

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

A PROGRAM OF
**MIX – THE NEW YORK LESBIAN &
GAY EXPERIMENTAL FILM FESTIVAL**

Interviewee: **Gregg Gonsalves**

Interview Number: **041**

Interviewer: **Sarah Schulman**

Date of Interview: **January 19, 2004**

ACT UP ORAL HISTORY PROJECT

Interview of Gregg Gonsalves

January 19, 2004

SARAH SCHULMAN: You just tell me your name, where we are, how old you are and today's date?

GREGG GONSALVES: Gregg Gonsalves, we're at 502A Atlantic Avenue, in Brooklyn, and today is January 19, 2004.

SS: Where were you born, Gregg?

GG: I was born about 30 miles east of here on Long Island, in East Meadow.

SS: Was your family in any way politically active or socially involved?

GG: Well, my parents are second-generation immigrants – Italian and Portuguese – grew up in Brooklyn. My mother and father were involved in the school board and PTA and stuff like that, but now my mom's a Republican legislator out on Long Island. So, in her retirement she's become politically active.

SS: So, were you raised with any kind of sense of duty towards other people, in terms of community involvement?

GG: Only because of my parents' sort of civic engagement in community affairs, but not in a political way, sort of neighborhood improvement and civic associations and stuff like that. Never overtly political.

SS: Were you involved in any other movements before ACT UP?

GG: I mean, in college a bit, in the anti-apartheid movement.

SS: Where was that?

GG: At Tufts, in Massachusetts. But it was a couple of years during the late '80s. And a little bit of stuff around gay rights, but nothing really substantial. It was just, I would say fairly – I wasn't deeply involved in any sort of social or political movement until ACT UP.

SS: Were you out in college?

GG: Yeah, I was out in college.

SS: What about in high school?

GG: Sort of coming out, during my senior year of high school.

SS: How did you live in the gay community? Were you involved with any kind of organizations? Was it only social? Did you have certain places that you went?

GG: So, I probably came out in '80, '81. My two cousins are also gay. So, there was sort of a gay community in our family. So, there are family bonds that I was nurtured and could commiserate with. But in college, I found a few gay people here and there, but really didn't get involved – maybe '84, '85, got involved in college gay organizations. And then –

SS: What was the group at Tufts called? I actually remember it.

GG: The Tufts Gay and Lesbian something or other. You didn't go there?

SS: No.

GG: And then, by the middle of the '80s, I had a group of gay friends in Boston and in Cambridge and Somerville and Medford – that whole area.

SS: So, what made you come back to New York?

GG: Well, it's a weird ACT UP story, actually, because Derek Link and I were in ACT UP Boston, I think, starting in '89 or '90, and my partner at the time – who was the first person I knew who was HIV-positive – came down here to go to law school at Queens College. I had just joined ACT UP in Boston, and I was totally overwhelmed and obsessed by the experience. And I said, "I'm not going to come down. You know what?

Go down, maybe I'll come down in a few months." And then, I remember Derek coming down, and then, six months later, I came down. This is where my family was. I was tired of being in Boston. I'd been there from '81 to '90 - '91. So, I'd also – through ACT UP Boston – had met some of the people in ACT UP. I remember there was an ATAC [AIDS Treatment Activists Coalition] or ACT UP summit or meeting in Washington DC. And, I can't remember exactly what it was called, but I remember meeting Mark [Harrington] and Garance [Franke-Ruta] and this whole crew of people back then. And then – also had done some – Derek and I and others in ACT UP Boston had done some treatment work in drug company meetings with them. So I did feel like I was coming – there was this ACT UP transition – there's a person who isn't coming down, but there's a boyfriend – and then coming back home, it was also because I had built these links to something that I had felt very strongly about in Boston, that was also happening in New York.

SS: Like a transfer within the company?

GG: Right. It was interesting.

SS: Your boyfriend, who was HIV – did you become aware of his status, while you were already involved with him?

GG: Yeah, we had been going out for a month, and he came over really drunk one night. This was in '86. He said, "We have to break up." "Tell me why, tell me why?" This went on for a couple of hours until he finally came out and said he was positive.

SS: It's hard to go back to where you were at that time – but do you remember what your reaction was, or how you felt?

