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

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Interviewee: Margaret McCarthy

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ACT UP Oral History Project Interview of Margaret McCarthy February 19, 2015

SARAH SCHULMAN: Are you ready, Jim?

JIM HUBBARD: Okay, yes.

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

MARGARET McCARTHY: All right. I'm Margaret McCarthy, I'm forty-nine, and it's February 19<sup>th</sup>, 2015, and we are in New York City in Sarah's apartment.

SS: Right. Because you came all the way from Ithaca for this interview. Thank you so much. Where did you grow up?

MM: In Brooklyn.

SS: Oh, you're a native New Yorker.

MM: Uh-huh.

SS: I didn't realize that. Were your parents New Yorkers as well?

MM: Yeah. Both my parents were born in Brooklyn, and two of my grandparents.

SS: Oh, my god. So you're third-generation Brooklyn Irish?

MM: Right. Yeah, mostly Irish. Like, my one grandmother was German, but they came here in the 1840s, and then one grandfather is, like, half-Welsh.

SS: So what neighborhood did you grow up in?

MM: East Flatbush.

SS: Oh, wow. Okay.

MM: Yeah, near Brooklyn College.

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SS: Okay, so were your parents involved in any kind of communityoriented activities? Like, were you raised with a community ethic?

MM: Well, when I was a kid, my parents were very Catholic. My family's very religious, and so everything that they were involved in was, like, church-related stuff. Now my mother does tons of community activities and activist stuff, but when I was a kid, that wasn't the case.

SS: So did you feel that your church was a sort of model for community accountability?

MM: No.

SS: No. Was it the anti-model?

MM: I mean, I went to Catholic school till twelfth—like, I went to public school for kindergarten and then Catholic school from first through twelve. So I wouldn't say that, no. It was pretty conservative, socially conservative. My elementary school, that was, like, first to eighth, was right in my neighborhood, and then my high school was in Bensonhurst. It was all girls, and so that was like the most dreadful experience ever. It was like complete culture shock for me, because most of the girls were Italian.

SS: Right. It was like the opposition in New York was Italian versus Irish.

MM: Well, it's also, like, my family's pretty intellectual. My dad was a college professor when I was a kid, and my mom already had some credits towards a master's when I was born. My grandmother was an elementary school teacher. So, like,

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the culture in my high school was really they assumed you were just going to get married, maybe go to secretarial school.

SS: So why did they send you to Catholic school if they were already so education oriented?

MM: Because they went to Catholic school.

SS: Oh, okay.

MM: My parents both went to Catholic college on scholarships, and then my dad got a Ph.D. at NYU, but it was—what is it? So after, like, the Sputnik thing, they funded all these math and science Ph.D.'s, and so my dad got fully funded for grad school, and so that's the only reason he could go to Catholic school for Ph.D.

SS: So you're in high school in Bensonhurst in the seventies, pretty much, right?

MM: And the early eighties, yeah.

SS: So where do you think you got your social justice values?

MM: I mean, I think my family did have social justice values. They just weren't expressed, like, that way. Like, I have an aunt who is a nun, and she went to live in Kentucky in the early seventies, and she still lives there, and she did tons of community work. My grandmother and my parents, like my mom, were very interested in the Catholic Worker Movement. They didn't belong to it, but they would always be talking about it.

SS: So what political movements were you first aware of?

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MM: I didn't get involved in anything till I was in college. So I started college in '83, and so the first things I was involved with were the Anti-Apartheid Movement on campus.

SS: What college were you in?

MM: I went to Columbia.

SS: Oh, so that was like the center.

MM: Right. So I was involved in the Anti-Apartheid Movement and the divestment campaign and then a whole bunch of other things on campus. I went there for college and for law school, like, one after the other. So it's kind of like a continuous time frame in those two different schools, and so I was involved in, like, feminist things, anti-racism work. When I was in law school, I was in a group that did—it was against Columbia evicting people from the apartment buildings that they owned. So I was in that group that was, like, a joint faculty-student-community group.

SS: Well, that and the Divestment Movement were both aimed at very powerful institutions.

MM: Right.

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SS: So you started out learning how to take on extremely entrenched authoritarian forces. Maybe that's where you got some of your training. Just thinking back, where do you think you got the idea that you could succeed, that you could defeat that kind of institution?

MM: I mean, I think, you know, the Anti-Apartheid Movement, like at Columbia was eventually successful, and they actually did get quite a lot of—the university did make a lot of concessions after we had the blockade of the Administration

Building, like more so than some other schools. I think with some of the things I didn't expect that we would be successful. I just felt like it was wrong, and I should be involved in the movements.

# SS: And so knowing that you were going to be a lawyer, you weren't afraid of getting arrested?

MM: Well, I was very careful. So the only time I got arrested in college was—because the police would often—we had – let me step back. So I got arrested in college at a demonstration at one of the trustees' offices who was the chair of Rolls-Royce, so we got arrested, like, on the sidewalk. But we had lawyers and law students who were advising us, and so we knew that we could only get a violation if we were on the sidewalk, and if we went in the building then we would be charged with a crime, and so we all got arrested on the sidewalk. And that was when I was like in my second year of college. So I wasn't thinking, "Oh, I'm going to be a lawyer. I'd better be careful." But when I was in ACT UP, I was in law school, so I was very careful not to get arrested. I only got arrested once, and it was the demonstration at the U.N., which was, like, the last demonstration that ACT UP negotiated with the police ahead of time.

#### SS: When was that?

MM: It was in November of 1987. So we had a demonstration outside the U.N. when they were having, like, a General Assembly meeting, because we wanted to draw attention to AIDS as an international issue. And so the police had – people had negotiated with the police that they would let some people get arrested, like, on stretchers, but we'd only be charged with disorderly conduct. So I know I was on a stretcher, and Frank Jump and maybe David Kirschenbaum. But then after that, that was

when people said, no, we shouldn't be negotiating with the police. You know, this is civil disobedience.

#### SS: Why did that change, do you think?

MM: I think people felt uncomfortable, like, first of all, cooperating with the police, and then, you know, civil disobedience, part of the idea is you're supposed to take the consequences of your actions, but if you're negotiating ahead of time, then it's kind of just for show.

### SS: Right.

MM: And I did get—when I was in law school, I had disciplinary charges against me because we had an anti-racism demonstration where we blocked the Administration Building, and they, actually, because of the anti-apartheid demonstrations that had gone on for weeks, they brought the police onto campus and dragged everybody off. But I wasn't there when people got dragged off, but then they went and tried to identify as many people as possible who'd been there, so we had a little trial.

### SS: What happened to you?

MM: That one, we all got, like, a letter of censure in our disciplinary files. It wasn't a very serious consequence.

SS: So you're here. Let me just turn off my phone. So you're here to. Goodbye, whoever you are. Go away. Okay, let me just unplug this. Sorry. Don't worry about it. That happens. Kind of thing happens all the time around here. Okay. So I just want to say that for people out there who are afraid to get arrested, you're living proof that it's okay, because you're now a professor at Cornell Law School.

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MM: Yeah. But I think—

SS: It's a happy ending.

MM: Yeah. I mean, I think the thing is, though, like, I know people who had misdemeanor convictions and they got brought in front of—to get admitted to the bar, you have to go before, like, the Conduct Committee. So in New York, everybody had to have a meeting, when I got admitted, with somebody. So, like, someone I know in ACT UP had misdemeanor convictions for some demonstrations, and he actually had to go to a meeting, not just with one person, like a whole panel of people around a conference table who asked him all kinds of questions, and I know he was concerned that they weren't going to let him be admitted.

SS: Wow.

MM: So I mean, I knew that if I had convictions, I could get disbarred or suspended or maybe not admitted to be a lawyer, and so that's why I didn't get arrested in any other demonstrations.

SS: So do you remember when you first heard about AIDS?

MM: Yeah. Like, I started college in the fall of 1983, and so I don't remember that I had heard—oh, I've heard of AIDS. Like, I knew about it already. I know that. The first person I know who died, died, I think, my sophomore year of college, and it was someone who had been—he was a couple of years older than me, and they have two student university senators at Columbia, and he was one of the two senators. He had graduated, and then he died like a year or two after he graduated from college. So, I knew him, like, "Hi, how are you?" type of thing.

SS: So how did it become an important event in your life?

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MM: Well, I actually—it's kind of happenstance that I got involved with

doing AIDS activism. I wanted to do, like, peer health education, and so at Columbia

they had a really good women's health peer education program, but I had a class that met

at the same time that they met. So the person in charge of it said, "Why don't you go to

the Gay Health Advocacy Project." which is like the one that Laura Pinsky and Paul

Douglas ran that is mainly HIV peer counseling and education, and so I joined that one.

SS: That was in the School of Public Health, right?

MM: No. Laura worked at the Counseling Services, which is part of the

Health Services for the students, and so we actually met at the Health Services Office,

and that's where people would come in if they wanted to meet with us, and so that's on

the main campus.

SS: So what was your training?

MM: For that?

SS: Mm-hmm.

MM: It was pretty extensive. They did their own training. So we did - I

know we read a lot of medical journal articles. We read things that they had written that

later became their little book. They have a book about HIV that came out in the eighties

that they had written. We had training, like, to do counseling that Laura did, like role-

plays. We worked with other places too. Like, we did some work with GMHC, with

their education department.

SS: So how did you feel when people came in? Did you ever counsel

anyone if they were positive?

MM: No, because we only did the pre-test counseling, and then Laura would do the post-test counseling because she had a degree. I mean, I think, you know, there was like one time that I was really stressed out, because the person was, like, really worried. But I really enjoyed doing that, and then from that, I started doing other AIDS things, like I—

SS: I just want to stick with that for a minute, because at that time there were no treatments.

