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Interviewee: **Mark Aurigemma**

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ACT UP Oral History Project
Interview of Mark Aurigemma
September 11, 2014

SARAH SCHULMAN: So the way we usually start is you just tell us your name, your age, today's date, and where we are.

MARK AURIGEMMA: Okay. I'm Mark Aurigemma. I'm fifty-two years old. Today is September 11th, 2014, and we are in my apartment on Leonard Street in Manhattan.

SS: Okay, great. And where did you grow up, Mark?

MA: I grew up—my family is from New York originally. I was born in Brooklyn. They moved to New Jersey to the suburbs when I was a kid, and that's where I grew up.

SS: So how was that for you?

MA: The trees were nice. I liked that. It was fine. I was always very New York focused. I started working full-time in the summers in Manhattan when I was fourteen years old.

SS: What did you do?

MA: I worked for my grandfather at the International Longshoreman's Association. So I did a lot of errand-running and a little bit of numbers-running, too, out of the mailroom of the Longshoreman's Association on Battery Place.

SS: So did you come from a union family?

MA: Yes. Yes, my grandfather was the pension director for the Longshoreman's union.

SS: Oh, wow. Okay. So growing up, I mean, we're approximately the same age, so growing up with the sixties on television and all of the social revolution

going on and coming from a pro-union family watching the war in Vietnam on TV, what were the messages that you were getting from your family about social responsibility or—

MA: Well, it was interesting. My mother was a public defender for the State of New Jersey, and she went to law school and became an attorney at a time—

SS: Wait, wait, hold on one second. James is [coughing].

MA: James.

JAMES WENTZY: Sorry, go ahead.

SS: Okay. So your mother was a public defender in New Jersey.

MA: Yes, my mother was a public defender. She went to law school in the sixties when I was a little kid. It was quite unusual at that time in my neighborhood to have a mother who worked, much less one who was an attorney. She worked in Newark and she worked in the Appellate Division, so she only worked with people who had already been convicted of crimes, serious big-time stuff. I think I took a lot of interest in what she did, and a lot of my thinking on social issues from her side. My father was much more in the conservative Republican mode, also an attorney but with a very different set of perspectives.

SS: Did they stay married?

MA: No.

SS: Now, what came first, gay or politically aware?

MA: They came at the same time. I was gay-aware by the time I was twelve or thirteen, and I had started telling my friends I was gay by the time I was fourteen. Politically aware, I think maybe politically aware came a little bit before that. I

used to like watching the Martin Luther King speeches on television and that kind of thing. I did a lot of campaigning for George McGovern when I was nine, and I dragged my mother to a George McGovern rally at the Hackensack Courthouse when I was nine. So that probably came a little bit before understanding that I was gay.

SS: And when did you notice that there was a Gay Movement?

MA: I feel like — it's interesting. A lot of people my age say that when they learned they were gay, they thought were the only ones. And I think that I always knew that there were gay people and I always knew where they were. I was fairly familiar with New York City and what the gay neighborhoods were, and I knew that when I was eighteen or so, I could go there. So it was just a matter of sort of biding my time.

SS: So did you?

MA: I did. I did. I went to college in Boston, I spent three years working in Provincetown as a bartender, and going back and forth to New York City in the winters. Then I got here permanently in 1986 to Hell's Kitchen.

SS: So AIDS begins approximately 1981, and you're in Provincetown at that time, right?

MA: Yes.

SS: How did you first become aware of it?

MA: I first became aware of AIDS in the summer of 1981, watching some
00:05:00 little TV segment which I believe was connected to the MMWR CDC first report of AIDS.

SS: What's MMWR?

MA: Sorry, the *Morbidity and Mortality Weekly Report*. I have since worked on a lot of work for CDC and other places, so I—so that was the first official government announcement that something was going on. I think it was in July of 1981, and I think I saw a network news broadcast about that. And I remember watching it with my boyfriend at the time, and him making fun of it and saying that the landlady in his building had told him that she had heard about this and was worried about him. But he sort of talked about it in a way of, “Isn’t she ridiculous?” But I remember being concerned and frightened about it right from the first time that I heard about it.

SS: So when did it first actually reach your real life?

MA: Well, I think when I got to Provincetown in the summer of 1984, and businesses were starting to shut down, tourism was way, way off, and there was a big stigma attaching itself to the town. And I met the first person who I knew had AIDS in the summer of 1984. He was a bartender at a place across the street from the place I worked.

SS: Where did you work?

MA: I worked at a place called the Everbreeze, and he worked at Poor Richard’s Buttery, which was a very, very popular place across the street from us. I knew that he had been in the hospital, and he came out of the hospital and he came into the bar and he looked very unwell. But he had a drink at the bar, and after he left, the owner asked me to get rid of the glass that he had used, and I was incensed, and I think the owner and I had words. But I was mouthing off all the time, so I don’t think it was that unusual.

SS: It was a gay owner?

MA: Yes, yes. Also that summer, I remember the owner of that restaurant had asked me not to kiss my boyfriend goodbye. We used to walk to the different restaurants where we worked, and I would kiss him goodbye in front of the restaurant, and he asked me not to do that anymore. And it was specifically because of AIDS. It wasn't about gay; it was about AIDS, or as much as gay had become linked with AIDS. It was bad for business.

SS: Wow. That's very late, because Provincetown has this reputation of being this place that so many people went to die, that had a lot of responsibility towards people who were ill.

MA: Well, it hadn't gotten there yet, and I remember that because that summer another bartender and I set up an information table about AIDS, and there was this little petition that we had cooked up together to Congress that said, "Please spend more money on AIDS research." And we went down to the Boat Slip, which was a very popular afternoon dance place, and the owner there gave us permission to set up the table because his partner had died of AIDS, but it was very much, "You can do it over in that corner" kind of thing.