GG: Yeah, it is very clear to me. I didn't really have anybody else who was positive – although my cousin was positive, and I had no idea at that time. He was obviously, in a lot of distress. So, I remember being in very sort of, caretaking mode – “It's okay, don't worry about it, don't worry about it.” I don't remember being worried about HIV, in terms of me getting HIV. I just remember wanting to calm him down, and make him feel like it was okay. That was how I ended up searching out ACT UP. I just remember being in our kitchen once, and he thought he had KS, and he had no idea what was going on. So, I went over and went to an ACT UP meeting.

SS: So, you came to ACT UP to find out treatment information?

GG: Yeah.

SS: So, treatment was your track from day one, really, when you came in.

GG: Yeah, mostly. In Boston, there's also a Harvard Treatment and Data, that Derek and I and a couple of others – about a group of eight or ten people – met regularly and talked about different treatment stuff.

SS: So, did your boyfriend make his treatment decisions based on ACT UP information?

GG: Not really, because he didn't have KS. He was fine then, he was fine when we came to New York. I mean, I've sort of lost touch with him, but I know he's still around. Mark and a bunch of other people in ACT UP know him. I don't think he had to make any sort of treatment decision – at least, while I knew him.

SS: So, you came down, and you got involved with that crew – Garance and Mark and all those people. Do you remember your first ACT UP meeting in New York?

GG: I remember maybe the first T&D meeting.

SS: Can you describe that to us? Can you tell us what a T&D meeting was like?

GG: It was at the Center, in one of those rooms on the third floor – something like that – very, very crowded – lots of fast talkers.

SS: How many people, would you say?

GG: It could have been anywhere between 20 and 40, or even more, because it was a large room – a room bigger than this, and there's a circle, but there also people clumped up outside the circle – so there was 30 or more.

SS: And what would it be like? Who would run it?

GG: God, what was his name? I have pictures of people's faces, but I can't remember. This one older guy, who generally did a lot of the facilitating moderating.

SS: Ken?

GG: Yeah, Ken, okay.

SS: Ken Jacobson.

GG: Yeah, it was Ken Jacobson. Mostly, Ken did it. I feel like Charlie Franchino did it a little bit, but I don't think so. There are certain people I just remember, because they were the people who came over to TAG when we left.

SS: Tell us what a TAG meeting would be like – a typical TAG meeting –

GG: A TAG meeting or a T&D meeting?

SS: I mean a T&D meeting.

GG: I remember there were reports. There'd be little snippets of information that people would want to update people on, and then there'd be more substantive

discussions about various different issues. And – I'm trying to describe the – it felt a little – it's not academic, but it felt like you had to know what you were talking about or you were going to get jumped on. So, I think people felt a strong responsibility to being informed about treatment and research and trying not to – it was very fact based, analytical, sometimes – but also, very passionate, at the same time. It's very strange.

SS: Well, if you're picturing the meeting – can you just go around the room and tell us who's there?

GG: Garance, Derek, Chris DeBlasio – who's now dead, Jerry Jontz – who's now dead, Rich Lynn – who's still alive, Charlie Franchino, David Barr, Jim Eigo, Iris [Long], Bob Huff, Spencer [Cox], Bob Rafsky. There's a core bunch of people, but it's hard. It's 10, 12, 13 years ago.

SS: Yeah, it's a while ago. Did you have any background in science?

GG: Not really. Actually, when I moved down to New York I worked at Columbia in the biology department as a lab tech, because I did have summer experience in college, working in labs. I was working in a laboratory for two to three years, after coming to New York. And Bob Huff was actually working in some video department in the engineering school. And Bob and I had a lot of discussions about what was happening in T&D and ACT UP on our lunch hours.

SS: So, what were some of the projects that you, personally were involved in, at T&D?

GG: The first thing I got involved in was on cryptosporidiosis. It was Countdown 18 Months. And I was sort of transitioning from Boston to New York, because talking with Garance and Derek and Jerry and Rich, and a bunch of Countdown

18 Months people, we added cryptosporidiosis to it and I remember coming back down and sort of being engrossed in diarrhea and stool diaries. It was pretty gruesome.