MM: Right. Well, there were, but not any that worked or were approved.

SS: So, I mean, to counsel people at that time was a big heavy thing.

MM: Right. So we did the pre-test counseling, and the big sell for it was that it was available on campus. It was mostly students. They didn't have to go somewhere else. And then they were tied into, like, we had connections to doctors that they could go see if they were positive.

SS: Right. To get nonexistent treatments.

MM: Mm-hmm.

SS: Right.

 $\,$  MM: Well, I think, I mean, there were some treatments, but, like, none of them were approved. So -

SS: So where did you go from there?

MM: So I did that my first year of law school, I started doing that, which was the '86-'87 school year, and then Laura had told me about this project that the New York State Division for Women had an AIDS Committee that was composed of people from all different agencies or members of the community, and they met once a month,

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and so I joined that. And they basically, like, worked on—we worked on policy issues, and so it was everybody from, like, community activists to doctors to people from different state agencies, like the Commission on Corrections, which looks into mistreatment in Corrections, Division for Women, OASAS [New York State Office of Alcoholism and Substance Abuse Services], which is Alcohol and Substance Abuse. I think we had representatives from some of the city agencies too.

SS: Now, was that one of the first groups to look at women with HIV?

MM: I don't think so, because the people there had looked at it in some of their other groups before. It was more to get everybody together.

#### SS: So what was revealed in those discussions?

MM: Well, I mean, basically, people had a lot of concern about lack of access to treatment, about kind of all of the societal factors that keep women from getting adequate healthcare or access to housing, you know, jobs, anything, kind of play out in more extreme way. And once you add on HIV and AIDS, some of the stuff we worked on had to do with the—because a lot of the safe-sex education at the time was focused on negotiating safer sex, assuming that there's, like, a level playing field and so one of the concerns people had was that's not necessarily the case for women, and that there's a lot of other things people have going on in their lives that are huge difficulties, that this is, like, the last straw. So we did work around all those different issues.

We had, like, public hearings that got transcribed. We put together a bunch of reports. We worked on setting up—there was at least one nonprofit that they tried to spin out, that I would help work on the grant proposal for, and then the thing I was involved with with that, after I was in ACT UP, I was on a subcommittee of the New

York State Department of Health that had a lot of the same people on it, which had to do with HIV testing of women after they've given birth. It was called the Obstetrical Initiative. So that was not the same thing as this Women and AIDS Committee, but it was a lot of the same people.

# SS: What were they looking for in the Obstetrical Initiative?

MM: Well, I mean, now New York State, you don't have a choice. If you give birth, they're going to take – they're going to do blood tests, which is supposed to be to look at the child, but it's actually, like, my blood, like I got tested, and there's no—you can say no, but they'll take your blood anyway. So this was before that, and so New York State was trying to put in something that was, like, halfway in between no testing and everybody gets tested. So what they were doing was they were going to offer testing to women who'd just given birth, like, postpartum women in the hospital.

And the committee was set up to get recommendations, but people on the committee had a lot of concerns, because women who've just given birth, like, they've just gone through a very physically stressful experience. There's all kinds of hormones that are affecting your functioning. You're exhausted, and then they're going to come, and how can you give informed consent for some blood test? So that was, like, what the report that we put out focused on those issues.

SS: It's interesting, because the issue of consent around women and HIV has always been very much about guilt, emotional state, anxiety. It hasn't been about hiding the procedure. It's been about a certain kind of emotional coercion around the procedure.

MM: Mm-hmm. And I think the concern that, like, I have in that committee was, I mean, it was ridiculous to expect that someone who's just given birth can make a decision and is going to even get what people are saying, like, not having slept for days or whatever. And, you know, a lot of the people on this committee with me were doctors, and their concern was their patients lacked access to healthcare. It was already hard enough for them to get healthcare. Maybe they didn't have prenatal care. All kinds of stuff is going on for them, and this is, like, the last thing that they want to be talking about.

SS: Because this was the debate around mandatory testing in a time when there was no treatment.

MM: Yes. It was when there was only AZT.

SS: And so what was the result?

MM: Well, at that time, I mean, our committee—I think for a couple of years, they didn't have—like, they did this initiative until now they have—everybody gets tested. I mean, I went in to give birth to my daughter, who's now sixteen, and they, like, didn't give me practically any information, and I had had, like, a terrible childbirth. The doctor wasn't there. I had gotten stitched up for two hours. After I gave birth, like, I wound up getting hundreds of stitches, and right after that, they're coming and, like, telling me about the HIV test, which, like, information they gave me wasn't even correct. And then I complained to the health department, and they didn't want to hear it.

SS: Oh, my god. So it's all still operative.

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MM: Yeah. I had a friend whose first kid was a couple of years older, and his wife had just given birth. So this would be like 1996. His wife, like, got up and went to the bathroom, and they came in and gave him all the consent forms.

## SS: Oh, god.

MM: And he was like, "My wife doesn't want to have these tests. Why are you giving this to us?" Which he can't even consent for her, to begin with. Then he got so worked up about it, because why are they handing him these forms? Like, she's just given birth. Like, she could barely get up to use the bathroom.

## SS: So you came into HIV through the issue of women really.

MM: Right. So then, okay. So then, like, my first summer job after my first year of law school, I worked at the New York City Commission on Human Rights in the AIDS Discrimination Unit.

## SS: Who was running that at the time?

MM: Keith —I can't remember his last name— and Katie Taylor ran it, and then Mitchell Karp was in charge of the lawyers, and so I worked for Mitchell. So that's how I became involved with ACT UP, because I was working on all of these AIDS discrimination cases and I was just outraged at what I was seeing, what the complaints were that we were handling.

### SS: What were you seeing? Can you give us an example?

MM: Yeah. So they had a lot of the dental cases, you know, where people went to the dentist often. At that time for people who had the money to go to the dentist, the dentist was often the place where people's HIV got diagnosed—AIDS got diagnosed, because they had conditions like hairy leukoplakia that were very unusual. So we had a

whole bunch of cases where patients had filed against dentists who refused them treatment. Then we also had handled the case for a dentist who was gay, who the dental practice wanted to kick him out because he was going to have patients with AIDS. So they did a lot of dental cases, but they also had employment cases, they had access to education, you name it.

So ACT UP actually—at that time my office at the Human Rights

Commission was right downtown by City Hall on Duane Street, and so ACT UP had a

demonstration in July of '87 at Federal Plaza, and so I went to that demonstration and
then I went to the next Monday meeting after that.

## SS: So what was that like, going to the meeting?

MM: It was really weird. I had never gone to an activist meeting before that used *Robert's Rule of Order*, and, I mean, I had gone to, like, these various committee meetings with the state, but it was run kind of like a board meeting, and, like, the fact that it had like a typed-up list of committees and everything, that I found very odd, because I was in groups that operated by consensus or you took a vote. Like, we didn't have to second motions and stuff. I mean, but I was really impressed by the work the people were doing.

### SS: So where did you decide to plug in?

MM: Well, the first thing I did was I joined the Issues Committee.

### SS: Can you explain what that was?

MM: Well, at that time, it was, like, not that well formed. It was like we didn't really know what to do. Like, when I joined it, there weren't that many people, and we met at some loft over Barnes & Noble that the guy—someone there worked for

someone whose loft it was, and so they let us meet there. So we did things like read proposed bills that were before Congress. Then a couple of months later, we switched to meeting at Herb Spiers' place, and then it became a lot more organized. More people joined, and we had more, like, actual things we focused on, like access to treatments, and, I mean, we worked on tons of different things. Then I was also in the Lavender Hill Mob, and so that, like—

SS: Now, how did you end up in the Lavender Hill Mob?

MM: They asked me.

SS: So who was it? Marty?

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MM: It was Marty Robinson and Bill Bahlman, Henry Yeager, Iris Long.

And at that time, me and David Kirschenbaum were the only other people, because, like, lots of people had been in it and quit before then.

SS: So what did you do in the Lavender Hill Mob?

MM: We had meetings, like, where we drank 40-ounce Budweisers out of paper cups. We did all kinds of stuff. Like, there were all these demonstrations. They had their own demonstrations, right? Like, Marty had all these contacts around treatment issues. He would get a lot of things from Project Inform, and so we did a lot of work on access to treatments. We did the things that were unapproved, like whether people could get experimental or compassionate use to get drugs.

We did work on things like state policies. So one of the things I did that was like—it's hard to separate them, because it was like—I mean, it wasn't like a communist cell, but it kind of operated like that. Like you have the little group of six people that then kind of goes out into the bigger group. So, like, we did the same things

that ACT UP did, but we had our meetings separately and then we brought our ideas forward. So we did a packet, like an information packet on HIV treatments that we would mail out to people. So there was a lot of like putting the packets together, collating them, sticking them in envelopes, and at that time there was no treatment education. Project Inform had some stuff, and that was it. So people would get excited when they got this thing in the mail.

SS: So do you remember what some of those treatments were?

MM: Like Aerosol Pentamidine, Bactrim, both for PCP prophylaxis. I don't know if we had articles about all those other things that wound up not working, like egg lipids and dextran sulfate. We may have had articles about those things, but most of the stuff we had was, like, pretty scientific.

SS: Now, I want to ask you about some of the conceptualization that was done at that time. So you were part of the people who were conceptualizing that access was the key issue.

MM: Right.

SS: Do you remember how those, anything about those discussions or how you came to understand that?