So this guy Billy and I set up this table, and we were trying to get people to sign these letters. One person came up to the table and picked up the letter, and I said, "Will you please sign this letter to your member of Congress?"

And he said, "I *am* a member of Congress." And I looked up and it was Barney Frank, and this was before he had come out. And I remember him showing the letter to the guys who he was with, and one of them said, very clearly, "But there are no cases of AIDS in Provincetown. I don't think there are any on Cape Cod." It was still

very much something that was in certain neighborhoods in New York and San Francisco. I don't think there was a lot of it there at the time.

SS: So by the time you stopped going to Provincetown in '87, had things changed there?

MA: Yeah, '86 was actually my last summer there, and then I moved back here. I think things had changed sort of for the worse. I think the town had just become more and more depressed and, my sense of it is, more sort of reactive, more, "Let's not market ourselves as a gay destination," more, "There is no problem here. Don't worry about it." So I think that that was my last sense, my sense that Provincetown had not risen to the occasion yet by the time I had left.

SS: That's interesting, because I was teaching at the Fine Arts Work Center, and, you know, Provincetown is so straight now, and do you think that AIDS had something to do with that? Do you think that was a deliberate decision?

00:10:00 MA: I don't know. I guess it just may have to do with the sort of politics and economics of gentrification, of people moving into different neighborhoods. I mean, there's no question that lots of neighborhoods changed and never changed back because so many people who had moved in and built them up and done so much work to make them wonderful died and died quickly, you know, and there was a fire sale on their assets, and there was a big and sudden turnover in terms of who was living there and what happened there. But I don't know if it was a deliberate decision. I mean, I'm not sure what Provincetown is like now.

SS: So then you moved back to New York.

MA: Yeah.

SS: And where did you move to?

MA: I moved to West 46th Street in Hell's Kitchen, and it was a very depressing winter. I was very—I felt like the same sense of intense anxiety about AIDS that I had felt in Provincetown but that it was fairly easy to escape from because you could go for a ride on your bike through the sand dunes and kind of forget about it, and also because there was a constant stream of new people coming in and they were on holiday, so they wanted to have fun.

In New York City, I felt like I couldn't get away from that anxiety. The neighborhood of Hell's Kitchen felt like there was a lot of AIDS going on there and a lot of worry going on about it. I remember that St. Clare's, I think on West 48th Street, which was this crappy Catholic-run hospital, was becoming the first AIDS-dedicated hospital, and it was two blocks away from where I had moved, so I really felt like I was in the heart of something that was big and scary.

SS: Did you feel like you had to change your sexual life?

MA: No, not so much. I had a steady boyfriend, and I had already—so I guess a couple years before, I had figured out the safer-sex rules, you know, and was—I can't remember if I was stringently applying them or sort of occasionally applying them. But I didn't—it wasn't so much about that. I kind of thought I was probably infected already, and I didn't know until a year later that I wasn't.

SS: So what was your job at the time?

MA: I was bartending at a restaurant on West 43rd Street, and I also had an office job back at the union offices downtown, so I was working two jobs.

SS: Now, that's really interesting. So what was happening in the Longshoreman's Union in relationship to AIDS?

MA: The only thing I remember happening was that someone came into the office applying for a medical pension with AIDS written on his medical information sheet, and they made him sit in the outer part of the office and nobody wanted to talk with him or deal with him. I think he had to sit there all day until someone finally passed him his papers somehow.

SS: And you observed that?

MA: Yeah.

SS: So when did you start getting politically involved around AIDS, besides the independent things that you were doing?

MA: Well, I wasn't really doing anything except reading Larry Kramer's columns and worrying, until the first ACT UP meeting.

SS: How did you find out about it?

MA: I found out about it through the *Native*. So I would pick up the *Native* and read it from one end to the other, and I saw the notice that Nora Ephron had cancelled and that Larry Kramer was going to be speaking at the Center, and I dragged my boyfriend there. And then when we got there, there was a \$5 admission, which almost turned me away from activism. But we decided to put the \$10 in the box and go in, and we went to the first meeting. And then from that point on, I kind of felt like I was a full-time AIDS activist for years after.

SS: What was it about the meeting that made you stick with it?

MA: It was a leader, in the form of Larry. It was someone who was as angry as I was worried. It was someone who was telling us what to do and how to do it. And it felt like an opportunity to sort of wrap my hands around this problem and figure out some sort of way of stepping forward and becoming involved in something that was bigger than worrying about it, more productive.

SS: So then you attended the very first meeting.

MA: I did.

00:15:00

SS: Can you describe that to us, like how many people, where it was?

MA: Yes. It was in the main first floor room of the old Community Center, and I remember it was weird. Larry had brought Martin Sheen to that meeting, who he had apparently either picked up on the subway or something like that. Martin Sheen gave this kind of odd little talk about having just buried, I think, the best man from his wedding, someone that he and his family was close to, and that was strange. That was a strange sort of thing. I didn't really know what was going on. But Larry gave that very impassioned talk in which he made us stand up and told us we would be dead within a year if we didn't do something about it, and I just found that tremendously compelling, and I wanted to come back, and I was hooked.

SS: Do you remember the name of the person who thought of the name "ACT UP"?

MA: I don't, but I remember that he was a nurse at St. Vincent's and he had a mustache and he was a little chubby. I remember that. I remember that particular meeting very well, because there was a lot of discussion about what to name ourselves,

and the discussion about what to name ourselves had a lot to do, I think, with what kind of group was this.