There's no treatment, and I remember people coming up to me in ACT UP, who had cryptosporidiosis, and there's nothing you could tell them. But the other thing – I was working at a basic science laboratory, and Mark had sent a letter to Fauci about long-term non-progressors. And it was the first bit of, sort of non-clinical stuff that I'd heard. So, ended up, through T&D, getting the NIH to do this conference on long-term non-progressors, which was the first time they ever looked at it seriously. I remember going down to NIH with Mark, Joe Sonnabend – who else was there? A couple of other people and pitching this and saying, “Look, this is what's happening. We know there are people in our community who haven't been on AZT or any” – I think AZT or ddI were the only things around – “who are doing fine. You have to tell us why this is happening.” And I remember this guy, Sten Vermund, who's at the University of Alabama at Birmingham now, who used to be at the NIH. I was at Columbia one night late, at seven o'clock, and all of a sudden through the fax machine came – I said, “Why don't you analyze your cohort studies, to see if this is true?” And all of a sudden, all of these pages came through the fax machine at night. It was the administrative office, so I could see it spilling out and I picked it up, and it showed that in the Multicenter AIDS Cohort Study, there was this small cohort of people who – ten, eleven years – who'd been infected early in the '80s, who were doing fine, and had really high T-cells, and their rate of decline was really slow. That was one of the big projects I worked on. I also remember that we had a meeting in the Center one day. Larry [Kramer] got all obsessed with basic science at one point, and so we formed a basic science sub-committee of T&D, and I remember for

Tape I
00:15:00

some reason Larry was obsessed with this. But, there was a small group of us – George Carter, Casper Schmidt, Mark, Rich Lynn – a whole bunch of different people, who, based on the long-term survivor stuff, started thinking about more of these non-treatment related issues around HIV and HIV research. I remember reading obscure scientific articles, and we'd all sit down together.

SS: I just want to decode some of this, for people who may not know all these terms. What was the impulse towards study of basic science? Why did you feel that was important?

GG: I think there's two reasons. The reason back then was that Joe Sonnabend was an incredibly influential person in how I thought about things, and Joe was like, "This whole HIV paradigm is – the way they think that HIV causes disease is not true, there are all these other ways it could happen." Remember, we didn't have viral load, and there was not a lot of basic information on how the disease worked. And, there were also other alternative theories about immune activation. There's a lot of different thinking that came in the middle of the '80s, towards the end of the '80s. In the '90s, it started dying out – trying to figure out reasons how HIV makes the immune system collapse. And Joe was very influential in wanting people to sort of revise how we thought about things. But I think also, there was some feeling that the drugs we have aren't working – there have to be other ways to confront what's happening. Is there a way we can intervene in the immune system? The reason we did the long-term survivors' meeting is because – can we figure out what these people are doing right? Or have right? And can we bottle it? Are there other ways to approach treating HIV other than antiretrovirals or immune-based therapies? Trying to look for other answers.

SS: Can you explain – looking back – how it was possible that drugs were being produced for AIDS, but no basic science had been done?

GG: A lot of basic science had been done. We knew a lot about the virus and the immune system back then, but I think until '96 or so, when David Ho and George Shaw did all these studies about how much virus is circulating in your blood every day and how many T-cells are being killed. People weren't sure – how does HIV destroy the immune system? And so, there were significant unanswered questions back in the early '90s that I think drew our curiosity, but also our hope that there are some unanswered questions that might lead to therapeutic advances.

SS: But, why was this ACT UP's job? How come the pharmaceutical companies weren't doing this?

Tape I
00:20:00

GG: Well, pharmaceutical companies do drug development, and this led – the people that do basic research are the academics and universities across the country and the National Institutes of Health. And this led into – I think Storm the NIH was happening around that time, as well. So, people were looking at the ACTG – the AIDS Clinical Trials Group – and wanted to be part of the decision making process around clinical trials. But when you started looking at the NIH, you realized that there is a lot of money that wasn't based on clinical research. And, you know, as soon as you started nose-ying around, you wanted to know what they were doing.

SS: So, let's go through the chronology of that a little bit. So, you guys realized this needed to be done, and then you investigated into the NIH and saw that they did not have a mechanism for doing this work?