MM: Well, I think, I mean, for me, like—so I think there was a tension, right, between people who said, like, we need access to healthcare, housing, everything, and access to treatments. But you need to be able to access healthcare before you can get treatments, and so there was a big tension between people who had that point of view and people who were just saying, like, drugs into bodies. Like, "We need these drugs. Give us these drugs."

SS: Do you remember who was who?

MM: No. It was too long ago. I mean, I think the thing is, like, most of

the people that I worked with on things, whether it was—like, everybody in the Lavender

Hill Mob had that view, right? Everybody that I had worked with, like, in all the

different jobs I had, they had that view. The people at the New York State Division for

Women, Women and AIDS Committee, all those people also thought, like, you needed

access to all these things. I think it was more—and I don't think that necessarily people

disagreed with that. I think it is more like, you know, I'm dying, my friend is dying, my

next-door neighbor's dying. "We need these drugs today." Like, not—

SS: Right. But some people in the Lavender Hill Mob died of AIDS

also, Marty and—

MM: Yeah, Marty.

SS: So, you know, it wasn't just—

MM: No. But I think the thing is, like, I mean, I know how I

conceptualized it. Like, I mean, if you don't have access to go to a doctor, like, you're not

going to get a treatment, you know. If you don't have a place to live you can't access

anything. So, for me, that's why those things were all tied together.

SS: So did you guys also talk about healthcare?

MM: Mm-hmm.

SS: And how did you see that?

MM: I mean, and I was also in Wave 3, and so that was one of our big

things, too, was access to healthcare.

SS: Now, who was in Wave 3 with you?

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MM: There were lots of different people. Marvin Shulman, Richard Elovich, Mark Harrington, I think Ken Fornataro, Ann Otto, David Kirschenbaum, Jim Eigo. I can't remember everybody.

SS: Okay. That's a lot of people, yeah.

MM: So you were asking about—

SS: You were saying Wave 3 had a focus on health insurance or—

MM: Yeah. We had a focus. In Wave 3, we had a focus on access to healthcare, drug treatment, housing, medication. Like, I mean, we came up with our own little list of demands for the City Hall action. Like, I brought my typewriter to the Center and I remember Mark Harrington and I sat there, and I think Richard Elovich and I typed them up on my typewriter.

SS: Do you remember what some of them were?

MM: Yeah, like, the big thing was healthcare is a right, and we had like ten things on a little card of what we thought people should have access to. One was drug treatment, medical treatment, like, everything being affordable, right? Like affordable housing.

SS: Okay, so when you're sharing information about available treatments, what did you guys decide was most ethical in terms of recommending or not recommending treatment?

MM: Well, like, when I was in the Lavender Hill Mob, we didn't recommend anything. We just, like, put together a packet of things that somebody photocopied and put them in the mail. I was on the board of AIDS Treatment Registry, and so, like, that was one of the spinoff nonprofits from ACT UP. So we didn't advocate

for anything there. Like, our whole thing was, like, there's not a place where people can go and get, like, objective information, what is this treatment or what is it to join a clinical trial, like what are my rights, and am I actually getting medication? And so the focus there was on giving people information so they can make their own decisions.

SS: Now, can you explain a little bit what AIDS Treatment Registry was?

MM: Sure.

SS: Because it's very important in the history of AIDS.

MM: So, basically, it formed out of people—a lot of the people were in Wave 3, but it was kind of people from the Issues Committee and Treatment and Data Committee, subcommittee, because that was like a subcommittee at the Issues Committee, and the people from Wave 3 had gotten together and decided that they should have a nonprofit. They couldn't really do all the stuff they wanted to do through ACT UP, and so they rented space in 1989, like the spring or summer, and then basically the idea was to be a place where people could get a directory of HIV/AIDS clinical trials, what clinical trials were available, what exclusion criteria applied, what they were studying, and is there a placebo study, like are you going to get a placebo. So that was like the idea behind it, because there wasn't an easy way for people to get information, and there was also a lot of discrimination in who could get into clinical trials, so that's something that ACT UP had done a lot of work on.

David Kirschenbaum would always be having me be filing these Freedom of Information Act requests with the federal government, and then they would send us, like, boxes of materials on all the trials and the exclusion criteria, and basically women of

childbearing age were excluded from, like, almost every trial. They didn't want to have people who were considered noncompliant, and they made a lot of race- and class-based assumptions about who would be noncompliant, and people just couldn't get into the trials. And since there weren't treatments available, people were desperate. They wanted to be in the trials.

So the first thing we did in AIDS Treatment Registry, before they had started, they had had all these meetings and put together what became *Deciding to Enter*, which was really the first publication of its kind in the U.S., and it was a book and then they also made a pamphlet that went through what is a clinical trial, why would I want to get involved with it or not, what would it entail of me, and what are the risks and benefits. We tried to use simple language, and it got translated into Spanish and Creole as well, so we had versions available.

Then once the organization formed, in addition to that, we put out—I don't remember if it was monthly or quarterly—like a little book of all the clinical trials, the contact information. And then right when the organization kind of fell apart, we were working on information sheets on different opportunistic infections and what the treatments were. So when they kind of fell apart, GMHC took over that piece of it.

SS: Now, how many people would receive—we have to say, for the audience, this is before the Internet.

MM: Right, there was nothing.

SS: You just mailed it in the mail.

MM: Right.

SS: So how many copies would you mail?

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MM: I don't know. Hundreds. They actually had, like—they got people who had to do community service for their various criminal cases. They had registered, so they got all these people who would come and volunteer to stuff envelopes for these things. I don't remember how many they sent out, but it was hundreds.

SS: So this was the only way.

MM: Yes, this was it. There were other places, like Project Inform had places. GMHC had, like, after this, because they folded in 1991, so after that, GMHC started publishing things, but at that time, it was the only place you could get the information unless you wanted to, like, go to every hospital and knock on their door or call them on the phone.

SS: That's amazing. Now, I have a lot of questions about it. About how many clinical trials were there?

MM: I don't remember, but the book was, like, that thick.

SS: Would you say, like, 100 clinical trials?

MM: I can't—I'm not the right person to say that.

SS: How would you get the information?

MM: Well, we got it a bunch of different ways. So in ACT UP, people would go to all these committee meetings, like federal meetings, and take notes or taperecord it, and then someone who had a typing job would transcribe it. Like, Tony Malliaris did a lot of transcribing because he had a secretarial job. So that was one way. Another way was, like, key informants. Like, David Kirschenbaum had a relationship with Margaret Hamburg, who now is the FDA commissioner. So they would actually

talk on the phone, and she would tell him what to ask for in his Freedom of Information Law requests.

SS: She was then the Commissioner of Health?

MM: No, she was then a lower-level person at the FDA, and she would tell him what to ask for, and so then I'd have to write a Freedom of Information request.

But then after that, people got the information directly.

SS: So the reason you would do a Freedom of Information request was because these clinical trials were run by the government.

MM: Right.

SS: So the government was the culprit in terms of excluding people.

MM: Well, yes and no. I mean, I think part of it is—I think it goes back to, like, all the abuses in clinical trials, and so in the U.S. there was quite a history of abuse of prisoners, people of color, in clinical trials, not telling them that they were in clinical trials, not giving them a choice, especially with prisoners. So it's partly the federal government not, is being restrictive, but it also has to do with people trying to obey the rules, I think.

SS: So how would the exclusions be stated? Like, would they have an income barrier?

MM: No. Like, the exclusions would be like no women of childbearing age, I mean, part of it is, like, you have to be able to get to the study site. You can't be taking other medications. They may not offer transportation assistance, and so that already is excluding people who can't get to the place.

SS: Oh, I see.

MM: In terms of, like, showing up so many times to get your bloodwork done, like, you have to be pretty organized and have the means to get to the clinical trial place to do that.

SS: Now, I just want to ask you about the placebo question. So this was highly, highly controversial. How did you come to your position on placebo?

MM: Well, the issue that I was dealing with was not so much placebo as death as an endpoint. So a lot of the studies were set up so that they would be comparing—like, the AZT studies and ones, like, after that were set up to be comparing people getting the drug and people in the placebo group, say, and we're going to see how many of them die, and so death was considered the endpoint of the study. It wasn't, like, do you get better. Like, if you read the blurbs that they have, right, like, in a magazine, it'll say, like, these many people treated with this antidepressant. Like, so such-and-such person of the people getting it, their depression symptoms went away, like, during a twelve-week trial. That wasn't what they were looking at. They were looking at, like, okay, in the "got the medication" column, this number of people died, and the "we didn't give them anything" column, the same amount died, so we can't say it worked.

SS: Oh, wow.

MM: So, like, in terms of whether they should have—I mean, they didn't have any other treatments, right, so there's nothing else to compare it to except for nothing. Later, I think it makes sense to do studies where you're comparing a proven treatment to a new treatment, right, so that you have arms of the study comparing Drug A to Drug B to Drug C or some combination. But at the time that I joined ACT UP, like, there were no approved treatments.

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SS: Wasn't AZT the first?

MM: AZT was the first one, yeah.

SS: Now, can you just explain—I mean, it's confusing for people now, I think, to understand why the government was constantly testing AZT and not anything else when the patent was owned by a private company.

MM: I think that the issue with AZT is complicated because it got benched as an anti-cancer drug, because they thought it was too toxic, right, but I think it was, like, a much higher dose that they were trying it for cancer. So they gave the patent to a company, and I think that's what people have a hard time with. Then the company started charging an outrageous amount of money.