Tim Sweeney from GMHC was facilitating those early meetings. I think maybe by the time we got to a second or third meeting, it was decided that someone other than Larry needed to actually run them and make sure they worked. And a lot of the discussion in those early meetings was about information sharing, and I, because I had an office job and access to a Xerox, would clip everything that was in the newspaper about AIDS and run ten or fifteen photocopies of every story and bring them to the meeting. And we had an information table at the front of the meeting, and people would pick up all of those pieces of information.

So there was a lot of discussion about whether this was an information-sharing group, and there was some name on the floor called, like, the New York AIDS Information or the New York AIDS something Group, but it was about information sharing. It wasn't necessarily about activism per se. Then I remember this fellow coming up with the name ACT UP, which was very much in a different direction, and that's what won. It was a vote.

SS: So how did your participation evolve? Where did you end up fitting in?

MA: I was a body-in-the-street person. I was arrested at the first demonstration. I dragged my boyfriend, and he was arrested at the first demonstration, and then this other—

SS: What was your boyfriend's name?

MA: Doug Montgomery.

SS: Now, did you expect to get arrested?

MA: Yes. It was arranged in advance. I think seventeen people were arrested, and this was all new to me. I didn't know how these things worked. I didn't know that someone talked to the cops and told them that this was going to happen. But, yeah.

SS: Did you do civil disobedience training?

MA: At that time, I don't think we had civil disobedience training. I think the time between the first meeting and the first demo, I feel like was a couple of weeks. I remember there was a flyer which I taped up around Hell's Kitchen, and there was a group of people who agreed that they would sit in the street in Wall Street, connected to the release of AZT and the price of AZT and what a crappy drug AZT was and how we weren't satisfied with it.

SS: So how did it feel to get arrested?

MA: It felt great.

SS: What happened ultimately with the charges?

MA: There were a whole series of arrests that ended up in desk tickets, where you basically promised that you wouldn't do this again, and it would get dismissed, and then you would go out and do it again. But I think maybe the record-keeping wasn't so good.

SS: Right. Now, were you on any committees?

MA: I was. I was the head, as it were, of the Communications Committee, the first Communications Committee. But since I didn't really know what I was doing in

terms of communications, it was just a pro forma thing. Everybody in the group was trying to figure out what communications were and how to do them.

SS: And what was the obstacle? What was the goal?

00:20:00

MA: Well, it was interesting. Larry very much wanted press attention to ACT UP as an entity, and I didn't think that that was appropriate. I wanted press attention to AIDS. So, now I understand. Now I'm more sophisticated, and I understand that you do those things together and that they serve reinforcing purposes, that kind of thing. So there was disagreement about what the goal was.

SS: And where did the press contacts come from?

MA: They came from people who worked in PR, and I don't remember. At certain points along the ACT UP history, Mike Signorile was a big part of that, and Bob Rafsky, who worked at Howard Rubenstein Associates and who knew a lot of reporters, was a big part of that. Ann Northrop, of course, was a big part of that. But I don't remember if any of them were involved at that point. I don't actually know. We may have cold-called *The New York Times* and *Newsday* and news desks. In fact, we probably did.

SS: And did they come?

MA: They did come. There was a lot of press attention on that first event. I remember being interviewed by Rosanna Scotto at Fox News. Interestingly enough, her father was an official of the Longshoreman's Union, like my grandfather, so it was a little too close for comfort at that point to be on Fox News being interviewed by Rosanna Scotto. I was out to my parents, but I was not out to my grandfather.

But then everything just sort of blew open in terms of not being public. There was a picture of me and Doug and this guy Steve Crouch being arrested, in *The New York Times*. The photo caption under that said, “Homosexuals arrested in AIDS drug protest.” It always amused me that there was only one non-negative word, and it was “at” in that caption. Steve Crouch called *The New York Times* to complain about that, and they issued an editor’s note saying that they shouldn’t have called us homosexuals, even though we all were. But there was actually a lot of discussion from the very first meeting about transcending the AIDS-equals-gay media paradigm around AIDS.

SS: What was the reason for wanting to do that?

MA: I think in part it was because it was true, and there were people, I think, involved from the very beginning of ACT UP who really wanted that information out into the world, and in part, I think it was probably because we thought it got less attention.

SS: Right. There were two conflicting reasons, right? One was that people had AIDS who weren’t gay, but then there was this belief in ACT UP that if straight people somehow thought that they were in danger, then they would do something.

MA: Yes.

SS: And ultimately that did backfire.

MA: Yes.

SS: Because it never panned out that they were in as much danger as we said.

MA: Yeah, I guess. I would think that for six months or a year or maybe two years, it helped, and then it really shut the door. I remember Larry talking about going to the White House. Reagan was still president, so it couldn't have been that long after ACT UP was founded, maybe '88. And Gary Bauer who was the domestic policy advisor maybe, Bauer asking Larry if he thought straight people were at risk, and Larry saying, "Absolutely they are, they are."

And Bauer saying, "Well, my numbers say they aren't." And that was a bucket of cold water, a need for a radical change in messaging and strategy.

SS: So then as the publicity professionals stepped into what I guess became the Media Committee, right—

MA: Yeah.

SS: Then where did you go?

MA: So I was on the Coordinating Committee as an at-large member.

SS: Who else was on the Coordinating Committee?

MA: Avram [Finkelstein]. I'm going to embarrass myself, because I'm really bad with names. I can fill in some names as I think about them. Steve Webb was there, but we called him a minister without portfolio, because he hadn't actually been elected to the Coordinating Committee, but he showed up. Yeah, I can fill in some other folks.

SS: So what were some of the things that went on there while you were on the Coordinating Committee?

MA: I don't have a real clear recollection of the week-by-week stuff, but I think it was basically planning demos, getting reports from—there was the different

committees like Logistics and Communications, and those groups were part of the Coordinating Committee, and then there were two people who were there at-large, and it was planning everything that went on in ACT UP and preparing reports for the weekly meetings.

