ACT UP
ORAL HISTORY PROJECT

A PROGRAM OF
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Interviewee: **Mark Milano**

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Interviewer: **Sarah Schulman**

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ACT UP Oral History Project
Interview of Mark Milano
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SARAH SCHULMAN: Okay, so if you could start by telling us your name, your age, where we are, and today's date.

MARK MILANO: Okay. I am Mark Milano. I am 51 years old. And we are in Greenwich Village. And you want my address, or –

SS: Well, the famous Thompson Street.

MM: On Thompson Street, yeah, Bob Dylan's old stomping grounds. And today is May 26th, 2007.

SS: Okay. Where were you born?

MM: I was born in Milwaukee, Wisconsin.

SS: And were your parents born in this country?

MM: Yes.

SS: So when did your people come over?

MM: My grandparents – on my father's side, my grandmother came from Sicily; my grandfather from southern Italy. He was 14 years old, and just got on a boat, with no money, and came over. My mother's side came from Prussia, which is now Poland, also in the early part of the century. So half Prussian, half Italian.

SS: And did you grow up with your grandparents around?

MM: Yes. My grandparents didn't die until I was an adult. But being born in the '50s, I was very much a part of the Americanization. So we were pretty much removed from any cultural background. There was very little Italian, very little Polish in our family. It was all about being Americans. I'm very much a Midwestern American boy.

SS: Did they go to church?

MM: Yes, I was a very devout Catholic. I was actually the most devout in my family. I was a Catholic Charismatic, which means I prayed in tongues. And I don't think I got prophecy, but did all that stuff; very, very intense religious experience, until my mid-twenties.

SS: Now what got you into charismatic Catholicism?

MM: I just, kind of going along with my involvement in ACT UP, I've always been kind of an extreme person. Things tend to be black and white for me. And so if I was going to be a Catholic, then obviously Jesus was the most important thing in life, right? I mean, either it was all about Jesus, or it wasn't. And I saw my family that would go to church on Sunday, but forget about it the rest of the week. And I said, it doesn't make sense. It has to be the center of your life.

So in high school, a teacher came back and told us about a charismatic meeting. And I was about 16. And a bunch of us went. And people were praying in tongues and getting baptized in the Holy Spirit, and it was very cool. And I totally bought into it. And really firmly believed that the Holy Spirit was coming back and giving us the gifts of Pentecost, and all that stuff.

And Charismatics, by the way, are different than Pentecostals. Charismatics are kind of like the intellectual Pentecostals. They do all the intense emotional stuff, but then they also are very concerned with theology and analyzing the Church and very smart. So it was good for me, because it was emotional and smart at the same time.

SS: So Jesus came into your life to that extent right around puberty.

MM: Right.

SS: Where was your homosexuality in that relationship?

MM: Very, very strained. I realized I was gay when I was 11, and never had a heterosexual thought in my life. And so of course being so devoutly Catholic and having a personal relationship with Jesus, I remember being on my knees every night, all through my adolescence, praying: Please, Jesus, make me straight. Very devoutly praying. I went to psychiatrists; I got aversion-shock therapy; I tried to date; I did hypnosis. It really was 10 years of hell. Nobody could have done more to try to be straight than me. And then, when I was 24, there was a moment — I remember the moment — I was actually going to a gay bar, because I had begun going out to bars then. And I was in a gas station parking lot, and I stopped. And I said, this can't go on. Because I was going to prayer meetings, and going to gay bars. And I said, I'm going to kill myself, because I cannot take this dichotomy. Either I kill myself, or I got to take a break from the Charismatic thing. And I said, I'm taking a year off from religion. And I'm just going to see how it feels to live without that for a year. And immediately, it was like a thousand-pound weight off my shoulder. And I was happy for the first time in my life. And after that, I could never go back.

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SS: But do you still believe that Jesus was the Son of God and died for your sins and rose again?

MM: No. I'm an ex-Catholic; I'm an ex-Christian; I have a difficult relationship with a belief in God. I believe in God, after that, in a different type of more of a spiritual presence. And then my boyfriend, who is pretty Catholic, a Filipino — they're raised very Catholic; but became ex-Catholic, actually when he was a teenager — through our conversations, he's kind of making me more and more agnostic as time goes

on, so he's having an influence on me. So right now, I'm kind of trying to deal with existentialism, mortality, spirituality, whatever, still searching. But definitely no longer a Christian; definitely no longer a Catholic.

SS: Now how did you get the referral to a psychiatrist?

MM: Went to my dad when I was 17, and I said, I think I'm having homosexual tendencies. And I expected this big scene, right? And there was nothing. And he said, well, okay, what do you want to do? Do you want to see a psychiatrist? And I said, sure. So he found a Catholic psychiatrist.

I saw them — I hadn't done a thing. And they said, well, you haven't done anything; you're just thinking about it, we think it's just a phase. And I said, it's not a phase; I know it's not a phase. And they put me in a group therapy, with some of the most psychotic, neurotic people I have ever met in my life.

SS: Now these were all people who were trying to make a transition from homosexuality –

MM: No. They were complete, one woman hearing voices; I mean they were real extreme – and here I am; the only thing I have is that I'm turned on by men. And these people are seriously mentally ill. And I'm thinking, is this what I am? You know, I'm now as messed up as they are?

I went for the whole summer. This is the summer of my 17th year. And I didn't say a word. I went to 10 sessions of group therapy. I never said a word. On the last session, I said, well, I'm going back to school now; I can't come anymore. I thought I should tell you, you know, why I'm here. And I explained why I was there. And a psychiatrist began jumping on me, saying, why don't you admit that you're scared

shitless you're going to suck some dick, and that's why you're here? And I just, I just freaked out. And it took me awhile to get back into psychiatry after that. But when I was in college, somebody had done a report in the student paper about aversion shock therapy. So I went to the student mental health thing. And they agreed to wire me up, and show me pictures of men, and give me shocks to kind of turn me off.

SS: Was that a Catholic university?

MM: No. That was University of Iowa; it's a state university.

SS: So a state university's mental health department did aversion shock therapy?

MM: Yeah. You know, shock therapy, it's just a little thing on your finger where they just give you a little zap.

SS: Oh, okay.

MM: It's not like serious shock therapy. It's just, you know, they tell you to put a rubber band on your wrist and snap it that kind of stuff. And that was pretty laughable. That was a real waste of time.

So that all went on — those attempts to become straight — until I was 24, when I finally said, I remember 24, watching the gay pride parade in Chicago. At the very end of the parade, people often join in. And I stepped off that curb, and I walked down the street, and I really realized at that moment that there was no going back, that there was, you know, I was a faggot. That was pretty much all there was to it.

SS: So how long did you stay in Chicago?

MM: Well, in April of ’82, I had been getting very, very sick. And I went to the ER, and talked to them. And I said, I’m 26 years old, and I’m sick all the time. You know, what’s wrong?

And the doctor closed the door. And he said, can I ask your sexual preference?

And I said, I’m gay.

And he said, okay, have you heard about something called AIDS?

And I said, no.

And he said, well, it’s an immune disorder that we’re seeing in gay men, young gay men.

And I said, what causes it?

And he said, we don’t know.

And I said, what’s the treatment?

And he said, there is none.

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And I said, well, what do I do?

And he said, we don’t know.

So I said, okay, thank you very much. And I had actually been very ill from a separate immune disorder, that I did not know at the time, called sarcoidosis. And that made me seriously ill with AIDS-like symptoms.

SS: Can you spell that?

MM: Sure. S-A-R-C-O-I-D-O-S-I-S.

SS: Okay.

MM: Autoimmune disorder, kind of like lupus, where your immune system attacks itself. Could have been triggered by my HIV infection, which I trace back to ’81.

So I was very, very sick, lost a lot of weight, and got myself better. So I was convinced I had had AIDS, and I got over it. Because back then, we didn’t know you couldn’t get over AIDS.

So I was fine until ’85, when the sarcoid reappeared. Very seriously, and I was in the hospital.

SS: And you were still in Chicago at that time.

MM: Still in Chicago. And that’s when I got the HIV test. And that came back positive, as I knew it would. You know, I was quite sure of that. And they were trying to figure out what was wrong with me. They hadn’t diagnosed the sarcoid. So when you’re in a hospital in ’85 — by the way, this was the week Rock Hudson died — so I’m in the hospital, I’ve lost 30 pounds of weight. I have a positive HIV test. And I’m watching the news that Rock Hudson has just died. So it was pretty – and there were biohazard stickers on the door, and being treated like a leper, and my family didn’t know, except for my father.

And they were, I said, tell me everything. They said, okay, well, you could have toxoplasmosis; you could have MAC; you could have lymphoma. They were listing all these things. And finally I said, look; don’t tell me until you know what I have, because I can’t take this.

That was the first time in my life that I really faced death. And I was laying in bed one night, and I was thinking about getting my boyfriend at the time to

bring me some cyanide. To say, if I have to kill myself, maybe Scott, who has a lot of drug connections, could get me something to kill myself. And when I thought about killing myself, I realized that I would be – my life, my opinion of my life would be very low. That I had done nothing with my life. I'd been trying to get into film. I was a film editor. I was trying to work as a film director. I was not doing well. And I just felt that my life had been a waste. I really felt my life had been a waste. And I remember crying that night, thinking, I've just wasted my life. And I was only 26.

So I decided, that night, that if I got better, I would leave Chicago. And I would pursue my dream, to work in film. And I wanted to go to New York; my friend wanted to go to L.A. And I agreed to go to L.A. And he backed out at the last minute. So I said, okay, I'm going to New York.

So June 15th of '87, I bought a one-way ticket to New York. I got a room at the YMCA. Came here with five thousand bucks in the bank. And I didn't know a soul. And I just plopped in the YMCA on, what is it, 47th Street? And I was here. I knew nothing about New York. I just knew, I had been here once or twice and loved it. And so I was here.

SS: So what job did you end up doing?

MM: I ended up being a production assistant on films. Which is entry level. Just kind of a gofer. Did that for a while. And then I got back into film editing, which I really wanted to get out of, but that's what I knew. I got a job as an assistant film editor. And that was paying as much as I was earning in Chicago, so that was good. So that's what I was doing for the first couple years I was here, was production work on

films and editing commercials, educational, industrial films. That's what I had been doing in Chicago, too.

SS: And what do you do now, by the way?

MM: Now, I work for ACRIA, which is the AIDS Community Research Initiative of America. And we do clinical research on HIV treatments. And I am an HIV health educator. I go out to people with HIV and nonmedical service providers, and I do workshops on HIV treatment, resistance, how to read lab results, the immune system. And I also am the editor of our quarterly treatment publication that we put out. So I write and speak on HIV.

SS: So in '87, when you came here, what did you do about your HIV?

MM: It's funny, because I've kind of grown up with the epidemic. I mean, from '82 on, I'm watching. And I remember, every year, I would think I was past, right? And every year they would increase the incubation period, right along with me. Every year it would be, three years, four years. And I said, when are you guys going to stop, and let me say I'm over this, right? But I didn't know anything about how to monitor your illness.

So I am part of a study called the Multicenter AIDS Cohort Study, which has been following, it began with 5,000 gay men in '84. And it was good that I joined, because they have frozen blood every six months since then. So I know, I have the confirmed positive HIV test from '84. But I have a low CD4 count from '82. So I'm quite sure it happened in '81.

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And I went back for my semiannual visit in October of that year. And when I went back, my CD4 count had dropped to 180. And I didn't know that that was,

you know, how bad that was, at the time. And this doctor at the MACS said, you need to see somebody good in New York. So he set me up with a doctor here in New York. I waited two months for the appointment, at Sloan Kettering. Went to see him. He was away at a conference.

So his assistant came in. Thumped my chest; thumped my lymph nodes.

I said, what do I do?

And he said, you don't qualify for our AZT trial, so there's nothing you can do.

I said, isn't there anything out there?

He said, no.

I said, thanks.

They sent me a bill for two hundred bucks. For literally five minutes of time. I called him up, and I screamed at the woman on the phone so badly, in the Billing Department, that I never heard from them again.

Those incidents — the thing in '82; the thing in '87; the experience in the hospital — really were changing me from being this very passive, nonpolitical, artistic guy, into somebody who was saying, I have to do for myself. No one's going to do for me, with this illness. I was used to, as a very sexually active gay man, in Chicago, in the '70s, you would go to the city STD clinic three or four times a year; see all the guys that you saw in the bars and bathhouses there. And you would get checked. And once a year, maybe, you would have gonorrhea, syphilis. They would give you a pill or a shot. You would be better. And doctors did that. Doctors saw you, made you better, and you went home. And now, the doctors were saying, you're out of luck; there's nothing.

And so it really made me think, okay, if I'm going to beat this thing, it has to be on my own. I don't get help from anybody else. And that was really the, the whole attitude of ACT UP; that we have to do it ourselves.

So in '87, I began looking for support. And I joined a group that had just been forming, called Body Positive. Michael Hirsch was forming it. And I was one of the first people involved in that group. And I was one of the first support group leaders that were being trained. And first I went to the support group myself; then I became a support group leader. And that's actually how I attended my first ACT UP meeting; is that we were having a planning meeting for Body Positive. And I looked online, and I found the date. Because I know it was September 9th of '87. I was coming from a Body Positive meeting, and I had to walk through the main room at the Center.

And I walked in this room, and it was jam-packed. I mean, it was filled with people. And so I sat along the back wall. And I just said, let's see what this is.

And it was, ACT UP meetings back then were pretty crazy. And people were talking about some action they were doing. And suddenly, a dozen people march into the room, wearing clown masks. And this huge cheer goes up from the room. And it turns into this party. And apparently they had been attending the President's Commission on AIDS, the first meeting. And every time some clown got up, they would get up with the clown masks and do an action. And it was just, it was madness. There were all these people laughing and screaming and telling jokes. And suddenly, in the middle of all this, Bob Rafsky — I'm sure people have talked about one of the most vocal members of ACT UP — stands up, it seems to me, on his chair, but probably not. But just stood up, and said, what the hell are you people doing? People are dying here, and you're laughing,

and you're wasting time! And he began screaming at the room. And I just thought these people are insane. I mean, they're just nuts! You cannot fight AIDS by wearing clown masks and screaming at each other, and just having these chaotic meetings.

And so I left. And I didn't come back for a long time. Because I just thought ACT UP, they were nuts. And I was a quiet, modest Midwestern boy who, did not yell or scream or do those kinds of things. I was just trying to live with this virus, and I thought these people were crazy.

So that was my first ACT UP meeting.

SS: So you stayed at Body Positive.