## SS: Burroughs Wellcome.

MM: Right. I think, like, that's similar to what's going on now with the Hepatitis C medication. Like, nobody gave them the drugs, but, like, the pricing is so outrageous. I think with AZT, I think the difficulty is, like, that was it. There was nothing else that was approved. They could charge whatever they wanted. I don't know if I'm answering that.

SS: Well, do you think AZT should have been approved?

MM: I think so.

SS: Ultimately, what was its benefit?

MM: I mean, I think that AZT—I mean, it's still in some of the cocktails. I mean, I think part of the problem is, like, they didn't know what dose to give it at. People who were getting it were very sick, you know. Like, now when they're—like, what they say now is when you should start treatment. Like, nobody was starting

treatment then, because they didn't know that they even had HIV. And they're advising people to start—like, so that's the thing. Like, I don't think you can compare it, like, to, let's say, protease inhibitors. Like, they work totally differently. And also they're telling people to start treatment, like, way early. I mean I know someone who was on AZT who had, like, two T cells. Like, that's not a good recipe for success.

I mean, I think the thing is before there was AZT, basically people just got all these opportunistic infections which killed them. So, that was an issue, I think, there was conflict over is, like—because when I was in WAVE 3, one of the things we were pushing is more opportunistic infection treatments, right? I mean, I don't think anybody was anticipating that drugs would get approved, antiretroviral drugs would get approved and kind of diminish the need for, like, treatments for every obscure opportunistic infection that people just didn't get before HIV.

### SS: Like KS.

MM: Right. Well, even, because people got things that were so rare, they didn't even know what they were, you know. They didn't have tests for them, or they weren't—like, I had a friend who died of cryptococcal pneumonia, and that's, like, a very unusual presentation of cryptococcosis. Like, so not only was there a not an adequate treatment for him, but also the way he was sick was not the typical way people get sick from that.

SS: Let me ask you this, did people in ACT UP ask you questions about treatments for themselves?

MM: I don't think so. I mean, I think that they would go to, like, the PWA Health Group or they would go to one of the doctors, like, that had a lot of patients with AIDS.

SS: So you were not in any kind of an evaluative position?

MM: No, no.

SS: And did anyone ever come to you guys for help in breaking down an exclusion?

MM: Yeah, definitely. I mean, people did. Like, I worked at Lambda Legal Defense, and people came to us for that there. I mean, one of the issues that people asked for help with—and it wasn't like they wouldn't come to me, right? They'd go to somebody else and then I would work on it. So one of the issues had to do with—there is all these narrow restrictions on who could get medications, right? So, like, for PCP prophylaxis, one of the issues I worked on at Lambda had to do with whether if you had already failed at Bactrim or Dapsone, which are sulfa drugs, like, what other choices did you have for PCP prophylaxis, and the FDA had very tight criteria. So, like, some things you could get on compassionate use, other things you couldn't, or the class of people who could get these things was, like, very small. So that was one of the things, like, that I worked on was accessing those things.

SS: Compassionate use, was that already in place as a concept?

MM: Yeah. And treatment IND was another way.

SS: What is that?

MM: That was something that ACT UP pushed for. It's Investigational New Drug, but that you should be able to get it as a treatment.

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SS: So I want to understand how you understand the obstruction. So

the government has all of these obstructions that are keeping people from getting

the medications that they need.

MM: Right.

SS: And those obstructions are based on fear of being sued or is it

indifference? What is the problem?

MM: I think it's complicated. I mean, I think with AIDS and HIV, there's

so much, like, racism and anti-gay sentiment, you know, hatred of people who shoot

drugs. Like, all of that was—poverty, you know. All of those things were on top of, like,

the normal drug-approval issues. And so the first thing is, like, can people even get a

doctor to treat them or a clinic that will, like, take them in, or are they going to be, like,

told they can't come here.

You know, in terms of the drug-approval process, one of the issues that

really upset people was it took so long for things to move through the pipeline, and I

think that part of that is that the science wasn't there, you know, looking back. Like, at

the time I didn't think that, but looking back, I don't think that they had a good

conceptualization of how viruses that are that complicated work. I mean, now they do,

but they didn't have that in the mid-1980s. And so to figure out chemicals that are going

to block such a complicated virus, they just didn't have the science.

SS: Now, did you interact directly with government people?

MM: Yeah, I did.

SS: Can you tell us some of those experiences?

MM: Yeah. So I did that Women and AIDS stuff, the New York City Division for Women, and then I was on that Obstetrical Initiative Committee, and those were, like, me going to the meeting like anybody else went. I was involved with the Food and Drug Administration demonstration, and so I was one of the people that met with the FDA to, like, lay out our demands, and we met with the commissioner.

SS: Okay. Tell the story, because I really want to hear what that was like. Who were you with from ACT UP?

MM: I'm not going to remember everybody—

SS: Just a couple.

MM: —but I know Mark Harrington, David Barr, Ortez Alderson might have been there. I can't remember all the people. But this was, like, part of the—so part of the FDA action, we had the ACT NOW, the AIDS Coalition to Network, Organize, and Win, which was like the national umbrella group for that action. So part of what we did was we had set up a meeting with the Food and Drug Administration to present our list of demands to the commissioner, and this was, like, maybe the day or a day or two before the meeting. I can't remember.

### SS: This was Frank Young?

MM: Yeah, Frank Young, yeah. So we met with him and, like, a couple of other people in their big conference room, and we just laid out our demands.

### SS: What was he like?

MM: He was very cordial. I met with them before, around that same time, because that summer I had worked for Lambda Legal Defense and we had sued them to get access to a drug for PCP, and so they agreed to settle. We didn't have to file the

lawsuit because they agreed that they would give more access to the medication that we wanted.

## SS: So how do you think they saw ACT UP?

MM: I mean, I didn't work as—like, I didn't meet with them as much as other people did. I think there certainly were people there that were very much in favor of what ACT UP was doing, but, like, I don't know what percentage of them that was. I worked with—I did a lot of stuff with New York State. Like, that was something where it was like 100%, just activism, going to the meetings, having demonstrations. That was a totally different issue.

SS: Well, let's save that. I just want to focus on the FDA for a little bit. So before, you were saying that in addition to bureaucratic problems, there were science problems and then there was prejudice and indifference.

MM: Right.

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#### SS: What was the combination at the FDA?

MM: I don't know, because I didn't work directly with them or, like, meet with them enough. I think that the overwhelming prejudices that were active at that time, like, in society, kept people from seeing this as a crisis, because nobody cared, right? So I think that that's, like, the big issue. So it's not just the FDA. It's the NIH. It's, like, the whole government funding structure. And I guess the only way I can explain this is, like, I don't know. Like, there was a *Frontline* episode or something that was, like, the *Anniversary of AIDS*, and it was quite a few years ago, and I started watching it. And I got so angry, because all the people in it were lying and saying, like, how concerned they were, because they were interviewing them in, like, the early 2000s about stuff they did

in, like, the late eighties, and these were all people that had said terrible things, like, not done anything, like, and they were all giving these speeches in the documentaries, and I had to turn it off. So I can't give you—

SS: Because they're not interviewing you; they're interviewing them.

I mean, they're not asking—

MM: Well, they did actually have footage, like, from demonstrations.

But, no, they didn't have contemporaneous interviews where they had said outrageous things. They were interviewing them after the fact.

SS: So what were the demands that you presented to the FDA?

MM: We basically wanted more access to treatments. We wanted there to be—I don't remember, honestly, the exact demands, but we wanted there to be, like, a way for people to get drugs before they were approved through a mechanism that they would set up, and that the drug-approval process had to move more quickly.

SS: Now, when we interviewed Garance [Franke-Ruta], which was now like seven years ago, I think, she pointed out to us, which has now become, I think, generally known that, in effect, we reduced regulations.

MM: Right.

SS: Do you think that that was part of why we won at the time?

MM: I think so. I mean, I think that the Reagan administration had a big push to, like, reduce regulations. I mean, that was my concern, like, looking back, right? Like, you know, is it that all of the things, like streamlining the drug-approval process, I mean, they had so much trouble with drugs getting approved that are no good, that they didn't do enough studies to see what the long-term consequences of taking them are. I

mean since they, like, just in general, not HIV-related, but there's so many medications that they've had to pull off the market in the past, like, fifteen years, because they either had severe coronary effects that they didn't know about, they didn't study them for long enough. Because a lot of these medications, like I think antidepressants are a good example. Like, the trials are really short, but nobody's taking them for twelve weeks and getting off of them. So, like, it's not reasonable to approve it without requiring the company to do a longer study, because, you know, they don't know what the long-term effects of things are if they only study people taking them for six weeks.

## SS: Now, do you think this is partially our fault?

MM: I wouldn't say it's our fault. I would say that, you know, we may have been used to get this stuff through. But the thing is, like, it's not like that many people were sympathetic to people with AIDS to want to give them anything.

SS: But do you think that there were corporate people who were sitting there saying, "We want this to happen because we want lower regs, so let's go along with this"?

MM: I don't think that there was—I mean, like, I wasn't in ACT UP, like, by the point that anyone was ever dealing with drug companies on that level. So I think now I think they have their own lobbyists that are pushing for deregulation.

SS: Okay. So now let's go to New York State. So how did that contrast with the Feds?

MM: I think, well, the stuff with the Feds, like, that was a bigger issue.

Like, there's tons of organizations working on the stuff with the Feds. With New York

State, like, I mean, the one thing I worked on that was quite effective for a while had to

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do with regulation of the sex industry. So they have a state committee that's called the Rules Committee, and they met once a month at, like, Friday morning at eight-thirty, I think, and it's the same committee that does the codes and rules for, like, nursing home regulations and which hospitals they should recommend to be closed. So that same committee had the authority to make rules that could affect, like, bathhouses, anyplace where there was sexual activity going on, which activities would be prohibited, did you have to have a door that shut or not. So we had found out that they were putting this other agenda, and so—

## SS: They were putting what on their agenda?

MM: They're putting on their—because what happened is at the beginning of the AIDS epidemic, they had put oral sex and anal sex on the list of activities that couldn't go on in these locations.