GG: The chronology is – there was interest in long-terms survivors – went to the NIH and said, “What’s going on with long-term survivors? Is there something in their immune system or something with their virus that makes them less susceptible to getting AIDS to progressing to disease?” And at that meeting, there were dozens of immunologists and virologists trying to figure out, why do we see this small proportion of people who seem to stay healthy, when others get sick? And so, I think that spurred thinking about – okay, there’s one set of mysteries. There are other mysteries about HIV that are going on, that need some investigation. And so, this is – the transition now is when ACT UP and TAG split off. I remember Mark and I wrote this report on NIH research. We went through every single grant. We read every single grant – whether it was just the title and the researcher, or was an abstract. And you can see what’s being done, and what’s not being done. And it wasn’t that there was no basic research, but you can tell that it was skewed towards one direction or the other, or there were questions that we’d been thinking about that weren’t necessarily being represented in what was going on.

SS: But, Storm the NIH was way before the split.

GG: Yeah, it was way before the split. Storm the NIH was even before. Storm the NIH was mostly around clinical research and the ACTG.

SS: What year do you think that was?

GG: It was right as I came down, so it has to be ’90 or so?

SS: I’m trying to help the future understand how ACT UP functioned.

Let’s focus on the Storm the NIH. Can you just tell us the whole story – how did

ACT UP come to realize that they were making certain demands on the NIH? What were those demands? How did they respond?

GG: It's strange, because I was still in Boston during Storm the NIH. I came down to New York right after it. My sense of it is largely around clinical research on HIV, around the AIDS Clinical Trials Group. When people were storming the NIH – and people went down from ACT UP Boston – I hadn't gone down. Peter [Staley] was in a meeting with Fauci about getting a seat at the table for ACT UP and some of the discussions about clinical research. So, in 1990 there's this initial, heavy focus on what's going on at the NIH. And then people are going to ACTG meetings, and being exposed to a whole broader range of scientific stuff, because there's stuff on opportunistic infections, Countdown 18 Months is happening at this point.

SS: So, ACT UP having access to the ACTGs – that was a result of Storm the NIH, would you say?

GG: Storm the NIH and T&D's negotiations with Fauci and others. And people building relationships with researchers at that time, as well.

SS: So, can you explain what the ACTGs were?

GG: The ACTGs are the AIDS Clinical Trials Group. They're still around. They're a large, multi-center clinical research network – mostly of academic sites – that enroll people in trials of AIDS drugs for opportunistic infections or for HIV itself.

SS: And they're government funded?

GG: They're government funded, but academics run the trials. And, they were closed meetings until the beginning of the '90s. And, ACT UP, actually Bob Huff – it would be important to discuss this, because there was first reaching out to the bio-

statisticians, who ran the statistical working group of the ACTG – I think before the foot was in the door for the ACTG, itself. And that was just, again – Rebecca Pringle Smith from ACT UP – I wonder what happened to her? Rebecca and Bob and Spencer – there's this whole cadre of people in T&D who were close to David Byers and some statisticians at NCI and other statisticians, for some reason – and Susan Ellenberg at NIH. And so, there's this interest in how clinical trials – how do we know what we know, when we see clinical trial results? And so, there were early discussions with the statistical working group, and they even invited, I think, ACT UP members to come present. And then, I think Storm the NIH is around that time, as well – where Peter, and less technical, more political members of ACT UP – the T&D committee – were negotiating about a seat at the table. I remember David Gold just walking in and not taking no for an answer. And then, lots of people – as soon as the doors were open, everybody was – we sent a large group of people down to the ACTG meetings, and people would sit and listen to these scientific lectures.

SS: So, these were group meetings with representatives of each of the trials? And they would come and discuss together?

GG: Yeah. There's hundreds of people – principal investigators, the lead scientists on the trials, study nurses, statisticians – all the different people that go together – pharmacologists – all the different personnel that would be involved in a clinical study, including people from the NIH, who supervise the studies and funded the studies. So, you'd have two or three hundred people there and an ever-expanding cadre of activists.

SS: So, what was the first one you went to? The first ACTG?

