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Interviewee: **Mark Harrington**

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Interviewer: **Sarah Schulman**

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00:01:38 **SARAH SCHULMAN: So, let's start by your just saying your name, how old you are, today's date and the address.**

MARK HARRINGTON: Hello, I'm Mark Harrington. Today's date, my age – 43 – March 8, 2003, and we're at my apartment at 611 East 11th Street, number 7-A, in New York's East Village.

SS: Thank you, Mark. Do you remember the first time you heard the word AIDS.

MH: No.

SS: Can you think back to when it started to become part of your life?

MH: Yes.

SS: Can you tell us about that?

MH: Well, I was 21, and I was a sophomore in college when what later became known as AIDS, was first reported about. And my first concrete memories of it are from the spring of 1982. I was taking a semester off from college to do a photo project in San Francisco, which is where I'm from, and I was working at UC Medical Center, to pay my bills. And my then lover, who lived in Boston, was sort of obsessed with anything that had to do with disasters and the end of the world – or, any kind of disaster.

So, I would Xerox for him all the articles that were coming out in medical journals – like the *New England Journal [of Medicine]* – about, what the gross things that were happening to people that were dying of what later became known as AIDS. And I was also – I was temping, so I got moved around between different departments, and one of the departments I was working for – in the nursing department, they were typing up

these protocols for how nurses should take care of people with AIDS, and they were all just seven lines long and ended with give palliative care, assist with pain, and just – they were all just – a short death, to death – there was no Bactrim or no prophylaxis.

So, I was 21, 22, and it was pretty scary. But, it was also – it seemed like it was far away and happening to people that I didn't know.

SS: What kind of photographic project? Were you an artist at the time?

MH: I was doing a photo project for my thesis at college, and I was just going around taking black and white pictures to sort of try and do desolate urban landscapes – it wasn't very original, but –

SS: Were you an art student?

MH: I was in the visual and environmental studies department at the time.

SS: So, what was your vision for you life at that moment?

MH: I thought I was going to be somebody in the arts, and I wasn't really sure whether I'd be a writer or a DJ or a musician or a graphic artist or a collage artist.

SS: You were at Harvard, right? It was a disciplinary type of –

MH: Yeah, I mashed together my own major, because I ended up doing some history and literature, visual and environmental studies. And my final – my thesis project was actually a translation by Walter Benjamin from something he did in the 30s. So, I was jumping around, trying to make my own thing.

SS: That was something you still do today.

MH: Yeah.

SS: Yeah. So, when did it first come near to your life?

MH: Well, we had some friends that were in New York's – in the downtown art scene, and friends of theirs were getting AIDS in the early, early '80s. And so, we would hear about it – rumors – and sort of – a friend of our – for example, David Armstrong, the photographer, had a lover who died of AIDS in 1983. So, it was semi-tangible. I mean, we would come down here and go to openings and see people and see people that were quite serious about using pretty hard drugs at that time. And we were pretty serious about sex ourselves. So, there was a lot of risk going around. But, in Cambridge and Boston, it was sort of – again, it seemed sort of – like it was happening somewhere else.

SS: Do you think you're a person who's attracted to danger or repelled by it?

MH: Both.

SS: I know it's hard to think back, but, as an outsider first experiencing people with AIDS, did you feel that you wanted to get close to them and understand what they were going through, or did you want to get far away?

MH: Well, it didn't really happen to me like that. What happened was – then, I subsequently I met a man who lived here in the East Village and moved to New York in June of '86, and he had a friend who had a big art opening at the Robert Miller Gallery, and came to his opening with what was obviously, KS, and he denied it. And I was sitting with – I just remember sitting with my then-lover, and sort of talking about it on the street. And they had an affair, so I was suddenly going, okay, I can draw the line, where I could possibly have been exposed via this lover – very important guy in my life.

Then, when we broke up, subsequently over different stuff, I recall him violently not wanting me to test or us to test – in '87. But, in '88, another man that I was friends

with began to develop symptoms of what used to be known as ARC – AIDS-related complex – so, he was losing weight, he was coughing a lot, he was having fevers. And most frightening of all, he was having kind of mental things going on – psycho – nervous psychological things. He didn't know what they were, and I didn't know what they were. Then, when he told me he had ARC in '87? It was '87 – it was the fall of '87. So, it wasn't like I had this – I went somewhere and saw a person with AIDS. It was this friend, sitting right here in this room, telling me that he had ARC. And he was a man that I was very fond of. And also, I could easily see myself in his shoes. He's the same exact age, etc. So, very quickly thereafter, I actually joined – ACT UP was already there. So, I went across town and joined it.

SS: So, when AIDS started to get really close to you, did you talk to your family about it?

MH: Not in terms of me or anything.

SS: Did they know you were gay?

MH: They were very familiar with the fact that I was gay, yeah. And they had actually ended up being fairly supportive, after a couple of difficult years. But, they were very supportive of me being gay. And then, later, they were actually very supportive of my ACT UP work, although, I think it probably had freaked them out, as well – since I wasn't telling them anything about my own status, until I did.

SS: Okay. Let's go back to this ARC time. I mean, that's a category that we don't use anymore. And looking back on it historically, what kind of function do you think it served?

MH: Well, it's interesting, ARC was the waiting room. You're waiting to get AIDS, but you don't have full-blown AIDS yet. And there was a whole lot of stuff going on in the late '80s about who's going to get full-blown AIDS. And what is the link between – it was still really possible to believe that there were quite a lot of people with HIV that wouldn't progress to full-blown AIDS, and that numbers would go banded about between – some people would say 50% are going to go on to get AIDS.

And then, suddenly, it turned into 95 or 90% and that was actually during the same summer as the Stephen Joseph demonstrations and the occupation of his office and, sort of, demonstrations about the city epidemiology.

SS: We'll talk about that later.

MH: Right. So, ARC was still around then as a sort of a grab bag of stuff that happens to you on the way down to getting, sort of, PCP or KS – which were regarded as the first – usually, the first two things that would happen to somebody with AIDS.

SS: Do you think it made people feel better to know that they had ARC and not AIDS?

MH: I don't know.

SS: How come it's not used anymore?

00:10:00 MH: Well, they still talk about B symptoms or symptomatic HIV. And if you had a cluster of those symptoms, most people recommend that you go on anti-retroviral therapy. But, I don't know – sometimes those acronyms come and they go. That one went.

SS: Okay. So, you went crosstown to the West Village to go to ACT UP. Do you remember if anyone brought you there? Or, did you just go in?

MH: I just went. I had drawing, usually, that night. And, instead of going to drawing, I went to ACT UP. And I actually never went back to drawing.

SS: So, did you believe that you were infected, even though you hadn't tested at that point?

MH: No. But, I thought I could be, but I was not really dealing with that.

SS: Okay. So, what do you think brought you there?

MH: I was really concerned about my friend Scott [Johnson] who – the one who had ARC – and I was concerned about Jay [Funk] and me – Jay was the lover that I moved to New York to be with – and our whole community. And I was very angry about the – what I felt was the general passivity of the population in the Reagan years – in general, about everything.

A friend of mine from Edgewood, in San Francisco, where I'd grown up had been killed in Nicaragua by the Contras while he was trying to build a dam there, for a small village. And I just remember – I was very angry about a lot of things during the Reagan years, and I'd just had sort of felt like I'd been pretty passive. And I didn't really know what ACT UP could do, but it seemed to me like the only possible first reaction would be to do something like ACT UP. And so, it seemed very intuitive for me to go there, even though I didn't know much about it.

SS: Had you ever been politically involved before?

MH: No.

SS: Had you ever belonged to any kind of gay organization or anything like that?

MH: No.

SS: So, where did you live out your gay life? Did you go to gay places at all, before you went to ACT UP?

MH: Well, my life in Cambridge was very mixed, so there was a bunch of people that didn't go to Harvard, and there were some that did, and there were a bunch of guys and bunch of girls, a bunch of gays and a bunch of lesbians, and a bunch of straights. And there was sort of a whole lot of mixing going on. And there was sex and drugs and rock and roll. It wasn't apolitical, but it was definitely more interested in the arts and personal experience. And then, when I moved to New York, I noticed that a lot of my friends were much more living inside of a gay male environment, and – which was one that I didn't really – I didn't like that, being. It felt more restricted. On the other hand, it was much bigger, so – And I felt like the women were not as part of our community and I couldn't tell if that was because of New York had always been like that, or was AIDS dividing up those groups?

SS: So, what kind of places – where did you go, when you would go out or something?

MH: The Pyramid, the World. Remember the World?

SS: Second Street!

MH: The World was so great. The Bar and sometimes we would go to one of those huge clubs – the Palladium or the Roxy.

SS: But mostly, it was East Village places.

MH: Yeah, it was mostly – we thought of ourselves as East Village people, but there was stuff – it was the '80s and there was stuff going on all the time. There were

huge parties. I remember going to an Art Against AIDS AmFAR event in '87, with Jay that John Kelly was at, and being blown away by that.

SS: So, you came to ACT UP. What were you doing for a living at that time?

MH: I had been fired from two restaurant jobs as a waiter, because my attitude wasn't right for being a waiter – not in New York, at least. And I was working in a film archive, doing data entry, in Chelsea, part-time.

SS: What were your career goals?

MH: I was writing scripts that I thought might be turned into screenplays at that point. I didn't have any concrete career goals. I was doing my mid-20s, with great glee and abandon.

SS: So, then you come to ACT UP. Do you remember what you saw when you walked in the door?

MH: I'd like to say that I think I saw Maria Maggenti and David Robinson in a dress, but I'm not sure that that might have easily been a later – a lamination of a bunch of different meetings. I remember walking in and seeing two very attractive young people that were my own generation in a large room of very enthusiastic people talking about a whole lot of activities. And principally, Wall Street II was being planned at that time.

SS: Can you say what that was?

MH: Wall Street II was the first anniversary demonstration done by ACT UP in New York. It was the anniversary of the first action, which was held on Wall Street, and the second one – we had become much larger. And I think the slogan was, "No More

Business As Usual.” And a lot of different affinity groups sort of did different manifestations around that idea so that Gran Fury – the artist collective – made these fake dollar bills that had People Are Dying While You Do Nothing, or the Burroughs Wellcome stuff. I was part of a new affinity group that just had been trained just for that action called Wave 3. So, we sat on Trinity Place and Rector Street, right near where the World Trade towers used to be and blocked traffic, until we were all put onto a bus and taken to some precinct. I can’t remember exactly which precinct it was.

SS: Who else was in Wave 3?

MH: Marvin Schulman, Jim Eigo, Russell Pritchard. Later, Scott Walls; later, Pam Earing. The first – I’m trying to remember who – Richard Deagle, Ken Woodard – Richard and Ken both did some of the graphics that were used in that and subsequent demos.

SS: So, how did that feel? You’d never been arrested before, I assume?

MH: It was really exhilarating. It felt, in a way, safe, too, because we’d done this training. Gregg Bordowitz was one of my CD trainers, they’re called. It felt very safe. I felt very protected and part of a group. And then, when it was over, I felt like we’d crossed this barrier and it was very exciting.

We spent the rest of the spring trying to get arrested as many times as we could.

SS: You stayed with Wave 3?