MM: Yes. Stayed at Body Positive. And then Body Positive had all these problems; factions fighting, breaking off, back and forth. So that was a real mess, too. But I was, yes, I was Body Positive support groups; helping people with HIV. I was also — very important at that time — a member of something called the Healing Circle. And the Healing Circle was like ACT UP in that it met once a week, with 400 people in a room. And you would go, and you would, one of the best things I've ever had in my life — the only alternative therapy that has ever worked for me — is hands-on healing. You would lay down. And three or four people gather around you, and lay hands on you. And the physical and mental and emotional benefits were dramatic. And it was phenomenal.

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SS: And that was led by Samuel Kirschner, right?

MM: Yes, yes.

SS: And what was he like?

MM: He was great. He was great in that you were allowed to find your own belief system; there was nothing pushed on you. And he would just, I think, the ultimate facilitator. He would just allow the group to go where it wanted to go. And he would, you know, let people; one time people came in, and began talking about how they had found immortality. And they meant actual physical immortality, living forever, in this body. And they then went on and on and on and on. And they wouldn't stop. And the way the room stopped them was slowly, this Om began arising from the room, very slowly and quietly. And slowly getting louder and louder and louder, until it got so loud that they had to stop talking. And Samuel just said, I think the room is saying that they've heard what you have to say and they want to move on.

So he was very good at letting, not saying to you, you have to believe in A, B, or C or D; but saying, find your own path, and we're just here to help you find your own path.

SS: And where did they meet?

MM: They met at a, I think an abandoned school on 17th Street.

SS: Okay. So what made you come back to ACT UP?

MM: I went back to the MACS, and my CD4 count had dropped to 120, the next year. And I was clearly progressing, I was clearly advancing. And I needed to know what to do.

So I said, well, I'm going to find out where the clinical trials of the treatments are. And I called up GMHC, a hotline. And I said, can you tell me where do I enroll in clinical trials for AIDS treatments? And they said, we don't know.

So I went, and I, someone told me about the AmFAR directory. And I got the AmFAR directory. And I'm a college-educated, pretty smart guy, was going to go into the sciences. I pick up that directory, and it was written for clinical investigators. I don't know if you saw the early ones, but you could not make heads or tails.

SS: And you had no private physician at this time.

MM: No.

SS: Okay.

MM: No, at the time I didn't, no. So I was literally in tears. I'm looking through, and here's this whole book of clinical research. And I can't make heads or tails of it. It's jargon, it's gobbledygook to me. And I'm like, my god, how am I ever going to figure this out? Because there's no way to learn this stuff. And some people told me, get a doctor, and you find out about trials through your doctor, and I didn't have a doctor. And I didn't know what to do. So I began to, and somebody in Body Positive told me that they heard that somebody in ACT UP was working on making a clinical trials directory for New York State. They were doing their own. And his name was Michael Cowing — not Michael Callen, but Michael Cowing.

SS: How do you spell it?

MM: C-O-W-I-N-G.

SS: Don't know him.

MM: I actually just ran into him, a few weeks ago. At the 20th anniversary, he was there. So I went to another ACT UP meeting. And I asked around for Michael Cowing. At the end of the meeting, I went over, and I said, I hear you're working on a directory. Can I help?

And he said, great, come on and join us for a meeting at someone's apartment Tuesday night.

So I went that week, some night. And there were, like, 20 ACT UP members there. And they had clinical trial protocols.

Have you ever seen a clinical trial protocol?

SS: No, actually.

MM: It's about like this thick. And it's pages and pages of detailed information. And they were going through, and they were reading through these, and trying to figure out, they had a form; is it double blind? Is there a placebo? How long is it? To try to pull out the important information.

They said what they had done is, they had sent letters to the boards of all the hospitals in New York State, saying, please tell us what trials you're doing. And the hospitals all wrote back saying, for legal reasons, we can't speak to you.

So they got nowhere.

So I worked with this one woman in the group. And the two of us said, okay, we're going to figure this out.

SS: What was her name?

MM: I don't remember her name. And I said, we said, we're going to figure this out. And we split the hospitals in half. And we said, look, we're just going to call the hospitals, each hospital. We're going to ask for the ID clinic. We're going to ask for a nurse. And we're going to say, are you doing any AIDS clinical trials?

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And I began doing that. And the nurses all said, oh, yeah; and gave us all the information we wanted. The nurses were fantastic, you know. The hospital administrators, and the men, forget about it. But the nurses, they were great.

So we began compiling this list of the trials that were going on. Because Bob Huff, who works at GMHC; we had come up with a better format than the AmFAR directory. And he wanted to just pull the information from the AmFAR directory, and put it out in our new format. And Michael Cowing and the rest of us said, no no no; we want it to be our own thing. We want to find the information ourselves. So we began this project. And within a few months, we had a lot of information on trials that AmFAR did not have.

So in '89, we finally, after a year of working on this, we published the first directory. And I remember that we brought it to the Montreal AIDS Conference, in '89. And that was the first local AIDS clinical trials directory. And I was quite proud of that.

SS: How many trials were there, at the time?

MM: How many trials were there? In the first one, there were – under a hundred. Between 80 and a hundred.

SS: And what were they studying, for the most part?

MM: AZT, AZT, AZT. It was just all AZT. There were a few other ones. There were some trials of ddC, some trials of ddI. They were trying some other things. They were trying CD4-IgG, they were trying to block CD4 receptors on cells. That failed. They were trying, like acyclovir with AZT. And then of course there were a lot of trials for the opportunistic infections, trials of Bactrim. I remember early trials of fluconazole. I remember when that was being researched.

So there were trials for the OIs; and there were trials for HIV, and then trials for the cancers. And we didn't do vaccine studies. Pretty much it was for people with HIV.

So then, what happened was, at that point, they decided to spin off as a separate organization. Like Housing Works spun off, and that kind of stuff. We spun off as the AIDS Treatment Registry. And we incorporated as a 501(c)(3). And I began work as a volunteer for AIDS Treatment Registry.

SS: And who were the other people in that? I know Iris –

MM: Iris Long, definitely, was our mentor; was the woman who really taught us how to understand these trials; how to make sense of them. What else?

SS: Who else was working on it?

MM: Well, I know one person. And I want to speak badly of him. That's why I'm uncomfortable giving his name. {LAUGHING} Uh – there were two people on, our board was made up of ACT UP members, which was a mistake. Because a board is supposed to be kind of rich people who can raise money for you, right? And our board was all just ACT UP members, who have no money. And two of the people — David Z. Kirschenbaum and another woman whose name I can't remember — they were so contrary. And there's a certain attitude some people have, which is not to say, I'm going to stop what you're doing. But they say, you're going to do it my way, or you're not going to do it. And they would come to board meetings, and they would dig their heels in, and they would make those board meetings so horrendous that eventually, a couple years later, ATR disbanded.

But Michael Cowing was with us as the executive director for the first year. Tony Davis was with us. So I was eventually hired, after volunteering. I eventually was hired, and became editor of the *Clinical Trials Directory.* And so I was the editor; Tony Davis was the managing editor. I actually have a directory here, and we could look at names. It's right there, underneath the iron fireman. Yeah, let me see.

SS: Is David Z. Kirschenbaum the one we interviewed, or –

X: Yeah.

SS: Okay. Okay. I know there were two David Kirschenbaums. Okay.

MM: Yeah. Tony Davis, manag-, BJ Cavnor was one of our assist-, Sally Cooper worked with us.

SS: Oh, Sally Cooper. That's right.

MM: Yeah. She came and worked with us for a while. The Advisory Committee was Iris; Gabriel Torres was on the Advisory Committee. So there's the last directory that we put out.

SS: Right. How many did you put out, ultimately?

MM: You know, we were putting them out, initially we were doing them every other month, six times a year. And then we went to four times a year. And then, I think, to three times a year. So we put out a good chunk. It lasted until the summer of

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'91, is when we folded. So from '89, '90, to '91. And it was the first job I'd had where I really looked forward to going to work, where I really felt good about what I was going.

I mean, when I was working as a film editor, you would work 16-hour days; you would bust your ass, for these people who were the most shallow, vain,

egocentric people in the world. And in the end, you would have a MacDonald's commercial. That's what you had to show for it. And I just thought, what am I doing with my life?

And I finally said, I don't want to – and plus, I said, there's no way I can work 16-hour days and survive with HIV. Not going to happen, you know?

So I decided at that point to leave film and to work for ATR and do work that I thought was worthwhile.

SS: Now given that you really became an informed person about treatment options, what treatments did you choose in '89 and '90?

MM: Ah. So here I am; I am stable at around a CD4 count of 300 now. I've gone back up again to 300. Which is in the safety zone. But you still would rather be above 500. Below 200 is where you're at risk.

And I was stable there. But everybody was saying, that's too low, that's too low, that's too low. Even though I was not really changing. And so I felt this tremendous pressure to do something. So I began talking to people who were involved with alternative therapies, and ACT UP people, like Jonathan Greenberg, and people like George Carter: what do you recommend?

I joined the Treatment and Data Committee of ACT UP, because they were the ones who knew this stuff, and I wanted to know what they knew. And one of the people there was Howard Grossman.

SS: Howard Grossman, the doctor.

MM: The doctor. And I said, well, this is pretty cool. A doctor is in ACT UP. He'd be a great doctor, right? So I went to him.

And I didn't realize that Howard Grossman was actually — and he still is — one of the most conservative HIV doctors there is. I mean, he follows mainstream, mainline thinking. There is nothing off the wall about his approach to HIV at all. That surprised me.

So I went to our first appointment. And we had a long talk, and whatever. And he said, well, basically, you're okay for now, and let's just monitor you, whatever. And then in, I believe it was in '89, when AZT was approved for everybody, not just for those with AIDS; anybody with a CD4 count below 500 was told to go on AZT. And he said to me, I think it's time for you to go on AZT.

And I said, I'm not comfortable with that. I'm concerned about the resistance from monotherapy. I'm concerned about the side effects; I think my CD4 count is stable at 300. I'm not ready to do this drug.

And he said, I really think it's time. And he was pretty pushing.

And I said, well, you know, I will do it, but I'll only do it at 300 milligrams a day, which is the lowest dose that had been found to be effective in clinical trials.

And he said, I won't prescribe it that way.

And I said, well, you can prescribe it at 600 milligrams; and I'll just take 300 milligrams, and lie to you about it. Is that the relationship you want?

And we got into a big fight, and a shouting match, really, about the fact that I would not do what he was recommending; and why was he my doctor if I wasn't going to follow his advice. And I left. And I was once again without a doctor.

SS: I want to ask you a kind of big question. Why are you a long-term survivor?

MM: Hm. This is something that I have talked about for years, and it's very frustrating. Because I think I have stumbled upon the best treatment for HIV there is, and I can't convince anybody else.

SS: And what is it?

MM: I have never been on antiretroviral medications; never taken an anti-HIV drug. When I was in the hospital in '85, and I had lost 30 pounds, and they came to me, finally, after three weeks in the hospital. And they said, look, you have one of two things. You either have MAC or you have sarcoidosis. If you have sarcoid, the treatment is an anti-inflammatory called prednisone. If we give you that, and you have sarcoid, it'll clear it up. If it's the MAC, it will suppress your immune system and it could kill you.

And I said, look, I was told in '82, sarcoid was brought up. I have looked into it. I'm convinced it's a sarcoid. Give me the prednisone.

They gave me a high dose of prednisone. Within an hour, after six months of hell, I was well. I couldn't believe it. I felt fantastic. After six months of not having a sexual thought in my head, I was so horny, you wouldn't believe it. And I called my boyfriend, because I had to have phone sex. And of course, they had just cut off the switchboard, and I couldn't talk to anybody. So it was, I had a raging hard-on, at 10 p.m. at night, in the hospital. And I went on the prednisone, and I got better. And I gained so much weight so quickly. I gained, literally, they were weighing me each day. I gained eight pounds in a day. That's how fast I got better.

Tape I
00:35:00

So within a few months, I was great. But prednisone, if you take it every day — I don't know if you know anything about prednisone every day —

SS: A little bit, yeah.

MM: — ton of side effects, you know. You get fat in your face; you get joint problems; you get swelling; you can get manic. It's got a tremendous number of side effects. So I wanted to get off it. So I worked really hard, after a year, to taper off the prednisone. And I got off it. And that's where my CD4 count began dropping. This was in the late '80s.

So finally, in the early '90s, I realized, I have to go back on the prednisone. Because I'm just really feeling sickish all the time, and it must be the sarcoid. So I went back on the prednisone.

Went back on it for a year. Same side effects all over again. And then, once again, I began doing my own research. And I found something in the medical journals called alternate-day dosing. And it said that the reason prednisone causes all the problems is because prednisone, your body thinks prednisone is cortisol. Your adrenal glands make cortisol. So when your body says, oh my god, there's all this cortisol in the body, what does your body do? It turns off the adrenal glands. So you lose your adrenal function. If you lose your adrenal function, you lose a whole range of important things that the adrenal glands do. If you take prednisone every other day, the adrenal glands are forced to work on the off day, and you don't lose adrenal function.

So I went to my doctor, who at that point was Don Kotler. And Don was much different than Howard. He was out there, ready to try whatever. And I said, look: here's what I want to do. I want to go on an injection called ACTH, which will kick-start

my adrenal glands, for three weeks. Then go off that. Then double my dose of the prednisone, every other day.

And he said, sure, let's try it. And I tried it; it was very tough. I got on alternate-day dosing of prednisone, which I have been on since, like, '92. No side effects. I don't think you see any moon face, or anything like that, right?

SS: Mm hm.

MM: No side effects whatsoever. I have spoken to a number of researchers, like Tony Fauci, and people from the NIH, and people from the Chicago university, where we were at the MACS; and they all say that yes, a lot of people are rethinking AIDS, not as an immune suppressive disease, but as an immune activating disease. HIV chronically activates the immune system; HIV needs an activated immune system in order to reproduce. And so if you could subtly suppress the immune system, you could delay progression. So I have been on prednisone for many years. My CD4 count is now 400. Even though I have a pretty high viral load, I have been stable at 400 for many years. And every time I talk to a researcher, they say, you know what? It makes perfect sense that this would work. But we're scared to try it. So –

SS: Okay. I understand what you're saying. But isn't everybody's HIV infection a different – I mean, isn't the word "HIV" as a catchall not really what it is? Doesn't everyone have a different genetic strain and a different preexisting –

MM: There's been a big debate: it's the host, or it's the virus. And pretty much, what they've found is that when you look at two people who have the same virus — because you have two people who have gotten the virus from the same person — they

can progress in very different ways. One can progress rapidly, one – so they're saying, it's not the virus so much, what strain you have. It's the host. It's the way your body responds to the virus. What they have found is that people who have an incredibly strong, powerful immune response to initial infection actually progress faster than those who have a less robust response at infection.

So this is all debatable. But there is a lot, and I've looked into this; a lot of people out there saying that it is the way the immune system responds to HIV, rather than whatever strain of virus you have, that is the most important. And for my money, if you could kind of chill out the immune system, and calm it down, and not let it be constantly so hyper-activated, that does not allow HIV to do what it wants to do.