GG: I remember them as sort of a clump. But, it was very different than being in T&D meetings, and discussing clinical trials. Just sitting in these meetings, where there'd be scientific data presented, and then somebody from ACT UP would get up at the microphone and deconstruct what was going on. Some of it would be sort of political hot air. The comments that came from ACT UP members would be just sort of like, crazy frothing. Or Garance would get up and sort of deconstruct what just happened in a presentation or ask something that showed that she knew what was going on.

SS: Was it because you raised your hand and they called on you? Or you were on the agenda?

GG: Think of a lecture hall – depending – there could be a huge lecture hall. And then, there'd be microphones. Somebody would do their 10-minute presentation, then people would line up at the microphone to ask questions. And, usually it would be ten scientists, three activists. I don't think the scientists had ever seen this before. I don't think the activists had – we didn't have any experience in these kinds of venues, either, so there was this very strange melding of cultures.

SS: What would you wear, for example, to go to ACTG?

GG: Well, back in those times it was the latest ACT UP t-shirt.

SS: And where did ACT UP – where was ACT UP in relation to the scientists, in terms of knowledge and ability to communicate?

GG: It depended. Some people like Jim and Mark and Garance and Bob Huff, Spencer – there were people who were extremely knowledgeable about the science – whether it was opportunistic infections or HIV trials themselves. The ACT UP treatment – they had treatment agendas that came out every year – would try to analyze some

component of the U.S. research system. And, looking back on some of that stuff – some of it is nuts, but some of it still stands true today. And some of the scientists definitely didn't want us there. The opportunistic infection researchers liked the fact that the activists were there, because people were caring about their research – which, opportunistic infections didn't get a lot of play among the virologists and the senior leadership of the ACTG. They're more retroviruses and virology and AZT and ddi. So, I think there were close relationships built with some of the researchers and some of the statisticians.

Tape I
00:30:00

SS: Can you remember any specific examples of ACT UP being totally on target with their critique, or totally off-base at the ACTG?

GG: Two things. One is, there's this trial called 175 – and it was a double nucleoside against another – AZT, ddi – I can't remember the exact regimens that were under study, but I remember T&D getting all worked up that this study was a waste of money and we didn't need to know this, we should be studying something else. And I remember Bob Huff came to the next T&D meeting and had a piece called “A Spanking for T&D” where he said well, actually, this study is going to teach us a lot of stuff about the clinical effects of anti-retroviral therapy in combination and what needs to be done. Meanwhile, David Barr and Mark and others had made quite a fuss down in Washington about the study, and everybody was up in arms about it, and then Bob came in quietly and said – which was true – that the study needed to be done, and it would give us some important information, and it ended up doing that. The other one was probably 076.

SS: Explain the whole 076 thing.

GG: Again, it's not too much on my radar screen, but we were against 076, I remember. Now, the only thing we can do 15 years later for people all over the world is to prevent mother-to-child infection, and if that 076 study never went up – if we had stopped 076 –

SS: Can you explain what it was?

GG: It was study of AZT to prevent mother-to-child infection. And, I can't remember whether it was we were upset because there was a placebo – I can't remember the details, it's all very fuzzy. I also remember there was a split a little bit in T&D, about – Maxine and Heidi – there's a bunch of people who were not in T&D who were mainly women who didn't support the trial, and then, there were all these men in T&D, who probably felt more strongly – that is, they needed to go ahead.

SS: But, you don't remember what the argument was?

GG: I can't remember.

SS: So, 076 has proven to be –

GG: One of things we can do really well is to prevent mother-to-child transmission, and it laid the groundwork for the HIVNET 012 study, that showed you could do single dose Nevirapine, and now thousands and thousands of women in poor countries are getting it during childbirth, and all of these infants are born HIV-negative.

SS: Would you guys socialize with the scientists?

GG: Yes and no. Not in those early days. I don't remember, in the early days, being in, sort of social relationships with them. I just remember the ACT UP people being very tight. Even the journalists sort of were more in – I remember Jon Cohen from *Science*, and Laurie Garrett from *Newsweek* – I remember certain people being around,

outside of the context of the meetings – in the evening, at a scientific meeting, or at some AIDS conference. And I think some people would sit and chat with some of the researchers who they felt like they had stronger bonds – with Judy Feinberg and Bill Powderly and some of the opportunistic infections researchers or some of the statisticians. But then there were the Gang of – this group of senior leadership in ACTG who, you know, we had a fairly sour relationship with.