MH: Yeah, I stayed with Wave 3.

SS: So, did those people become close friends?

MH: They became close colleagues, and we would do a lot of things together. We were insane. We met every week. We met every week. So, somebody had to go to

each committee in ACT UP and come back and report to us what they were doing. Close colleagues, I would say, as opposed to close friends.

SS: And did Jay come to ACT UP with you?

MH: No, he came later. By the summer, when we had the Gay Pride March, he was there, in front, with Bush, I think – a big Bush poster, in the hall – remember the hall of shame?

SS: What was that? Why don't you –?

MH: It was a list of AIDS criminals. I mean, a bunch of pictures of huge posters of AIDS criminals, and it had their picture and a horrible quote. So, it had George Bush, the senior, and it had Reagan and it had the Cardinal. It had Dukakis, it had Helms. It had people that we thought were particularly egregious.

SS: Okay, so, how long did you stay with Wave 3?

MH: Well, I was actually formally still with Wave 3 as late as the NIH demo in May of 1990. So, I was still – I mean, I would sort of – I was also doing other stuff by then, too. But, that was my sort of base.

SS: And what was the first committee that you joined?

MH: The Actions Committee.

SS: Why did you pick the Actions Committee?

MH: Because that's where the action was. And then I joined the Issues Committee, because we wanted the Treatment and Data sub-committee of the Issues Committee to give a training to Wave 3, so that we could understand the research and treatment issues. And this was in summer, 1988, when some of us, and ACT UP in general, had already begun planning what became the FDA demonstration. So, we didn't

really understand it. So, I thought – I went to the Issues Committee to meet the people who were doing that work and the Treatment and Data sub-committee sort of, quickly, over the next few months, became a full committee.

SS: And so who was in that?

MH: That was – Vito Russo was in that, Jim Eigo was in it; Gary Kleinman, David Z. Kirschenbaum, Iris Long, Ph.D., and it sort of waxed in – Margaret McCarthy was in it. It sort of waxed and waned over the next six months, but that became another base of activity for me. And then, I also joined Gran Fury and worked on things like the Read My Lips poster and the bloody hand. So, I was joining a lot of different groups.

SS: So, every week, you went to Actions Committee, Issues Committee, Wave 3, Gran Fury, and the Monday night meeting.

MH: Yeah. It was nice that I had a part-time job where I set my own hours. It was great.

SS: So, it was an entire way of life.

MH: It was an entire way of life. It was totally engrossing. And then, everyone would go to Benny's Burritos afterwards, and have Margaritas and burritos and talk about it. It was great. It was really, really exciting.

SS: Had you ever had, like a posse like that before?

00:20:00

MH: Yeah, but in a different setting, in a different way. In Cambridge, I had a group of really, really close friends that we just did a whole lot of different things with. But, it was different. But, both were very good.

SS: So, what were the treatment issues when you first came to T&D? What was available, actually? Let's start with that.

MH: Well, AZT was available, if you had a diagnosis of AIDS.

SS: Which was defined as what? This is '88 we're talking about?

MH: This is '88, and AIDS is a clinical definition. It's any number of, any one of 21 different opportunistic infections or cancers.

SS: That was the definition in '88?

MH: Yes. And later, it was changed, in '93 – if you had under 200 T-cells or — and then they added some other indicator conditions, like cervical dysplasia. But, in '88, it was a clinical AIDS diagnosis, following an opportunistic disease.

What was available was AZT, if you had full-blown AIDS. Bactrim was available, but not widely used for PCP prophylaxis. Aerosol Pentamidine was still experimental, for PCP prophylaxis. And there was a whole group of activists and researchers in New York, who had been doing, sort of, community-based alternative — not particularly alternative, but community based research, because they felt that the medical establishment hadn't been studying treatments to prevent the opportunistic infections. So, Aerosolized Pentamidine was seen as a treatment that had sort of come out of the community.

SS: Who was doing the —

MH: Joseph Sonnabend, who's still around and is a great clinician, and Michael Callen and Tom Hannon at the Community Research Initiative. And they'd actually founded that, to do the research that they felt the government wasn't doing.

The first issue, as far as I was concerned was that the language that was being used in the Treatment and Data sub-committee needed to be explained to the rest of ACT UP. And the very first thing I did was, I went to their teach-in, and I just wrote down

every word that I didn't understand, and I looked it up and made a glossary out of it, and distributed to ACT UP in July, when they had a teach-in. So, I felt like, the very first thing was translating that language and getting people to be able to – I remembered that Jim Eigo and Iris Long presentations seemed very academic and they were very full of words that maybe not everybody would immediately understand what they were talking about. And I felt it was very important for the FDA demo to be a success for people to understand what the issues were.

And then, the second issue was to get drugs to be studied faster. So, we had to list all of those drugs – many of which didn't pan out, like AL-721, Dextran Sulfate, Peptide-T, etc., and we had a pretty long list of what we thought the FDA should approve or test faster.

In those days, a lot of people felt the FDA – thought that the FDA actually tested the drugs. They didn't understand that they actually just oversee the testing which is done by NIH or by industry. So, there was a whole lot of explaining about an institution, a set of regulations and laws and some scientific concepts that had to be done in two months, so that everybody in ACT UP could understand it, so that we could get across the message to the American people, when we went to the FDA in October of '88. And I think that was largely pretty successful.

SS: I just want to ask you about some of those meds, before we get into the FDA. Okay – how would you find out about a drug? How would they know about Pentamidine? That it existed and needed to be studied?

MH: Well, Pentamidine was a drug that was available by a special compassionate use protocol from the Centers for Disease Control, on an intravenous

basis. And at some point in the '80s, the supply ran out because doctors were getting it sent to hospitals where people were dying of PCP pneumonia and that was intravenous and was very toxic and had a lot of bad side effects. So, I think, Dr. Don Armstrong from Memorial Sloan-Kettering was trying to figure out if we could just give it to the lungs, which is the area principally affected by PCP, thereby reducing the toxicity to the rest of the body. So, they developed a series of different devices to do that, and did studies both in New York and San Francisco, to show that it worked – and it did, although it actually, later turned out that Bactrim, which is an oral pill, was more effective.

SS: How would someone from ACT UP know this doctor and know that he was doing that?

00:25:00 MH: Oh, you wouldn't. It was impossible. First of all, there was another problem with – the research into treatment was just getting off the ground. The National Institutes of Health had funded 14 medical centers in 1986 to start doing treatment research. And then, later that same year, the Burroughs Wellcome study of AZT suddenly burst out as a positive result, and so that federal network that was going to study all sorts of different drugs – it ended up sort of being an AZT network – looking at all the follow-up AZT studies. And we couldn't even find out where in New York you could get into a study. And I think Iris Long probably did the best, most important work on that, which is that she went – she figured out a way to go to each center and talk to them and try to figure out which studies were going on. And lo and behold, once we found out where the studies were, we found out that nobody could get into them, because of really restrictive entry criteria.

SS: Like what?

MH: Women of childbearing age being excluded from a study. Period. Or, if you had one other opportunistic infection, you couldn't get into a study for a given opportunistic infection. But, with AIDS, you could have 23 different ones. Or, you couldn't be on two experimental meds at the same time. Well, the only approved drug was AZT, so everything else was experimental.

SS: So, were they filled?

MH: No, all the trials were empty. They were accruing really, really slowly. And Iris, actually, out of the Treatment and Data Committee, they formed the AIDS Treatment Registry, which became kind of a national model, and it developed a directory of all the studies that were available in New York City and later, in New York State, for people with HIV.

SS: But, what about people in ACT UP who were being treated? Would they come in and say, my doctor sent me to such and such?

MH: No. In that time in ACT UP, there were not that many people that were really talking a lot about their experiences with HIV and AIDS. I mean, I remember when Peter [Staley] – Peter got up at the Town Meeting in May of '88, and talked about having HIV and it was quite – it was a memorable moment for me.

And the same when Gregg Bordowitz announced it in April, before the nine days of actions. There were some people, like Vito, that would talk about it. But, a lot of people – ACT UP was sort of like ARC, in a way. It was a way station. A lot of people didn't – maybe they would talk about it in their affinity group, or in a smaller setting, but they wouldn't necessarily get up on the floor and talk about their experience. And so, in Treatment and Data, we would do a lot of things like reading John James's newsletter to

try and find out gossip and rumors about potential treatments. And we had talked to people at CRI. Or researchers. It was hard to get information in those days.

SS: So, you're saying that people who were in T&D at that time, who had AIDS and were in treatment, would not discuss their treatments as part of their work in T&D?

MH: Who had AIDS? Other than Vito, who hardly ever came to the meetings. Jim Eigo was negative, Gary Kleinman was negative, David Z. Kirschenbaum was negative, Iris was negative. I didn't know my status. Herb Spiers, I believe, was positive. Most – a lot of the people weren't on treatment, even if they were positive.

SS: Do you know what kind of treatment Vito was doing? AZT –

MH: He probably was on AZT and I don't know what else. I don't remember.

SS: Okay, so let's take a drug like Dextran Sulfate – who would be the people who were advocating for that? And who would push that? And who would get it into the consciousness of someone in ACT UP? So, that it would get on our list?

MH: Well, we had drug buddies. So, once we had a list of stuff that we thought was interesting, we would assign a member of Treatment and Data, to sort of become that drug's buddy, and they would do the follow-up work, and call the investigator, if there was one, and try to find the literature about it, and maybe write a little report about it, and bring it to the group, to see what could happen next. For example, Dextran Sulfate was being studied in San Francisco by Donald Abrams. So, maybe the drug buddy would have called Donald, who was a very community friendly – is, a very community friendly doctor – and try to find out what was going on in that study.

SS: Okay, so you would survey every study related to AIDS and they would be introducing AL-721 or something else, and then you would get on that.

MH: A lot of them weren't even studies. A lot of them were stuff that the community was using that wasn't being studied or that we were trying to get them to study.

SS: Like what?

MH: Well, AL-721. I think the AIDS Clinical Trial Group ended up doing a study, but they didn't want to. There was no basis – there was no scientific basis for how it possibly could work. There were a lot of things that there was no possible scientific basis for how it might actually work – that we wanted to be studied – because some group in the community was using it and trying it. I mean, AL-721 was this greasy, sort of buttery crap that you sort of spread – it was pretty disgusting, but there was some theory about –

SS: Who was using it?

MH: I don't know. People were using it. There was nothing else. And then there were all these flaky substances like IMREG-1 and IMREG -2, where you'd meet with a sponsor and say, well, what's in your product and they'd say, well, we chop up the cells and it's something that comes out of that. A lot of it wasn't based on very good science.

SS: When did the Compound Q thing happen?

MH: 1989.

SS: Okay, so let's hold on for a minute. So, you came in '88. What were your feelings about AZT at first?

MH: It was, obviously bad and not an adequate therapy.

SS: So, did you recommend to people not to take AZT?

00:30:00

MH: No, I didn't ever think I should recommend anything to people. I thought we should get the information out. And when I said, obviously bad, I didn't mean they shouldn't take it, I just meant that a) it was toxic and b) it failed rapidly for most people – leading them to continued progression. And the toxicity, which included anemia, often made people sicker and more prone to other infections. One of our early successful actions was an effort to force NIH and the FDA to lower the dose of AZT, which we did in, I think, December '88. There were five studies that showed a lower dose was better. And we wrote to Tony Fauci at NIH and to FDA and Gina Kolata covered it on Page One of the *New York Times* and they changed the dose, they lowered the dose. That was one of the really good things that we did right away.