So, I mean, I –

SS: So you don't believe in protease inhibitors?

MM: No no. I absolutely believe that they work. I mean, I do lectures on this, and I have clients who have done tremendously well. I just think prednisone is better. And I think –

SS: For you, or in general?

MM: In general. I think if you took people who were early in disease — like a CD4 count above 200 — and you gave them prednisone, that they would progress very slowly. And the simple way to prove this is you take a trial of a few hundred people who are above 200; you give half of them prednisone; you give half of them placebo. You follow them for two or three years. And you see if the people on prednisone progress more slowly than those on placebo. It would not be a major thing.

SS: So in this day and age, you would advocate a –

JAMES WENTZY: Sarah?

SS: I'm sorry.

JW: Maybe we have to –

SS: Oh, okay. Change tapes. I'm going to hold the thought.

Tape II
00:00:00

MM: – on therapy. CD4 count above five, no, right? We know that below 200, you must be on therapy. There's no question of that, right? Between 200 and 500, it's guesswork. You know, there is no data saying when you should start. The government recommends 350; they realize that's a guess, right? It was 500; they lowered it down to 350. So there's this range we don't know, right? But as long as you're above 200, you are, you're not going to get sick with anything serious. So as long as you're above 200 — you could make it even high, you could make it 250, right? — and you give half placebo and half the prednisone. And then, if they do begin progressing, moving to 200, then you put them on the antiretroviral drugs. Then you offer them the standard of care. But until that time, they don't need it. And there are many people out there, by the way, who don't want to go on these drugs, who would say, I want something else.

So yes, you have to make sure that if they do progress, they roll over onto treatment. Absolutely. But until they progress, they can be on just the prednisone or the placebo. So you'd have to design it so that you weren't putting people at serious risk, but you were giving them an option if they did become sick.

SS: Is there anyone else out there who thinks that steroids are the best treatment?

MM: Oh yes. The NIH did a trial of prednisone in people with AIDS. The problem is they gave 40 milligrams a day. Which is an incredibly high dose.

SS: I see.

MM: And because of that, they had all these side effects. I would do 10 or 15 milligrams every other day. I see Tony Fauci at every AIDS conference. And he gets up and talks about the inflammatory problems of HIV. And I always say, when are we doing the prednisone trial? And he goes, you're absolutely right, we should do it. But people are frightened of giving an immunosuppressant drug to people with HIV.

So absolutely, there are many researchers I have spoken to who think this is a valid approach. But I don't know how to make a clinical trial happen. Even though I know all about them. It wouldn't be that hard to do, but I have not been able to get it.

SS: Okay. Let's move on.

MM: Sure.

SS: Okay. So now you're in ACT UP, and now we're getting into the dangerous early '90s, when ACT UP starts to faction off –

MM: Right, right.

SS: – and all this infighting. Now you were one of the very few people who did not leave ACT UP –

MM: Right.

SS: – when it fractured. Why?

MM: I never — the same thing with Body Positive — I never got these people, who were splitting up into factions. Because I knew that those of us who were in the progressive organizations, oftentimes, infighting led to the thing collapsing. While those on the right seemed to march in lockstep. And I said, look, there are a lot of people in ACT UP that I can't stand. And there are a lot of people in ACT UP that can't stand

me. But I am not here to make friends. I am not here to get along with people. I am here to fight AIDS. And even though I can't stand you, I never, I never said, I will not take part in an action with you, I will not work with you. I don't care who you were, or what you did to me; I was still there.

So this idea of, we can't get along and agree on things, and therefore we're splitting up, was bullshit to me. I just said, you work out your problems. You compromise; you figure out a way around it; and you keep fighting, together.

SS: So what did it feel like to watch everyone leave?

MM: It was good and it was bad. I always had a real love/hate relationship with ACT UP. I loved ACT UP because it made me, for the first time in my life, proud to be a gay man. All those years of horrible self-hatred of being gay; then I come out in my mid-twenties; and I enter the gay world. And I look around me, and I say, what is there in this community that I am proud of? Everybody I see is into disco and drugs and *Dynasty* and there was nobody here that I could point to and say, I'm proud to be a part of these people, right?

I come to New York; I get involved in ACT UP. I'm proud to be a part of this group. I came out to everybody. I came out to my mom; to all my aunts and uncles; to all my friends; after I was in ACT UP, because it made me, I was personally proud to be a gay man. But I wasn't proud to be a part of the gay community. Now, in ACT UP, I was. So that was great. And we were doing, we were kicking ass and we're doing great stuff, right? I mean, I was at Storm the NIH. That was the first time, at Storm the NIH, when I got arrested. We locked arms in front of a door of the NIH building. And here I

was, going to jail to fight for what I thought was right. Civil disobedience, Martin Luther King, it was great, right?

At the same time, ACT UP itself was so much like high school. And I'm sure others must have said this. It was very –

SS: Did you have a lot of sex in high school?

MM: No, no!

SS: {LAUGHS}

MM: And I didn't have sex at ACT UP, either.

SS: You didn't?

MM: No, I was not, I was not hooking up at ACT UP. I was hooking up more at the Healing Circle than I was at ACT UP. But ACT UP was very cliquish. And if you weren't in the in-group, you were not in. And I was not in the in-group. Absolutely.

Tape II
00:05:00

First of all –

SS: For the record, who's the in-group?

MM: Mark Harrington, Peter Staley, Garance Franke-Ruta; who else? Other names I forget. But in Treatment and Data, they were clearly the stars. And they dominated the meetings; what they wanted to move forward on the agenda moved forward; when they spoke, the entire room shut up. Garance Franke-Ruta bought Countdown 18 Months, which was to, let's not focus so much on fighting HIV, but fight the OIs instead. And I really felt that that was a mistake. I felt, I want to get this virus under control, and we should be equally focusing on the virus; and I don't think we can

do this in 18 months, to deal with these very serious illnesses. But it was Garance. And so that everybody got lockstep –

SS: Now why then, I mean, Garance was 19.

MM: I don't know. I, because she was cool. Because she was cool.

SS: What made her cool?

MM: And she was also smart. I mean, she was smart; she did know this stuff. But there were always the T&D stars. And I would bring stuff to T&D. And I would, doctor came to me to say we have a better nebulizer to use for aerosol pentamidine, and it's being blocked. And I brought that to T&D. And it was just, and it was clearly an issue that we could have taken on. And the room just, I don't know if it was because me, or because the issue; but they just weren't interested.

But I have to admit also, initially, I was not the bigmouth that I am now. I was totally petrified of getting up on the floor of ACT UP and speaking. I would speak at T&D, but I would never speak on the floor. I never said a word for the first two years. Until — when was it? — when we went to Chicago, April of '90. They were discussing, and I was from Chicago. And so I remember getting up on the floor, for the first time — and my heart was pounding, and I was sweating like a pig — and I said, we have to go to Chicago for A, B, and C. I'm from Chicago, I know what it's like there. And I remember being so proud that I was able to get up in front of 500 people, or 400, or whatever, and actually speak on that floor.

So I was not courageous enough to actually be a player back then. So part of being a player, or made you a star, was that you had the confidence to get up there and say, this is what I think we should do, blah blah blah.

There were also people, I think, who, some of them, I think, were not working full-time, and they had the time to devote themselves completely to becoming experts in this illness. And they were also, I mean, Mark Harrington and Peter Staley to this day, we are much closer now. I remember Peter Staley e-mailed me, like a year ago, to say, hey Mark, how have you been? We haven't spoken in a while; I just wanted to touch base with you. We had a nice series of e-mails. And Peter and I now. But back then? I really felt like he didn't have the time of day for me. And Mark Harrington always was more kind of noblesse oblige. He would, like, speak to you even though he didn't think you knew too much.

I remember one time cornering Mark at a party, and coming up with these ideas of things we should be doing. And he said, boy, these are all really great ideas. Why haven't we heard from you before? And I said, because, Mark, when I speak, nobody listens to me.

So I was really frustrated in that I felt I had a lot to offer. I felt I had good ideas. I felt I was an intelligent member of ACT UP. And yet, I was not able to get my foot in the door, and to be heard and make a difference. Until TAG broke off. And they all left. And all the stars were gone. And suddenly there was this empty space. And I was one of the people who stepped in to fill that. And now, after they left, suddenly I had more respect, and I was able to be heard, and I was able to speak, and I was able to have my voice heard.

So it was bad in that we lost some very brilliant people. And plus, we were not together anymore. But it was good for me as an activist, because I was able to take more of a leadership position after they left.

SS: I see. And so what did you do? Were you now running the new T&D?

MM: Well, I, first of all, nobody ran it. But I was more of a presence in that room. And then we got Bill Clinton, finally – he kept promising, after Bob Rafsky confronted him, in that famous –

SS: Can you tell that story? Because we don't have that.

MM: Clinton was at a campaign rally. And Bob and some other members of ACT UP were there. And Bob began shouting him down from the floor, and began saying, what are you doing for people with AIDS? I'm dying, and you're dying of ambition. What are you going to do for people with AIDS?

Tape II
00:10:00

And Clinton responded to him. And then after it was over, Bob went over to Clinton; Clinton saw him; and then began talking. And Clinton said, I do care about people with AIDS. And I will meet with you. And they met; members of ACT UP, I believe, met with Bill Clinton. And he promised to give an address on AIDS before the election.

And this was, I don't know what month, but it was early in the election that Bob confronted him. And we kept waiting for Bill to give his AIDS speech. And he kept promising and prom-, and finally, a week before the election; he finally gave his AIDS speech. I don't know if you remember that. But he finally gave it. And in that speech, he promised a Manhattan Project for AIDS. Which is what we'd been calling for. We said, we can beat this thing if we would do it like the Manhattan Project, like the Apollo Project. America's always been the one on the cutting edge of research. And if we can really make this a national effort, we could beat this thing.

So we decided to hold him to that. And we got people together. And the first thing I did was I read a number of books on how the Manhattan Project and the Apollo Projects worked. And me, John Riley, Maxine Wolfe, I believe David Robinson was involved with that; some other people; got together. And we began working on, what would a Manhattan Project for a cure for AIDS look like?

And we came up with a very reasonable plan, with a reasonable amount of money. It was, I think, like 5 billion dollars over five years. It wasn't like this incredible, unheard-of amount of money. There were certain things we had to have. One of the things was we felt the project had to have the powers of eminent domain. Because we felt drug companies were sitting on drugs, and were not moving quickly enough, and the government had to have the right to go in and say, look; if you're not going to develop that drug, then we're going to take it and develop it ourselves.

It was very carefully worked out. Some of the things went too far. Maxine pretty much demanded that the board of the project be majority people with AIDS — which of course a lot of researchers would never have accepted. And we called it the Barbara McClintock Project to Cure AIDS, based on the great research of Barbara McClintock, who really was known for thinking outside the box. She did not follow the mainstream idea; she looked at the material and let the material speak to her.

One of the things I learned from the Manhattan Project is that when they were trying to figure out how to detonate the bomb, there were a couple different theories. And the main theory was they were going to have the chunk of uranium, and they were going to shoot a bullet into it and ignite it. And another group said, it's not going to work. We want to have a thing where it hits a sphere, from all sources at once.

And the leader said, well, you're nuts. It'll never work, we can't do that; it's crazy. But, go off on the side and work on that.

So non-mainstream, radical, crazy theories were allowed to be pursued. And that was eventually the way the bomb was detonated, by that crazy theory. So it was the fact that the Manhattan Project allowed crazy thinkers to do their bit that they found a solution so rapidly. And we felt the McClintock Project had to have that kind of philosophy; where we will let people outside the mainstream pursue.

So we began working on this. And right from the start, we were at odds with TAG. Because TAG was working with AmFAR. Their plan was much more, now we thought, we had Bill Clinton in office; he promised us a Manhattan Project; we should be asking for that, right? And they said, no no no no no; all we want to do is to reorganize what's going on at the NIH.

And we said, you're crazy. You know, we can get more than that. No, we can't, there's no money, be realistic. I go what, it's not ACT UP's job –

SS: Who at TAG was saying this?

MM: Mark Harrington; Peter Staley; I think Garance was still involved. All of them were saying that you're living in a fantasy world. This is not going to happen. And I said, but that's the job of activists: to demand what is right; not to say, we have to reduce our expectations. Because we won the damn election; he promised this; let's ask for this. And they went to the NIH, and they said, we want the Office of AIDS Research to be reorganized so it coordinates all the research at the NIH. And that happened. But we said, that doesn't solve the problems that people who think outside the box do not get funding at the NIH, period. Because they know that in order to get NIH

funding, you have to have a proposal that's going to get past that panel. And that panel is mainstream thinkers. So you don't even submit a non-mainstream proposal, because you know it's not going to be funded.

SS: Now who were the specific people you had in mind, who were thinking out of the box, that you felt should have been funded; that you were advocating for?

Tape II
00:15:00

MM: There weren't specific people. We just felt that the only way you were going to find a cure within, say, 10 years, was if you really allowed people who were looking at alternative therapies; who were looking at alternative approaches, like the immune activation versus the immune suppression; and I didn't know where it was going to come from. But we really felt, from studying the Manhattan Project, that the reason it worked so fast was that they had brought freethinkers into that project; and they did not say, there is one path to this thing. They said, there might be 10 different paths.

SS: But who were the freethinkers?

MM: You know, I can't say that we specifically had specific people in mind.

SS: So you just believed, it was a principled idea. You had an ideology that there were people out there who were –

MM: Well certainly, at the time, there were many people who had different ideas. But no, I can't say now who we were thinking of. We did feel, though, that you had to let the non-main-, and when we spoke to people who'd submitted grants to the NIH, they all said, those of us who have ideas that aren't standard ideas cannot get any money for these things.

SS: Do you remember who any of those people were?

MM: Nah, I can't –

SS: Okay, so now here we are. It's 10 years later. So looking back at what's happened in the last 10 years, can you point to specific things that you feel were ignored because there was no Manhattan Project?

MM: I think that the approach we've had — which is suppressing the virus over the long term, but not removing it — is very much a mainstream approach that has certainly worked quite effectively. But I think if we had had what was later renamed the AIDS Cure Project, that we might have had a cure by now; that we might have, it's going to take two things: curing AIDS and finding a vaccine are going to require radically different approaches than we've ever had in medicine. A standard vaccine will not work. So a vaccine is going to have to be a completely different type of intervention than we've had in the past. And the same thing with a cure. Getting rid of a viral infection has never been done before through treatment. So it's going to have to be totally new. So I think 10 years of an AIDS cure project, we might have had that by now. But it would have to be a groundbreaking, eureka-type discovery, which the AIDS Cure Project might have found. The way we're going now, it's going to be very, very slow. And it's going to be decades before we have a cure, and decades before we have a vaccine.

SS: What is your image of a cure?

MM: My image of a cure is every particle of the virus removed from the body.