SS: Were you there during, for example, the planning for the FDA action?

MA: I don't recall, to be honest, if I was still on the Coordinating Committee at that point. I think it was a one-year term.

SS: Did you go to the FDA?

MA: I did.

SS: And how was that for you?

00:25:00

MA: It was wonderful and tense. I remember that the police—so it was the first, probably, event that I had been to where we were dealing with the police outside of New York, and I came to understand that the police outside of New York were not as sophisticated about demonstrations and were, in general, not as nice to people who were participating in those demonstrations. And I don't have any love or particular respect for the New York City Police Department, but I thought that the police department in Rockville, that they were amateurs and thugs. So I thought — they were in riot gear and they had sticks, and they were hitting people and shoving people. So the day was exhilarating, but the day was also upsetting from that perspective and also kind of exasperating. You are—or we were standing outside of this building, and the people were watching us from the inside of the building, and you really felt the gulf. I really felt the gulf between us and them. And so it was an emotionally mixed experience.

SS: Now, you participated as part of an affinity group, right?

MA: Yes, but I can't recall which.

SS: Because didn't you wear a white coat? I don't know why I think that.

MA: I don't think I was wearing a white coat, actually. I don't think I was.

SS: What's the footage we have of Mark at FDA? Are you lying on the ground?

MA: I saw one little clip of me lying by a tombstone, but I think I'm wearing my own jacket.

SS: Oh, were you holding one of those tombstones?

MA: Yeah, yeah, so actually, yeah. In fact, I wondered if anyone ever took a picture of me standing up.

SS: Were you in any affinity groups?

MA: I floated around different affinity groups, and I did not develop a strong attachment to any particular one.

SS: Now, was there any kind of controversies in ACT UP that stand out in your mind, arguments or—

MA: Well, I very clearly remember the very first one, which was within a couple weeks of ACT UP founding, when the political party that Lenora Fulani founded.

SS: The New Alliance Party.

MA: Yes. When they sort of infiltrated. All of sudden, fifty of them showed up and did little speeches about how there was a whole vast Social Justice

Movement that we needed to be part of, and we couldn't be issue-focused in this way, and then started voting. And then there was a great deal of tumult about that, and eventually there were some rules put in place that you had to be at two meetings, maybe two consecutive meetings. I'm not sure exactly what it was, but it was enough to discourage them and make them go away.

I think my recollection is that there were always undercurrents in terms of how broadly defined the ACT UP agenda would be and how representative ACT UP was of everyone who was impacted by HIV, and whether or not ACT UP's approach to HIV was connected to all of the other social and economic justice issues that surround it. But I don't remember those becoming acute, at least for the first year or two.

SS: We have footage of you at a housing demonstration. Were you involved in the Housing Committee or were you just at the demo?

MA: I must have just been at the demo, yeah. I don't recall being on the Housing Committee in particular. I was sort of enthralled by the drugs-into-bodies theme that started ACT UP, and that was my sort of principal emotional motivator in those first couple of years.

SS: So can you talk a little bit about how that principle evolved?

MA: Sure. I think that in the first maybe six months to a year we believed—I believed that AZT was a lousy drug that was being foisted on people with AIDS to enhance the profits of the drug companies, \$8,000 a year, the most expensive drug ever marketed, just outrageous, and that there were a bunch of better options that FDA or others were sitting on because they didn't have big pharma support. And it took a long time and it was very discouraging to realize that there actually weren't, which is

not to say that the research shouldn't have been done or couldn't have been done better in order to identify them, but that the things that they had on hand or that people were kicking around were just as bad as AZT. And so then it sort of switched from release the drugs to change the way the drugs are researched and investigated and approved and that kind of thing, and the agenda became much more complex and in some ways harder to grasp. That was my experience.

SS: So in that moment of realization that ddI wasn't going to save people's lives and this type of thing, do you think that there were people who gave up?

MA: Yes, I assume so, and I think also that when it became clear on an individual level, on a personal level, that things weren't going to change significantly in six or twelve months, that you or people you loved and cared about and people who were motivating you to be in ACT UP were going to die or had died, that it probably became harder for people to continue to come.

SS: I want to ask you a little bit about your personal experiences in ACT UP. Were you ever in a care group?

MA: I'm not even sure what a care group is.

SS: You know, where someone's sick and dying, and then people started a support group around them.

MA: Not formally, no. I would certainly visit people who were sick or dying, but not as part of a formal group.

SS: Did you have close friends in ACT UP who died?

MA: Not so many. I knew of people certainly who I liked and who were part of ACT UP who became sick and died, but I was not dramatically impacted by the illness or death of someone who was very close to me in my little circle of people. There were people with HIV, but not people who were seriously ill.

SS: Did you ever date anybody in ACT UP?

MA: Yes, very much so. Yes, within the first couple of meetings, I fell madly in love with Stephen Gendin, who was co-facilitating the meeting. So it was great, because he would stand in front of the room and I could sit in the room and just stare at him for the whole meeting. And my relationship with my boyfriend was waning, so I very expeditiously, in the way that twenty-four-year-olds do, broke up with him.

And then on the June 1st demo in Washington, we went to Washington, D.C., Stephen was part of the group of people who got arrested in front of the White House. I had somehow missed the meeting or the signup or the opportunity to be part of that group, and it was closed because the Washington police were so much more strict, so there was a cap on how many people could get arrested in front of the White House. So he got arrested. I was totally dejected because I really wanted to ask him out.

We went back to where the AIDS Conference was being held at the Hilton Hotel in Washington and did our little picket line. Then just before our buses were going back to New York, the people who'd been arrested were released, and I think they came back to the Hilton in a bus, maybe. He came off the bus, and I then got on to his bus to New York, and I followed him on to his bus to New York, and I asked him if he would go out with me, apparently loudly enough for several people around us to be aware of

what had happened. And he said yes, and then we were together for almost five years after that.