SS: Were there people in ACT UP taking AZT?

MH: Hmmmm mmmm.

SS: And were there a lot of discussion about that?

MH: Probably, but they weren't having debates on the floor about it. My whole exposure to the big debate about AZT came more in the spring of '89, when I started meeting and working with Joe Sonnabend and Michael Callen at CRI.

SS: And had you tested yet?

MH: No.

SS: So, what brought you to CRI, to work with these guys?

MH: I got offered a consultancy job by David Corkery, who used to work at AmFAR, to work for two months – to work on a conference that CRI was doing with the

community consortium in San Francisco, and with the National Institute of Allergy and Infectious Disease and AmFAR. And it was going to be this conference to jump-start the community-based clinical research movement which, at that point, not only was being funded by community groups in New York and San Francisco, but had achieved several million dollars in federal funding, as a result of Congressional hearings and, also, AmFAR was going to get involved. So, suddenly, there were going to be 20 different community-based research clinics around the country, and they needed a conference to jump-start the process. And it was sort of ironic that they hired me to be the consultant, to help work on developing that conference, because at that point, I had not been to a scientific conference yet, at all. So, I think Joe was suspicious about somebody from ACT UP, which he felt had a pro-AZT reputation.

SS: Was he totally opposed to AZT?

MH: Pretty much, yeah. He was still not sure that – or, at least he said he was still not sure, that HIV was the cause of AIDS, back in the –

SS: Were you sure?

MH: Well, I mean, he exposed me to the arguments that it wasn't and, actually, the argument seemed to strengthen the case that it actually was. I mean, the more I thought about it, the stronger it seemed likely that HIV was the cause, but that didn't mean that everybody should be on AZT.

SS: Let me just get – we're getting a little confusing here, but I know that the science is complex. This question about cause – now, I remember that there was a discussion of AZT as a co-factor – that there were other co-factors –

MH: Yeah. Co-factors.

SS: When would you say the discussion shifted from co-factor to cause, around HIV, sorry – not AZT.

MH: In the scientific community or in the HIV AIDS community?

SS: In the HIV AIDS community.

MH: You could make a pretty good argument that it didn't really completely – the shift didn't really completely end until the introduction of highly active anti-retroviral therapy in '96. And I don't even think it was over, but I think by then, you had combination drugs that were specifically designed to stop that virus – that brought it down from a million copies in the blood, to under 50. And simultaneously, people's T-cells went back up to 900, all the opportunistic infections went away, and they re-gained weight – that was pretty good evidence that HIV was the cause of AIDS.

The co-factor debate focused a lot on what other things could be working with HIV to accelerate the decline of the immune system. And because of the way the immune system acts, any infection or activation of the immune system actually functions as a co-factor. So, if you get tuberculosis, it accelerates the progression of your HIV. If you get pneumocystis, your HIV viral load might go up 80 percent, because of deviant activation. So, the virus is a parasite that preys on every time the immune system gets activated. So, any time you – so people who got exposed to a lot of other infections maybe were more likely to progress faster. And then, some people would say, there are certain things that are required co-factors. That turned out not to be the case, because of the way – unless we lived in a bubble, where we were protected from all pathogens, we were going to experience continuing exposure to other organisms and be an activation and stuff like that.

00:35:00

SS: And what about the question about genetic predisposition and why some people who are exposed got infected and others not? Did that figure in at that time, also?

MH: We started working on that in 1990 and '91.

SS: Okay, so it was a little bit later.

MH: Hmmm mmmm. Exposed uninfecteds and also, long-term nonprogressors were both issues that we thought were very interesting in Treatment and Data. And I think there was some degree of – long-term survival was so exciting. There were some people who didn't know why they hadn't gotten AIDS yet, and there was other people who had really low T-cells, who were still doing pretty well. And we thought there might be a lot of secrets or scientific answers in looking at those people. And it turned out there was, but that's a later part of the story.

SS: Why don't you tell that part now.

MH: Well, in 1991, we started getting very serious about really basic science, and pathogenesis, which is how the virus and the immune system interact to cause disease over the 10 years from infection to AIDS. And we really – it was really clear to us that AZT-like drugs and the ddI-type drugs, and the opportunistic infection drugs – they were not, any of them, going to stop people from getting AIDS and dying. They would only slow it down. And the evidence was all around us. There was a tidal wave of people in ACT UP that were dying, in spite of being on AZT or even AZT plus ddI. Or, having good prophylaxis or having good doctors like Joe Sonnabend. I mean, Vito Russo died and Ray Navarro died, and there was just a huge, huge number of people that were

dying and a lot of them had been doing aggressive medical interventions with the very best that we and the medical system had to offer.

So, we started a pathogenesis group at Treatment and Data and Gregg Gonsalves had recently moved down from ACT UP Boston, from Boston, and we started looking into other theories and really wanting to put more money – wanting the National Institutes of Health to put more money into basic science, because we just thought more trials, more studies of the AZT-type drugs, weren't going to lead to the answers. And we asked them to have a workshop about long-term nonprogressors and exposed uninfecteds. And they did. And the exposed uninfected proved very, very interesting and it led to discoveries about cellular immune protection that can occur in people that are exposed – like a famous, later cohort of sex workers in Nairobi – that appeared to have some sort of a protection, in spite of repeated exposure to HIV. And then, later, they found some genetic gene deletions in HIV second receptor. They found out in 1996, that there was a second receptor, and that certain people didn't have it, because of a mutation that was otherwise silent and harmless. And if you had gotten that mutation from both parents, your chances of getting exposed to HIV – your chances of getting infected, in spite of repeated exposure to HIV, were almost zero.

So, this sort of explained why some gay men who had been very sexually active throughout the '70s and '80s – hadn't gotten HIV, and some of them had been part of the study at the Aaron Diamond Center, so they really wanted to give their blood and get studied. So, this discovery was made. But, it took seven years from the time we started pushing for them to study it and for that particular discovery.

SS: Okay, now how did the AZT/HIV debate play out in the community, in the gay community.

MH: Well, it was very violent and very unpleasant and actually, I think, very destructive. People on both sides of the debate did not tend to really give the other side – they tended to try to demonize the other side, and there wasn't a lot of – there was a lot less good will than there should have been.

I remember there was a conference at Columbia in '88 where – Marty Delaney was there from Project Inform in San Francisco; and Michael Callen and Joe Sonnabend. And I read the transcript. I just remember being surprised about how polarized people were about it.

I also think that – so that, depending on your point of view, somebody would try to make you feel bad if you did or didn't try to use AZT. I think it was disempowering to the people with HIV that were actually having to make those really difficult decisions, because it turned it into a sort of ideological debate, instead of a discussion about medical uncertainty and personal choice.

SS: How did it play out inside ACT UP?

MH: It wasn't as bad inside of ACT UP as it was in the broader community. There was also remember the *New York Native* – the *New York Native*, which originally had some of the very best coverage of the academic in the early '80s –

SS: By Larry Mass.

MH: And where many of Larry's early screeds appeared. By the late '80s, had become just a hotbed of flake, quack science – where every week, there was a different theory that HIV had come from a certain kind of monkey or dolphins, or you name it. In

any case, it wasn't – or it wasn't the cause, and there was another virus that Bob Gallo had discovered. And they also took up the AZT-as-poison cause and wrote a lot about it. It must have been very confusing for people with HIV. I mean, I remember one of the useful things that Treatment and Data did was that we put out a newsletter to the floor every week about stuff that had happened in science. And so, I think a lot of people started coming to T&D. So, I said it early in T&D – there weren't a lot of people with HIV. I think there were a lot of people with HIV in T&D, Treatment and Data, later. They weren't necessarily coming and telling us what their T-cells were or what they had, but they were sure coming and listening to the information and using it in their everyday life. And I think that's one of the good things that we did.

SS: So, you said more and more people with AIDS were coming to ACT UP and coming to T&D, but they weren't giving personal information, they were there to get information.

MH: Some did and some didn't.

SS: Did you find that people were coming to you and having personal discussions with you? What was that like?

MH: It was really scary and I felt like I was often asked questions that I didn't know the answer to, but I also felt like I could sometimes give people information that might help them make a treatment decision.

SS: Would you see similar problems across the board?

MH: You mean with all the different people?

SS: Well, like, you have five people come to you and reveal that they were having similar problems.

MH: No, everybody's course was extremely different. And that was one of the things that was – I was very AIDS naive when I joined ACT UP, and so – my friend Scott developed – he sort of got AIDS and got very sick in parallel to me getting more and more active in ACT UP. And so, I saw him after he had PCP and then I saw him when he got wasting. And then, I saw him right before he died, and he was extremely wasted, and it was very shocking to me. And then, Brian Damage was an artist from the East Village who joined Wave 3 in the summer, before the FDA action, and he got sick and had MAI and stayed at Beth Israel. And Wave 3 would go to the hospital every day and different people would – Sally Cooper – different people would – Richard Elovich – we would have shifts, and people would talk to him and the doctors, and there was no approved treatment for MAI. There was a bunch of TB drugs that were used in combination. Brian had a very good intuition and he would take out a drug that later turned out didn't do anything. And then, one day in May, we went to his room and he wasn't there, and we were a little freaked out, and the nurse said, oh, he's in the park. So, we went out, and he was in the park, in this wheelchair with some people from Wave 3. It was a nice moment., but a lot of it wasn't – a lot of it was just being there, being able to question the medical person or being able to help the social services or going out and getting the food and cleaning up. There was so much of that kind of collective activity. That was really, really powerful and great, I think.

SS: Were the families present?

MH: Often not.

SS: Can you think of examples?

MH: Brian Damage's family wasn't present at all, when he was dying. My friend Scott's family was not available. He was taken care of by an ex-lover in San Francisco. Jon Greenberg's family was present. His brother –

SS: His gay brother.

MH: His gay brother. His gay, HIV-positive –

SS: Right –

MH: A lot of gay men didn't have a family that supported them. The alternative family was what supported them.

SS: Did you discuss that overtly?

MH: Yeah, very much.

SS: What was --?

00:45:00 MH: We had a discussion about whether or not we thought we should keep on working to keep Brian alive. It was very, very painful. We went and sat in – I can't remember which park we sat in – but there were some in Wave 3 who thought that it was hopeless and that there was no, really more than we could do, and that we should just sort of palliative care and try to help make his last, whatever, period of time as comfortable as possible. Then, there was another group that thought we should really try to go push back as far as we could with the doctors on the MAI treatments. That group prevailed, and he did live for six more months. And I'm not saying that the people who thought we should sort of move to palliative care were wrong or bad, it was – it's just – the decisions are very hard to make. And of course, what we did is we went back and said, Brian, what do you want to do? And he said, I want to try –

SS: Okay –

MH: Everything. So, we did that with him.

SS: But, did you discuss watching young people, gravely ill and suffering and their families not being present?

MH: In T&D, or in Wave 3?