SS: But I mean, do you see it as multipart treatment approach? Or do you see it as one kind of treatment?

MM: HIV hides in a number of reservoirs in the body. One of them is resting memory CD4 cells; it hides in the macrophages. So you have to find a way to purge the body of all those reservoirs, and that's going to be extremely difficult, and I don't know how we're going to do that. They just came up, announced last week, a new approach they're trying to purge the resting CD4 memory cells.

So I don't know what it will look like. But I know that just like a conventional vaccine will not work, it's going to have to be something that we have really never seen before.

SS: I ask you this because in the very early days, when there were no treatments, the way we conceptualized cure was very primitive. Like there would be a pill, or Compound Q, or one thing. And you would take it, and AIDS would go away.

MM: Right.

SS: Now, we don't think that way anymore.

MM: Right.

SS: Or do you still think that way?

MM: I mean, I still think that it is possible to find some kind of therapy that would eradicate the virus in the body. And they're still talking about that, at NIH last week. The other thing that wouldn't be quite so much a cure — and we actually defined a cure very specifically, in the AIDS Cure Project. But what might happen much more likely is, as you know, there are people called long-term nonprogressors, which is

not me, because I have been as low as 78 CD4 cells in the past. But there are people who have never had a CD4 count below 500; never had a high viral load. They just control the virus on their own very well for 20 years. And they have been studying them to see how they do that.

What I think will happen in the next 10 years — I'm hoping — is that they will find out how they do that. And they will train everybody else to be a long-term nonprogressor. And they'll be able to control the virus, on their own, without medication. They'll still be infectious; they'll still have the virus, just the way we all have chickenpox virus in our body for our whole life; but they will not progress.

SS: I understand.

MM: So that is probably the cure that we're going to have sooner than eradication.

SS: So to recreate the biosystem, somehow.

MM: To retrain the immune system, to control it. As you know, your immune system controls many viruses. So you would teach your immune system how to control the virus on its own. And that's possible. And that's one of the actual definitions that we had in the AIDS Cure Project. But my dream would be to actually eradicate the virus completely so that I could have unsafe sex with my boyfriend once again.

Tape II
00:20:00

SS: Right.

MM: Because that's what I want to do, and even though you're a long-term nonprogressor, you're still infectious, so you can't do that.

So the sad thing was — and this is what was really sad — is that when we announced the AIDS Cure Project — and we went, by the way, we zapped Jerry Nadler.

He gave a town meeting; we zapped him; he was talking about motorcycle noise. And we said, what are you doing about AIDS?

SS: And what year is this?

MM: This was — well, it was after Clinton was elected, so it was probably '93. And he met with us afterwards. And said, come and talk to me. Let's introduce a bill. And we went and met with him. And we wrote the AIDS Cure Project as a bill, which he introduced into Congress. And we actually got this bill in Congress. We got, I think, close to 30 cosponsors on the bill. And he basically wrote it with us, although he allowed us to write it. I mean, we did it, and we worked with him. And it was there, it was in Congress, as legislation. And it was still a lot of work, but it was possible now, it was a bill in the House, for this, sponsored by Jerry Nadler.

People in TAG not only did not support us, they began actively fighting us. And they began actively going out and saying, it's stupid, it's crazy, it's dangerous, it's distracting. And that was really hurtful to me; to see people in TAG — people like David Barr — actively, and I would, and so ACT UP had this huge meeting. Where people got together and said let's debate the AIDS Cure Project. And I was pro–AIDS Cure Project. And Mark Harrington was the one opposed to the AIDS Cure Project.

SS: So this was a public event?

MM: This was an ACT UP meeting; it was a big ACT UP meeting –

SS: So he came back to ACT UP to debate this.

MM: Yeah, a lot of people came back, yeah, to that meeting. And what I wanted was, I got up, and I presented the idea of the AIDS Cure Project: why we think it's important, why do you think it would work, what it would look like. And by the way,

we were very aware that once it began moving forward, it would change radically, right? I mean, Congress would change it. But this is our template and go from here. And I wanted them to get up and to say, this is why it won't work: A, B, C, D and E. And they didn't do that. They just said, you're kind of, you're wasting our time, and it's not going to happen, and it's a pipedream, and it's utopia, whatever. And I said, look, he promised us. And frankly, very soon, the economy began turning around, right? And then we had all the surpluses. So the money might have been there if we had pushed for it.

I can totally understand people in TAG saying, we got the OAR reforms; we think that's enough; we're going to stick to that, we're not going to help you. But they actually did an active campaign to stop us; to fight us, to say, you're wrong; it's dangerous. And that really hurt, that they were actually actively fighting us in doing this. And I though it was worth pursuing. It was worth at least to have the debate: what would the dream AIDS Cure Project look like? If this country wanted to cure AIDS as much as they wanted to go to the moon — which could have happened, right? — what would that look like? Let's have that discussion. What is an Apollo Project to cure AIDS look like? And people in TAG said, no; you will not have that discussion, and we will prevent you from having that discussion. And that, I didn't understand.

SS: So what happened to the bill, the Nadler bill?

MM: We began working on picking up cosponsors. Then the term ended. He reintroduced it. We tried again. And then, after I think two or, it really was so disheartening to have AIDS activists — and stars; the big names —

SS: But did they testify in Congress –

MM: – fighting us –

SS: – against you?

MM: No, there was never Congressional hearings, or whatever. But they put out, they put articles; Marty Delaney and Project Inform put out articles against us. There was a debate in the community newsletters, right? And after a couple years of that we were invited to Project Inform to speak, and I went out to San Francisco to speak, and was attacked there by David Barr — we became disheartened. And it was just, it was too hard to fight not only Congress and the White House and Clinton; but to also fight fellow AIDS activists.

SS: Okay – I want to be really succinct.

MM: Okay.

SS: What do you think was their motive?

MM: I think — what was their motive? — I think they thought that – they had problems with the AIDS Cure Project as written. That was clear. But that was fine with me, because I wanted that debate, right? And then they, I think, just thought that it was never going to happen, it was unrealistic, and it was a waste of time.

Tape II
00:25:00

SS: Okay.

MM: Yeah. But why they actively fought us like that, I don't know. I cannot tell you why they actively fought us. So that was a big chunk of my life and my time in ACT UP, working on the AIDS Cure Project. And it was very difficult to see it die. But eventually it did. And then, when combination therapy came out in the mid-'90s that changed everything, and then there wasn't this big cry for a cure anymore, because people were living longer. The new drugs were very effective. But certainly not a cure.

SS: Now once we get to '95, and you're still in ACT UP; were there any other people from the early ACT UP days who were still coming every week, like you were?

MM: Oh sure, absolutely.

SS: Like who?

MM: John Riley was still coming; Bob Lederer was still coming. There were a number of people. And up until the mid-'90s, we still had very healthy, large meetings. There were still well over a hundred people coming to meetings for a long time. So it's critical to know that for three or four years after TAG left, ACT UP was still a very potent force. It was a very active room; there were a lot of issues.

See, TAG left because TAG wanted to work on treatment issues. They said, we are working on finding HIV treatment. And you're talking about social issues, and housing, and all this other stuff that's distracting, and we don't want to deal with that. We want to focus only on treatment, which is fine. I mean, you can focus on whatever you want to focus on. One thing I've always said in ACT UP; choose your battles. I never worked on prevention issues. It's not my battle. My battle is helping people with HIV.

So that's fine. But I don't think you had to leave to do that.

So we were there, and we were still focusing on the AIDS Cure Project and a number of, a broad range of issues. There's always been debate in ACT UP that ACT UP should focus on AIDS, or AIDS is just one problem of all the oppression that people go through — racism, sexism, homophobia, classism, economic problems — and we should focus on all of those. And I always wanted us to focus on AIDS. I always felt

ACT UP should be focused on AIDS. But I didn't have a problem with focusing on other things. Now, some people were coming to ACT UP — Dana Beal — after TAG left, Dana Beal really managed to get to that floor, and get there every week to talk about Ibogaine.

SS: Ibogaine?

MM: Ibogaine. I-B-O-G-A-I-N-E.

SS: And what is that?

MM: Ibogaine is some kind of hallucinogenic that you take that's supposed to cure you of heroin addiction in one treatment.

SS: I see.

MM: And because he said that getting people off heroin makes them stop using needles, so therefore it's AIDS-related; this is an AIDS issue, he would get up on the floor almost every week and ramble on about Ibogaine. And it got to be so horrible that we eventually had to have a vote on the floor of ACT UP, after like a year of this, that you could not discuss Ibogaine on the floor of ACT UP anymore.

One of the problems with ACT UP – a couple problems in ACT UP. One of the problems was that if you have an open organization, the crazies have access, right? And they can come, and they can really take over the agenda, if you're not able, and the room was very uncomfortable – ACT UP, the floor was very uncomfortable saying no to anybody. Saying no to Dana Beal and saying no, you're not going to waste our time with this. It took us a year to do that, because people were very uncomfortable with doing that.

Secondly, the other real difficult thing I had with ACT UP is that it was – I don't want to use the word 'fascistic," but I want to use the word "mono-something." If you did not toe the party line in ACT UP, people had serious problems with you.

SS: We're talking in the later, in the mid-'90s.

MM: No, no.

SS: Oh, okay.

MM: Absolutely, in early ACT UP.

SS: Oh, early, okay.

MM: Yeah, all the way through. If you had, for example: I remember, in the early '90s; Tony Malliaris was a member of ACT UP who had a big crush on me. And he would always tell me he had a big crush on me, and I had never had a crush on Tony, but he liked me a lot and he'd always give me goo-goo eyes when we were together. We had, we're having a discussion, a group of us, about what to do with people who intentionally infect others with HIV. The party line of ACT UP, very clearly, was, you can't do anything, becau-

SS: What does "intentionally infect others" mean?

MM: That they know they have HIV; they are having sex with other people; and they are not telling them they have HIV. Whether or not they intentionally want to infect them or they just, I don't want to use a condom and I'm not going to tell you I have HIV. A lot of women that I've worked with over the years — women of color, particularly — have been infected by boyfriends who knew they had HIV, and did not tell them. And one woman told me, this guy infected me; he knew he had HIV; and he said, well, now we both have HIV; now we can get married. And she said, fuck you;

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no, you're not marrying me. And now she knows that he has a new girlfriend, who he is also not telling he has HIV.

SS: Okay, now so this conversation, was this on the floor of ACT UP –

MM: No. This is off the floor of ACT UP.

SS: – this is private, private. Okay.

MM: I believe it was at the San Francisco International AIDS Conference, which was in 1990, I think.

SS: But it was a public conversation there, or –

MM: Uh huh.

SS: – okay.

MM: It's a group of us sitting around, talking. And I said, I said, you know, I don't know what to do about them; but I don't believe they should be untouchable. I think –

SS: You don't believe –

MM: That they should be untouchable; that we can do nothing to them. I don't know about locking them up, or whatever, or criminalizing their behavior. But I do know that I think it's a terrible thing that people do this. And there should be, because working on the AIDS Hotline, I had a lot of women call me up to say; my boyfriend infected me; he didn't tell me he had HIV: I know he knew. And they would cry on the phone to me. And I heard this day a-, because I was working for the city AIDS Hotline. I would hear this day after day after day, and it really bothered me. And I said, I'm not sure what to do. But I think we should be able to do something to stop somebody who is concealing their HIV status and infecting other people with HIV.

SS: Okay. I have to stop you and ask you some questions here. Because this is a whole new arena here. Aren't most people who've been infected in the last 15 years been infected by some – I mean, they had sex with someone who was infected, right?

MM: Actually, they have found that a lot of infections are occurring in people who, in that 25 percent that have not been tested, and don't know they have HIV. A lot of it's occurring in people in the first three months after infection, you have an extremely high viral load, but you test HIV-negative, because the test looks for antibody. So they think they're negative, and they actually have very high viral load.

SS: Okay, so you're saying that that's 25 percent of infections are from people who don't know that they're –

MM: Twenty-five percent of people don't know they're infected. And they think actually a lot of the infections are happening from that group that don't know.

SS: Okay, but that's a separate issue.

MM: Yeah, all right.

SS: But what is the percentage of infections that you feel are caused by people who are withholding that they are positive?

MM: You know what? This is the whole thing. In this conversation, I said, look; I don't know how often this is happening. I know it does happen, right? I don't know what to do with those people who are not informing people and infecting them with HIV. Of course the ACT UP line was, it's your responsibility to use a condom, da da da da da da. And I just, all I said was — I didn't say they should be locked up; they should be against the law, anything like that. I just said, I'm not totally

comfortable with the idea that they are untouchable, that we can't do anything to those people who are intentionally infecting people with HIV. That's all I said. I said, I'm not sure what to do; but it makes me really uncomfortable.

Just saying that; Tony Malliaris stopped speaking to me ever again. A number of people stopped speaking to me.

The point I'm making is –

SS: Oh, okay.

MM: – you were not allowed to have, express opinions that were outside the party line. If you did, people would stop talking to you; people would ostracize you.

SS: And what was the – okay – since you have a specific thing that you said and there were specific people who stopped talking to you; what do you think it was that was going through their minds or their hearts to make them feel that uncomfortable?

MM: I don't know. It was like they were so adamant in what they believed; that HIV prevention was the responsibility of everybody. And they were so, everybody had to be trying to use a condom; and people with HIV were not responsible; and you couldn't hold them to that. And anybody who says, it was an us and them thing. Either you're with us, or you're against us. And if you have an attitude that is not the ACT UP party line, then you're on the other side, and I'm not going to deal with you anymore.

The best example of that, and probably my worst experience of ACT UP, was the whole sex-club issue. Which came up in '94. And this is when we were meeting

at Cooper Union. And I recall that this was, I think before TAG left. You know when exactly TAG left?

SS: They're gone by '94, that's for sure.

JW: Ninety-three they're gone.

MM: I recall that people from TAG were still there at the meeting. Maybe they gone, but they were still coming to meetings. But I recall –

SS: Well, some people were both in ACT UP and TAG.

MM: Yeah, and TAG. So they were still at the meeting.

JW: It was '91 at Cooper Union.

MM: Yeah? But I'm quite sure the sex-club issue didn't happen till '94. Because I looked online to find dates. Anyways, so some gay man snuck a Channel 4 NBC reporter into a sex club.

SS: Oh, this is the Signorile-Rotello era. It's '94.

MM: This is slightly before that, yeah.

SS: Okay.

MM: Yeah.

SS: Yeah.

MM: Sneaks into a sex club; does an on-the-camera expose of unsafe sex at the Bijou sex club, which is still open, by the way, on East 4th Street. And right away, there's this huge thing. And Giuliani administration, to close down the sex clubs. Stop this from happening, right. And it's all in the papers. And there's a real possibility that all the sex clubs are going to be gone, are going to be closed down, right?

