're talking about.**

LM: We don't know what prevention is successful in terms of the decline in the number of new infections in women. We don't know.

**SS: What are you working on? Are you currently in the AIDS world now?**

LM: I just got reactivated a little, and I'm still trying —

**SS: Is that your job-job?**

LM: No, I've never had a job working in AIDS.

**SS: I want to go back, then. So basically ACT UP totally changed your life.**

LM: It did.

**SS: You moved to New York.**

LM: Yes. I moved to D.C. I started ACT UP D.C. with Michael Petrelis.

**SS: Oh, god. One sentence, what was that like working with Michael?**

LM: He's brilliant. His ideas were about two years before anybody else thought of it — and he was lambasted for a lot of that stuff.

**SS: Can you give us one example?**

LM: Outing closeted congressmen on the steps of the Capitol when we both lived in D.C. We fought all the time, and he threw himself onto the hood of the car that I was driving at one point and screamed bloody murder at me. But I love him. He's super smart.

**SS: So you guys started ACT UP D.C., and then you moved to New York.**

LM: And then I moved to New York.

**SS: So when you came to New York, what year did you move here?**

LM: That's a very good question. Ninety-one. '91.

**SS: So how did you plug into ACT UP New York at that point?**

LM: I started going to the meetings, and obviously they were still at the Community Center.

**SS: Were you in an affinity group?**

LM: I was in the Costas.

**SS: And what was that like?**

LM: For me it was great because there were men and women in that affinity group, and all of us cared — not to say we didn't have debates and discussions

and stuff — but it seemed that all of us cared about the issues that we cared about in the exact same ways. I felt very supported by the men in that affinity group around the work that myself and others were doing on treatment and research for women. And it fit my political ideology, my ever-now-changing-again political ideology. That group fit. I had been a peripheral member of the Costas before I ever moved to New York.

**SS: So then what else did you do in ACT UP when you were in New York?**

LM: Those were the years when I was working with some folks to try to get the ACTGs to do research in their clinical trials system that included women. That was kind of the majority. That was my full-time job.

**SS: Who was the person who you were asking to change?**

LM: So there was a guy named Dan Hoth, who was at that time the head of the ACTG clinical trials system, reporting directly to Tony Fauci. So he was mostly the target of our asking, if you want to think of it that way.

**SS: Did you ever meet with him?**

LM: Dan Hoth?

**SS: Mm-hmm.**

LM: No. We met with Tony Fauci.

**SS: How did that go? Tell us about how that happened.**

LM: Can I tell you something else first?

**SS: Sure. Go for it.**

LM: So when the NIH demonstration happened, our affinity group went off the main campus to Dan Hoth's office, which was in a different building. That was the focus of our NIH action, and we occupied his office. He wasn't there. But Marion Banzhaf and I dressed up like businesspeople and went past security and let the rest of our affinity group in through a fire escape door. We went up the stairs, and we were in his office for a couple hours.

On his bulletin board was Tony Fauci's number, so we called him a whole bunch. We had fact sheets about what the ACTG system needed to study, from our point of view, specific to women with AIDS. We put those fact sheets in every Pendaflex folder in all of his filing cabinets. Then we all were arrested, but that was the first of it in a direct action kind of way.

00:55:00

**SS: Is that the first time he'd heard from you or had you tried to contact him before?**

LM: No, that was really the first time he had heard from us. We had done something before that, just a few of us because — oh, no, a little after that — because after the NIH action, a few select people were allowed then from the community to go to the ACTG quarterly meetings. I went, and a few other women also. Maxine went. I forget who else was there.

This is one of the things I loved about ACT UP — the work that we did. Our direct action was both on target and hilarious. They would have these cocktail receptions, starting at five, after the regular meetings were over, and we had these custom

fortune cookies made up. We got one of the servers at the hotel to let us have one of those silver trays, and we put the fortune cookies on there — right with the cheese platter, and whatever. The fortunes all said, “NIAID, Form A Women’s Committee.” When you opened up the cookie, that’s what it said. And the looks on the people’s faces when they saw what the fortune was in those cookies, really, there was nothing better.

You asked me something else. I forget.

**SS: Let’s say I’m Dan Hoth and I don’t know who the fuck you are, and you take over my office. How come you never just first asked him?**

LM: Because we had been asking — in the context of the ACTG in general, not to Dan Hoth directly — to do research on women.

**SS: And who was saying to you, “No, we’re not going to”?**

LM: It wasn’t really “No.” It was just complacency and inaction. No one really said, “No, we’re not going to study women.” It’s just that they never did. They studied fetuses and babies, but that’s not what we were asking. The Women’s Health Committee that eventually formed — turned actually into spawn of Pediatric Committee — isn’t what we were asking for either.