SS: At any –

MH: Yeah, we talked about it in Wave 3. It was a big thing in Wave 3 when Russell Pritchard came out – at our retreat, at Tommy Tune's house in Fire Island that Marvin Shulman had gotten for us. It was really big. And it wasn't news that was supposed to go outside of the Wave. That was very – it was very big.

SS: What made it so big?

MH: Just because nobody else in the group had done that, and Brian – we had adopted Brian, or he joined us as our already sort of totally out person with AIDS – already quite sick. And Russell was healthy, looked healthy. That was before Mark Fisher had come out as HIV positive and stuff. He was also in Wave 3.

SS: Oh, I see, so it was getting closer and closer. There was no –

MH: It just was – I don't know, it was just because we – I guess we were very close. I mean, we did everything together and we loved each other in a certain way.

SS: I want to get back to the family abandonment question – were people surprised that people could suffer and die and their families never show up?

MH: Well, I mean, I was. But, I also – remember, the context of ACT UP was also this incredible homophobia of the Reagan years, and this incredible, sort of, hatred and disgust of gay people. So, given that all those things were going on in the broader society, those parents were part of that hatred of gay people. So, we knew they existed,

and they were not taking care of the people that were dying all around us. So, I mean, it was terrible, but I guess it wasn't that surprising – at least to me.

SS: Do you remember people missing their parents? Or, crying, because their parents weren't there for them?

MH: No. A lot of – again, a lot of the people who were in that situation were very proud and they were very loving to their support and their alternative family. Everybody's story – again, it's sort of like their progression to AIDS – everybody's story is very unique and different.

SS: So, like, in Brian's case, did your group make the funeral arrangements, or did his family?

MH: We did.

SS: And what were they, do you remember?

MH: There was a really great memorial gathering at – there was a hotel that was in the 20s, the East 20s – that a bunch of artists had painted a different – each, a room at some point in the '80s. Can you imagine that happening now? And he had a room that he painted. So, a bunch of us from Wave 3 and a bunch of his artist friends got together, and we just did the thing where you just sit around and tell stories. But, it was great, because we were surrounded by his art and – yeah, it was really neat.

SS: One more question on this, and then we'll move on. Do you remember any situations of having family members present and having them be in conflict with ACT UP people?

MH: Well, Ray's mom was there – around, when he was sick.

SS: But she was very supportive.

MH: She was supportive, yeah. Yeah, I don't remember them coming and sort of zapping us.

SS: Okay. Let me ask you one thing about – when you came to CRI, was that your first paid job – AIDS-related job? Or, had you –

MH: Yeah, but it only lasted for two months.

SS: Right.

MH: But, still it was a big thing. It was great validation to get paid some to do some AIDS work.

SS: So, let's go on to the Compound Q thing. How did that unfold?

00:50:00 MH: I don't remember where we were, but one night, Larry Kramer came to the floor of ACT UP and said that they're dancing in the streets of San Francisco. They have a cure. And we weren't there – at least, I wasn't there. And I heard about it, and I was very disturbed because I was very disturbed about that being given as the report. And there had been some coverage of it, I believe, in the *Native*, but then there was a really big, really inaccurate article by Gina Kolata in the *Times* and I think I was quoted as saying something like, it's not health food, it's a plant-derived substance. So, a lot of people were saying, it's got to be really non-toxic and stuff because it's just like from a plant.

Well, of course, plants are great at making lots of poisons and stuff that are bad for us. And it hadn't been tested. And the kind of underground test that was being done was not what many of us thought was being done in a shoddy way – not very scientifically rigorous. And I got caught up into a battle that was actually happening between Tom Hannon and Michael Callen at CRI. And I was pretty naive about that. I

think, to some extent – to some extent, I was willingly manipulated, but CRI was falling apart on the issue.

SS: Of Compound Q?

MH: Yeah, Tom was in the trial, and thought it would save his life. And Michael thought it was poison and even worse than AZT, and so did Joe. There was lots of questions about the informed consent, and some of the doctors in New York were doing the underground study, including Barbara Starrett, who was my doctor at the time. And there was quite a – sort of a debate about it, over the summer of '89, which was the same summer that a lot of other stuff was happening with parallel track and ddi and post-Montreal. And then, someone died in August, and his roommate called me and gave me the whole sorry story. In retrospect, it's not at all clear what role Compound Q played in this man's death. He was, obviously, very sick when he went onto it. And I couldn't tell from talking to the roommate whether the Compound Q accelerated his death. But, what I could tell was the way the people that were involved in the underground trial sort of, like, backed away, as he was dying. And the roommate was left to take care of him. And that sucked. Then, there was this piousness about community-based research that was going on – about, well, it can't be bad, because it's being done by community and we're good and everything we do is good.

And community can do bad science, just like the scientific establishment. And I didn't like the idea that people were risking themselves to go do these underground trials and then, if something bad happened, the people in the emergency room wouldn't get told that they had been on this substance that was injected and intravenous, and seemed like it

could cause a lot of horrible, neuro-psychological side effects. So, the controversy was very, very painful and ended up –

SS: Why do you think Larry [Kramer] was such a cheerleader for Compound Q?

MH: I don't know.

SS: So, Gina Kolata, what was your relationship with her?

MH: Well, it was a tricky relationship, because we really felt like we needed to use her, to get into the *New York Times*, because the *New York Times* often set the agenda for the rest of the media. And, if there was one thing that ACT UP was determined and savvy about, it was media. And, I think, in retrospect, one of the most effective things that ACT UP as a whole did, was really put AIDS onto the national agenda, and into the national consciousness in a way that it just sort of, was like, okay, it's not going away and neither are we. So, I think that was a huge – so, I think, say between '87 and '91, there's a huge shift that happens inside of the consciousness of the American people because of ACT UP. I really do. And so, Gina Kolata was just one part, and she was, and is, a science reporter, so she would be important for the medical stories – do you remember Marty Robinson?

SS: Sure.

MH: Marty was really a huge – he was really angry about DHPG or ganciclovir – the drug – it was a drug that was the only then available known treatment for CMV retinitis, which causes people to go blind or have terrible diarrhea. And, the FDA and NIH were causing the limited access to that drug to be shut off, so that everyone would go into a placebo study. And Marty was just outraged and all of – and he brought it to

00:55:00 T&D, and we were outraged. And, how could you force people to be in a placebo study where, if they're on the placebo, they're going to go blind. And, he sort of taught us about using the media, because he was from the '70s.

SS: The Lavender Hill Mob.

MH: The Lavender Hill Mob, but before that –

SS: Oh, he did that zap of the psychiatric –

MH: He did the duck zap, in the early '70s, where –

SS: What was that?

MH: Where somebody who was running for governor said, if it walks like a duck and talks like a duck, it's a duck. And it was some kind of anti-gay thing. So, he dressed up like a duck and went to that candidate's office. Anyway – so, he's like, you have to use the press. Here's her phone number, call her up. And, we did all this stuff around DHPG and she started running it. So, then she would use us, because it was part of the story, and it was a good part of the story.

But, she didn't always get her facts right, which created a lot of problems. So, she would over-exaggerate side effects that happened in a trial of an expanded access program for ddI, and thereby endangering the whole expanded access. On the other hand, we weren't objective, either. We wanted her to run a certain message our way, and she didn't always do that. But, she did it a lot.

SS: Do you think that she got it, in terms of homophobia and the personal cost of AIDS?

MH: No, I don't think she ever got it.

SS: And, how did that play out in her work?

MH: Well, she really – she covered stuff like a naive science reporter who really thinks that science works and that it's not affected by business or politics or other social forces. She had trouble putting together the business, the science and the political and, sort of, the personal. That wasn't her specialty. Her specialty was, sort of, explaining why randomization is a good idea or the basis for placebo studies. So, she had a sort of limited frame. Actually – ironically, it was the *Wall Street Journal* reporters like Marilyn Chase that really were better able to cover, say, the Compound Q story, from all angles. There was a business angle, and there was a medical angle, and there was a huge community story going on. She was able to integrate all that, in a way that the *New York Times* wasn't able to do.

SS: Overall – in what ways did the *New York Times* best help people with AIDS, and in what ways did it most obstruct them?

MH: Oh, I don't think they helped people with AIDS. I think – Larry Altman, who's the chief medical reporter and has been covering this story since '81, is fundamentally a very lazy reporter. And, you can see him at conferences watching Laurie Garrett and Jon Cohen, and trying to figure out what they're doing, and what they're covering. He, at the International AIDS Conference, almost never leaves the media center to go to the real conference and talk to the real people that are there.

He also – he likes to do that kind of medical coverage where there's that one, lone, heroic researcher guy that discovers the cure for syphilis. And, I think he's terribly disappointed, for example, by the news about the VaxGen vaccine phase III trial that just ended two weeks ago, because Don Francis from the CDC was one of those hero guys that would have been great in a movie, and, in fact, was in an HBO – was played by

Matthew Modine in an HBO movie. We'd love to see him go all the way from the CDC warning about AIDS to discovering, against the odds, this great vaccine. But the vaccine is garbage, and Don Francis lied about the results to the world – and particularly, to the African-American community. So, that kind of reporting – where you just make this one little hero – it totally doesn't tell the story.

SS: Why does he want that? That paradigm?

MH: I mean, he comes from an older generation, but I don't – I think the *New York Times* has always had trouble putting the story together. Remember? There would always be – there was a good reporter called David Dunlap in the early '90s, who used to cover a lot of stuff. They took him off the beat. That was in the Metro section. They took him off the beat and put him onto obituaries. I thought that was very ironic. Good reporters had trouble getting support from management – have always – not good reporters, good AIDS reporters at the *New York Times* have always had trouble getting support from management.

SS: What was it about AIDS that made them so uncomfortable? Or, that they were unable to grasp?

MH: Who was the editor in chief at that time?

SS: I don't know.

MH: Was it Rosenthal, still? Or, was it Max Frankel?

SS: It was Max Frankel.

MH: Abe Rosenthal had been a huge homophobe and Max Frankel wasn't, supposedly, but I think there was this institutional culture that made it very hard to deal

with gay people, gay issues. I think that's changed a lot in the last few years, but during ACT UP's life, it didn't change.

SS: Okay. So, what was your relationship with Burroughs Wellcome?

How did you first have contact with them, and how did that progress?

01:00:00 MH: In January of 1989, Peter Staley was planning his zap occupation of Burroughs Wellcome headquarters in Research Triangle Park, and he wanted to have a meeting with them first – to set up the issues and let them know what our concerns were. And, he invited me to come as the, kind of the science guy. So, Peter and I went down and went into the building, and the PR woman – Peter said, oh, that's a really nice fountain, that would look really great dyed red, blood red, in a demonstration. And she sort of grabbed his arm and said, let's go in here, where the meeting's going to be.

So, we met with Dr. David Berry, who is the head researcher, and had been actually involved in the AZT teams since the very start. We had a very stimulating, weird conversation with him about science and business and price. And he said, the eventual – he said that the only way to treat HIV that mutates so rapidly is going to be with powerful combinations of drugs. That's the direction this disease is moving in. So, in that respect, he was very smart. He also said things about – you couldn't give it away in Africa – even a price of zero would be too high. Their limited, sort of, sense of the human cost of AIDS was really, was really apparent from that.