### SS: Into commercial -

MM: Right. But vaginal sex wasn't on the list. {LAUGHS} So someone had brought up that they should put it on the list, too, and so we went, like, for, I think like a whole year every time they had a meeting. And some of the times, like, a bunch of us just went and sat in the meeting, right? And that made them nervous enough, they never put it on the agenda. Other times, we thought they might actually discuss it and vote on it, and so we had, like, a demonstration outside with flyers. There was one time where we—

## SS: Well, what was ACT UP's—what did you want?

MM: Them not to make the regulation more restrictive. Like, we were never going to get them to overturn the ones they already put in place, but to get them not

to put any more restrictions in place.

There was one time I went, and I don't even think they were—because

they usually were talking about nursing homes, but I remember Marty Robinson and Bill

Bahlman got really mad, and they went and pulled the microphone away from the table

and, like, started talking and totally made the meeting disintegrate. But for that whole

time, nobody changed the regulations. I felt like that was actually fairly effective.

SS: Now, in that story you just told there are some really interesting

dynamics. Okay. So first of all, there are these men, one of whom is dying, Marty,

going to bat for women.

MM: Right.

SS: And that happened all the time in ACT UP.

MM: All the time. And, I mean, especially like the people in Lavender

Hill Mob, they were always talking about women and children. I mean, a lot of the stuff

like Iris Long did had to do with children and the lack of access to treatment for children,

and getting them to be able to get IVIG, which was, like, the only thing they had to boost

your immune system.

SS: And then the other thing that comes out of that story is ACT UP

taking this kind of pro-sex position.

MM: Right.

SS: And I think that that was never questioned, actually.

MM: At that time it was never questioned, no.

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SS: Right. That's really interesting.

MM: We also had, like, at that same time, that was around the same time

that ACT UP had all those ties to the Reproductive Rights Movement, like that

demonstration that we went to in Washington.

SS: What was it?

MM: I think it was, like, a NOW March on Washington. It was an

abortion-rights demonstration, so ACT UP had a big contingent. There had been a

Supreme Court decision that restricted abortion rights, and so I had actually written an

article about it that got published in, like, two different newspapers.

SS: Which papers?

MM: It got published in—oh, my gosh. I can't even remember. I think it

was in OutWeek, and then it was also in, like, a little leftist publication, but they edited it

totally differently. And I went to a lot of meetings that other people in ACT UP went to.

Like, there was a whole group of people that met at the Center for Constitutional Rights

around abortion and reproductive-rights issues. I know that I went, and so Joan Gibbs

was involved in that because she worked at the Center for Constitutional Rights, and

David Barr was involved in that. So I did some work when I was at Lambda where we

put together information on reproductive rights.

SS: It's amazing how radical Lambda was at the time.

MM: Well, that changed.

SS: When you compare it to now, my god.

MM: That changed, though, rather quickly.

SS: Wow. Shocking.

MM: And then also, like, the people at the Human Rights Commission, like, we—like, I had written one of these things, I think, with one of the people there, too, maybe Tony Glover, who I knew from college.

SS: I want to get back to pediatrics, because I covered this as a reporter. So how much did ACT UP do for pediatrics?

MM: I think, I mean, there were people in ACT UP that did quite a bit. I mean, I think the work that was done was really, like, ground-level work, like meeting with doctors, meeting—like, I know both Iris Long and David Kirschenbaum did a lot of work where they went to the hospitals and met with people. So David, at one point, had a thing going with Kings County Hospital where he went and met or talked to the doctors there. Iris did a lot with people.

I think the difficulty is, like, people whose kids had AIDS are, like, the most disenfranchised people. So, like, were those parents represented in ACT UP? Not really. But I think that people took it on as an issue that they really felt like these kids just aren't getting—nobody's advocating for them. But the doctors who treated them, and I think the nurses, like, really wanted their patients to get treated decently, and so they were, like, kind of aligned with the people in ACT UP who were working on those issues.

SS: Also there were enormous consent issues for pediatrics, because they were putting infants on placebo, double-blind. I mean, it was ridiculous.

MM: And the thing – yeah. So they worked really hard on those issues, and so some of that was through the Lavender Hill Mob, some of it was through ACT

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UP, and some of it was through, like, AIDS Treatment Registry, like they were wearing different hats doing the same thing.

SS: One of the things that we can't do is interview dead people, so we're always asking living people about dead people. Can you just talk about Marty a little bit, like how he handled his illness and how that progressed?

MM: Yeah. Like, I kind of—like, we weren't spending a lot of time together when he was sick, and so I'm not the best person to talk about that. I went to see Marty in the hospital.

# SS: What hospital was he in?

MM: He was in Beth Israel, but that was, like, the first time he was in the hospital. He was totally in denial. He said, like, "I have regular pneumonia, so it's not AIDS!"

And I just was like, "Oh, my god." Like, he was on, like, a regular ward, right? Because they had that Center of Excellence or whatever they called it, like, the special AIDS floor where they had extra staffing and everything, and he wasn't on that. He was just on, like, a regular ward with the oxygen tube they give you if you're having trouble breathing. My impression—and this is, like, second- or third-hand—is that there were different ways to go with your HIV treatment, and he picked the one where you're taking interferon, which turned out in the long run to be not the one to take, but, you know, who knew, right?

# SS: Right.

MM: Like, other people took the road that was AZT, and maybe they lived or they didn't, but the interferon way just didn't work, and so that he had chosen, and he

had been—there were doctors that were AIDS specialists, and he went to a doctor who tried that route. So I think for him, like, he was working on all these issues, but when push came to shove, it's really hard to acknowledge, like, "This is what I have." Like, "This is why I'm sick." Then I know it affected his brain. Like, he just—I mean, he was never, like, the most focused person, but he just was completely demented. Like, I ran into him on the subway once, because we lived in the same neighborhood, and he was just talking about stuff, like, that he was clearly, like, demented at that moment.

But people would come in and out of dementia with the HIV-related dementia. I know David Kirschenbaum was very involved with taking care of him, because I actually—we had breakfast in, like, the end of December, beginning of January, and he was telling me about it, like, how he had died and how he was at home with, like, a morphine drip.

SS: What did you do with really crazy treatments, like Compound Q?

Did you just put them in the packet like everything else?

MM: I think we did when I was in the Lavender Hill Mob. I think—the thing is, like, everything had someone pushing it, right? Like, and I think that the problem that—like, my personal feeling about it was, if you just take that stuff, we don't know if it works, and if there is actually something you could take that could help you—because I remember the PWA Health Group was selling AL721, and, like, one of my friends in ACT UP had already taken AZT and, like, couldn't take it anymore because of the side effects, and so we all chipped in money to buy him dextran sulfate, which, like, wound up never being approved, right? It didn't work. But we thought it did, because it worked in a test tube.

SS: Do you remember how much it cost?

MM: I don't remember, because you had to order it from Japan, and so we each had contributed, like, a bunch of money. I know it was like hundreds of dollars to get it, but it didn't' work.

SS: People spent their life savings chasing drugs that were pointless or even detrimental.

MM: But, honestly, I totally understand. Like, what are you going do? If you're dying and your friends are dying, and everybody you know is sick you're going to chase that thing. I mean, I think the difficulty, too, is, like, people were taking so many different things. Like, there's no way to tell which thing was helping them or not, because people had something they got from the doctor, something they picked up at the health food store, the stuff that they got, like, from their friend just so many different things they're taking, like.

SS: Well, a lot of these drugs, especially the high-priced, pricey ones were recycled cancer drugs.

MM: Yeah.

SS: Do you think that it was just like a patent that was exploiting the moment or-

MM: I think the difficulty is that, like, they had no idea how many people would use this drug, like how big is the market, and if you have something that's, like, an orphan drug, nobody makes it. You can't get it. Like, there was a drug that I wanted my doctors to prescribe for a condition that I have, and it's, like, it cost them nothing to make it, right? But all of a sudden, it's categorized as an orphan drug, and so even with

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insurance, it'd be like \$600 a month. So that's the thing. That's the other side of this, right? There's a side of it where they give the patent to a company that then exploits it, but on the other hand, they did spend all that money on the trials that would have never happened had nobody been given the patent. Then on the other side, you have the ones where nobody wants the drugs because they're not going to make enough money, and they could produce them for cheap if they did, but, like, they don't.

SS: Well, when it's a failed cancer drug, all the development money was already spent.

MM: No, but they haven't done the trials. Like, the thing is with AZT, they had to start all over again with the human trials, right? So they have to do the study to see—like, first of all, they do the safety studies give it to a bunch of people, and is it safe to give to people. Okay. Then they had to do the dosing and then they had to do the efficacy studies. So all of those had to be done with people with HIV, because just because they gave it to somebody with cancer, like in the sixties, it doesn't matter. Like, that doesn't—it's a totally different population.

SS: Did you have friends who were in clinical trials? Like, did you have a sense of what that experience was like?

MM: Yeah. My friend John Bowne was in the AZT trial. I mean, like, I knew people who were in clinical trials, and then, like, but people didn't always talk about it.