SS: So what was that like to be involved with somebody who was such a figure?

MA: Well, personally, around Stephen, things changed around him. He was very much a sort of shy, shy boy when we first started going together, and he became much more of a sort of public person toward the end of our relationship and then certainly in the years after the relationship. It was hard. And it was also hard for us because I had gotten tested for HIV in the fall of '87, and it was at the time when you had to go to the Health Department in Chelsea and then you had to wait two weeks and then you had to go back. They made it as suspenseful and dramatic and gut-wrenching as possible.

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Then it turned out that I was negative, and I thought I was the only one of the two of us who had been tested, but months later he confessed that he had been tested the year earlier and was positive. So we were six months into our relationship at that point. And I thought, because I was three years older, that I was the one who was at higher risk in the couple, and I never really imagined. He was twenty-one when I met him, and I guess he was twenty when he had been tested and tested positive. So I had never imagined that he was positive, and so our relationship, we had to adjust to that.

SS: How did you? How did you adjust to that?

MA: I bought all the things that the PWA health group was selling, and Stephen took everything that was available, including AZT monotherapy and lots of bad drugs monotherapy in the early years of drugs being available. So he was in the "hit

early, hit hard but with really weak drugs” camp and eventually developed so much resistance that he couldn’t be treated.

SS: Did you feel that he had endangered your life?

MA: No. I felt more—it was more of an emotional thing, that I was sad that he hadn’t told me.

SS: It’s so interesting because what you’re describing is a very normal experience in our community, right? And now if you do this in Canada, you can go to jail.

MA: Yeah, yeah, and in a lot of places.

SS: Why? I mean, this very human issue of shame, vulnerability, and fear that we understand in our community, why is it that thirty years later, or whatever it is, this is now suddenly illegal?

MA: Well, a corollary question to that is why are we doing all of the old things over again that didn’t work? Because I think there was a lot of criminalization of HIV stuff going on maybe twenty, twenty-five years ago, and then it was shown that it was totally ineffective and counterproductive, and now it’s back in a big way, and it’s a real mystery to me.

SS: What do you think about that? What are the reasons?

MA: I can’t imagine why—I can imagine why you would do it once. I can imagine that you are overwhelmed, that “you,” being a policymaker, are overwhelmed. You’re looking for easy, quick, popular policy solutions, and vilifying the person who is trying to figure out how to deal with an HIV diagnosis and with their lives is an easy thing to do. Heartless, fruitless, but easy.

SS: But I also think it's somehow—I'm actually working this out in conversation with you right now, so it's not like I have a—but somehow it has to do with the way that gay people have changed the way we see ourselves, because now with these criminalization laws, the state is telling people like you to pick up the phone and call the police and bring charges against your boyfriend, and they're convincing the negative person that they've been criminally wronged, and people are doing it. And there's some kind of shift in how HIV-negative gay men see themselves in relationship to the state, in relationship to anxiety.

MA: Yeah, that's a really challenging thing to think about. Certainly the shift from individual, the shift from it's your responsibility to keep yourself HIV-negative to it's someone else's responsibility to protect you from what they have is disquieting.

SS: But also to call the police.

MA: Yeah. Well, that's beyond my comprehension. I can't—I can't imagine how people do that. I can't. I was so in love with him, as I imagine most people are with the people they're with. I don't—I can't imagine how that would happen.

SS: Were you guys involved when he went into business?

MA: Yeah, I think so. No, no, no. Actually, no. He was working for Sean Strub, but maybe just in a much lesser capacity. The pharmacy service started after we broke up. We broke up in '92, and that pharmacy service was probably going six months or a year after that.

SS: So you don't know anything about the early days of that.

MA: Well, we remained very close, so we were close while that was going on, but I don't know. I wasn't part of it.

SS: Because it's an interesting transition, because that business—I forget what it was called. What was it called?

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MA: It was called the Community Prescription Service.

SS: Right. It was a quasi—it was still a grassroots event, but it linked to corporate, and it's sort of the first bridge between those two entities. And did they understand that to be true?

MA: I think so.

SS: And that was considered a good thing?

MA: I think it was controversial from the get-go. There was an ad where Stephen is in a suit and he's being dragged away like this [demonstrates], and the caption on that ad was "Activists Live Longer," and it was a connection to the pharmacy service. Well, my head was in the bottom right corner of that photo, and I made them airbrush it out because I really didn't like the whole thing. But I'm not sure how sophisticated an analysis I did or others did about this, but in retrospect, it really did break through something significant.

SS: So looking back with hindsight, do you think that that was a positive step?

MA: Probably. I don't know in terms of its larger repercussions, but in terms of did that Prescription Service benefit people, and were more people attracted to it because Stephen was attractive and because activism was attractive, I'm sure they were. And I suspect that that Service really did benefit people, because in 1992 or subsequent years, I think it was very hard for people in many places to get their HIV meds, and I think people were also, in a way, through this Prescription Service trying to become part

of a larger community and maybe an activism-driven community. But the morality of selling them a product at the same time that you're inviting them to be part of a community is weird and murky.

SS: Also it's a beginning of a partnership with pharma, and now there's no separation at all, so that's the first step into that, and ultimately that has not been beneficial globally.

MA: No, probably not. Certainly nothing about the core model of how drugs are developed, marketed, and sold has changed as a result of that partnership. There have been little things around the edges. Well, bigger than little things. The access programs, the drug-access programs that make drugs available in developing countries, that's a big change, but in for-profit markets, it's the same model. We've been looking at it and saying this is a dying model, but it's been a dying model that's making billions and billions and billions of dollars year after year.