SS: What did that mean, that statement? I don't understand that?

MH: Well –

SS: You couldn't give it away in Africa.

MH: You couldn't give it away in Africa. We were saying, well, AIDS is a problem around the world, not just in the U.S., and your price is way too high here, and it's totally out of reach for people in Africa. And, he's, like, well, even it was free, they wouldn't be able to use it in Africa.

SS: Why?

MH: Well, probably the argument that the drug companies still use, about the lack of infrastructure, poverty, illiteracy and so on. But, in any case, I think I came home and wrote an article for *Outweek* about "Interview with a Vampire" where I talked about – I had some of the quotes of what he had said, and David Berry. Then, later, Peter did the demo and got arrested and that was great.

SS: What did he do?

MH: He brought in four – they were called the Power Tools – and it was an ad hoc affinity group, and they were dressed up in business suits, went into the building, asked the receptionist where the bathroom was, went – didn't go there – went upstairs, occupied a room, barricaded themselves in, used drills to block doors with metal plates and went to the window and unfurled a huge banner that said, I think, Lower the Price, or something like that. Or, Burroughs Wellcome has Blood on Their Hands or one of those slogans. And, I think media were out and took pictures. And then, Peter – they voluntarily surrendered, and Peter had even lined up money to pay them back for the expenses – in other words, for the cost of the damages, so that they wouldn't have to go to jail and do a long sentence. That's what happened. And, that was part of a campaign that went on for the next eight months, to get Burroughs Wellcome to lower the price of AZT at that time -- \$10,000 a year, the most expensive drug ever marketed.

That culminated in a huge – well, a fairly large ACT UP demonstration on Wall Street, and congressional hearings by Congressman Waxman, and editorials for once, in the *New York Times*. There was pressure coming at them from all sides. And, right around the same time as they lowered the dose, I think, they also lowered the price. So, the combination resulted in a significantly lower price. And, it's now less than – I believe it's less than 3,000 bucks a year now.

Okay, so my relationship with them – didn't really go very far beyond that. I mean, it was my first exposure to drug company people. And, he was a very smart one. I happened to think he was evil, at the time. In retrospect, I don't really think of him as evil, as just as much as he's a fairly typical smart drug company scientist.

SS: Okay. So, '91 begins the basic science investigation, is that correct?

MH: Yeah. You'll see a little bit of it in the 1990 treatment agenda, but it's much more obvious in '91, I think.

SS: And, had you tested by that point?

MH: Yeah, I – no, actually. Jay tested in July of '90, and I came back, and Jay had turned out to be HIV positive, so I just went in to see Joe Sonnabend and had my T-cells done, and Jay came out with 25 T-cells.

I took Jay there because he didn't have insurance and we needed to get his T-cells done right away. So, I went with him and had T-cells done, too, and mine were 500, and my T-cell ratio was inverted, so I knew I was HIV positive, but I didn't actually take the antibody test.

SS: Why not, by the way?

MH: Well, I think there was some denial still going on. It went on all the way until I had my lymph node biopsy in April 1992.

SS: So, what medication did Jay go on?

01:05:00

MH: So, Jay went into the ddI versus AZT trial at NYU, and I don't think he took the drug for very long. We thought he should be in the trial so that he could get the monitoring. So, he was getting his free T-cells there and stuff like that. He might have taken the drug, which was a blinded trial, for a couple of months. But, I don't remember which one it was. He didn't stay on it for very long.

SS: Why is that?

MH: I don't think we really thought there was much reason for him to be on it. I actually think we were wrong, but at that time, it just didn't seem like being on either one of those – it wasn't clear how much being on either one of those drugs would help somebody who was still healthy, but had 25 T-cells.

SS: Were you making treatment decisions for him?

MH: No.

SS: No.

MH: But, we would talk about them a lot. And then, we'd talk about them with Joe, who was our doctor. And then we'd talk about them with each other. So, he made his decisions.

SS: And you wouldn't do any meds?

MH: And I wasn't going to do anything, because I had 500 T-cells, and I was healthy.

SS: Right. So, at this point, you knew more about AIDS than almost anybody. Or, you were one of the very small group of people. So, in other words, you could give people information that could change their life. Were people coming to you? And, were you getting a lot of attention, or was there a lot of tension around you?

MH: I think some people would come, and I imagine that they were – I think what I said probably could have a big impact on them, and I tried to be very careful about giving information and then making it clear which was information and which was my opinion. And, also, to try and find out, sort of where they were already. For example, my friend Scott, who all this time is dying – and we finally get a ddI out on parallel track in October of '89, and I haven't seen Scott for several months, so I don't know that he's wasting away, looking really gaunt. I remember calling him up, saying, ddI is out. He said, Mark, "It's way, it's way too late for me." And, I went out and saw him in December and I said, well, maybe it is, but I was pretty naive, too. I had sort of this funny kind of information without existential experience. I hadn't lived through the horrible '80s, the way a lot of people in ACT UP had – here in New York, with lots of their friends dying all around them. I hadn't lived through that.

So, when I went and saw Brian, it was my first time to go see a person with AIDS in the hospital. So, it was all happening at once – the learning, the book learning, the, sort of, meeting people – the reporters, the scientists or the doctors and in being part of ACT UP in the community. And, I guess, being a – what your question gets to – is being a representative and being a member of that community, and also being somebody who can sometimes be – there was later tensions about people who are at meetings, and T&D

was at a lot of meetings. I think, yeah, there was a lot of tension around that, but it wasn't always around the people that were – there was a lot of tension within ACT UP.

SS: But, did people want to be your friend? Did they want to have sex with you? Did it make you a focus of people's needs?

MH: I think some people wanted to be my friends. I think – I didn't – some people in ACT UP had a lot of affairs with other people that were in ACT UP, and I didn't. So, I tried to keep my sex life sort of semi-autonomous and outside. That doesn't mean that there weren't, of course, a couple of flings or brief affairs, but I don't think that – I mean, there was lots of charismatic, sexy people that were doing amazing work in ACT UP. So, I don't think that particularly was happening to me.

SS: Did it change the way that you related to other people – to have so much information?

MH: Yeah. I think it was overwhelming for a while, and I think it probably went to my head in a way that, in some respects, I regret, in retrospect. I think – yeah, I think – it was very hard to deal with all that energy and passion and I think there was a certain kind of power that came with it for awhile that was both attractive and dangerous.

SS: Well, with ddI, there started to be – this is my perception, and you may disagree – as the science became more complex and as there were more choices, there would be people in ACT UP and in the AIDS community who had access to more information and would therefore make – or, could understand the information – and would make different treatment choices than people who couldn't understand the information, or couldn't get a grasp on it. So, there might have been people in the rank and file, still taking AZT, at a point where really nobody in the know

would have continued to do that. Would you say that that's – or do you think that's wrong?

MH: No, because I think some people probably stayed on AZT because – and, they were fine. A lot of people were on AZT and maybe it didn't even slow down their progression, but it didn't accelerate it. And so, later we would call them, maybe, slow progressors. Or, maybe people who started too early or who didn't really need it. And then there were some people – there were probably some people in T&D that started on a combination therapy earlier than some other people, but, at the same time, we weren't pushing it. We were saying it was being studied, and that some people thought it was a good way to go, but we were also saying, there is no evidence that it is any better, yet. This is all '90, '91.

SS: Right. So, by '91, how come basic science had never been done?

MH: It had been done. In fact, even in '92, when we did a report about what NIH was doing, there was \$800 million going to AIDS, and \$100 million was going to the clinical trials. So, the rest was going to different kinds of basic science and epidemiology and natural history. But, we thought even more should go into both. And we also – there was a sense, both – there was a sense in the scientific community that a lot of the basic science in AIDS had happened up to that point and wasn't very good.

SS: Did you agree with that?

MH: Hm mm.

SS: So, at what – at this point, how influential were you, in terms of national research – national research agendas?

MH: Well, I mentioned before that there were several different bases that I did my work from when I joined ACT UP, so that there was Wave 3 and then there was Gran Fury and there was Treatment and Data Committee. But, also in this – then, there was this other base, that sort of came out of that work I did with CRI that was sort of amorphous. It was in-between organizations. It was sort of as a linker or connector. And then, there was also a base from the – after the – around the time of the National Institutes of Health demo in May, 1990, there was a national committee established by NIH called the Community Constituency Group that was a group of representatives of supposedly all the communities affected by HIV. And there, I was doing work on the committee that worked on opportunistic infections. So, we had the ability both to affect their – and T&D worked on that. And T&D had a committee at that point called the Countdown 18 Months Working Group – that a lot of the PWA's that were on the committee joined, and it was lead by Garance Franke-Ruta and Derek Link, who were both younger members of T&D. And, instead of adopting a drug, each of them adopted an opportunistic infection and laid out a research agenda for the next 18 months. And, actually, they got a lot of it accomplished. So, I was trying to do some of that from the inside, and they were doing – fanning out and doing a lot of it on the outside. But, I was also able to use the CCG as another sort of base of operations and within the AIDS clinical trial group, we wanted more resources to go to opportunistic infections research, and not just to AZT-type drugs. And after the big demo at the NIH campus, that actually started to happen.

SS: So, was getting on the inside – was that one of the demands of the NIH demo?

MH: Hm mm.

SS: And so, what was the consequence of that within ACT UP?

MH: Well, the consequence was a civil war within ACT UP. And, eventually, it led to the fissuring of the organization.

SS: So, can you explain it from your point of view?

MH: Well, when we were all on the outside and we were demanding to be let into the inside of a lot of different institutions and structures. And, I always thought that the Denver Principles which had been put out in 1983 were – they were about empowering people with AIDS by putting them into positions of power in every institution that had any kind of choice or power over people with AIDS's life. And so, originally, I think that was written from the point of view of PWAs should be on the board and staff at GMHC. They should be on the board and staff. But, we were also looking at research and we thought that they should be involved in the committees that were doing the research on us or our friends and colleagues. And, that was part of the principle behind the establishment of the CCG. And, it was also part of the principle behind some of our demands at NIH.

SS: Just explain what the CCG is?

MH: The CCG is that Community Constituency Group that I mentioned – that's the committee of, say, 24 representatives from around the country that now, and for the last 12 years, have been part of the AIDS Clinical Trial Group, and they sit on and vote on every committee and they participate in the design of scientific protocols. And they participate in educating the community about them and the help – or, they're supposed to help make policy decisions with the scientists about which trials are appropriate to do,

how they should be designed, what the eligibility criteria should be, whether they're ethical or not.

SS: As administered by the NIH?

01:15:00 MH: And, it's administered by the NIH, yeah, but it takes place at academic centers in cities around the country. And, it's actually become a paradigm now, that in every program that's funded by the NIH, whether it's a vaccine program or a prevention program or epidemiology program, has a community advisory board and has some degree – whether token or real – of community representation. So, that was a big empowerment demand that was one of the many demands that were going on at the NIH action. There was also less AZT – don't just study AZT, study the opportunistic infections; study women with AIDS and women – what was going on with women? The definition of AIDS and women; establish a women's health committee, etc. A lot of those demands were met, but I don't know if this conflict was inevitable, because a lot of other groups started having influence in their policy areas and it never caused a civil war in ACT UP. I mean, the Housing Committee is a good example. We just supported them. We said, great, you're going to a meeting with the city, great. Or needle exchange? So, anyway, we – there was a group within ACT UP that thought we should stop going to those meetings.