SS: Who were they?

GG: Like Marty Hirsch, and Margaret Fischl and Doug Richmond. Who else? Chip Schooley. They're still here.

SS: You called them the Gang of Five?

GG: I think Mark gave them that name, which they didn't like very much.

SS: And what was their problem with you?

GG: I think – and it's still the truth today, is that – they're a small group of people who have enormous amounts of power over what happens in clinical research.

And, they've changed a great deal and our relationship with them is very different, but I do think they're not very interested in outside opinion. It's very sort of – this oligarchy of clinical research, which still –

SS: Were any of the scientists openly gay or openly HIV?

GG: Victor DeGruttola, who's a statistician at Harvard, was definitely gay. Spencer knows him very well. I don't remember anybody being out as HIV-positive. And not that many – even now, it's hard – that early crew of people was definitely not – a lot of them were straight herpes researchers, who came into AIDS as the epidemic began. The generation that's around now – there's many more out, gay researchers.

SS: When you guys would come down to Washington, to meet with them – how often were you down there?

GG: I felt like we were down there – it became more and more, as it got more involved. But, remember there's also drug company stuff happening. I remember being chained to the gates of Roche in weather like this. So, there's drug company focus stuff happening. But, going to NIH to go to an ACTG meeting – they were quarterly meetings, so at least quarterly people would go down. There were meetings with NIH people, with Fauci, or something, that would happen a couple of times a year.

SS: Did ACT UP pay the expenses, the travel?

GG: They had to have. It had to have come out of T&D.

SS: How did you guys all get off work to do it?

GG: We took vacation time. I ended up leaving my job, because it was clear – by the time '92 – after I had been down here for about 18 months or so, I was deeply engrossed in all the Treatment and Data work, and it was obvious that I really wasn't paying too much attention to what was going on at work. That's actually during the transition of ACT UP to TAG. But, there's a lot of stuff – my evenings were really spent in doing a lot of T&D stuff. And the social circle was becoming much more T&D-centric.

SS: So, what percentage of your life was ACT UP related?

GG: Back then, it became – before I left Boston, I had thrown myself into ACT UP Boston and Queer Nation, and by the time I left Boston, a large chunk of my life was around people doing work either with ACT UP or with Queer Nation or whatever. And then when I came to New York, probably 100%. Derek Link had come down. My old

boyfriend Dan had come down. Derek and Dan knew each other. I didn't have any friends here, per se, and so the first interactions I had with people were with the T&D group. So, most of my friends – Mark, David, Peter – all these people who were friends when I moved to New York and came to ACT UP.

SS: Also, you and Mark were boyfriends, right?

GG: Oh yeah.

SS: So, it was like 24 hours you were in ACT UP.

GG: Yeah. It seemed like it was – the vaccine conference – again, it was after about a year of being down here – a year or 18 months being down here. And again, it straddled the transition between ACT UP and TAG, but it was insane. And, it wasn't only the relationship with Mark. It was my friendship with David or with Spencer. A little bit of it is still the same.

SS: Did you have friends in ACT UP who are not in T&D?

GG: No. I feel like I came in at the end of – I just feel like when we split off from ACT UP, there was a pretty distinct transition what happened to the organization. I felt like I came in, went to T&D, and then very shortly afterwards – a year or two years – we're moving off. And so, I wasn't part of the early meetings of ACT UP. A lot of the people in T&D had much longer histories in the organization – much stronger relationships outside of T&D itself.

Tape I
00:40:00

SS: What was Countdown 18 Months – can you explain that?

GG: Countdown 18 Months was Garance, and I think Derek and Jerry Jontz, Rich Lynn, Chris DeBlasio – a bunch of T&D members decided that while everybody's worrying about AZT and ddI and antiretrovirals that most people are dying of

Tape II
00:00:00

opportunistic infections. And they believed that within 18 months, we could treat and prevent five or six of the major opportunistic infections.

SS: Which at the time, were what? Do you remember?