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So I, right away, said, okay, I was an active user of the sex clubs. I also, a love/hate relationship with them. I like the sex, but I hated the fact that it, I think, kept me from getting a boyfriend, because I was just having too much sex. So I said, okay; let's get together and deal with this.

And I went through, and I spent weeks, contacting every owner of a sex club in Manhattan. And this was really hard, because these are not public people. Gay and straight sex clubs. Plato's Retreat came. And we had a meeting of 30 sex-club owners, and some of us in ACT UP. And we sat down, and we said, what can we do? They were very frightened that they were going to be closed down; it was very possible. And of course, as you know, they all were, right? So they were very worried about that. What do we do?

And the plan we came up with is that we'd go to the city. Now by the way, the state law said, no anal or oral sex allowed in a commercial establishment of any kind. You could not have in a commercial establishment, very clearly defined, any anal sex, any oral sex. Vaginal sex was not in that law. It was added after this happened. But at the time, it was anal and oral sex.

So we said, look, let's go to the city, and say, look; what we'll do is we will hire what we called lifeguards. They will be people who will have lifeguard uniforms on. All the sex has to happen in the open, not behind closed doors. And the rule posted when you come in: no fucking without a condom. If you're going to come to our sex club, and you want to fuck, you've got to use a condom. And all the owners said, fine, no problem. And if somebody is seen fucking without a condom, they'll be tapped on the shoulder, and they'll say, hey, put a condom on, or you got to leave. If you want

to go home and fuck without a condom, you can do that. But in our establishment, you have to use a condom.

And I liked this, because I had been at a sex club the week before. And I had seen a 20-year-old boy, on a table, surrounded by 30 guys, while one guy after the other fucked him without a condom. And that was, to me, sad — and this was, by the way, right below a "Safe Sex is Great Sex" poster. So here I saw this poster on the wall. And I said, okay, they're getting a message from the poster; you got to have safe sex. And then they're getting a message from their peers, who are all saying, all of us there: I implicitly approve of this behavior, because I'm watching it, and I'm getting off on it, and I'm watching my peers take part in it. And this message is a thousand times more powerful than that poster on the wall.

So I said, if we as a community said, we as a community of AIDS activists say; we do not condone fucking without a condom — just that one thing — in public sex spaces, and we band together to say, as a community, we say, if you want to fuck in our spaces, you use a condom; that would send a powerful message. I said, GMHC could train the lifeguards; ACT UP could monitor the clubs to make sure it's being done correctly; the owners would hire and pay for the lifeguards. And I had seen clubs do this, by the way. There's a club called the New York Jacks –

SS: Um hm, sure.

MM: – been around for 30 years, no lips below the hips. If you get down and gave somebody oral sex, {SNAP} you were out. Worked completely well. I mean, there is, I've been to their things; no one does anything but jack off. That's all they do.

So I went to the floor of ACT UP to say, okay; I met with the owners; here's the plan we have. Keep the clubs open, but no fucking without a condom at the clubs.

I was crucified. James, you were there, you remember. It was a horrible night. People got up; they called me a Nazi; they called me a sex police; they called me a fascist. People stopped speaking to me. Jim Eigo — you know very well — refused to speak to me after this, said terrible things to me. Many people who I worked with for years in ACT UP would no longer talk to me. It was horrible. I went home in tears. I was really brutalized, on the floor and afterwards, when I spoke to people. And I made a tremendous amount of enemies. People said, people have a right to be infected if they want to be infected. You cannot tell them how to have sex. You cannot let the government come in and tell us how to run our sex clubs. It was horrible. And people really hated me, because I went against the ACT UP party – and it wasn't like, I disagree with you; you are allowed to have your opinion, and we're going to have our opinion. It was like, no; you're an asshole, I'm not speaking to you; you're a Nazi; fuck you. And it's like, guys; aren't we allowed to disagree in this organization?

SS: Okay, I have so many questions.

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SS: Okay –

MM: Sex clubs.

SS: – all my questions. I guess the first question is a lot of people say that in the early years of ACT UP, there was almost always safe sex, that safe sex was part of the culture of ACT UP. That is something that many people have said. Do you think that that's true?

MM: No.

SS: Okay.

MM: I mean, well, okay, I don't know what ACT UP members were doing, because I was not hooking up through ACT UP. It was not happening. It was very strange for me, because I would go to ACT UP meetings on Monday night, which were very stressful for me, very difficult for me. I remember, during some of the AIDS Cure Project debates, when I was really being ripped for the AIDS Cure Project, I got up in front of the group, and I was almost in tears, saying, it's very hard for me to be up here and to be attacked like this. And I look like I'm really strong, but in reality this is very painful for me. So please, you know, if you want to disagree with me, fine, but don't attack me personally. And Andy Velez – there was a thing called TITA, Tell It To ACT UP –

SS: Yeah, Bill Dobbs's thing.

MM: – which allowed anonymous, what a bad idea for a group to allow anonymous rants. But Andy signed a thing in there, pretty much saying, get over it, honey. You're in ACT UP; deal with it; sing out, Louise. We're going to attack you, and you handle, and that really hurt me, you know, to be publicly dressed down in that thing, when all I had said was, look, it's hard for me to be personally attacked like this on the floor of ACT UP. And the next night I would go to the Healing Circle, which also was 400 people, where you could, there was love abundant, you know. So it was Monday ACT UP, which I would always leave feeling horrible; and sometimes in tears, usually just feeling really awful. And then Tuesday night was the Healing Circle, where you

were, people laid hands on you, and no matter what you did, there was support. And it was dramatically different.

SS: Yeah, but the Healing Circle never got a drug released and never –

MM: Oh no no, I'm not saying that, they were very different things, and –

SS: Yeah, yeah.

MM: – I'm not saying that ACT UP didn't do wonderful things. ACT UP did do fabulous things. But I'm saying the meetings themselves, for me, were very painful. And the fact that, the main thing, like I said is, you know, I'm an opinionated guy. And I have my opinions. And you were not allowed to have opinions in ACT UP.

SS: Okay, I understand that. But I want to focus on the sex stuff.

MM: Okay.

SS: So if you weren't having sex in ACT UP, did you go to sex clubs that ACT UP people went to?

MM: Sure, sure.

SS: So you saw them there.

MM: And I, well, yeah, you know what? I can't, all I know is that I always saw, from the day I got to New York I saw a lot of unsafe sex in the clubs. I saw a lot of fucking without condoms in the clubs, all the time. And it got me, and I, I cannot say ACT UP members or not; I don't know. But I know that the amount of unsafe sex in that clubs, never significantly went down, from the time I was there.

SS: Okay.

MM: And the problem, for me, that really drove me crazy, is that, okay; here I was, a person with HIV. Hook up with some guy in a sex club. It almost always, the burden of the safe sex landed on me. The guy, many of the guys, the majority of the guys, were willing to be unsafe, you know. And until I stopped it, until I said, no, right? If I told them I had HIV, at that point, it was often {SNAP} over. So if I don't say anything, I can do whatever I want. If I say I have HIV {SNAP}, goodbye.

It's like, okay; so I'm supposed to be, now the reason I'm having safe sex is, why? I already have HIV, so why am I having safe sex?

SS: To not infect anyone.

MM: To protect them, right? So I have to be concerned about this stranger, who I know, that if I tell him I have HIV, is going to treat me like shit. So it's very difficult, you know? And I knew that there were times that I slipped; that I, I was safe most of the time, but there were times when I wasn't. And I felt really bad about that. But there were all these guys out there who were tempting you. And sometimes, one guy, he'd want me to fuck without a condom. And I would get right to the edge. And then I would stop. And the way I would stop myself is I would come. I would come before we fucked, and that way I knew I wasn't going to do anything, right?

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And so when we were zipping up, I would say, I have HIV, and you'd be positive right now if I had gone forward with this. And they were always really shocked and really upset. And I said, why were you willing to let me do this without a condom?

Well, because I thought you were so top, I thought you, you, you had to be negative because you're such a top.

And I said, well, I'm actually not a top. I'm actually versatile. And I've been fucked a lot.

And so I say, I, as an AIDS activist, I need help staying safe, right? And back then, by the way, back in the '90s, there was virtually no reinforcement for people with HIV that you have a responsibility to be safe as much as those who are HIV-negative. So, I needed to be told, regularly, you should not be infecting people with HIV. That message never came from ACT UP. ACT UP never said to people with HIV, you have a responsibility to not infect others. It never came from the CDC; never came from GMHC. Now there is Prevention for Positives; HIV Stops With Me. And that's good. I like that.

But here I am, with this virus for 25 years now.

Luckily with my boyfriend, I told him we had, I had HIV before we had sex. And he knows. And so, like, there's no way it's going to happen any other way. But when you're with strangers, it's different. And so I thought – that having clubs where the rule was you couldn't fuck without a condom would really help people to say, hey, this is what I want; I don't want to get fucked, or fuck, without a condom. And if that's the rule of the club — and I had seen it work in clubs. Some clubs did have that rule, and it was effective. But people in ACT UP, man, I tell you; there was almost no support for that in ACT UP, whatsoever.

SS: Okay, now just a couple of things about this. First of all, it's not just that HIV-positive men are not getting, in your view, enough messages telling them not to infect anybody. Men, straight or gay, do not use condoms. Right?

MM: I wouldn't say, do not, but a lot don't use them.

SS: Right.

MM: Men hate them. I would say, men hate condoms, generally.

SS: Okay.

MM: Dislike them.

SS: It's not a gay thing; it's not an HIV thing. It's a man thing.

MM: Right.

SS: So women are raised to have defensive heterosexual sex, because it's, for the second you're out there, you're being told by everybody that men are never going to use condoms, and you have to make it happen.

MM: Um hm.

SS: So now, you're asking men to step into that role that women have been trained in all their lives, and women still get pregnant all the time who don't want to.

MM: Right, right, right.

SS: So it's much larger than gay and HIV.

MM: It's true. And it's also, the same thing that, it's the roles in gay life. When I'm a bottom, and I'm with this very hot, very aggressive top who wants to fuck me without a condom; it's very hard for me; because I get into this kind of submissive, accepting frame of mind. You're the top, I'm doing what you say, you're going to fuck me, right? And suddenly, I have to stop, and say, wait a minute: I'm in charge now; you got to put on a condom. And that's very hard. I don't know if women experience that, too, when they have a very aggressive man, and suddenly, for the woman to say, wait a minute, now; you're not in charge anymore; I'm in charge, and you're putting on a

condom. I know for me, as a bottom, it was sometimes very hard to say, you must use a condom.

So I felt that, so for the bottom, who has a hard time asking for a condom, this rule in the clubs would be great. For the top, who is just worried about getting, or making his dick feel as good as he can, right, it would be good for him to have a rule you got to use a condom. So I thought, the clubs could stay open; we can have lots of sex; it can be very sex-positive; we can have these sexy lifeguards in lifeguard T-shirts; we're all going to be using condoms when we fuck. For oral sex, I said, it doesn't matter, that's very low risk, so we can, people can work that out. But for anal sex, we're going to say, we're ACT UP; you want to fuck in our clubs, you use a condom, right?

Boy, did people hate me.

SS: Okay. I understand.

MM: I mean, really hate me, Susan, I can't tell you.

SS: Sarah.

MM: Sarah, Sarah.

SS: Now why do you think this all happened in '94? What was the context for this? Because there was a huge, this is when, what was the name of that group? This radical –

MM: Sex Panic came –

SS: Sex Panic and, this is Mike [Signorile] and Gabriel [Rotello] –

MM: Right. So what happened then –

SS: Why did that emerge at that moment?

MM: Okay, okay. So then after I put this proposal on the floor, right, it died a horrible death. And nobody was on my side, okay? So I said, look, I want to make this happen. Because if it doesn't happen, all the clubs are going away. And I don't want to lose all the sex clubs. So I want to get a group together to make this happen.

So I called some people, including Gabriel and Michelangelo. And said, let's have a meeting to see about making this happen. ACT UP won't do it with me. So I got the owners on my side. Are there other gay men out there who want to make this happen? And there were. And a group of about 30 or 40 of us got together to say, let's see about this.

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Well, actually what happened was, people in that group were very different than me. And they, a lot of them actually wanted the clubs closed down, and wanted different things than I wanted. And a group of them went and met with Giuliani. I did not meet with Giuliani. But they went and met with him. And they were really seen as traitors by gay men for working with the enemy. And what happened then was, I called up Mark – he was the lead counsel for the city at the time — Mark; I'll remember his name eventually. And I said, I have a group of sex club owners that wants to meet with you to talk about the sex club thing, and talk about our proposal for this lifeguard thing, right? And he said, fine. Come down to City Hall and meet with us.

So I remember this day. We're all in City Hall. And these sex club owners are like, they're like, types, right? They're dressed in leather and stuff, and piercings. And we're all in this room in City Hall. And Mark Barnes, Mark Barnes. Mark Barnes walks in the room. And we're all there. And I stand up, and I say, because

I had organized the whole thing, right? And I said, I want to thank everyone for coming. And Mark said, uh, Mark, I'm in charge of the meeting, I'll run the meeting.

And, really humiliating, right? And I just said, fine. I sat down. And he got up and pretty much said, okay; we're the city. Oral sex, anal sex are illegal in your clubs. We're going to send monitors in there, all the time. If we see any of that happening, you're shut down. See you later.

That was it. They just absolutely refused to even discuss anything.

So my plan, you know, in the end, had been absurd to begin with. It was never going to happen.

So in response to all that, then the group that actually formed, before Sex Panic, there was a different group. And they said, okay; we're going to address the problem of unsafe sex in the sex clubs in our own way, right?

SS: And who was in that first group?

MM: There were a lot of the – kind of the, what do you call them? The gay intellectuals, like –

SS: The academics, you mean?

MM: Yeah, the academics.

SS: What's the guy's name?

MM: Michael something?

SS: Michael, come on. He was the guy who started –

JIM HUBBARD: Oh, Michael –

SS: – Sex Panic. I can see him.

MM: Yeah, I know I know him, too.

SS: He's bald, and –

MM: He was in the –

JH: Michael Warner?

SS: Warner!

MM: Michael Warner –

SS: Right.

MM: And I believe –

SS: Lisa Duggan.

MM: What's his name, who was with United for Peace and Justice now; the main organizer for them; I'll think of his name, too; we never got along. But I went to their meetings, too. And I said, look, I just want to find a solution to this thing, and I'll be with whatever group that wants to work on this. And so I'm sitting there, waiting s-, okay; I had an idea that I think, if implemented, would have worked. Because you would have had clubs, you would have had sex; but there wouldn't have been HIV transmission. And I think it worked. Now, what's your plan to make this work, right?

And their plans were: make a poster; make a brochure; go to sex clubs, and do visits. So they planned a visit to the Bijou, which was the club on 4th Street that was first targeted by the news station. And we all went there one night. And I'm not sure what they did, other than to have sex. I mean, they just kind of went there, and hung out, and they were going to talk to people about having safe sex, or whatever.