**SS: So how did you get to Tony Fauci?**

LM: Well, the first thing we did after that was the San Francisco International AIDS Conference. There were people from lots of ACT UP there. How that worked on site at this AIDS conference, was that every night the people who

represented — or were there as ACT UP — would meet and discuss stuff, and decide what would be done for the next day or whatever.

Dan Hoth was giving a major plenary talk the next morning, and we brought to that ACT UP group the suggestion of an action to disrupt his plenary talk around the issue of ACTG's studying drugs and women with AIDS. A vote was taken about the action, and we were told that while we could hold a banner, we couldn't say anything.

**SS: Who told you that?**

LM: The rest of the ACT UP people. There was a "Everybody raise their hand if you want to allow this affinity group, this onsite affinity group, to be able to go do this. Yes or no?" Lots of no. Why? "Because it's a scientific conference, and we want to dialogue with the researchers, not disrupt the information that is given there."

**SS: Now, would you say that this was a key moment?**

LM: It was for me.

**SS: And who were the other people that opposed you?**

LM: Many of the men who were onsite from the Treatment and Data in ACT UP. Some ACT UP Golden Gate folks. That was primarily it.

**SS: Explain to us why their position doesn't make sense to you.**

LM: Because from our point of view, we were working on trying to get the government to study women with AIDS for a lot of reasons. There was a paucity of

data, and they weren't doing anything. So what possibly, scientifically, could have been shared there if nothing existed?

01:00:00

**SS: So in other words, when they say, "We want to dialogue with them about research," they mean about men.**

LM: That's right.

**SS: So, therefore, your effort to try to get them to do research about women will interrupt our ability to get information about men.**

LM: That's exactly right. And I just got it — like I was looking in a crystal ball and somebody had cleared the thing up.

**SS: Can you say at least two names of people who opposed you?**

LM: David Barr and Mark Harrington.

**SS: Interesting. Now, did they do anything to try to help you?**

LM: No. They just told us that the consensus of the group was that we'd be allowed to go and hold a banner, but we couldn't speak. That was our demo. We made a huge banner that night that said, "NIAID, Form a Women's Committee." There were probably eight of us, ten maybe.

**SS: Can you just say some names?**

LM: Marion Banzhaf, Risa Denenberg, myself. And we unfurled the banner, and the banner was facing — it was a major plenary, so like everybody, right?

So the banner was facing them. And we had made these spray-painted t-shirts on the fly, after we realized kind of how the demo was going to have to go down.

At a women's conference previously to the thing we're talking about right now, Dan Hoth had spoken, and he had said when we were challenging him about a research and treatment agenda for women, "We've not actually paid much attention to how we actually do these trials."

I said, "What?" So we spray-painted that quote from him on the backs of our t-shirts and put his name on it. So he was looking at that while we were holding the banner, and that was the demo that we did.

**SS: So did T&D ever try to help get the ACTGs to study women?**

LM: No.

**SS: No one in T&D?**

LM: No. What was going on scientifically around HIV medications and antiretroviral therapies and at the time a lot of research activity on O.I.'s — because people were still dying left and right from opportunistic infections — for women was done outside of T&D. T&D never had that on their agenda. They never did anything about any of that.

**SS: Who were the men in ACT UP who supported it?**

LM: David Robinson.

**JW: Aldyn [McKean]?**

LM: Aldyn, not so much, not so much. Lee Schy, and Joey Ferrari, just to name a few.

**SS: So then what happened after that when you all came back from San Francisco?**

LM: Right. So then we had a discussion amongst a lot of us who had been working on this about what went down, in terms of the demonstration at the conference, and so we decided we were just going to get a meeting with Tony Fauci. I forget who called, but we just called his admin, and called and called and called and called and called.

And finally, he agreed to meet with a group of us. So there were probably about nine or ten of us; a few HIV-positive women but honestly, at that meeting, not many. So we go in this conference room. He's going to meet with us for an hour, or maybe it was ninety minutes, but I think it was an hour. The only time he had ever met with any activists around women and HIV, and he's going to give us an hour. He brought his secretary so there was an NIH female, and I felt bad for her because it was at four o'clock on a Friday afternoon, and she had to stay.

01:05:00 So what we had decided that we were going to do was that each of us had some piece of what the problem was and what we wanted as a demand from the NIH around that issue. And we were each going to go around the room and take five minutes — each of us — to say what our thing was. That was how we had envisioned the structure of the meeting.