SS: Who was in that group?

MH: Well, it was, I think perceived by some that the leader of that group was Maxine Wolfe. And, Tracy Morgan was in it, Heidi Dorow was in it. Sometimes, Walter Armstrong was in it. It was unclear, because it – like many groups in ACT UP, it was partly a social group and partly a political group, and so they didn't – it wasn't like you

were a card-carrying member of different ones. But, there would be, there'd be really dramatic arguments on the floor and screeds and manifestos would be passed out. At one point, it was proposed that there be a six-month moratorium on meetings with people in the NIH system. And then, other people wrote manifestos that HIV-negative people should get out of our way and people accused each other of slowing down research and there was a demonstration by one group of people from ACT UP at the ACTG to stop the ACTG-076 trial of AZT, to prevent transmission of HIV from mother to child, and later, that study broke out positive and became really influential, in terms of getting HIV treatment starting to be used in developing countries.

SS: So, was that proven to be effective?

MH: AZT?

SS: In utero, right?

MH: Yeah, it's dramatically effective in reducing by over 50% the transmission of HIV from mother to child, if it's given for the third trimester, and then during intra-partum and then, I think, for some short period of time to the mother and baby after birth. But, it was dramatically effective, yeah.

SS: Why did these people want to stop 076?

MH: Well, they said that they were against it because it was using the mother as a vessel and not treating the mother – and there was a lot of reasons on their fact sheet – why they didn't want the study to go forward, but that was one of them.

SS: So, what do you think was the real conflict?

MH: Well, at the time, I told myself that there was an ideological conflict and that they didn't like the style of activism that had evolved within T&D. And that the

style – actually, the substance of the activism that we were doing was based on trying to understand and change scientific culture and institutions, with political means, using citizen power. So – and I think that was influenced by – for example, the ideas by Michel Foucault that I and others had read about when we were younger. And, I think there were other ideas about how you engage with institutions that are your “opponent” that were based on a different kind of antagonism. In other words, I think we were still antagonistic to the NIH or drug companies or people, when we met with them. But, sometimes, we’d work with them on one thing and then fight with them about another thing. And, also – unlike – well, the war in Vietnam gave us feedback from the war that the war wasn’t working. But, the peace movement wasn’t meeting at the Pentagon.

01:20:00 There was this sort of pseudo-analogy that the NIH was like the Pentagon or something – that we shouldn’t meet with them and that they were bad or evil. There was evil Anthony Fauci – as one of the letters to *Tell it to ACT UP* reported. And, there was a meeting that I and Rebecca Pringle-Smith and David Beyer from the National Cancer Institute had with Fauci to talk about doing a different kind of study that would be larger – it would be larger and simpler and would get answers that were more reliable. And the dinner happened the same time as there was a big women and AIDS conference at NIH, where there was a demonstration. There was a lot of legitimate anger at NIH at that time about not dealing well with women with AIDS. And so, I think the fact that I, from T&D, had a meeting with Fauci at the same time as there was a demonstration and also a women and AIDS conference, revealed that there was a lack of coordination, if not outright distrust between these groups. And, I’m sure that contributed to some of the mistrust and antagonism that was taking place.

SS: Okay, so, women with AIDS were not getting basic benefits and some men with AIDS inside ACT UP were having – were doing advanced treatments and having access to advanced information inside the NIH. Do you think that that was what was playing out?

MH: Well, it's interesting to hear you put it that way, because that's not – I don't think that's how a lot of people saw it. There was a group within T&D that worked closely with the State AIDS Institute to construct what became the AIDS Drug Assistance Program, which later was enshrined into law by – well, not enshrined, but written into law by Senator Kennedy and the CARE Act, and became a nationwide program. But, the model for that was actually developed by people in – among others – from people in T&D, and that was a special program to buy AIDS drugs for people that couldn't afford it.

SS: Who were the people who worked on that?

MH: David Z. Kirschenbaum, Gary Kleinman, Iris Long and probably others. But it wasn't only men that were in T&D, and a lot of the legitimate issues that were being raised about women with AIDS were similar to legitimate issues that were being raised about minorities and AIDS and about injecting drug users and AIDS. There were a lot of groups that were focused on identities within ACT UP. And then, there were groups that were focused on institutions and issues. So, there was, like, the Housing Committee. It wasn't the Housing for People of Color Committee, or the Housing for Injecting Drug Users Committee, but it did incorporate issues relevant to those. And then there was the needle exchange group. So, Treatment and Data didn't see itself as the treatment for gay men group, it saw itself as the group that was working on research and

treatment and treatment access for everybody. And, ideally, if the therapeutic research worked out and the drugs would be approved and put into the system, then private insurance and Medicaid and then, later, ADAP would cover them. But – and there was some degree to which the healthcare access issues were very hard for ACT UP to deal with, because they were so huge. And, we would have demos at hospitals, but a lot of the issues had to do with federal entitlements, and they were huge. So, Treatment and Data focused more on the research and treatment, sort of, FDA and NIH and drug company issues. They didn't focus as much on, say, Medicaid, Medicare. But, they did have a role in constructing ADAP.

So, and, then there was a feeling, I think, by some of us, that around, in the events around the 076 demo, that there were women with AIDS and they were being manipulated by a group of women without AIDS, who were running that committee and that demo and that campaign. And, it was very, very striking what happened at the CCG in Washington, when the ACT UP women's caucus, or whichever subset of it that did the action, had the 076 action. And, by then, the CCG had been formed and there were representatives – there were Black women and there were Latin women and Black men and Latin men and injecting drug-using men. There were people from the hemophilia community and Native American community that were all in the CCG, and that they felt – they had a purchase and a legitimate right to be there, but also to affect the research that was being done.

And, they felt like the argument had been hijacked by a group of New Yorkers who were having an argument among themselves and that the zap and the demo prevented there from being at meeting about the 076 trial between the investigators, who

01:25:00 were running, who were designing the trial and the rest of the people in the ACTG who were going to actually implement the trial and the community people that were interested in the trial. So, there was a feeling that the zap actually shut off that kind of debate and discussion, and information that was very important to the people on the other communities that were part of the CCG. So, it almost led to the CCG falling apart. And, then, back in New York, it led to a lot more unpleasant and very painful debates about who we were and what we should be and how we should do things. That was in March, 1991, and by August, there were serious discussions going on inside of Treatment and Data about whether we could, in fact, stay in ACT UP, or whether we should leave.

SS: Because now you've had all these years of hindsight and let me just ask you to tell me the truth. What do you think those women's motives were?

MH: I think they're all different. I think that there were some things that we did that must have pushed a lot of buttons about guys doing deals – white guys – closed-door meetings. There was a lot of mistrust. We came to the floor every week and when we had – when I went to the ACTG with these elaborate transcripts about every single thing I did and distribute them at T&D and we spent thousands on Xerox. But, there was still mistrust.

SS: But, had it been there from the beginning?

MH: No.

SS: So, you worked with Maxine and Tracy and Heidi for years before there was this –

MH: Not really.

SS: No?

MH: No. I mean, I did some civil disobedience that I remember Heidi and Tracy as being on the same bus and stuff. I think I sang songs, we sang songs. We went to parties, we went to dances and demos together. But, we didn't, I don't think, do committee work together. But, in any case, there were lots of people in ACT UP, so it wasn't – I don't know what everybody's motives were. You'd have to ask them.

Our motives were – I mean, our motives were to get the research to happen as quickly as possible to get answers for people so that we could find out if drugs worked or not, and if they worked, what were the risks and side effects and get the information to people, so they could make treatment decisions.

SS: Okay, so when you decided to leave ACT UP, which was August of '91

–

MH: No, no, that's when the discussion started. That's not at all when it sort of happened.

SS: So, what happened from then on?

MH: Okay – well, we've skipped – we haven't covered Montreal, parallel track, ddI, the approval of DHPG or fluconazole.

SS: Do you want to do that?

MH: Well, I just – there was a whole lot of other things that were going on, and that were accomplishments in those years that they should at least be mentioned.

SS: Okay. Let's take it – say that list again?

MH: Montreal, parallel track, ddI, the approval of aerosol Pentamidine, DHPG, Fluconazole and a bunch of other drugs. The expansion of studies into opportunistic

infections, and the establishment of the Women's Health Committee; the changing definition of AIDS by the CDC.

SS: Well, yeah. All right, let's start with ddi.

MH: Well, between the FDA demo in October '88 and the Montreal AIDS conference in June '89, I think Treatment and Data had developed some experience in, sort of – not all the drugs that we asked for in October at the FDA really panned out. So, I think our standards – we started to understand a little bit more about the science, and our standards got a little higher. So, by '89, Treatment and Data decided to write – we decided that the federal government didn't have a research plan for the epidemic, to comprehensively cover everything from opportunistic infections to HIV and to women and children and so on. So, we wrote our own treatment agenda, and we brought it to Montreal, and it had concrete proposals for what they should study, how they should study it, and what they shouldn't do, and gave concrete examples of 16 AIDS drug development disasters, and had specific demands out of different agencies and institutions in the government – from NCI, National Cancer Institute, to NIAID, to FDA, CDC and the Congress and the President, and the community and the press. And so, we held a press conference that was really big – there was like nine people there – Michael Callen, Vito Russo, Joe Sonnabend, Peter Staley – it was a big test. There were a lot of different approaches. But, we said, look, the federal government doesn't have a plan, we do, here's what they should do.

01:30:00

And this was after all of ACT UP had just stormed the opening ceremony in Montreal and had really taken over the opening of that conference from the Prime Minister of Canada and the President of Zambia, who were supposed to open it. And all

the AIDS activists that had come to Montreal just started going inside that hall the night of the opening ceremony and I don't think they knew – they all didn't have registration – but, that made big news. And that was a great moment of ACT UP.

SS: Let's go back to the FDA thing around ddi – who was your contact there?

MH: ddi hasn't happened yet. This is June '89, and ddi is still in phase one.

SS: Okay, so when you were responding to the FDA –

MH: We had a meeting with the Commissioner, Frank Young and with Ellen Cooper, who was the director of anti-viral drug products, right before the FDA demo. And, we came with Ortez Alderson, Margaret McCarthy, Jim Eigo, me, Terry Beswick, from ACT UP/San Francisco; Sue Hyde, who I think was from the National Gay and Lesbian Task Force, and a couple of other people from non-ACT UP, New York orgs. That was a big meeting, where they brought a lot of FDA bureaucrats, listened to our demands, shook their heads, told us they were on our side, but we didn't understand the science. The things we were suggesting would really challenge the very scientific process itself and couldn't be done. Then they issued a press release about how many common areas that we'd agreed on. They had written a press release before the meeting. Anyway, it was a bad faith meeting and not much came out of it, but we started going to these hearings that were being held that winter and spring by a committee that was known as the Lasagna Committee that was established by Bush, with an agenda to both, sort of weaken FDA regulation and also speed up approval of drugs for cancer and AIDS.