And we met week after week after week; and I never saw any ideas coming out, of what are you going to do where the fact of the matter is, is that a huge number of guys are fucking raw in these clubs?

And one of the reasons is, sex clubs, I felt, facilitate unsafe sex. Because they facilitate multiple anonymous partners. You cannot go to a bar and do 10 guys a night. You can't bring one guy home and go back and bring one guy home. But in a sex club — and I've done it — it's very easy to do 10 guys in a night. So that's really – And then secondly, sex clubs are nonverbal spaces. Safer sex oftentimes is a verbal thing. You're in your right brain, which is the emotional, feeling part of the brain. And then you got to switch to the left brain, which is the verbal, thinking part, to actually kind of communicate; I need you to put on a condom, or whatever. So because there is no talking, it actually makes it, I think, more difficult. If you meet somebody in a bar, and you talk to them, and you know them, and you go to your place, or you have the condoms there; I think it's easier to move into that let's-be-safe thing, because they're kind of more of a person. Whereas a person in a sex club is a complete fantasy, right? You never said a word to them, and you can project onto them whatever you want to do. And so that makes someone say, I thought you were so top that you must be negative, because he's projecting onto me what he wants me to be.

So I felt that sex clubs were actually facilitating HIV transmission. And plus, they were charging for it. And they were not, money wasn't coming back to us; it was coming back to the people who run the clubs, who usually were not gay. So I said, hey, look; they are charging us to increase HIV transmission rates. Let's go in there and say, you know, we demand that you make these clubs safe.

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SS: I understand.

MM: But, so Sex Panic's point of view was pretty much to say, hands off our sex clubs; no sex police; we can do whatever we want to. And the ideas for actually lowering transmission in the club, I never saw them.

SS: So in other words, ACT UP and Sex Panic had similar responses.

MM: Oh yes, very much so.

SS: Okay, now, I just want to, I think we need to get off this soon. But I just want to say: '94 is a very specific social moment for this to happen. Because Clinton has now been in office. He came in with Don't Ask, Don't Tell. You're starting to get these assimilationist politics.

MM: Right.

SS: Marriage is being pushed everywhere.

MM: Right, right.

SS: And so there's suddenly a significant faction in the gay community that's pushing normalcy, and behaving like straight people, and –

MM: That, that, that could have been a reason they were so against it. But for me, the idea of active, open sex — and by the way, I said, no rooms, because you couldn't monitor the rooms, right? So we had active, group sex clubs, where gay men are fucking each other while other people watch; this does not seem very, like, and by the way, when I went public with this — I was in the newspapers about this, right? — I got hate mail from straights like you wouldn't believe; hate phone calls from straights; hate mail from gays, ACT UP people, sending a letter; and then hate mail from gays saying, how dare you promote sex clubs in the gay world. You're telling people that we're promiscuous, so gays who were like more to the right than me –

SS: Right.

MM: – everybody hated me. I was universally hated. And I thought I had a pretty reasonable idea.

SS: Right.

MM: But I got it from all sides. And this is not normalcy. Group sex orgies, where condoms are required, I don't see this as a white picket fence at all.

SS: Right.

MM: You know, I mean, it's not like –

SS: No, I understand –

MM: – assimilation.

SS: – I understand.

MM: But in ACT UP, maybe that was one of the reasons that people were seeing this as one more assimilationist tactic.

SS: Okay. Well thank you for all of that. Oh, just one more last question. What were these sex club owners like? I mean, are they like little Jewish businessmen from the Bronx, or what are they, who are they?

MM: No, they're kind of like, kind of like when you watch the cable shows at night, like "The Groove Tube," and you see those kind of weird, old, kind of gross men who I think the only way they can get sex is maybe to own a sex club. They were kind of strange people that you didn't really necessarily want to hang out with –

SS: So they weren't, like, organized crime figures?

MM: No, I don't think so. I, it's not, it's possible that the actual money was from organized crime. But the owners themselves, no. They were just older white men who were a little bit – I don't want to say gross, but a little bit –

SS: Sleazy.

MM: – yeah, a little bit sleazy. I think "sleazy" is a good word for them.

SS: Okay, let's go back –

MM: Especially the owner of Plato's Retreat. He had, like, I think, a gold shark's tooth, and that kind of stuff, on his neck. That was really scary.

SS: Bob Guccione. Okay, so let's go back to ACT UP. I'm trying to get a little bit about what's happened in ACT UP since '95.

MM: Okay. So I began focusing, after the AIDS Cure Project died, I began focusing on the things that were most important to me. And one of those things was drug pricing.

SS: Drug pricing.

MM: I really was upset about the price of these medications, and the fact that we could not get any information on what the actual costs of research, development, manufacture, all this stuff, was, right; to see if these prices were justified. Because the average cost of triple-combination therapy is between ten and fifteen thousand dollars a year. And every new drug that came out was priced higher than the last drug. And I wanted some idea of, were these prices justified in any way, or were they just charging whatever they felt like. We could not crack any idea of what their actual costs, it's a very closely guarded secret.

So the first one for me was Sustiva, which came out in, I think, '98. Well, the first big ones were Crixivan and Norvir, which really came out very high; like eight and nine thousand dollars. Well, Norvir came out first, at eight thousand dollars. And then Crixivan came out a few months later. And Crixivan was a better drug than Norvir. But Merck actually priced it significantly lower, even though they could have gone higher. Because there actually was a debate in Merck about being ethical, and saying, we're going to not charge as much. It's still way too high, we felt. But they actually went, like, two thousand dollars less than they could have, a year. Which was great. So they were the first one. But then other ones, they had coming out from Roche and whatever, and they were sky-high again.

So then Sustiva came out. And Sustiva, the drugs in its class — non-nukes — were all around five thousand dollars a year. And Sustiva came out, in the same class, at, like, seven thousand dollars a year. So way outside, because they said, it's a better drug, and we can charge more.

And we said, you don't charge the price based upon how good it works. You charge the price on what it cost to develop; what it cost to make; and then you add some profit; and you, you know. And they, they said, no, we charge based upon how good it works.

So we were really angry. And we did a, there was a lot of protests about
Tape III
00:20:00
the pri-, we went down to DuPont's — it was made by DuPont at the time — went down to their offices, in I believe South Carolina, and did a big protest there.

But the one that was the most fun for me was I organized a few people — Nanette Kazaoka; Ken Bing; Ann Northrop; and I think another person, I can't recall.

And I was looking for a DuPont office here in New York City. And the only thing they had was, they had a textile division, at 41st and Broadway. So Ann went to scout the place out. And saw that there was a receptionist, and then there was a door. So we went there with a big banner — DuPont's Greed Kills — to hang from the window. And the six of us went up there. And Ann went to the receptionist and said, okay, this is a nonviolent ACT UP action. Please, please stay calm. And we went to the door. And the door was locked. Couldn't get in.

So I went, fuck. So I began going around the side way, and I found that somebody had actually propped a door open. And I said, hey, it's over here. And three of us — me, Nanette, and Ken — got in the office; walked right down past the cubicles; went to the window; and hung our banner outside the window. So it was a great success.

And then we sat down, in the middle of the office. And people, and Ann had not come with us. So Ann was stuck in the lobby with another person – I'm sorry, I can't recall. And the office manager came down, and said, what is this? And I said, we're from ACT UP. We're protesting the price of Sustiva. And he said, no no no no no. You don't understand. We're a textiles firm.

And I said, no no. You're owned by DuPont. DuPont makes Sustiva. So we're here. And we're not leaving until you get the president of DuPont Pharmaceuticals on the phone to agree — they had been refusing to meet with ADAPS. ADAPS wanted to meet to get a price reduction. They refused –

SS: Can you just say what ADAPs is?

MM: ADAPs: AIDS Drug Assistance Programs. They provide medicines for people who make too much money for Medicaid, but who don't have private health

insurance. They have a limited budget each year. Once that money runs out, there's no money left for the year. Some of them actually have to shut down before the year is over because they run out of money. They needed to negotiate a lower price in order to not break the bank. And DuPont was refusing to meet with ADAP owners in order to negotiate a new price.

We're not leaving until you get the president on the phone; I know his name. And until he agrees to meet with the ADAP programs, we're not leaving.

So we sat on the floor, and we began chanting, ACT UP. And so what they do: they clear out the entire office – because now there are terrorists in the office. And we sat there for a while, and they got the guy on the phone.

And he said, what are you doing? And I said, look, we're not going to leave until you promise to meet with ADAPs. And he goes, I promise you that we will meet with ADAPs within the month.

And so we said, fine. And the cops were there. And the cops, the cops were asking us, why are you here? There have been a number of times, like at the NIH, my first arrest; we had to sit in the cop car for like an hour. And during that hour, we educated the cops completely about the issue. And these cops, we heard them on the phone with their supervisor: Yeah, they're here protesting the price of this new AIDS drug. They say it's way too high, and they want to bring it down.

So they were learning. And they were great.

And then, we assumed we were going to be arrested. And the cops said, well, no, if you leave after the phone call, you can go.

And we said, okay. Can we have our banner?

And they said, sure. And so we, we took the banner back, which we used again in later DuPont actions.

So at this point; now, '98; ACT UP really had begun getting much smaller. And meetings were down to like 20 or 30 people. In fact, some meetings, we were even having just like a half a dozen people, which is pretty disheartening. But I was determined that there was still stuff you could do with these small, focused zaps. We couldn't do a thousand people, like Stop the Church, or whatever, right? But we could do these small, little zaps, which were very effective, because they did meet with ADAPs; they did negotiate a lower price. And so we were successful.

So we had a new attitude then, in the late '90s: that, okay, we are not big anymore. But focused zaps really can work. And the best one of those are the Gore zaps. Has anybody told that story?

SS: No, we want to hear it.

MM: Oh, this is a great story. So in '98, at the AIDS conference, I believe in Geneva, there was finally talk about, is it possible to get treatment to developing nations. And the standard at the time was, it's absolutely impossible. It's fifteen thousand dollars a year; they spend, like, a penny a year per person on healthcare there; the only option for the Third World is condoms. And you do prevention, and those who have HIV, I'm sorry, you can't do a thing.

Tape III
00:25:00

And some of us began saying, well, is that true? How much do these drugs cost to make? If we can actually get them made generically, you know, can we get treatment over there, with some extra money?

So people began working on this. And the first people to take the step were South Africa. Not AIDS activists; South Africa. Passed a law in '97, saying, we're going to make or import generic AIDS meds. Because South Africa had, like, 25% infection rates in some areas of the country; the worst AIDS epidemic in the world, by far. So we're going to get generic meds.

So of course, the drug companies are pissed as hell. And so there was a big debate about, now first of all, South Africa is not buying any AIDS meds at full price, because they can't afford it, right? So they're not going to lose any money if South Africa imports them, right? Because they're not selling them there anyways. In fact, all of Africa is not buying these drugs. So if they make them themselves or import them, the drug companies won't lose a dime. So why are they so opposed to this happening?

Well, the reason, I finally found out from an executive, was, if these drugs become available widely on a generic basis, people in America are going to learn how much these drugs actually cost to make; and that's going to increase pressure for price controls in America.

So they were willing to let 25 million Africans die of AIDS just to keep their markup a secret.

And I'm like, can anybody be more evil than this?

I began working on drug pricing issues in the mid-'90s. I'm doing it now for 12 years. The more I work on drug pricing issues, the less gray it becomes; the more evil the drug companies become. It's incredible. It's more black-and-white. They could not be more profit- and greed-oriented than you think.

SS: You have that list of markup rates. Can you share that with us?

MM: Sure. I did research on the average wholesale price per year of drugs for our 20th anniversary, in March. And I found that Epivir, which costs forty-one hundred bucks here in the U.S., actually costs fifty-one dollars a year to make generically. Zerit, which costs forty-six hundred dollars in the U.S., actually costs twenty-four dollars a year to make. And these are numbers from Doctors Without Borders, the list I did. These are made in India, and that kind of stuff.

Viramune, which costs fifty-three hundred bucks in the U.S., actually costs fifty-six dollars a year to make.

So the markups are dramatic. And of course, you got to markup to make some money on these things. But that kind of markup is not, and they do spend and buy about three times on advertising what they do on research. So it's not for R&D; that's a lie.

So South Africa's going to — and there's a whole list; they're all the same. And all the drugs like that. U.S. is the only developed nation, I believe, without price controls on drugs. And so we pay10 times more than other nations do for these drugs.

So South Africa is going to make them themselves, right? Well, drug companies go crazy. And they go to the U.S. trade representative in the U.S. And they say, we want you to put South Africa on the Trade Watch list. The Trade Watch list is the first step towards trade sanctions. They were considering putting back the trade sanctions on South Africa that were removed when apartheid was lifted, because they were going to import generic AIDS meds.

We found out through a leaked document from the U.S. Trade Department that Al Gore was actually talking to then–vice president Thabo Mbeki to pressure him to drop this plan to do this. So we said, Al Gore is working to prevent generic AIDS medicines from getting to Africa on behalf of the pharmaceutical industry. His campaign manager, Anthony Podesta, was a former lobbyist for Pharma. So it's like, this seems like a pretty good target. And Jamie Love, of Ralph Nader's Consumer Project on Technology, actually tipped us off to this stuff. And we had a document proving that Al Gore had been actively involved in these, in this pressure to stop this.

So some people from ACT UP, and some people from a group called Fed Up Queers — and I got to tell you, one of the, if not the main motivating forces in ACT UP, from the beginning and to this day, lesbians. They were the ones who made things happen. And this group, it was an ad-hoc group. But it was ACT UP members, like Sharon Ann Lynch and Mel –

JW: Stevens.

MM: – Mel Stevens and a couple others. And then a number of lesbians from Fed Up Queers — got together on a Sunday evening –

SS: What is Fed Up Queers?

MM: Fed Up Queers –

SS: Who's in it?

MM: – was a bunch of queers who just did actions about what they were pissed about. Like they sat down when Rudy Giuliani marched in the parade, and I believe blocked him in the Gay Pride Parade. So they were just, like, just a very ad-hoc group, that would just do actions –

Tape III
00:30:00

SS: Who are they?

MM: Who are, I mean who was in, what were the names of them?

SS: Yeah.

MM: Don't know the names. Because I only did –

SS: You don't know anybody?

MM: No, no –

SS: Okay, okay.

MM: Other than Sharon Ann. And oh god, I'm so bad at names.

JW: Kate Barnhart.

MM: Kate Barnhart was in them, yeah. A few others that I –

SS: So some old ACT UPers, actually.

MM: Oh yeah, absolutely.

SS: Oh yeah.

MM: There were definitely ACT UP members in this group.

SS: Okay.