We're sitting around this big conference table, and we start going around in kind of no particular order. It's about thirty minutes in, and other than, "Hi, I'm Tony Fauci," he hasn't really said a word. Because we're talking. Same principle, actually, in our minds: "You haven't done the research, so what the hell are you going to tell us?" "We're here to tell you, and that's what we're going to do."

So about thirty minutes in, he says, "Let me just stop you for a minute." "We basically have — our time is almost half up, and if you don't allow me to speak, we're going to run out of time."

And we said, "Okay, fine, because we don't really care to hear what you have to say. We're here to tell you."

And he got very ruffled, and he said, "I have an agreement with the men in ACT UP that they don't speak to me in that way."

Honestly, pretty much, the meeting went downhill from there. I think Maxine said, "Well, you don't have that agreement with us." And then I said, "I've never even met you before. How could we possibly have that agreement?" So, instead of talking about the research and treatment agenda, the rest of the meeting really devolved into that.

**SS: Okay. I've got to ask you a theoretical question here. Many, many, many, many, many, many, many men, not the two in this room, have no concept of how wrong the way they treat women is.**

LM: I know.

**SS: And a lot of these guys have all the power. So when you go in there, there's two possible strategies: one is to play along with their distorted self-perception in order to try to convey information to them; and the other is to prioritize, changing the way they see themselves in relationship to women as being a priority over trying to play the game with them to get your issues across. So you're choosing "B" as your strategy. Why was that?**

LM: I think part of what I used to feel like was that I couldn't bear to think that many of the men in ACT UP — after having had politicized, radical, fierce lesbians side by side with them for years — couldn't change their minds. It was beyond my comprehension that I would put my body in the street, and that they couldn't respect me as an equal human being.

**SS: Let us just have a reality check, then. It's now 2013.**

LM: And I was wrong.

**SS: And they're still like that.**

LM: And I was wrong. Yes, I was wrong. I've had some times lately where I've thought, "Wow, I don't know why I did that work." Not the work that we did

with women, but the larger context of the work. When I was in grad school in '87 when ACT UP first formed, I was the person who used to Xerox the articles that were coming out in the peer-reviewed medical journals, and I would send them to Mark, and I would be on the phone with him for hours, essentially having a journal club to tell him how to read them.

**SS: It's very painful that these guys haven't changed.**

LM: It's super painful.

**SS: I'm experiencing that today with Peter Staley. I had some shit from him today, and I just think — wow, it's unbelievable.**

LM: I feel really sad about it. I feel super angry about it. But mostly, I guess, the pervasive feeling is, wow. I worked in ACT UP on a lot of things, 24/7, right beside you, in the jail, on the street, in the meetings, for seven years. The thing is, I always knew there was an inkling of it, but it was suppressed a little more. There was a façade to it that I remember. Or maybe I'm just more of a rabid-dog feminist now that I'm fifty-seven years old.

**SS: Well, they were more vulnerable then, and now it doesn't matter.**

LM: Right. Yes.

**SS: So when did you leave ACT UP?**

**JH: Wait. I want to ask a question. What about the women in T&D? What was your relationship to them?**

LM: You mean Garance and Iris?

SS: Yes.

**JH: Yes, and Rebecca Pringle Smith.**

LM: I don't know Rebecca Pringle Smith that well. I know Iris and Garance well. I don't have a Ph.D, Iris does. We both come from a research background, and Iris' approach to research is so different than mine ever was. I don't know how to explain this but to say that you can be a woman and not be a woman — in how you think, in how you view science, in how you question stuff. Iris fit very well with T&D because she bought into the entire epistemology of the research system. It would never occur to her to say, "Why is every hypothesis always proven true?" It was just a different take on it.

**SS: But also, they didn't treat her that well.**

LM: No, they treated her miserably.

**SS: She was kind of mocked and she was disrespected by them.**

LM: Yes. They treated her miserably. And then there was Garance. And I don't know if I — maybe you could help me. I'm not very good at — Jim, you were fantastic last night. That's now how I convey what I think. It's a little more —

**SS: Well, Garance was seventeen.**

LM: Yes, but she's the same now, in the way that she's typified herself around the film. That cut — can I just say — you can throw this on the floor later if you want. That one moment in the *Plague* film where she's talking about the moratorium and

with disgust says, “And then Heidi and Tracy wanted to have a six-month holding period for meeting.” Then she just kind of — there’s a sneer and a snort to it that is just so dismissive. Never mind the decisions that were made about how to talk about all the stuff we’re talking about right now. But that’s when I left the film. I don’t know if you know the part I’m talking about, but that’s when I left the film.