And that's where we use that as an occasion to bring up the DHPG ganciclovir issue. A bunch of people from ACT UP went out to Fauci's office after that, and got him

to call the head of the FDA and say that they should change the policy. A month later, they changed the policy and if people who had CMV retinitis that was life threatening could all get access to the drug. And within three months, it was approved by the FDA, even though it hadn't gone through a controlled clinical trial.

SS: Why do you think your relationship with Fauci was so much better than your relationship with the FDA?

MH: Our relationship with the FDA was very – was actually – improved very much during the process of the parallel track initiative in '89. So, at Montreal, we made a list of drugs that we thought should be studied much faster, and one of them was ddI, which had just gone through Phase I, and a couple of journal articles had come out.

And the company, Bristol-Myers was headed by a man who had been a chief fund-raiser for President Bush and maybe a Yale classmate of his. And Larry Kramer, being a Yalie, was very excited about this, and decided that he would use his own Yale background to messenger a letter up to Bristol-Myers headquarters, which is up on Park Avenue, saying that we wanted to meet with him immediately to discuss ddI. And, Jim Eigo had had this idea for this kind of expanded access program that would take place while the trials were being done, but it would open to people who couldn't get into the study. And starting at Montreal, but really moving very, very fast right after that, Fauci endorsed it, Frank Young endorsed it, and Ellen Cooper endorsed it, and Bristol Meyers said that they would be willing to do it, and by July, we were sitting down with the company and actually talking about the design of those parallel track programs, and who should get in, and how much AZT failure do you have to have and how sick would you have to be? Apparently, they decided manufacturing wouldn't be a problem, and so, that

both the controlled trials and the parallel track opened that fall and before it was approved two years later, about 35,000 people got access to ddI from that program. So, it was a major turning point in our relations with the FDA.

SS: Did they ever acknowledge to you directly that they had been wrong?

MH: Yeah. They did.

SS: How did that happen?

MH: Well, I think most concretely they did it by changing their regulations to put parallel track expanded access and accelerated approval into the regs in 1992, when David Kessler had become the much more competent and intelligent and reformist commissioner. And so, ddI and then, later, ddC, d4T – most of the anti-virals that are on the market now were approved via accelerated approval. So, by '92, many, if not most of the FDA problems had really gone away. They had said that women of childbearing age had to be let into studies, that injecting drug users could be let into studies, that you could study multiple experimental agents, that you could be in a study for more than one opportunistic infection at the same time. Meanwhile, the AIDS clinical trial group was changing their studies, too, so that there was a whole lot of push about just sort of practical – how trials should be done – that really makes them more accessible to people with HIV that happened between '89 and '92. And it didn't all happen because of ACT UP, but ACT UP played a huge part in making that happen.

01:35:00

SS: So, when you were talking earlier about Burroughs Wellcome and Peter's strategy, ACT UP had this paradigmatic strategy of going and making a demand and then, if it wasn't met, doing an action to force the hand.

MH: Yeah.

SS: Would you say that these accomplishments that you've just laid out were primarily achieved through negotiation – interpersonal negotiation?

MH: No. I think the inside-outside strategy had a huge, huge impact. And, I think there's many parts of the outside strategy. There's the – okay, we always thought you should go have a meeting and talk about your demands. Then, if you – they don't give them to you, then you should do your demo, and then you can escalate. So – but, the demo is only part of the outside strategy. Another one is the press and another one is Congress, which at that time was run by the Democrats, and there was some great Congressman, like Ted Weiss from New York, and Henry Waxman, from L.A., who were willing to have hearings and embarrass the hell out of Tony Fauci for not doing anything about opportunistic infections in '88, and that's on the cover of the New York Times. And so there's a whole bunch of players in, both the inside and the outside strategy, but we're still outside in '88 and in '89, we're let in a little bit to the FDA, but not to the NIH. And then, in 1990, we have to have a demo at the NIH to be let in. And then –

SS: Who were some of the ACT UP people who were on the inside?

MH: Who became let in on the inside, when the inside opened up? Jim Eigo was – he represented ACT UP on the parallel track regulation writing committee. So, he was sort of the first. Then, there were people who were two-organization people – like, Jay Lipner and David Barr, who had affiliation with Lambda Legal Defense and Education Fund. And they would also be affiliated with ACT UP.

And then, through the CCG, I became involved on the “inside.” Then, a lot of different ACT UP people would get involved with various committees or opportunistic

infections or protocols, like, Garance, or Derek Link or Chris DeBlasio, who is now dead, or Scott Slutsky, who is now dead, or Jerry Johns. There were a whole bunch of T&D people who were involved in Countdown 18 Months, who did a whole lot of unglamorous, heavy-lifting inside work and interactions with companies and with researchers that might have sped up research on a lot of opportunistic infections, but wasn't – didn't get into the *New York Times* and stuff.

SS: So, if you were going to have a meeting with Bristol, let's say, would you have a contact person on your Rolodex and you would pick up the phone and call them?

MH: Hm mm.

SS: Okay, Pentamidine.

MH: So, also as part of that whole amazing June Montreal summer, the FDA also approved Aerosol Pentamidine and ganciclovir, and different people from T&D were at each of the hearings, testifying on behalf of the approvals. I think Gary Kleinman was at one and, maybe, David Z. Kirschenbaum was at the other. And, both of those were approved without really going through the traditional three phases of clinical trials. Then there was a whole slew of other drugs that came on a little faster – partly because of stuff that we did.

SS: So, in terms of your own treatment – in '91, you said that you did lymph –

MH: '92, April.

SS: Was that your first personal step into the –

MH: Yeah.

SS: And what was that procedure?

01:40:00 MH: In the Florence AIDS conference in 1991, Tony Fauci gave a talk about where HIV was hiding in the body while you didn't have AIDS yet – when you were still asymptomatic. And so, dovetailing into the whole issue about long-term nonprogressors, and what's really happening with pathogenesis, I started having some talks about it with Dr. Don Cotler, at St. Luke's Roosevelt, here in New York, and he was taking care of my friend, Jay, because Jay had developed a horrible wasting syndrome. And Don is probably one of the best AIDS G.I. doctors anywhere. And he did a biopsy and found out that Jay had a kind of E. coli that could be cured with Cipro in two weeks. So, he saved Jay's life, and in the middle of those conversations, I was talking to Donald about what Fauci had said about lymph nodes, and whether it was true, and if so, did they need lymph nodes, and I'd be willing to give one. And they needed lymph nodes, and Don was willing to do the surgery. It was elective, so, obviously, my insurance wouldn't have paid for it. It was science. There was no medical need for it. So, I went up there and had a lymph node taken out in April of '92, and then it so happened that I was giving a plenary talk at the Amsterdam AIDS conference in that July, and it was supposed to be about pathogenesis and activism. So, I was able to actually take – use pictures that were taken of that lymph node that showed the HIV inside of it, and showed the immune response to it, as well, which at that time, was a healthy immune response. And sort of just talk about the unanswered questions about AIDS and pathogenesis and talk about how people with AIDS were giving their bodies for clinical science, but they also needed to be contributing to basic science, if we were going to understand better.

SS: Why do you think you did that?

MH: Because I wanted to know. And, I felt like I could do that concretely. I didn't want to join a drug trial. I didn't think I was a candidate for the drugs, and the approach to drugs that was being used at that time, which was early intervention with a single drug like AZT and, so, I thought, well, how can you give something, give something more and that was what I could think of.

SS: Are we ready to talk about TAG leaving?

MH: Sure.

SS: So – actually, we haven't talked about TAG. We've only talked about T&D. When was TAG founded?

MH: Well, Peter, with his love of affinity group and guerilla-like actions, had – Peter established a group called the Treatment Action Guerillas in August of 1991, and their mission was to go Jesse Helms's house and unroll a giant condom on his house that would say, Senator Helms, Deadlier Than the Virus. So, they did that, and – so, that was the guerillas. And then, we were having these agonizing talks in Treatment and Data about what to do about all the tension that was happening in ACT UP and whether it was better to stay and fight or whether it would be better to leave and form a dedicated organization to research and treatment. And there had been other groups that had been spinning off around that time. And, I think Housing Works and the needle exchange group formed around that period, but in much less hostile circumstances. So, we didn't want to leave. But, it also seemed – well, at least, I didn't want to leave. The great majority of people in ACT UP didn't want us to leave. There was really – there was a polarization between two groups, neither of which spoke for the majority. I think the majority wished that we would just work it out.

But, who spoke for that group? That group sort of sat in the middle. It was big, but we were on the edges and we were shouting at each other. It was very unpleasant. It was definitely getting in the way of us being effective and doing our work. So, eventually we decided that it was not effective to keep on fighting.

SS: Did it get in the way, just emotionally? Or, were they actually holding back funding or not approving your projects?

MH: More the former than the latter. But, the kind of the personal attacks that were being made also included Peter, who had, by then, had been appointed to the Board of Directors of AmFAR, had requested some money from Burroughs Wellcome for AmFAR's community-based clinical trials network. And then, some people said that was a conflict of interest. There was a lot of – you could argue indirectly that there was some impact on funding. But, I would say it's more emotional. You're spending most of your time defending yourself on the floor, or in T&D reports or from some flak than you are actually doing committees and – remember, by the end, I'm not on the CCG, so there are 8 sub-committees – one for – each for different families of organisms. And, I'm on all those conference calls every month, plus the OI Committee, plus the CCG, plus T&D and a lot of other T&D committees, and still Wave 3 would meet intermittently. So, I'm doing a whole lot of, sort of, treatment stuff every day, and going to ACT UP and having to deal with that stress is really making it harder for me to do my treatment work.

SS: And how are you supporting yourself financially at that point?

MH: That year, I am getting money from my dad.

SS: Okay. Why do you think you let ACT UP or allowed ACT UP, or had the privilege of having ACT UP be your whole life at that moment?

01:45:00 MH: The privilege of it. Well, I had the part-time job, where I set my own hours, when I started. And then, I was able to get consulting gigs from '89 until TAG started, and then when that wasn't enough, I was able to get money from my Dad.

SS: No, but I mean – I don't mean financially, I mean spiritually. Why do you think – you were saying, I'm on 8 committees and I was doing this –

MH: Because people would come up and after the DHPG thing happened, people would come up and thank us for saving their eyesight. I would see – there would be concrete output from our work that would help people that we knew and also people that we didn't know. There's huge changes that had happened in the FDA and the NIH, in the way that research was done and the way that – I mean, I thought that we could get closer towards having a sort of a democratization of science and research in our country and that ultimately that could benefit a lot of people, and right now, it could benefit people with HIV and people that I knew and people that we didn't know.

SS: Do you feel that you gave up anything, personally?

MH: Yeah.

SS: Like what?

MH: Well, there was that whole, sort of other path of what I thought I was going to be doing with my life. And, I remember once, somebody from the Film Archive said that maybe you'll just be an activist, Mark, and I was horrified. I said, no, I'm going to become, like, a – I'm going to be in the arts. I'm going to be a writer or I'm going to be a filmmaker or something. And there wasn't any such career as an AIDS activist at that point. And it took a while to realize that we should get to the point where there was available resources to pay people to do this kind of work, because it was worth it. And

that was also part of what the formation of TAG was about, although, that wasn't so clear at the start.

SS: So, when did TAG start, as a – ?