MM: But it was not a, actually it was not an official ACT UP action; but we called it an ACT UP action, because we wanted to use the ACT UP name. So there were a number of ACT UP members there. It was very much an affinity action. So we met on a Sunday evening. And people said, okay, here's the deal. Al Gore, ba-da-ba. And compulsory licensing; a government can issue a compulsory license, which takes away the license on the drug company, and they can make their own version. Or parallel importing, which means you import from India, that sort of thing. And they had been trying for a year, at various groups, to get the press to cover this. But the press: South

Africa; HIV meds; compulsory licensing, parallel importing; forget about it. No one's going to cover it. The *Chicago Tribune* had done a nice article on it. But that was it. And they could not get it in the press. So we wanted to zap somebody.

So Al Gore is announcing his candidacy for the presidency of the United States. And Al Gore, who is concerned about the gay vote, who is concerned about the AIDS vote, is actually involved in suppressing this.

So we had a discussion. And he was announcing his candidacy in Carthage, Tennessee, the following Wednesday. And then coming to New Hampshire and New York the Thursday after that.

And so we were discussing where do we go? And I said, have to go to Carthage. Because if that's where he announces it, that's where the cameras would be. Other people — also Winkelman; no, not Winkelman; Emily Winkelstein? She, have you interviewed her, or –

SS: Never heard of her.

MM: – she also argued for going to, a number of people argued to go to Carthage. And we decided, yes, to go to Carthage.

So we got in a van. I actually flew down, but they went, took a 16-hour van ride down there. And we were told that you didn't need tickets to get in. So we got there; 7 a.m. in the morning on the day he was going to announce. And it turns out, if you didn't have tickets, you were, like, two blocks away from where Al Gore was, and we hadn't gotten tickets.

So I said, what the fuck are we going to do? And I, there were 10 people taking tickets. And I picked this very sweet Tennessee grandmother. And I went to her.

We were wearing Columbia Students for Gore T-shirts. Underneath, we had T-shirts that said, Gore's Greed Kills: AIDS Drugs for Africa. So I went down, and I said, we just drove 16 hours in a van from New York to support Al. Is there any way we can get up front?

And she went: oh, come on in; come on in, sure, we love having New Yorkers down here!

So we all got in. And we got right up front. Now it was three hours until the thing began. So we're there, with these wonderful Tennessee Democrats. Who were great. They're won-, and we're chatting, we're from New York, we support Al Gore. And we can't, and we think that George Bush is terrible. And it was wonderful. For three hours, right?

So then Al's wife comes, and his daughter comes, and then Al comes. And I had agreed to kick off the action. So I said, I'll pick a point during the speech to blow my whistle and take my shirt off. And when I do that — there were a dozen of us; 10 lesbians; me and Mel. And I tell you; it's the lesbians who do this. The gay men, once we got HAART out there, and they could go back to the bars and the sex and whatever; a lot of gay men left ACT UP. When we were dying, they were there. But now that they can afford the drugs and whatever; they weren't there. But the lesbians stayed. And the lesbians were, been not really that impacted by HIV. I mean, lesbian-lesbian transmission is very rare. And the number of lesbians with HIV is there, but nothing like among gay men, right? But they were there for us. And many people have said, if this was a disease affecting lesbians, would gay men have been there the way lesbians were? I can guarantee you, they would not have been. I mean, so it was a very

different point of view. And to this day, most of my AIDS, a lot of my AIDS activism is done with primarily lesbians who do the work, so I'm not tremendously proud of gay men in terms of that regard.

So 10 lesbians and me and Mel. And we're down there. And Al gets up to speak. And I have this on videotape, by the way, which is great. He's up there. And he's talking about immigrants' rights and women's rights, and there's nothing that he's saying that I can really blow my whistle. And then he begins talking about stronger families. And at that point, I said, okay, I can blow my whistle there. So about a minute into his speech, I got up on this fence, and I blew my whistle. And all hell broke lose. It was great. Our signs went up; we threw up fliers; we began chanting, "Gore is killing Africans: AIDS drugs now." And Al Gore, on that tape, he is so pissed. He is like, oh, fuck. I'm announcing my presidency, and here are these assholes.

Tape III
00:35:00

The crowd began screaming at us. That raised the volume level much more than we ever could, right? So now there's hundreds of people screaming at us; we're screaming at them. The crowd begins getting violent. And one woman had a whistle pulled out of her mouth, and her tooth was chipped.

So we chanted for, it seemed like eternity. On the tape, it's actually only like three minutes. And then finally, I said, okay, we need to go, because people are getting violent.

To get out, we had to actually go back through the whole crowd of people. And Mel got punched by somebody as we left. And I finally said, we can't go through this; we have to go over the fence. So we went, but we had positioned ourselves right between the cameras and Gore, so they got the action on tape beautifully. And at CNN,

the announcer says at the end: these things are very carefully choreographed. And the campaign cannot have been happy that a protest broke out about getting AIDS drugs to Africa, which was great. And, immediately, it was national news. The next day, the *Washington Post* ran a front-page story on the issue, that they had been holding for weeks.

We got in the van — they did not arrest us — got in the van. We drove back to New York. And that morning, the next morning, he was on Wall Street. We got in past the barricades. And I once again agreed to blow the first whistle. And Al came on the stage, and I was right in front of him, and I, he looked me right in the eye, and I know he recognized me, and I just smiled at him, like, here I am! And at the same point in the speech, I blew the whistle again, and we started it right again. And now he was prepared: I love free speech! Let's hear it for them! Come on, let's hear it for them. So he was all prepped on what to do this time.

Other activists, from ACT UP Philly, inspired by our action, got into a car, drove up to New Hampshire, where he was speaking that afternoon. They got onstage behind him. And they held a banner, saying Gore's Greed Kill — like, two feet behind him, as he spoke, they were holding the banner. Until some firefighters got up, apparently, and jumped on them. But they were holding it for a long time, and there are pictures of them holding this banner behind him.

So we began targeting every Gore campaign appearance; saying, we're not going to stop this until you meet with us, until you talk to us about what's going on here. And he kept saying, I'm willing to meet, they won't meet with me. He refused to ever meet with us. But the issue then became not his campaign, but what was this thing about

Al Gore and AIDS drugs, and why was he working against getting AIDS drugs to Africa? And that's, like, the death knell for a campaign, right? So we knew. This was only a group of about 20 or 25 of us. And we knew that the right target, at the right time, with the right issue, and being persistent, we could achieve results. And sure enough, within three months, Bill Clinton announced a change in the U.S. trade policy; that they would no longer fight companies that wanted to import generic HIV medications.

So within three months, we changed trade policy. You did not need 400 people at ACT UP meetings to make major change. You could do things with a small, and what's the, Margaret Mead, never doubt that a small group of committed individuals can change the world? That's what I was really going on. I say, okay, everybody else has left. They're either bored with ACT UP; they're burned out; or they're being paid to do AIDS work, they're in organizations, so they can't do it, get arrested anymore; or they've got their triple-combination therapy, and they're not dying, and they're fine. Okay; we'll do it ourselves. We'll work with the people who want to stay here. And there were definitely people who wanted to do that. And we'll do these small, focused actions.

The U.S. trade rep refused to extend this beyond South Africa. It was only South Africa. We wanted it for the whole world. So we decided to go down to the U.S. trade rep's office, in Washington, D.C. And that was a great action; that once again, the same group of people — now a little bit bigger, because we had been getting some press, right? — Kate Barnhart was there, Sharon Ann Lynch was there; Staci Smith was there — and we scoped out the scene. This wonderful thing, Kate Barnhart — you've interviewed Kate?

SS: We did already.

MM: You know, Kate looks like this kind of Midwestern schoolgirl, right? I mean, she's the perfect decoy. She dressed up as a student. And there is a library in the U.S. trade rep's office. And she had made an appointment to use the library. So her plan was to go into the library. And then, at a certain moment, she would raise the blind on the window, and go by the guard, and she would fall, and drop all her books. And when he was helping her with her books, we would all come in and run upstairs. So it was great.

Tape III
00:40:00

It was like another action I was in, in the early '90s, with ACT UP, was the Roche action, where we all went to the Nutley manufacturing plant – I'm sure people have talked to you about that.

SS: No, go ahead, tell us.

JW: We better stop and change the tape.

SS: Oh, change tapes, okay.

Tape IV
00:00:00

JW: Rolling.

SS: Okay. Roche.

MM: Roche. So this was my first action where I really saw the machinery of ACT UP working. Roche, in the end, looking back, the target was not good. We thought that they were delaying an important HIV drug. In reality, it was not a good drug, and –

SS: What drug was that?

MM: T-something. T–

SS: Was it the thing that you had to shoot up –

MM: No, T20 came much later.

SS: Oh.

MM: But that I recall, it was 220. James, do you recall the name of the drug?

JAMES WENTZY: I don't.

SS: No.

MM: T – it was just a number at the time.

SS: Okay.

MM: And we felt that they should be pursuing the drug more rapidly. It was one of the things that led us to do the eminent domain for the AIDS Cure Project. We thought they were sitting on the drug. In the end, the drug was a washout and a failure and it didn't matter. But at the time, we were mad because they weren't moving ahead quickly enough.

So we decided to target their manufacturing plant in Nutley. And a very cold day in February, we decided to do this thing where we would lock every gate to the plant, so we would shut the plant down. And I remember, we, like, the vans all met in a supermarket parking lot, at like five in the morning, and we all synchronized watches, and we all had like pla-, it was really the ACT UP machine working beautifully. People took on every aspect.

Planning an action is a real art. There's the media contacts, there's scoping the site, there's planning the action; there's legal, for those who are going to get arrested; there's support. There's a whole bunch of things, and they were all in place for this action.

And we went there. And the question was, how were we going to block the gates and prevent them from – And Greenpeace has this thing where you put your, you lock to each other through pipes. So I argued for that. And it meant that we were actually sitting in this sub-zero weather, with our hands locked in these – some people used metal pipes; we used polyethylene pipes, plastic pipes, so they couldn't saw into them. And in reality what they did was they just closed the plant down. So we sat there, piped together like this, for a half an hour. And nobody was coming to try to remove us, so we finally just said, okay, we're going to go, because we can't take this any longer.

But that was an action where I really, the first action where I really felt, wow, I am part of a well-oiled machine that really knows how to work things, that really knows how to work well. And this USTR action was the same type of thing: that people, particularly Sharon Ann and Staci, had planned out this thing down to the last minute. And ACT UP Philly – ACT UP Philly, by the way, it's important you know that ACT UP Philly has never had the low numbers ACT UP New York had. Right from Day One, they have been large meetings; they were able to reach out to people of color, as we in ACT UP were never able to do. ACT UP had a number of attempts over the years to get more people of color involved. We were never successful at that. ACT UP has always been primarily white, and that's been debated on the floor many times — why is that, what do we do — never been able to solve that problem. ACT UP Philly is primarily people of color.

So they were there, too. And so the thing was, is that Kate would fall. Once she fell, we knew it was our cue to run in, and we all ran in; ran upstairs to the second floor, where all the U.S. Trade reps' offices are; and went into her office, and

chained ourselves to her desk. She was not there that day. And then ACT UP Philly would come from the outside. And they actually put a ladder up. Now, the ladder would not reach the balcony. So they put it on a light post, next to the balcony, and actually jumped from the ladder onto the balcony, and they came in that way, and dropped a banner in front of the building.

Well, people in the building freaked out. You know, terrorists, whatever. So they cleared the building completely. The U.S. Trade rep was supposed to be doing an interview for PBS, in her office. And she came back to the building to find that there was a police cordon around it, nobody could get in, there was a banner at the front. And they had to move the interview, and she was furious, she was really pissed.

And those kinds of actions really increased the pressure. And finally, in February of the next year, Clinton signed an executive order extending that — not to the entire world, but to all of Africa, for, I think, it's any medicine for a life-threatening illness. And the big question was, would George Bush sign an executive order again when he was in office. And we put pressure on him, and he did, when he got in office.

Tape IV
00:05:00

So a very small band of us effectively changed U.S. trade policy. That moved into an organization that I'm also part of called Health GAP. And Health GAP now has been focusing on actually trying to implement – and as you know, now the figure is that 25 percent of people around the world who need HIV medication are getting it. Not a hundred percent, but that's a lot better than it was before. And once this began being talked about — at the Durban AIDS Conference I gave a presentation on this very issue, about, could we get treatment — and even at that conference, a lot of AIDS researchers and whatever were coming to me, and saying, standing up when I was

speaking, and going to the microphone, and saying, you can't do this. We can't afford this; it's more than just the meds; you need the healthcare workers, which is very true; you need the infrastructure; prevention's more important than treatment. And our argument always was: you have to have prevention *and* treatment. Because if people think that once they get HIV, they die, then they are not going to get an HIV test; they're not going to talk about HIV; they're not going to think about HIV; and it's going to be the most horrible thing ever. So if they see people living with the virus, then they will get a test; then you're able to talk about it.

And so that group of people, that small group that came from ACT UP and from Fed Up Queers and ACT UP Philly, ACT UP New York, and other people; working with Ralph Nader's project and whatever; we did what ACT UP did best. What ACT UP did best was to change the conversation. We said, it's not about the fact that we can't get treatment to Africa. It's about, how do we get treatment to Africa. ACT UP, from its beginning, said, it's not about should people with HIV be quarantined? It's about, how do people with HIV continue to have sex, but have it safely? How do we educate people to have safer sex? It's not about our doctor curing us. It's about us getting involved and saying, we're going to be on the panels that make the decisions about how research is done.

So ACT UP has always reframed the discussion. And it was great to have thousands of people available at the drop of a hat. But you don't have to have that to do that.

SS: Okay, well, you proved it again, at the Republican National Convention in 2004. What happened there?

MM: So I knew they were coming to town, and I really wanted to be a part of protests against them. And I was looking for the right way to do it. Of course my dream was to disrupt George Bush on the floor of the convention. That's what I really wanted to do, but how do you get in to do that? And some women were able to do that. Code [Pink] was able to do that, and a couple of others were able to do that. I kept looking for a way to do that. And the action people had planned was the naked action. Which was, a number of ACT UP members and Health GAP members, ACT UP Philly members; the Thursday before the convention began, we went to Madison Square Garden, and we were to get naked on the street. And we were working on that point, dropping the debt. There was a plan for the G8 nations to forgive the debt of many of the poor countries, the goal being they could use that money for healthcare and that kind of stuff, right?

So they painted "Stop AIDS" on one side, and "Drop the Debt" on the other side. And I had to decide if I was going to get naked or not. And we knew we'd be arrested. And I said, you know what? I really want to be inside the RNC, and I can't take two busts in one week. And I've been very careful to space out my civil disobedience history. And I've been involved in a number of arrests for civil disobedience over the years, but I don't do them two in a week. So I said, okay, I'm not going to get naked, but I'll hold a banner when we do the action.