**SS: I don’t know. But Jim, there’s always — there’s Phyllis Schlafly, there’s always —**

**JH: I just was wondering how it worked out.**

LM: They loved Garance. I remember the first time I ever — after ACT UP was allowed into the ACTGs, right, after the NIH demo, there was the first quarterly meeting when we all could come. Mark invited me — that’s how long ago that was. Garance was there, right, and she would follow behind him, and he would introduce her as his protégé, and then she would follow behind him and never speak.

She identified — I don’t mean to make this about identity politics, I don’t — but I don’t articulate some of this stuff very well because it’s so close to me, and it’s been so eradicating and — anyway, whatever. She was a lesbian at that time, but I thought of her more as Mark’s protégé. I don’t know how to explain that any more than that. There’s all sorts of different kinds of women.

**JH: Yes. And then what happened when they left? How did that change the dynamics within ACT UP in terms of the change in the CDC definition?**

LM: Well, the CDC definition was changed by then. Was it? No.

**SS: Yes.**

**JH: No. Okay.**

01:15:00 LM: Yes. Just barely, yes. Essentially we had just had that first meeting with Tony Fauci; and then they left, and it changed a lot of things. First of all, a lot of people left with them. Mostly people who I think — this is a broad generalization; it could be untrue from other people's point of view. But mostly people who were desperate to get drugs to save their own lives at that moment in time.

There were people who came to ACT UP and went to TAG. Some of those people were incredibly antagonistic against the work that we were trying to do on behalf of women because, somehow, they had translated The Split into something related to trying to do women's treatment where, I don't know —

**SS: It was around —**

LM: Tracy and Heidi's moratorium.

**SS: No, no, no.**

**JH: 076.**

**SS: 076.**

LM: Oh, jeez, we didn't even talk about that.

**SS: That's why, because 076 was one of the pivotal split issues, and that was about women's care.**

LM: Right. So, yes. I was at an ACTG meeting when they were designing the 076 trial, and I was living — I forget where I was living. Who cares where I was living? Anyway, a few of us that always did the women's treatment deep dives — I'd gotten a copy of the draft 076 protocol, and I'd spent several days just poring through it, taking notes and figuring out what I thought about it. Then we all came together the day before and wrote a fact sheet about what we thought needed to happen around the 076 protocol. It was the first drug that had been found to be carcinogenic in animal models, that they were fine allowing a pregnant woman to take.

**SS: What drug was that?**

LM: AZT. Now, isn't that interesting? Because women aren't in the Phase 3 pivotal trials as a woman to see what happens with the drugs that are being studied for FDA approval and marketing. But teratogenic compound, it was okay to give to a pregnant woman. I just found the science and the politics of that to be so appalling.

We were at this meeting and we were handing out this fact sheet, and there were men from Treatment and Data there, ACT UP New York there, who very much wanted this trial to go forward.

**SS: Why did they want it to go forward?**

LM: I don't know, because they had never done any work around women and HIV. I'll never know the answer to that. Do you know the answer to that?

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

LM: That's when the full bore "You're not HIV-positive" divide started to be levied.

**SS: Where was this meeting?**

LM: It was at an ACTG meeting. The construct of how those meetings worked back then — it's been years since I've been to one — I don't know if that's how they work now.

**SS: This is in Washington?**

LM: They're always in Washington at a hotel, and often the protocols that are being developed are discussed and separate — so the members of the working groups that are variously associated with a particular protocol that's in development will have a meeting for an hour or two, present the data in support of the protocol, discuss various amendments to the protocol. That's what this was. We were at an 076 ACTG working group meeting. We were handing out fact sheets to the audience about the 076 study for concerns that people had. Mary Lucey was there. She was diagnosed with HIV when she was pregnant. But that's when some of the men who were rabidly in favor of getting this study done — it was the first time I recollect them trying to silence me by saying I wasn't HIV-positive.

**SS: Now, I have a question. So what is the drug now that keeps —**

LM: Nevirapine.

**SS: Nevirapine.**

LM: Depends on what country you're in.

01:20:00

**SS: But in the United States.**

LM: Mostly Nevirapine.

**SS: So when did they go from AZT to Nevirapine?**

LM: Well, some people still use AZT. Here's the truth of the matter: For women who know that they're HIV-positive and they're pregnant, they take whatever the combination is that they're taking to save their own lives, and it works just fine. Less than 2 percent of babies born in this country are HIV-positive now. It kind of depends — if I'm pregnant and I'm HIV-positive and I already know, and I just take whatever my little cocktail is —

**SS: But isn't Nevirapine in the compound?**

LM: My cocktail, in that case?

**SS: In standard?**

LM: No, no.