SS: Right, right. It's a thriving model.

MA: It's a thriving dying model. It's like the theater or something like that.

SS: So let's see. What else did you work on in ACT UP?

MA: So I was a regular attendee and regular demonstration-goer. I was also working full-time at Gay Men's Health Crisis, which—

SS: When did you start there?

MA: I started there in April of '88.

SS: I want to ask you something about that. There's this false story in history that ACT UP and GMHC were enemies.

MA: Uh-huh.

SS: But it seems like everyone that worked at GMHC was from ACT UP, that there was an incredible amount of crossover. Or is that not right?

MA: I don't think that's quite right, at least in the time when I came in. I would say there was a fair amount of tension between GMHC and ACT UP, and when I went to work for GMHC, I feel like some people felt I was going to work for pharma. It was that kind of, "Yes, they're involved in AIDS, but everything they do is wrong."

SS: And why did people feel that way?

MA: A variety of complex reasons. I think GMHC was late in starting its advocacy in policy work. That didn't really get going until about the time that ACT UP started. I think it actually started just a little bit before ACT UP started, because Tim Sweeney was hired to do that work and Tim Sweeney was there when ACT UP started. But it seemed like late '86, early '87, there was this moment where everyone agreed it was *intolerable* that so many people were getting sick and dying and that the AIDS organizations per se were not getting more angry and upset about it and doing more about it.

00:45:00

So GMHC started a policy program and ACT UP began within a couple months of each other. But I think that Larry had criticized GMHC very strongly for facilitating a good death and sitting on the sidelines and being too polite to the Koch administration and being too polite to the Reagan administration, and I think there was a lot of people—there were a lot of people who agreed with that and felt like GMHC had taken a lot of money from the community and had not helped the community in the ways that they felt like they should.

SS: So when you went there, what was your job?

MA: So I started there as a receptionist, because I had left the job that I hated and needed a job really quickly, and that was in April. And in August, I was hired to be the assistant coordinator of intake. So I was interviewing people who were coming in to be new clients, and I was managing the volunteers who interviewed them to come in to be new clients. And I had precious little experience. It was amazing, actually, that they hired a kid who had a little bit of activism behind him to do this job, but that's how those jobs were going.

SS: So what were you finding about the people who were coming in?

MA: Most people were in really bad shape. Most people were broke. By the time they got to GMHC, most people were broke. Many of them had lost their partners or lots of members of their support network. Many of them had problems with their families. Many of them were uninsured or were not getting proper medical care or were experiencing those stories of people being turned away from hospital emergency rooms when they were terribly, terribly sick. So a lot of people who we dealt with coming in for help were in very serious situations and needed a lot of help right away.

Another reason that I think there was a lot of tension between the gay community writ large and GMHC is because people had lots of different kinds of experiences when they came to GMHC for help, and it was a catch-as-catch-can kind of situation. And some people got great buddies and immediate help and really wonderful service, and some people got really lousy service and didn't get the help that they wanted. And there was this kind of mythological sense that when you were down and out, you could call GMHC and they would come in and clean your apartment and get you a buddy

and cook your meals and everything would be okay and you'd have a friend, and it frequently didn't work out that way, and a lot of people felt angry and disappointed about that.

SS: Who was in the leadership? Was Tim still alive at that time?

MA: Richard Dunne. Richard Dunne was the executive director.

SS: Now, do you have a sense of him as someone who was frightened of authority?

MA: No.

SS: Why did GMHC have this persona of being timid?

MA: Well, I think the persona had preceded Richard. So Richard was the person who hired Tim and started a policy department. Richard came from city government, so I think had a fairly conservative bias in terms of how you deal with public officials. I didn't get the sense of him as being frightened. He seemed like someone who always wanted to project that he knew exactly what he was doing.

SS: So why was GMHC so timid with the government?

MA: Well, GMHC became less timid as time went on. But why were they timid? A lot of rich people were involved in funding them, including a lot of rich gay people who did not want to have a lot of controversy and screaming going on, so that was part of it. I think the sort of founding model for the organization was direct services to people who were sick, and there were people who—a lot of the people who founded the organization were still alive and still involved or it was the people they had hired who were still working there. So the transition to a more activist policy-focused GMHC was slow, too slow for some people.

SS: So were you able to do anything about bridging anything between GMHC and ACT UP?

MA: Yes. So people would ask me all the time what ACT UP was involved in, what ACT UP was upset about. Eventually I worked in the Client Services for two years and then I went to work for Tim Sweeney in policy, and my role, at least from GMHC's perspective, was to try to bridge and understand the activist community. I was the in-house activist. And by that time, the policy program was much more robust and much more activist and much more confrontational at the city government level. So the two organizations were coming together, and GMHC really learned from ACT UP, I think.

SS: So what happened there around things like St. Patrick's?

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MA: I don't recall what GMHC's perspective on St. Patrick's was. I recall my own perspective.

SS: What was it?

MA: I was outside at St. Patrick's, and I thought the St. Patrick's demonstration was important, but I was uncomfortable about the inside, the Cathedral part of the demonstration, and not because I didn't agree with everything that was said about John O'Connor and the church's influence on how HIV was being addressed in the city and worldwide. I couldn't go face-to-face and scream at people who were going to Mass. I don't know if it was baggage I carried from growing up Catholic myself, or I just didn't feel like those people in the pews were in the top tier of the people I was angry at. So I was outside.

That was a rough-and-tumble demonstration too. That was one where the New York City cops were *not* nice. And I did not get arrested at that demonstration. I remember walking down maybe 50th Street from the Cathedral to the subway and passing Radio City Music Hall, and Rockettes had opened up the windows of the dressing rooms and were cheering us, and I thought, “This is so cool. The Rockettes are on our side. This is fabulous. What a great demo,” really having very little sense of what the backlash to that demo was going to be. So I was surprised at the vitriol that was directed toward ACT UP after that, and the huffing and puffing about sacred spaces and all that hokum.