### SS: It was kind of a secret experience.

MM: The thing is, yeah. I mean, I think that the issue is, like, a lot of these trials were placebo trials, so people didn't know if they were getting the medication,

and there were people that went and broke the pills up and had them tested. I know there was someone I talked to who had done that. They had the money and they went to have the stuff tested at a lab to see what they were getting. So, like, I mean, I knew people in trials at the time, but there were plenty of people who wanted to get in trials and couldn't.

SS: Well, there was that also. There was like being in it and then wanting to get in it were these oppositional positions.

MM: Right.

SS: Do you know people who are alive today who were in those trials?

MM: No.

SS: Me neither. Those trials didn't really save anyone's life, did they?

MM: Well, I think the thing is, like, you know, a lot of these trials you had to be sick to get into them, right? If they're testing a drug for AIDS, you had to have an AIDS diagnosis, and the likelihood of somebody surviving that had full-blown AIDS before there were medications is pretty slim. I mean, there are people who have survived, but they just managed to get the drugs, like, at the right moment.

SS: And now, what is the relationship between the development of protease inhibitors and all of this early-stage failed-drug stuff?

MM: I wasn't doing ACT UP anymore. I had moved out of New York
City when the protease inhibitors got approved. But what I can say is that—so one of the
issues is looking for the access point on where do you interrupt the process of the virus
taking hold in the body and then replicating, right? So initially, people tried—they knew
that it was using reverse transcriptase, right? Because it's a retrovirus. So they were,
like, "Okay. AZT's a reverse transcriptase inhibitor." Like, that will keep it from doing,

like, step number one, right, of getting into the body. So a lot of those drugs, like, ddI, ddC, a whole bunch of other ones, those are all reverse transcriptase inhibitors, so it's using the same theory of how do we keep this virus from getting into the body. But I think that they learned more about how the virus worked, and so then they tried to figure out other places to interfere with the process, right? So, like, each little step that goes on in the virus, like, either replicating or invading cells or tricking your body into thinking it's your own, you know, cells, not—the way in which it hides in cells is something they're looking at now, and so I think the science had to catch up.

SS: But was that science done separately from these trials?

MM: Yes.

SS: Okay. So that's basic epidemiologic process.

MM: So that science is, like, the science stuff that they would do, like, at the NIH, for instance, like, Anthony Fauci's research, the people that worked for him. There are drug companies that do that work, but the issue is, like, how—it's like so when they first were trying to explain, like, how HIV worked, I know there was a lot of criticism because, like, they said it was like a Pac-Man, like the videogame, like it would be eating all your T cells, right? Like here's a little Pac-Man, like, eating all the T cells, just like in a videogame, and that's not really what it does, but that's how it was being explained to people. So I don't think the science was there, right? Like, but also it's not that easy to find agents that are going to, like, interfere with all these steps, like—

SS: So basically the concept that if you go into a clinical trial, you may be making a sacrifice, but it's a sacrifice that will help people in the future, it really didn't work that way, ultimately.

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MM: Well, I think it did in some ways, because, like, all these drugs had to go through clinical trials to get approved, and if nobody wanted to be in the trials, like, we wouldn't have—like, for instance the drugs that are used for PCP prophylaxis, none of them were approved for PCP prophylaxis at the time. They were on the market for other uses. And so they had to do trials to get them approved for that application.

SS: I see.

MM: So the thing is, like, you know, aerosolized pentamidine, right?

They were doing that at the Community Health Project for PCP prophylaxis, but it wasn't approved for that use. So let's say that you lived in, like, Upstate New York or, like, in a place that didn't have a major research center. You're never going to get that medication. You know, people in New York who were going to, like, the few doctors who specialize in AIDS treatment were getting Bactrim as PCP prophylaxis. But if you lived somewhere else, your doctor didn't know about that. It's not written up in the medical journals. You'd have to go to an AIDS-specific conference to learn that information, and most people, if they have a doctor, they have, like, a family doctor or an internal medicine doctor to go to, you know. Like, there's not, you know in small—outside of, like, major, big cities with major research universities, there aren't really tons of practices that would have this information, like, "Oh, I read in the back of, like, the PWA Health Group magazine that they're having this treatment." Well, how many doctors are reading that?

SS: So ATR in a way was sort of a protest against the exclusion—

MM: Right.

SS: —from the mainstream medical literature.

MM: I mean, and it was also a way to—our idea was people would become informed consumers, right? Because, like, you don't—like, what if you're misled into joining a trial? Like, you have to be given the ability to weigh the risks and benefits for you. Or what if you really want to be in a trial because this drug you think might help you is the only way to get it is to be in a trial? Like, at least we can give the people the list and they call up and see if they'll take them.

SS: It's so interesting, because you can sort of see how that's morphed into all these TV ads aimed at patients to go to their doctors and ask for drugs.

So now that we're seeing that with protease inhibitors that they—I mean, with the current standard of care now, we're seeing that women become undetectable. It's much more difficult for women to become undetectable on the very same meds than it is for men. Doesn't that indicate that women are still not being studied in the developmental ways?

MM: Yeah. I don't know anything about that. I feel—I mean, what can say is I think that a lot of medication is not adequately tested in women. They make a lot of assumptions based on studies of men. Like, heart attacks are a good example, right? I mean, that's totally different. But, like, how do heart attacks present in women? They present completely differently. I mean, I think one of the other issues is, like, medicine in general doesn't adequately look at hormones and their effect on medications, and so especially because with HIV you're talking about women of reproductive age, so so you're talking about teenagers who have, like, a huge burst of hormones, like, both male and female teenagers, right? You have people getting pregnant on birth control pills, like, going through menopause, like, all of those things completely affecting how

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women's bodies work. I mean, and then there's people who are transgender who are taking hormones or hormone blockers. Like, they're not studying that. They don't know how it affects medication. So I think that that's the big issue, right, is, like, overall medicine, how is it that—because women's health is different.

SS: I just want to ask you some questions about the social experience of being in ACT UP.

MM: Sure.

SS: Okay. So there you were totally surrounded by all these queer people and all these sick people and spending a huge amount of time with people. I mean, it sounds like you were in ACT UP, like, your whole life you were in—I mean, you spent a lot of your time in ACT UP.

MM: I did. And then everything else I did, like—because I was in ACT UP from, like, July of '87 to March of '91, and so everything I did was, like, ACT UP or, like, my friends who were also in ACT UP.

SS: So I'm going to start with the illness. Looking back, like, how do you think that affected you?

MM: I mean, I think it had a tremendous effect on me. Like, at the time, I didn't—I mean, I was so young. I was twenty-two when I joined ACT UP, and it didn't really hit me until, like, much later, like, what the huge effect was of—I mean, I guess the thing is people I know who haven't gone through that they have their friend from high school and they call them up, or their friend they had in college, like, they don't assume, like, "Oh, my friend's dead," like, "Oh, yeah, they died." And so to me, that's a huge

impact. Like, all these people who I was good friends with or I used to, like, bounce ideas off of, they're dead.

But also I think, like, kind of my assumptions of how life will go are totally different, and I guess also—I don't know. It's really hard to explain. I was thinking about this. When your movie came out and then *How to Survive a Plague* came out—my sister's a year younger than me, and so she's going to be—she's forty-seven. So we were talking to—right before our kids started college, because my nephew is nineteen and my oldest daughter's nineteen, so they were eighteen, and so we're talking to them and trying to explain to them, like, what it was like before there were medications, and they just couldn't get it. Like, we tried—because they had—like, I think one of them—like, my daughter had watched part of one of the movies, and, like but my nephew just couldn't understand it, and we tried, like, every different way to explain it. Like, I said, well, I didn't go to my sister's graduation from college because one of my best friends died the day before, who was twenty-three. My sister's kid is named, like, for her husband's uncle who was dying of AIDS when they got married and couldn't come to the wedding. One of my mom's best friend's ex-husbands died. Someone else who's, like, a relative by marriage father died. But, like, we said all these things to them, and they just couldn't get it. Like, it was just too, too huge and so the only way I could actually think of to, like, try to explain it to them was there's that scene at the end of Longtime Companion, which, like, I thought was so tacky when it came out, where the guy's on the beach, and then all the dead people he knows, like, are on the beach. Like, at the time I thought it was tacky, but that was actually the only way to explain it to them, like, where they could even comprehend, like, what it would be like to have, like, everybody you know die. I mean, and I'm a little younger than people who've had all their friends die, but every single job I worked at, at least one person died, and that's not ACT UP. That's, like, working at the Legal Aid Society, like, you know, where it's just like a random bunch of people.

SS: But also, I mean, there were plenty of straight women in ACT UP, but, I mean, do you ever ask yourself, like, of all the places in the world that you ended up, why did you end up in the middle of queer AIDS land? I mean, why? What was it about you that got you there?

MM: I think it was because, I mean, I was already doing AIDS stuff, and I came out, like, after I was in ACT UP. So I had, like, this weird relationship to people. Because when I joined ACT UP, all these people assumed I was straight, and I was, like, coming out, and so I didn't want to be saying, like, I'm straight, because I was, like, trying to figure that stuff out. But then it was—I think being in a place that's, like, all gay men was also, like, a really strange social environment to be in.

So, yeah, I don't—I mean, like, the way I got into ACT UP was kind of, like, by happenstance because I had a class that met when the Women's Health Group met, but the other people I knew were all working on AIDS stuff, too. Within like a year, like, all my college friends and, like, people from my jobs and stuff.