MH: Okay, so Peter had the guerillas, and he had actually filed some paper – some incorporation papers for that, with a very minimal board. I think it was him and Garance and Derek Link or something like that. And, their main thing was to take the money from whoever the donor was that gave the money for the condom zap and just make sure that it was spent on the zap. So, then there were simultaneous discussions about starting this Research Action Group or RAG or – Gregg and I and Garance and I wanted to do a group that focused on research and then, different groups would meet after T&D and talk about it and how – and then, eventually, in January, we had a meeting at Charlie Franchino's house – this is '92 – and we decided we would go to T&D on, I think, January 22nd, and we would say that we were forming a separate organization that is not – that was – I think it was envisioned sort of like an affinity group originally, which is – that's a closed group that's open by invitation to people that you feel like asking to join it.

SS: And what was TAG doing that T&D wasn't doing?

MH: Nothing. It was the same group. I mean, we were also going to do more CDs I think – civil disobedience, so that TAG would do policy and civil disobedience – so that we would link kind of the stuff that Peter was good at and the stuff that T&D had been good at. And we would go to Astra for the price of Fosarnet or we'd go to Daiichi to speed up the KS drug, or Roche to speed up the ddC expanded access. There was a lot of CDs in the early years of TAG. And many of them were done with ACT UP. So, it

wasn't really clear if we were independent or not, but we were clearly separate, to some extent. And a lot of us still went to T&D or to group meetings in the spring. And, I can't remember what the final reason why I stopped going to group meetings was – but, anyway, TAG – Gregg Gonsalves and I did a report for them that summer that deconstructed the whole NIH AIDS research program and recommended some changes in the way it was run that the Democrats became very interested in. When Clinton was elected, Senator Kennedy and Congressman Waxman wrote those recommendations into law, and that became part of the NIH revitalization in 1993. So, in December of 1992, TAG started paying me a consulting fee to work with other organizations and to make sure that bill had got pushed through in Washington. So, that was the start of people getting – well, Gregg and I had actually gotten paid for two months to do the report. So, that was the start of people getting paid to do TAG work.

SS: Does TAG still exist?

MH: Yeah.

SS: And, is it still by invitation only?

MH: Well, TAG is now – it's a 501(c)3 non-profit, community-based organization with a Board and a staff and consultants and we use – it's not a like a group meeting where you go and you sit at Marvin's house and have a meeting. Now, it's a non-profit organization.

01:50:00

SS: And is that – would you say that's your primary arena?

MH: Well, that's my day job, yeah.

SS: Right.

MH: I'm the Executive Director of TAG – Treatment Action Group. I've been Executive Director for two years, and we just celebrated our 11th anniversary, and we have an annual budget of 600,000 bucks, and four full time staff and consultants and a newsletter and a lot of other things there. So, we became a small, professional organization, out of being a larger, volunteer activist organization, and the transition was very painful, from one to the other.

**SS: So, did you announce on the floor of ACT UP that you were leaving?
Or, did you just not come back?**

MH: Yeah, we did.

SS: What did you say? Do you remember when?

MH: I remember writing a very – a very angry fifth anniversary letter to ACT UP in March of '92 that itemized what I thought we had accomplished in T&D and criticized some of the attacks we had gotten and probably explained more or less why we needed – why I thought we needed to get away.

SS: How was it received?

MH: I don't know.

SS: Nobody said anything to you?

MH: I think a lot of – some people came up and said, we're sorry you're going. And, I think the people who were glad we were going probably didn't come up to us and say anything. It was really hard. There was this huge – there was this really exiting energy about the group when it worked well, that a smaller group, by its very nature wouldn't be able to replicate, but it was also a relief.

SS: Do you think that a mass movement around AIDS is possible again?

MH: Here, in the U.S.A.? There is a mass movement around AIDS in South Africa, and there was one in Brazil. I don't know how functional it still is. In South Africa, they really are a real mass movement with links to labor and youth and capable of mobilizing many more thousands of people than we did. On the other hand, their epidemic is much, much larger than ours – both absolutely and relative to their population. They have five million infected people in a country of 40 million. We have one million infected people in a country of almost 300 million. But, they do have a mass movement right now. And, not only is it possible, it's fighting very, very hard to get treatment to be provided by the public sector in South Africa.

SS: This is something I've asked every person we've interviewed who has AIDS. Would you mind telling us what meds you're taking now, just for the record?

MH: Well, I started taking anti-retrovirals in August of 1996, because my T-cells had gone down to 150, and I had a viral load of 200,000 and I developed thrush, weight loss, and some skin rashes, and I wasn't feeling good and wasn't looking so good, either. So, I started on a protease inhibitor, plus two AZT-like drugs. So, I've always been on a protease inhibitor and two AZT-like drugs, but it switched – the actual ones, due to side effects. And right now, I'm on a protease inhibitor that's called Viracept or, the generic name is Nelfinavir – twice a day. And, I'm on Combivir, which is ironic – which is a combination of AZT and 3TC taken twice a day. And my T-cells are about 900 and my viral load fluctuates between 1,000 and 10,000.

SS: So, which of the drugs that you're taking were you personally involved with creating or having them come to the surface?

MH: Well, none of them – I was involved in creating none of them. I was in – we did a report about the protease inhibitors and how their development should be sped up. So, both Crixivan and Nelfinavir – we had affected the actual way that studies were conducted, and maybe – possibly the way they were approved. But, that was a huge – I mean, everybody that ever went to a demo was part of that work.

SS: Okay. So, let me just ask you one last question – looking back and your life was full with ACT UP and so complex. What would you say was ACT UP’s greatest achievement, and what would you say was its most disappointing?

MH: I have to mention one more thing about why I left.

SS: Okay.

01:55:00 MH: From that summer of 1990 on, when Jay came in with 25 T-cells, and I found out I had HIV. Finding out that I had HIV liberated me, so that I didn’t feel that I had to – I wasn’t making treatment recommendations about other people anymore, and I had a different kind of stake or purchase in the work I was doing. And, also, my priority was really – my first priority was to keep Jay healthy and alive. And so, throughout the next couple of years, while all those fights were going on in ACT UP and Jay was developing his wasting and then his KS going pulmonary – that fighting in ACT UP was really taking away from my ability to take care of Jay, whom I loved, really more than anyone else, and really wanted to keep him alive. And that was another reason why I just felt like I had to leave ACT UP. I felt like the validity of my AIDS work is not at stake here. I have no question that I’m doing the right thing. But, to survive and to have a life, and to have an inner life, and to be able to take care of Jay and just be able to survive, I need to be able to get away from this stress, and where people are swearing and shouting

and – it was almost kind of a survival thing. As you said, there was a lot going on, and there was, maybe, at some points, too much.

SS: Is Jay still alive now?

MH: So, Jay died in February of '94 of pulmonary KS. His picture is on the fridge. So, your question was best and worst? Can you re-phrase it? Because I'm not quite sure how you put it.

SS: What do you feel is ACT UP's greatest achievement and its biggest disappointment for you?

MH: Well, I think one of ACT UP's greatest achievements was letting gay people and lesbians be powerful in public, and be seen by a lot of people in the American public that had never thought of us as creative, good people – as creative, good people who are doing stuff to fight for each other. And, I think – something about the FDA demo that's so – I think is very powerful to people about people with the disease, surrounding a building that's a bureaucracy – that's slowing down, that's throttling us with red tape. I think that message got across. So, I think – now, even though not everyone in ACT UP was gay or lesbian – I think that one of the greatest accomplishments was that it was a very powerful movement, where the majority of the people in it was gay men and lesbians, and that my guess is that that led to changing social attitudes to them in the '90s. And, I think – and I hope that that's lasting – even now, even under this administration.

The second thing I think is that they put AIDS into the national consciousness and on the national agenda in a way that it hadn't been put before. And, also, that didn't go away. So, all the stuff that started being pushed for, in the late '80s – more money,

attention, research, etc., access, equity – I mean, the treatment revolution that happened in 1996, with protease inhibitors and combination therapy wouldn't have happened that soon, if it wasn't for those people. So, for every single one, that went to those demos – so, even if they're not alive or they're still alive, or they're still activists or they're not – I mean, they did save lives. That was one of their goals, and they did. And they also did with needle exchange and other things.

The greatest disappointment was that it ended so fast, and that it flew apart into so many directions. And, is that a necessary part of a maturing movement? Or, is that a premature break-up, because the tensions were so horrible of – we were trying to fight on so many fronts, and also we were trying to take care of our loved ones and ourselves. Maybe it was just too much.

Not having a mass movement or the simulacrum of a mass movement is, I think, has some bad consequences, and we haven't been able to have an impact on the lack of healthcare in our country. Clinton was President, and the movement just sort of – poof – it went away. I mean, the people in Washington didn't even have a plan for how we should get national healthcare. And, I mean the gay and lesbian leadership, and I fought them.

SS: Who you thinking specifically?

MH: Just all of them – everybody in that whole – every single person. They let David Mixner – who was an experienced fund-raiser, kind of hijack the whole gay agenda and turn it into gays in the military. And we were this tiny new organization that had a little tiny legislative thing about AIDS research at the OAR – Office of AIDS Research, and we were able to get it through, but it was quiet, it was under the radar, and

02:00:00 we had a policy piece ready to go, and the national leaders didn't. I was surprised. So, the biggest disappointment was that it didn't last and it didn't do even more – that it didn't result in national healthcare, or better equity or needle exchange for everyone.

SS: I just want to ask you about your book. This is the most famous, unpublished book. Now, you got a MacArthur in what year?

MH: In '97.

SS: And is that when you wrote this book?

MH: No, I wrote it from '92 to '96.

SS: Oh, before, okay. So, what happened? How come it's not published and what is it?

MH: So, it's a book about ACT UP and TAG and treatment activism and it's also – it's sort of a mix between a memoir and a history – sort of a personal history. And, it was commissioned right at around the time that Clinton had been elected – not elected – Clinton was running and had talked about a Manhattan Project for AIDS, and AIDS was hot and there'd been -- for some reason, the media thought AIDS was big, in the start of '92, and I got a contract with Random House, and I wrote the first half of the book. And then, Jay died. And then I wrote the second half of the book after leaving. So, I was already writing a history because I was already leaving ACT UP, when I was writing about it. And then, it was finished the month before Vancouver, and the month before the treatment revolution in 1996. And so, the editor didn't really think it was a very – she didn't think it was going to sell much.

SS: Who was the editor?

MH: Her name was Ruth Fecych. I'm sure she's somewhere else now. I'd be very surprised if she was still there, given all the changes. But, anyway, she didn't think it was commercial, and it probably wasn't. I mean, it was long and detailed, and I tried to put in names of people that were into demos, even if they weren't famous, or even if they didn't do something else, because – one of the great things we used to do in ACT UP was, we would mention the names. We would list the names. And we would list the names of people that were at demos, or who got arrested, or who, or who died.

And there was something like the honor – like the honor and glory of the ancient Greeks. Like, we would list all the names, and everybody that went to the demo or got arrested – they were all just as important as everyone else. And, we all really took care of each other for a while, and that was so nice. And it's too bad that that didn't last, either.

02:02:18 If that had lasted, we would have survived for longer, I think.