SS: Now, were you involved in the NIH action?

MA: Yes.

SS: What was your role in that?

MA: I was a foot soldier in that. I don't remember having a big organizational role. I do remember trying to turn over a car. A couple of us were walking around the NIH campus and had probably found what looked like the lightest vehicle available, an old Volkswagen or something, and tried to flip it over, but we couldn't flip it over.

SS: What was the point of that demo?

MA: I recall pieces of the point of that demo. I recall that the makeup of clinical trials did not reflect the makeup of the epidemic, and I think that it was also that there were lots and lots of promising agents that were being held up in an arcane system. I have to admit that by that time, the background information that went into informing ACT UP as to why we were going on a particular demo and what the objectives of it were had become so much more complicated and less interesting to me.

SS: Do you think that it was being withheld?

MA: No. No, I think people were doing a great job of trying to share the information. That's my sense. People were doing intense investigations of ACTG committees and how things worked at the NIH and how things progressed through the system. It just felt to me like what once felt crystal-clear and easy, "I'm going to lay in the street until you release the drugs," became committees and how committees work and who's elected to the committee. And so by that time, things were feeling less viscerally connected to me, less immediately understandable, and I think I was also going through—maybe that was like '90, '91, becoming more pessimistic about whether all of this was going to end anytime soon and whether the people who I loved were actually going to be saved.

SS: Now, do you know what we actually won at the NIH demo?

MA: I believe it was the inclusion of a few people from ACT UP on those committees that I do not understand why they existed or how they operated.

SS: Now, were you still in ACT UP when the split occurred?

MA: Yeah. I think I only—I was, and I attended those meetings, and I remember that fighting. I only think of it as "the split" sort of retrospectively and because that's how the story's being told now, and I think it's accurate that that's how the story's being told, but I felt like people were fighting for a long time.

00:55:00

SS: What were they fighting about?

MA: They were fighting a lot about how broadly or narrowly to define the ACT UP agenda.

SS: And what were the reasons? Why did it have to be one or the other?

MA: Well, I think that a bunch of us came into ACT UP with a pretty narrow—a narrow agenda, right? We're getting screwed because we're gay, and nobody cares about us, and we hate the for-profit pharmaceutical development model, and we're going to shine a light on this injustice and change it.

Then I think a lot of very intelligent people who were more experienced in social justice than we, than I, came in and started saying, "Well, you can't look at this without looking at that, and you can't address this small piece of the problem without looking at much, much larger concentric circles of issues that affect people who are marginalized and at risk for HIV." And I think there was a lot of fighting about that. I saw people get up and scream about how this was all becoming too diffuse, and those rants would always end with, "And I'm dying."

SS: But was that true?

MA: Well, "too diffuse" is subjective. Whether or not you could look at it, whether or not you could effectively look at a piece of the picture without looking at the whole thing, I think you could argue that forever. What the process was getting, was slowing down. Yes, the process was slowing down, and people who had a real intense sense—

SS: Because?

MA: Because more and more complex issues were being brought into the discussion, so there were race and gender and economic justice, housing, access to a variety of services, the spectrum of things that impact people with HIV or just people

who were poor and marginalized were becoming part of the discussions. So choosing a target for a demo, figuring out what the signs were going to say, getting there, doing it, feeling a sense of accomplishment, my sense is that that all became a harder process, a harder score to make.

SS: So you actually really think that access politics or looking for total care for the whole group of people with AIDS actually impeded progress towards new medications?

MA: No, I wouldn't say that.

SS: No. Okay.

MA: I wouldn't say that. I would say it made the meetings more complicated and it required a different level of interest and involvement. It became harder to drop in. My sense is that ACT UP had 100 people or maybe 200, I don't know, who were there every week, and it had somewhere between 200 and, in some cases, 2,000 people who showed up for the demo, because you could make a quick and pithy message about, "Here's what we want. Here's why we're here. Koch is doing this. That's why we're going to City Hall."

I think our biggest demo was City Hall, '89, 2,000, 2,500 people. That's my recollection of New York City. And it was an easy message to communicate about why we were there and what we were doing there. I think as the agenda became more complicated, it became harder to engage people that way. You really had to come and study it and know about it and understand it in order to know why you were there.

SS: So what did you do when TAG left ACT UP?

MA: I don't recall doing anything.

SS: Were you part of TAG or did you stay in ACT UP?

01:00:00 MA: I was not. Stephen was part of TAG. I felt—so I have to think back to what I was actually experiencing at the time. I felt like I didn't understand what was going on in TAG, so I felt like there was a lot of belly-button-staring going on in TAG. I felt like there was a lot of—I felt like TAG or even the Treatment and Data Committee before TAG was elitist, and so I didn't—I wanted to do more street action. I wanted things to be easy and direct. I wanted the attention to be on the epidemic and not on ACT UP. So going back to that first tension I had with Larry, like in March of 1987, about what we should be focusing on, and there were lots of personalities emerging from T&D and from TAG, and I felt like that was the wrong way for ACT UP to go to. So I guess I didn't do anything except probably become less involved.

SS: So when did you leave ACT UP?

MA: I think I left my boyfriend and I left ACT UP at approximately the same time, and I didn't have a moment that I recall of saying, "I'm not going to ACT UP anymore." But I do know that probably for the first four years, I never missed a meeting, and like other people, I was probably doing ACT UP things three or four nights a week, the wheat-pasting or a different committee or that kind of thing. And I didn't have that sense of commitment to it anymore.

SS: Now, did you continue to work in AIDS at all after you left ACT UP?