**SS: It's added if you're pregnant?**

LM: Well, sometimes it is and sometimes it isn't, but mostly it is. That baby cure story that just came out after the — this time, they added Nevirapine during that delivery.

**SS: So 076 was not successful?**

LM: No, it was successful.

**SS: But not with AZT.**

LM: Yes. The 076 study was about AZT monotherapy to prevent maternal-fetal transmission.

**SS: And it did prevent maternal-fetal —**

LM: And it did, to a statistically significant extent. Nobody knows what the kids that were negative look like now from being exposed in utero to AZT. Nobody knows.

**SS: There's no follow-up?**

LM: There's no follow-up. Nobody knows how those women have done in terms of viral suppression to save their own lives now after becoming resistant to AZT as a result of taking that monotherapy during pregnancy. There's no follow-up.

And a lot of what we were trying to do — because it was clear they were going to try to save those darn babies no matter what in that 076 protocol, so we were trying to get long-term follow-up studies, at the very least, mandated into that protocol. It just never happened.

**SS: Now I just want to go back to something that I wanted to ask you before about the NIH action. What did we win at the NIH?**

LM: What did ACT UP win at the NIH?

**SS: Yes.**

LM: The ability for a select few to go and interact with the academicians who represent different teaching institutions and are members of the ACTG clinical trials system.

**SS: And what did ACT UP think it had won?**

LM: I think that's what they thought they won.

**SS: Because we have footage of Maria Maggenti and Bob Rafsky at the post-action evaluation saying that the action was — what does he say exactly? That they don't understand why we were there, they don't understand what we got out of the action.**

LM: Right. But that could be Maria and Bob, because my sense is that a lot of people thought that it was a fantastic thing. The elite who were working on treatment would now be able to go and be involved in the ACTG clinical trials quarterly meetings. That was essentially when the inside-outside stuff was really codified. Because now we had a select and self-identified group of folks who were inside the clinical trial system, and then all others who were waiting for their reports and, essentially, trying to tell the rest of us what we should or should not think about the science that was coming out of there. I didn't get to hear that stuff too often with my own ears anymore. Because what happened after it was open to everyone, it wasn't really everyone. It was a small group of people, that Fauci and others put their arms around and let in.

And then there became this press, because the executive committee and a few of the other committees still wouldn't let activists inside their closed-door meetings.

If you looked at a plenary or if you looked at an ACTG meeting agenda, you could see open, open, closed, closed, closed, open, and that was for us. That was for the activists.

Mostly the Treatment and Data folks took it one step further to say, "We want to be representatives on the committees of the people that were closed, closed, closed." So one person got to go. Then they formed a Patient Advocate Committee. They're very smart, the government, about how to still maintain control and make it look like they were inclusive. Think about it. If you're going to vote with nineteen people from Harvard and Brown and Columbia and UCLA, and you're one person, how often do you think your voice is going to be heard? But it was the only person that could go in.

**SS: And who was that person usually?**

LM: Well, they rotated it, but I think Mark was probably the first person on the executive committee, although I could be wrong.

**JH: David Barr was.**

LM: It was David Barr?

**JH: Yes.**

**SS: When did you leave ACT UP?**

LM: I left ACT UP in 1994.

**SS: And why did you leave?**

LM: Because I was tired. Because I felt pretty despondent about the progress that was being made on the issues that I cared about at that time. Because I felt, honestly, there was a time when there were those of who — we met with the FDA. I

don't mean ACT UP; I mean the folks that were working on women's treatment issues. We met with the FDA, we met with people at the NIH. All that was happening. Then, after The Split, there was no way to get to those people anymore. There was a lot of resentment at the folks who had been working on the kinds of issues that I was interested in as being the cause of the split. And because I honestly could just organize a little bit of stuff with the HIV-positive women, and the other dykes I knew around the country, outside of the context of ACT UP. So I just felt like, "I've got to go."

**SS: So I only have one more question. Is there anything that we haven't covered that you think is important?**

LM: No.

**SS: So, looking back, what would you say was ACT UP's greatest achievement, and what do you feel was its biggest disappointment?**

LM: Its greatest achievement was that it gave a community of people a politic as a group. It gave us a place to rest, to feel safe and people had our backs at a time in the world when it was really scary to be queer.

**SS: And what is its biggest disappointment?**

LM: That we were co-opted by the system. That we let the system of government policies and science convince us that they were right, and we were wrong.

**SS: Okay. This has been a very illuminating conversation. Go ahead.**

**JW: Just a quickie. You went to the Amsterdam AIDS Conference in '92, did you?**

LM: Yes.

**JW: And did you meet with Curran and a group of —**

LM: Yes.

**JW: Yes, I have you on tape.**