SS: So how do you feel about where, like, queer culture is now? Are you shocked, surprised, or—

MM: Not really. I mean, I think it's always evolving. I mean, I think the thing that is—I guess, to me, because one of my kids is gay, and so the difference in, like, her life, like, what it's like for her being a gay teenager is totally different. I think—so I

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think that some of the things that have happened are good, because, like, my kid doesn't have to be ostracized everywhere she goes. I mean, she did have an experience. She didn't go to regular high school. She went to an alternative school, and she took one class of regular high school, AP Physics, and, like, because she was there, like, for one class, a kid could, like, shove her up against a locker and yell "dyke" at her, right? But that didn't happen every single day. I mean, she, like—so that I think those societal changes are good. I mean, I certainly didn't think marriage would become, like, the number-one issue.

#### SS: It was kind of unimaginable at the time.

MM: Yeah. I mean, I think it really—yeah. I was very surprised, I mean. But I think, like, my reaction to—like, I had a complicated thing. Like, I didn't want marriage to be the big issue, and I was so upset when they voted *not* to have marriage, and I watched all those speeches of people saying horrible things. But then when it passed, I was like, "Oh, my god!" Like, I was so excited. And I think, you know, but that's like a personal feeling, not like a big political-movement-type thing.

I think the thing is, like, looking back in ACT UP a lot of things that people were having trouble with was social exclusion because of being gay. Like, you couldn't be gay and hold a regular job. You'd get fired. Your family would ostracize you. You know, you would have trouble accessing any kind of service or anything that you wanted. And then when you add AIDS on top of that, there's even more chance of, like, just getting fired or being excluded, like, nobody will treat you in the hospital. So that's the thing that I think having something like marriage actually makes a difference, right?

Like, I mean, like all this crazy business I went through to do secondparent options with my kids and get these new birth certificates issued, like, people don't
have to do that anymore. And that's like—you know, the fact that people can get, like,
Social Security benefits if they're married to someone, they could never get that before. I
mean, I know someone in ACT up who wanted to apply, and Lambda said they wouldn't
take his case because they knew they wouldn't win.

SS: Right.

MM: But, like, those are things that I think, like, they're huge access issues. Like, health insurance is one, where people couldn't get coverage for their partner or their kids because they're legally not their kids or legally not—and so now I think—so some of the access issues, I think, marriage actually addresses, even though I would never have said so back—you know.

SS: Right. Now, is there anything else inside ACT UP that we haven't talked about that you think is important?

MM: I don't think so. Unless—

SS: So when did you leave ACT UP?

JH: Wait. Can I—

SS: Oh, go ahead.

JH: One is you're talking about the tapes, and I was wondering if you showed your kids "Seize Control of the FDA."

MM: I didn't. You know, my kids—like, my older daughter, she watches things with, like, a million electronic devices, and so I think she may have watched them on her own. My younger daughter, she just, like, came in, and I was watching one of the

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movies and I was crying, and I was, like, pointing all these people I knew, and so she was shocked that I knew people in a movie. Like, so they're not, like—it wasn't like—you know, I did actually—actually, I take that back. I did show my younger daughter some clips of things, but I can't remember which ones. But they don't have a big attention span for—

SS: They don't realize that you helped change the world.

MM: No. Well, the thing is, like, so I had actually went through your movie and I found, like, one image where there's—I'm in it for like a second, and so I made a still of it, and then my daughter was like, "Oh, okay. Now I believe you."

JH: I wish I had put you in more.

MM: Because, like, you know—but, like, they did actually—like, my younger daughter's very into media, and so *How to Survive a Plague*—actually, he contacted me because he wanted a picture that I had taken, and so he made it into one of the movie posters. So then I could tell my kid, "Look, I took that picture," and I showed her the movie poster, and she was, like, "Oh, wow. Okay. I believe you." Because kids never, you know—

SS: They don't get it.

MM: No.

SS: But when they do, they'll start bragging about you.

MM: Well, teenagers are hard, right? They don't want to brag about their parents.

JW: I have a quick one. There was an ACT UP Ithaca for a time.

MM: That was before I lived there, yeah.

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JH: Then were you involved with 076?

MM: I was.

SS: Oh, we need to talk about that. What was your involvement

there?

MM: Well, the first thing was I did the Freedom of Information Act request, and then all the huge amounts of paper came into our house, and I worked on, like, a position paper or something on it. I wrote some letters, and I don't remember if I signed them or David Kirschenbaum signed them, because I would always be writing these, like, legalistic letters.

You know, I mean, my big concern then was, like, women as vectors. So women were seen as vectors of transmission to men or to fetuses. Then also, like, nobody cared about these pregnant women getting treated. Like, it's all about giving this treatment that maybe the baby will be born without HIV, without really looking at, like, does this woman need HIV treatment. So that was the part that I worked on with that. I mean, I think the thing is, like, they have actually been really successful in reducing the rate of maternal-fetal transmission, which is huge. And so, like, in that sense, like, maybe I was on the wrong side of the issue, because if it were my kid I would do anything not to have them, you know, be sick.

SS: Right. Except that at that time there was this other factor, which is that the women were then—and they were going to be deprived of future treatment.

MM: Right. And that's, I think, the big thing is, like, at that point women were not getting treated. They were dying more quickly. You know, a lot of—not every

woman with HIV, but a lot of women with HIV already were, like, poor, had little access to healthcare. They were really stigmatized. They didn't have the same social networks that some gay men had been able to form. Like, because ACT UP was really the first, like, Patient Advocacy Movement, was around HIV. Like, there weren't other advocacy movements like that for other diseases until ACT UP and all the different people-with-AIDS groups. There weren't. So, like, there's cancer groups now that model their stuff on what people did with AIDS. But the thing is because of that, I think maybe we were right for what you said, like, women weren't getting treated.

SS: Right. I mean, it's evolved into a different situation.

MM: I mean, I think the thing is now they know that, you know, using AZT during pregnancy is quite effective, but at the time we didn't know that.

SS: Right. And now it's Truvada. So there's other issues.

MM: Right.

SS: But it also gets back to the question of consent that we were talking about earlier, because most of those women just felt guilty that their children were going to be infected.

MM: It's a huge—I mean, that's the thing. And I think the thing is, like, a lot of the way that society was looking at women with HIV was just like, "We've got to nip this thing in the bud, like, make sure they don't pass it on to anybody else," without saying, like, "Oh, this is a person who deserves to get medical treatment on their own." You know, like, if this woman weren't pregnant, would she be able to get medication? Probably not.

SS: No, they wouldn't even be looking at her.

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MM: Right. So, I mean, I think it's a big—you know, I think it was a really hard issue.

SS: And why was it so divisive in ACT UP, looking back?

MM: I think that—well, I didn't work on the part that was divisive. I don't know how, but I didn't. I mean, I think there was—there was a division in the women in ACT UP on what they were working on, and, like, I found that very divisive, and this somehow fell into that.

SS: Can you just characterize it? I mean, everyone we've talked to, we've asked them about this.

MM: I mean, I think the thing is—like, I was thinking about this, because I knew I'd get asked about it. The thing that concerned me was that some of the women in ACT UP would say, like, "Only men have access to this information, and we can't understand it."

And I was, like, "This is really totally untrue, because I go to all these meetings and I have total access." All I have to do is go, and, like, I learn the stuff just as well as the men did. And the people who were complaining like that never went to the meetings and they didn't want to read the stuff. Like, and so—

### SS: So what was it really about?

MM: I think it was about power within the organization. It was about activist tactics more than about, like, what the actual subject matter was. So, like, because I know one of the—like, one of the big actions—like, the big actions that the Women's Caucus put on, like the Cosmo demonstration or like the condom at Shea Stadium, like, those are big, flashy things. I wasn't interested in those at all. Like, I

wanted to do stuff that would actually be directly related to people getting access to treatment or services. So, like, but that's a completely different type of activism, right?

#### SS: Right.

MM: Those are two completely different paths, and, I mean, I don't think—like, I mean, the thing that I found disturbing about it was that the people I was working with on these access-to-treatment issues were all very concerned about women's issues and children. It wasn't just about men getting medication. It wasn't just about gay men. Like, we talked all the time about people who had histories of IV drug use and why they should be included in treatment and trials, and you shouldn't say that people are not going to be compliant just because they have a history of drug use. And so I felt like it wasn't actually accurate, like, the complaints that people were making.

The other thing I think that was, like, an underlying conflict in ACT UP, which in ACT UP New York people didn't really talk about, had to do with people who actually had AIDS and people who didn't, and, like, people were not that open. Like when we had the FDA action, I was on, like, the Metro or the bus or something with all these people from San Francisco, and they were all wearing big things on their head that said "HIV-positive" if they were positive, and, like, in New York, that would not have happened. Like, people would be, like, never saying anything and then they'd be dead. So, like, not everybody, but there were quite a number of people. So, like, the thing is, like, I felt like I didn't have HIV, I didn't have AIDS, like, my opinion on stuff is not—if it's like a life-or-death issue for somebody else, I felt like I should not be the one, like, pushing what I, you know, had to say about it, because it's not the same thing for me.

SS: Okay. So, I mean, I've talked to—we've interviewed 175 people, right?

MM: Right. That's a lot of people.

SS: There's so many different points of view on this. But, I mean, I guess the thing I really want to know is what do you feel about all of that now that's different than what you felt back then? Like, what's your hindsight on it, now that you're more, you've lived longer, you're more psychological as a person, whatever?

MM: I mean, I think it was kind of like high school, you know, disputes. I mean, there was a lot of sexual tension between the women in ACT UP and it played out in a very odd way.