MA: I did. I still work in AIDS.

SS: So what do you do?

MA: I do communications for NIH, CDC, UNAIDS, Gates Foundation, other organizations.

SS: Oh, so you're a consultant?

MA: Yes.

SS: And you have your own company?

MA: Yes.

SS: Oh, so you stayed in communications.

MA: Yes. I figured out to a certain extent what it was about. I learned.

SS: So now you don't have to cold-call anymore.

MA: No, no, no, I'm not cold-calling, no. I work on—it's funny, and I don't exactly how to square this circle, but the stuff that I was less interested in in my activist career is the stuff that I have been working on ever since.

SS: So what do you see as the biggest issues in AIDS right now, or in HIV?

MA: I guess you'd have to say where and for whom, because they differ a lot depending on what—

SS: Well, tell us some of them.

MA: —part of the world you are and whether you're a man or a woman or a kid or rich or poor.

SS: Well, everyone being equal, what would you say?

MA: But everyone's not equal. One of them is maintaining interest and maintaining funding. There's no question that we're just now at the part of going like

this [demonstrates] in terms of the funding, but there's no question where this curve goes, in my mind. So that's a big thing.

SS: What's the biggest obstacle? Is it lack of access to existing treatments? Is it lack of vaccine?

MA: So there are a lot of really good prevention things happening now, PrEP (Pre-exposure Prophylaxis), and we'll have a microbicide that will—we know now actually that microbicides work. Getting people to use them and getting people to use PrEP and getting people to use any of these things that we know work is a huge obstacle. So there's a knowledge and information and human-behavior piece that is—

SS: But are they available for people to use?

MA: Not really. Not really. But they may never become available for people to use if there isn't more enthusiasm about them. The clinical trials of a bunch of these interventions have shown mediocre interest among the people who use them. I mean, just parenthetically, the storyline that frequently gets cited is the people who are in clinical trials are the most highly motivated users, but it's actually not true. People are in clinical trials for a variety of reasons. The most highly motivated users are people who understand that they're at risk and want to use something. So women use birth control very, very effectively when they understand how people become pregnant and that they don't want to become pregnant. So getting this stuff so that people can use it and finding people who will use it, I think, is a major issue.

From the statistics I see, the percentage of people who are getting treatment is getting better and better, so that's moving along well. Whether they're taking it properly, I don't know. I guess in the United States, the fact that understanding

why most people living with HIV are not getting the benefit of treatment, so about 70 or 75 percent of people living with HIV are not virally suppressed in the United States, and you've just got this miserable healthcare system that doesn't follow up with them, and still tons and tons of stigma about learning your HIV status and getting treatment. These are huge issues.

SS: But then you have the Canadian model where they have health insurance and everyone can be virally suppressed, and the government knows every single person's viral load. And the level of surveillance is frightening. And now you have HIV criminalization that's nationalized. So how did that happen?

MA: I don't know how that happened. I don't know. Underestimating nefarious ways that people will use information like that, I guess, is maybe how that happened.

SS: Okay. Is there anything that you guys want to ask Mark?

JIM HUBBARD: Well, I just want to ask you about the shot at Target City Hall. You're lying there in a suit and tie. Why are you in a suit and tie?

MA: So you asked me before about affinity groups. So there was an affinity group that decided—the affinity group I was associated with—I don't recall what it was called—that decided to dress in suits and ties, and we had this vague idea that we would get into City Hall if we looked that way. The funny thing about that is—and I only know this because there was this picture on the front of *Newsday*; I don't know if I have it anymore—of a bunch of us walking with our fists in the air, in suits and ties at that demo, and the headline on it was “AIDS Anger.” It was this great picture. But I'm

wearing bright blue sneakers. I wasn't smart enough to know that you had to wear dress shoes with a jacket and tie.

SS: Oh, okay. So it was on purpose.

JH: Who was it that shoved the microphone in your mouth, in your face?

MA: I don't know. One of the DIVA people, I assume, yeah. Yeah, I don't recall who it was.

JAMES WENTZY: I have one. Stephen Gendin, were you around when he was working harm reduction and needle exchange?

MA: Yeah, I was.

JW: Can you talk about that?

MA: I don't have a lot. I don't remember a lot about that. Stephen was involved in so many different things that I don't really know that. I don't really recall.

SS: Okay. Is there anything that we haven't addressed?

MA: No. It was great. It was nice to talk about it.

SS: So we have one last question. So, looking back, what would you say was ACT UP's greatest accomplishment and what was its biggest disappointment?

MA: So for me, ACT UP's greatest accomplishment was giving people a sense of their power, and its greatest disappointment was that that power did not transcend into saving enough people's lives.

JW: Since you work for CDC, what were your thoughts remembering about changing the definition of AIDS?

MA: Oh, those were good and interesting. Yeah, so it was about—yeah, that was something that I could grasp. So I remember being interested in that. But it's funny, and I think it comes more from watching your film or other things that I've heard or read since then. I look at those and I think about, well, that took a long time and it took a lot of effort, right? And from all I know, it had a significant impact. But I look at all those things, and I wonder is that what we should have spent six months working on, and I have no answer to that question. It's not like I could say, "This is what we should have spent six months working on."

But one of the sort of lasting—I don't want to say regrets, because that's too—one of the lasting questions that I have is, how could we have taken those couple of years where we were so intensely powerful and when we realized we charged after a lot of false targets, not the change in definition. The change in definition was real. But we spent an awful lot of time advocating for dextran sulfate and things that didn't help anyone, and you wonder if we could have done things better or differently.

01:10:00

SS: All right. Thank you so much, Mark.

MA: Thank you.

SS: Thank you. That was great.

MA: Good.

SS: I learned a lot.

MA: Good. I'm glad it was useful.