So at noon on the Thursday before, we went in the crosswalk. And I held up the banner. And about eight people stripped naked. And the reaction was just, it was kind of like shock and awe. The cops were all there, and they were just so stunned that they just kind of sat there, and didn't do anything, you know. And they didn't, I thought

we'd be arrested {SNAP} immediately, right? They just sat there, and like, looked at us. And we were there for10 minutes before anybody did anything, because they just didn't know how to handle these naked people with "Stop AIDS" painted on themselves.

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They finally came over and said, you have to leave. And one woman was actually allowed to actually just go and get dressed. So I could have done it and not even gotten arrested. But the rest of them chose to get arrested. And they were all arrested. And it was front page of the *Daily News* the next day, and it got tremendous press, and we beat everybody to the punch. And it did get some discussion about dropping the debt in the newspapers.

So then, over the weekend, the word came that we had found a way to get into the convention itself. It wasn't during the evening, but it was during the day, when they were having the Youth Convention.

I said, okay, who's speaking? Well, the Bush twins are speaking – okay – and Andrew Card is speaking. Andrew Card was then the White House chief of staff.

I said, well, that's a pretty good target, the chief of staff. Okay, I'll do that.

So 11 of us — you had to go to the area where they were selling the pins and that kind of stuff, and you had to — and this is not secret, so I can say this — you had to register to get a ticket to go in. So I gave my name, Social Security number; and they gave me a ticket. And so, it was completely legal. So we all got tickets. And the plan was for us to go and act like Bush supporters. And there were 11 of us who were going to get arrested, and there were like two or three who were just going to be there to report what happened to everybody else.

So we go in. And we actually sat in the seats of the New York delegation. And there's all these young, very white Republicans; young people, in their teens and twenties, and here I am, 50 years old, and I'm, I was with Katie [Kaytee Riek] – okay, I'm blanking on her name now.

JW: Swenson?

MM: No. From ACT UP Philly. I'll think of it. But Paul Davis was there, Sharon Ann Lynch were there, Staci Smith was there. And then we had some people who were first-timers, who just came to a meeting the weekend before, had never done CD before, and we explained to them what would happen, and they said, fine.

And so once again, I volunteered to kick off the action. And it was between the Bush twins, who had had the most press; and Andrew Card, who was a better target. And they said, we'll let you choose. When you think we're going to get the most attention, that's when you do it. And I said, fine.

So I was there. And we had to act like Bush supporters.

So they came out. And they passed out signs. So all those signs you see people holding; those are all made by the RNC, and they're all hand-painted, and they pass them to you. And then you had to get up and stand and cheer when they did, right? Which I found very hard to do, because I hated George Bush so much at that point. So I would just get up, and I would go – I would just mouth it, but I wouldn't chant "Four More Years." At least it looked like I – nobody could tell. And so we were with them all the time talking about Bush's chances in New York and all this kind of stuff. And so then people begin speaking, and the Bush twins get up to speak. And the Bush twins;

they really are dumb. I mean, they're just, they do not speak well at all. They're just getting them saying pap about how much they love their dad, and nothing.

And so I, I just couldn't interrupt during them, because they're so meaningless. But Andrew Card – but there's a lot of press for them, a lot of cameras for them. But Andrew Card was right after them. So that was great, the press would still be there, and Andrew Card is speaking, so hopefully they'll stay.

So Andrew Card gets up. And I just waited a minute or so. And got in the aisle, and blew my whistle, and took my shirt off. And we had "Drop the Debt, Stop AIDS Now" T-shirts. And I said the crowd in Tennessee had gotten violent. But it was like minimal violence. There was a whistle pulled out, there was somebody punched, right? I have never seen the kind of violence, at any action, that I saw from these young Republicans. They were vicious. They began jumping on me immediately. So I moved back to my seat inside, and sat up on my chair. And they began pushing me off the chair. I had a big gash on my leg and on my shoulder, bleeding. One of our, it was about half women, half men. One of the women — very petite woman — was on the floor. And ABC photographed this young 20-year-old asshole guy kicking her while she was on the floor. There was so much hitting. And the press, of course, there was so much press immediately; they were all over us. And it just was pandemonium, it just went insane. All we were shouting was, "Bush lies, stop AIDS now; Bush lies, stop AIDS now." And they just went insane.

But I mean, really I'm serious, more violent — because we'd been in a lot of places; infiltrated a lot of places. Christine Gebbie, the AIDS czar; we infiltrated a speech she was giving, and we did the same thing, we disrupted. I've done this a lot of

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times. Nobody has ever gotten anywhere near as violent as these Young Republicans did. It was really scary.

So we all were arrested. Some 17-year-old kid came by, to try to snap a picture of us, right? And he was wearing an anti-Bush button. Because he was there with his class, but he was anti-Bush. So the cops followed him back to his seat, and they arrest him, because they said, he's with us. They bring him over to where we're being held. And we said, excuse me; he's not with us. We don't know him; we have not seen him before.

Yeah, right.

No, really, he's not with us.

He spent 36 hours in jail.

This was right when the cops were doing all those sweeps, arresting a whole block of people who weren't doing anything. So by the time we got to the Tombs, which are the jail cells down at the court system, there were hundreds of people who had been held there for over two days, still waiting to get out, going stir crazy.

But I got to be on the floor of Madison Square Garden, during the convention. And the fact that we had infiltrated, and gotten in there, got a lot of press. And we got the debt issue in the news again. Once again, people were talking about – and they eventually did forgive a lot of that debt at that time. So that was very successful.

The only action I did that I am actually prouder of than that action was shortly a-, now we did the Gore action; that was June of '99. So I felt quite comfortable that any action in '99 was not going to affect Gore's chances in 2000, because it was a

year and a half ahead of time, and even though I wanted Gore to win, I felt okay with doing that, right? But I really felt I had to hit Bush, too; because I'd hit Gore, I had to hit Bush.

So in September of 2000, a number of us from ACT UP Philly and ACT UP New York, and I guess other non-affiliated – went to Pennsylvania, where Bush was speaking, to protest him as he left the engagement. And then we knew he was going to speak at a fund-raiser luncheon. So a bunch of us went. And once again, this was like, two guys and a dozen lesbians doing this.

And so we're walking up to the Holiday Inn. And I'm walking in front. And we went up, separate, because we didn't want to all be together, right? So we go up there. And the cops say, why are you here?

And I say, I'm here for the Bush fund-raiser.

They said, fine, go in.

And then there's a group of six lesbians behind me. And they say, why are you here? And they say, we're here to have lunch.

And they said, no, you can't come in, it's a fund-raiser.

So I don't know why they didn't say they were there for the fund-raiser. But the result was, I was the only one who got in. Nobody else got in.

So here, I'm in the Holiday Inn. And you have to pay your five hundred bucks, and get your nametag, and then you go and do your thing.

So I'm all alone. I'm thinking, okay, what the fuck am I going to do? I'm alone; there's nobody here. And it's pretty scary to be alone.

So I look around. And the woman with the nametags turns around. And I swipe a nametag. And so now I have a nametag, with the name, I think it was like "David Robinson" was the nametag.

So I go in the bathroom. And my heart's pounding. And I'm like, what am I going to do? Okay, I'm going to put the nametag on. And I'm just, I got to go in. I mean, I'm alone, but I got to go in.

So I go in. And I sit down, at a table. And I say, hi, I'm David, you know. What's up? And we sit, and we discuss Bush's chances in Pennsylvania for an hour, while we eat rubber chicken, right?

And by the way, I have a bright orange "Bush kills" – whatever – poster in my shirt that keeps kind of like creeping up, and I got to keep pushing it down to make sure nobody sees it.

So we're talking. And I have to play – and people keep coming over to say, you're not David Robinson, are you? And I say, well, no, we have the same name. Apparently he was some very famous wrestler from the area, and they all knew him, and I was obviously not David Robinson.

So then Bush enters the room, and begins going around, table to table to table. And I'm like, oh my god, I get a fuckin' Bob Rafsky moment. I get to actually confront Bush, like Bob Rafsky did.

So I'm all set. And I'm, like, what am I going to say?

He's coming over to our table. They call him up to the podium, and I miss the chance. Oh, well, I missed that, but I can still, I got to, I got to do something.

So he begins speaking. And I say, okay, when he begins talking about healthcare — because he was announcing his Medicaid plan that day — when he begins talking about healthcare, I will stand up, and say my thing.

So he's talking; and he's not saying anything. He doesn't say anything about anything. It's just about, we're all here, we're all together, let's win this thing. And it's like, so I said, okay, I'm just going to count to five, and just do it.

I have to tell you honestly, this is the moment of my life I am proudest of. Because being alone, in a room with 500 Republicans, with a poster in my shirt, and confronting the nominee for the Republican Party, it taught me that courage is not about being unafraid – because I was scared shitless. But courage is being scared out of your mind, and doing it anyways. You know? And I just said, I have to do this, for all those people that didn't get in here. And so I just stood up; I pulled my poster out. And I said, George Bush, you're a drug-company stooge; you haven't done anything for AIDS in Texas; you're a pawn of the drug companies. And I tell you, there were people all over me immediately, like right to the ground, on top of me, and they're ripping my sign out, screaming. Secret, Secret Service immediately pulling me out. And I'm chanting ACT UP, fight AIDS, fight back. And they drag me out, and look for my ID.

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And I think I'm going to get arrested. And I learned later that one of the men who were down there with us was going to block his car so I wouldn't be in jail alone, which was very nice of them to do, so I wouldn't be alone. And in the end, they didn't arrest me. They just said, where are you from, why are you here? And I just said a couple of thing-, and they let me go.

But being alone, against your enemy, like that, is a very powerful thing. So that was great, to be able to confront him. It didn't get a lot of press. But for me, it was very visceral.

The thing inside the RNC, that was good, because that did get press, both at the naked action and the action inside. And once again, it was great to be in the belly of the beast, and actually confronting people. And once again, with a small group. So the thing I learned is that – and it was tough for me, because during this time period, of the late '90s and the 2000s, people kept saying, ACT UP is dead; ACT UP no longer exists. And I kept saying, excuse me; we meet every week. It's a small group. We're doing actions; we're getting arrested; we're changing U.S. trade policy; we're confronting the candidates. Why are all of you being interviewed to say that ACT UP is no longer here? Because we are here. And it was very frustrating that because we weren't – I remember the guy who, in St. Patrick's, threw the host on the floor? Now you know, before that happened, we had long debates on the floor. And we agreed; nobody was going to do anything sacrilegious. There was a lot of debate. They were going to stand silently, and there would be nothing that would disrespect the views, the beliefs of the people in that room. And that guy ignored all of that, and threw the host on the floor.

He left ACT UP shortly afterwards; was not involved with ACT UP very long. But I remember five or six years ago, him being interviewed, in his cushy job in Connecticut, as to why ACT UP was dead, what happened, and what happened to ACT UP. And I was, I felt like saying: Fuck you! You were involved for a couple of years. You didn't play by the rules. Now you're gone, and now, because you did this one thing

— which is your claim to fame — now you're telling everybody else that ACT UP is dead.

It was great to have thousands of people available to ACT UP at the time. But it did prevent me from being able to be actively involved. I had to kind of toe the party line, and do what other people said. And once we became small, I have done a number of actions that I'm very proud of. But I've done those actions because we aren't this huge organization.

Of course, one of the problems when you have a very small organization now is that if you have a room of 400 people, and you have 10 crazies in the room, you can deal with them, right? If you have a group of 20 people, and you have 10 crazies in the room, it's much more difficult to control that room.

So I have to be honest, to say that in the year before the anniversary action, I had really stopped going to meetings. I was working with Health GAP; I was working with the AIDS Treatment Activist Coalition; and I couldn't handle the difficult people in ACT UP anymore.

Since the 20th anniversary action, I have come back and been going to meetings. But there was a time there where I just said, it's too stressful for me. There were a lot of people in the room who had problems with me. I don't deny that I am not the easiest person in the world to get along with. But there comes a point where you, throughout my time in ACT UP, I have taken breaks — six months here, a few months there — because you need that, to kind of recharge and come back.

And so it's – it's just important to know that there are different types of activism that work in different ways. Now we're trying to form this new group that Larry

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Kramer called for; it's called the Queer Justice League. And it's struggling. Because when we met, there was a roomful of big people.

ACT UP, from the beginning, had a broad age range; from Iris Long, in her sixties, to Kate Barnhart, who was 16. There has always been a large range of ages in ACT UP. The same thing for this new group. There were those of us old-timers, who had been doing this for years. And there were people in their teens and twenties. For some reas-, but there was never, in ACT UP, I never felt any ageism. I never felt that there was a generational problem. The younger people respected the older people's experience; the older people respected the fierceness of the young people.

In this new group, right from the start, there was a lot of intergenerational anger. A lot of young people saying, you fucked-up old gay white men; stop telling us what to do; stop thinking you know everything; we're sick and tired of you for setting the agenda all the time. And there was incredible amount of anger from the young people towards what they called "old gay white men." And therefore, a lot of the older gay white men were really pissed at being called these names by the young people. And that group is not doing so well, because of this tremendous anger directed within the group. And it's getting smaller every week.

So at ACT UP, at least – most of the anger was directed outside the group. But the anger inside was there, but not strong enough to destroy us.

SS: Okay. Well, Mark, we're at the last, very last question.

MM: Okay.

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

MM: The greatest achievement, like I said before, was reframing the question. I don't think our greatest achievement was what many people say, getting drugs out there faster. Because we did that. We shortened drug approval process. But we did that because the drug companies wanted that, too. And that's why we were able to do that. And it was important, and we did that.

But what we did was we changed the questions. And we said that people with a disease are now going to have an active part in setting the agenda for that disease. So, patient empowerment: I think being on the panels at the NIH, deciding what clinical research would be done, deciding what prevention messages would be done. To say that, for the first time in history, the people who have a disease are going to be the ones – not only part of the agenda, but really setting the agenda, saying that our needs are more important than the needs of the researchers or the people, the bureaucrats.

So that was, I think, and that has changed in all the diseases now. Now every disease recognizes that it's the people with the disease who really need to be included in the discussion. It never happened before.

The biggest disappointment was what I also spoke about, was the fact that you were not allowed to disagree with the group. And when I did disagree with the group, on any issue, it wasn't like, I think you're really wrong; I'm going to debate you; but I'm going to work with you. It was like, fuck you; how dare you say that. I'm not talking to you anymore, goodbye. And a group that cannot accommodate dissent within the organization really loses a tremendous resource in its members, because a lot of the ideas I had, while they may not have been popular, were certainly worth debate.

So I think it was the monolithic nature of ACT UP that was, for me, the biggest disappointment in the group.

SS: Okay. Thank you, Mark.

MM: All right?

SS: Thank you.

MM: Thanks so much.

It did get cool in here, right, eventually?

JW: Yeah.

SS: Yeah.

JW: That was Katie Krause you were talking about?

MM: No. Oh, what was, oh, about –