## SS: Oh, that's interesting.

MM: I mean, because there was this whole issue of, like—because at that same time the people were in ACT UP, like, most of them were in their twenties and thirties, and so they were still, like, figuring out their sexual identities, right? That was at the same time that it was, like, considered very taboo to be bisexual, and so there was this whole dispute about, like, authenticity. I mean, nobody said that, but that's what it really was, right? So, you know, like, is that person, like, really a lesbian or not? Like, and then people would say one thing and then do the opposite. So there was this whole thing going on that was, like, a tension between women who I think were primarily attracted to men, but, like, they were saying they were lesbians, and then, like, all the other women that, like, didn't have that going on.

## SS: Very confused.

MM: And, like, I mean I put in a Facebook friend request for one of these people, and they blocked my friend request—

SS: Oh, no!

MM: —and that's the only person that ever rejected a friend request of mine.

SS: Thirty years later?

MM: Uh-huh—

SS: All right.

MM: —which is, like, ridiculous.

SS: It's ridiculous.

MM: I was, like, "Oh, my god." Like, "I'm not—." I don't want to say blocked, but, like, didn't accept my friend request twice. And, like, the thing is, like, that's ridiculous. Like, I'm not going to hold a grudge for twenty-five, thirty years.

SS: Also because the two of you helped save many, many 01:35:00 people's lives by doing your own different things.

MM: But it's just—like, to—

SS: It's amazing.

MM: I was surprised, but then my reaction, like, I was mad.

SS: Yeah, of course.

MM: Like, because nobody else, like, wouldn't be my Facebook friend.

SS: Can I throw out a theory and hear what you have to say about it?

MM: Sure.

SS: I think that when we had no inside power, people were valued for certain kinds of strengths or gifts, but once there started to be some people who had inside power, some of the people who had been quite valued before would never have been accepted on the inside, and so who they were going to be in the story started to change, and I think that that was difficult.

MM: Absolutely. I agree with that. And the thing is, like, that was after I wasn't in ACT UP anymore, but I totally agree with that. I mean, I don't think there should be, like, inside meetings that nobody else knows about, like secret meetings. Like, I was never involved in anything like that. Everything was always aboveboard. I think the thing is, like, when I was in ACT UP I had access to all these things, right? Because I worked at Lambda Legal Defense as an intern. So if I wanted to talk to someone there, I was already, like, in their office. I could just call up the phone, and somebody would talk to me. But I found out, like, after I moved, you know, like, these organizations come to town, right? And they only want to meet with people that they vetted, and these are the gay organizations. This isn't like, some government organization or drug company. No, this is, like, the gay organizations that are supposedly, you know, representing everybody. So, like, that's the thing. Like, it's a deeper issue of access, and I think, you know, the thing is, the stuff I was involved with, we didn't keep anybody from coming to the table, and I would never be a part of anything like that.

SS: In other words, there were two different cultures of treatment activism in ACT UP.

MM: Right.

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SS: One was on more of an elite trajectory and one was coming from a

more healthcare access point of view.

MM: But, see, the thing is, I mean, I left before this big schism. The same

people worked on all of it. That's the thing. Like, because at the time, like, the same

people were working on both access to healthcare and on treatment.

SS: So this happened later.

MM: Yeah.

SS: And what made it change?

MM: I think that they had more access to the people in the government.

Like, there's a change of administration. I think that people's understanding of the

science improved in ACT UP. Like, I didn't belong to Treatment and Data. I went there

sometimes, and, like, sometimes they'd ask me to go and do something, but I didn't—

like, that was a whole different group of people, like, plugging away at things.

SS: I really hope that whoever writes the history of ACT UP will note

that there were, like, two different strains of—

MM: I think—and that, like, I don't—like, all of that happened, like, after

I moved to Ithaca, and so I wasn't even—well, I moved in '94, so it was I moved, like,

right after it happened. So I didn't even know any of it had happened. Like, I remember

somebody called me up once, like, *OutWeek*, before they folded, and I was, like—I didn't

even know what they were talking about, like, this split, because I wasn't there.

SS: So when you left ACT UP, what was going on? What were the

last things that you worked on?

MM: I don't even remember. At the time, like, I had just started handling felonies in my job as a criminal defense attorney, and I could not do activism and, like, be on the ATR board and represent all my clients who were facing prison, and so, like, I just stopped going.

SS: Right, so it was just like a personal—

MM: Yeah. It wasn't because of, like, disagreements or anything, because I was still friends with all the same people.

SS: Right. So I only have one more quick—

JH: But—

SS: Oh, go ahead.

JH: Wait. You said you weren't in on Treatment and Data or in Treatment and Data, but you were doing all the same type of stuff.

MM: Well, Treatment and Data—see, this is the thing. Treatment and Data started out as a subcommittee of the Issues Committee, and so for a lot of the time I was in ACT UP, there was no Treatment and Data Subcommittee, and then it formed afterwards. But by that point, like, I didn't go—like, I didn't go there that often. I mean, there was a year when I was roommates with David Kirschenbaum, and so we did all the stuff, like, at our house too. Like, we had a photocopy machine and, like, these big boxes of stuff would get delivered.

SS: In your living room?

MM: We didn't even have a living room. It was, like, in his bedroom, the photocopy machine. But so I went there sometimes, but I didn't go to their meetings.

Like, they had their meetings a whole other day of the week.

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JH: So all that work you were doing, it was related to it.

MM: Yeah, but that was before there was a Treatment and Data Subcommittee.

SS: It's pre-T&D.

JH: Yeah. But what did she—well, the subcommittee started pretty early, didn't it?

MM: But they didn't, like—

JW: When did it split off as a separate committee?

MM: I did all that stuff, like, in 1988. Like, that was when the FDA action, that was all done through the Issues Committee and, like, through all the, like, special committees set up for the action and stuff.

SS: Because we interviewed Jim Eigo, like, maybe thirteen years ago, and it's a really interesting interview because he has a whole story about what happened in ACT UP. His story is that early on there was, like, Vito [Russo], there were more right-wing people, Marty, they had this big left-wing analysis. People died, and then people came from Harvard who had this more drugs-into-bodies analysis, and it was, like, death was a factor in the changing politics.

MM: I think that makes sense. I mean, I remember going to ACT UP and, like, Michael Hirsch would be there and Griffin Gold, and Vito would be there, and all these people would be talking about stuff. One of the biggest things I got out of being in ACT UP was, like, ties into people who had been involved with progressive movements in, like, the sixties and seventies, and, yeah, a lot of those people died. But that was one

of the things—like, being in the Lavender Hill Mob was really good for me. Like, I really liked being with those guys and hearing what they had done.

SS: Did you do zaps with them?

MM: Yeah, we did zaps.

SS: Can you just tell us about one?

MM: I mean, we did the ones at the Codes Committee of the New York

State Department of Health. They did a lot of zaps before I was in ACT UP. Like, I saw
them do a zap.

SS: What was it?

MM: They did it at the International AIDS Conference, and so, like,

Marty—

SS: Where?

MM: In Washington. It was the third International AIDS Conference, and I went to that before I was in ACT UP. So they had lab coats on and they were asking questions. But we did one—we got ACT UP to pay for us. Me and Bill Bahlman, they paid for us to go to this right-wing AIDS conference that—

SS: What was it?

MM: I don't remember what it was called, but it was, like, Gary Bauer did a presentation. Like, it was all these super, super right-wing, like, people, the Republican Party. Like, the anti-gay groups, they were all represented there. So we went to this conference and, like, asked questions at, like, every single panel. But it was just, like, the two of us and then, like, everybody else. It was really quite eye-opening. They had—but they called it, like, the National AIDS Conference, and so they had gotten scientists to

give talks. Like, Robert Gallo gave a talk. Then they had Nat Hentoff on a panel, because he had written all those things about women that they liked, I think, about not having abortions. I think that was—

SS: Right. Yeah, that's right. That was his—

MM: So they had him on a panel. I mean, it was, like, frightening, and they had the most frightening handouts that I collected. I don't have them anymore.

SS: It's also so typical of ACT UP that you and Bill would just, like, walk into this thing and just be so bold.

MM: Well, we just went there and, like, raised our hand and said stuff, but that was like—I mean, I think that was as effective as you could get. Like, I don't know how—there wasn't a lot we could do. We also wanted to hear what they had to say. I mean, they were trying to—they had some really concerning things that didn't get out. Like they—I think that they had this idea that they were going to spread the idea that HIV can be transmitted casually, because they had these handouts about Langerhans cells, which are cells that they found HIV in, but they could be on the hand. But they didn't explicitly say anything about it, but I was quite concerned when I saw the little handouts that they had. But, yeah, that was the most bizarre thing.

SS: Of course, the *New York Native* was saying that AIDS was airborne.

MM: Or dolphins or pigs, right?

SS: So I only have one more question. Is there anything else that you think about?

MM: I think you covered everything.

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SS: Okay. So I think you know our final question is—

MM: What?

SS: So, looking back, what do you think was ACT UP's greatest

achievement and what was its biggest disappointment?

MM: I think its greatest achievement was in actually getting people access

to treatments, in getting people to—like, there were other groups that were working on

this as well, to, like, actually think of people with AIDS as people that deserve to be

treated with dignity. I think that, like, many, many other groups were working for that,

but I think the treatments was the biggest thing that ACT UP got.

I think the biggest disappointment, I guess, is that I think that, at least in

the gay community, like, the momentum was kind of lost, right, for progressive activism,

because a lot of people were doing AIDS activism at that point and not so much other

issues affecting the gay community.

SS: Well, thank you so much, and I hope that your children read this,

so they know what you did.

MM: Hopefully.

SS: That was really great.

MM: Oh, thanks.

SS: Thank you so much. That was so important.

MM: Well, thank you so much for having me do it.

SS: Yeah. I just hope that someone in the future pays attention to

these interviews.

MM: People go to the website.