GG: PCP, mycobacterium avium complex, cytomegalovirus, KS, candidiasis, other fungal infections. So, they wrote a report called the Countdown 18 Months Report, where they went through all the research that was going on in these various opportunistic infections – what drugs were in development, what the current treatments were. And I remember, again, as I was just coming to New York – that they had a big meeting to follow – either before or during an ACTG quarterly meeting, where they invited the leadership of the AIDS Clinical Trials Group. And, I can't remember if Fauci actually came, as well. But basically, the Countdown 18 Months group sort of presented their manifesto about, here are five or six OIs that can be prevented and treated – how are you going to deal with this? How is the federal government, how is the ACTG going to respond?

SS: What happened?

GG: It was a fascinating moment for me, because all of a sudden we were in a hotel room, where all the ACT UP people were staying, and the researchers were all coming to us. So, it was an interesting – we're all invading their ACTG meetings, but now, they're coming to us and, remember, there's this group of people like Judy Feinberg and other opportunistic infection researchers who are pleased to have people interested in opportunistic research, and probably feel very strongly that, yes, we can invest in anti-viral research, but treating and preventing opportunistic infections is going to be the key, until we have something like we have today, in terms of protease inhibitors. I think they

were generally supportive, and I think the Countdown 18 Months work did make the federal government and the ACTGs shift resources to more strongly work on opportunistic infection, prevention and treatment. So, I think it was one of the better things that ACT UP Treatment and Data did. It really put the spotlight on opportunistic infections and raised the profile of researchers who were working on it so it gave them more clout within decision-making apparatus. And then, it got the NIH to take it seriously and offer more support for that. So, I think they were also meeting with drug companies who did opportunistic infection drugs – Pfizer with flucanazole – whatever – and again, raising the profile and the spotlight on it.

SS: Can you be precise with any of those particular infections, and tell us what precise trials came through the government, as a consequence of Countdown 18 Months?

GG: No, but Mark could definitely go back through – Mark was on the Opportunistic Infections Committee at the ACTG. What happened is a lot of people got – they formed a Community Constituency Group, which a lot of activists from around the country – we demanded a seat at the table, so they formed a Community Constituency Group, where advocates and people with AIDS would advise the ACTG and representatives from the Community Constituency Group would be on all these different committees – whether it's the Executive Committee, or the Primary Infection Committee, which did the antiretrovirals. The Opportunistic Infections Committee, which Mark originally sat on, and I think, David Barr did the Executive Committee or something like that. So, Mark probably has an excruciating record of all the trials that were done back then.

Tape II
00:05:00

SS: And how many of those infections ended up becoming controllable, as a consequence?

GG: As a consequence, it's hard to say. PCP had already – largely through Joe Sonnabend and others – and Bactrim people already knew how to control it. There's other work on alternatives to Bactrim that were done. Ganciclovir studies for CMV, clarithromycin – I think there were incremental gains in treating and preventing all of them, over the early '90s. I think if we didn't have highly active antiretroviral therapy, we'd still be struggling with how to manage and treat them. But I don't think opportunistic infection management – the whole, sort of – we've got a lot of new pharmaceutical tools. We were able to figure out how to manage them better. I think the medical management of opportunistic infections got a lot better in the early and mid-'90s. And I think what you see when you look at the mortality curves in the U.S., they start dropping down before the advent of highly active antiretroviral therapy, and I think that some of that is around PCP prophylaxis and other opportunistic infection management, that I think people became better at, in the early '90s.

SS: Just one more question about the government – what was your guys' view of Fauci? And what was your relationship with Fauci?

GG: I'm trying not to let my current relationship with him – it was interesting, I remember. It's very complicated, because first of all, there's enormous anger about what was going on at the ACTG or going on in research, and all our friends were dropping like flies. Chris DeBlasio, Jerry Jontz – a lot of these Countdown 18 Months people died during this period. So, there's a bit of that. I remember these meetings with Mark and David and me. The time period is fuzzy in my head, so it could be later. I don't think it

was under TAG. I still think it was under T&D. You know, there's enormous respect for him. It's a very strange relationship – both of admiration, anger. A weird sort of student/teacher thing going on. I just remember both Mark and I trying to talk to him about science – so you could have these –

SS: What did you admire about him?

GG: I think we thought he was a good researcher. And I still think he's a good researcher. I think when we can think of him as a scientist, we sort of liked the work he was doing. We were looking at how the immune system and HIV interact. I remember, back thinking about long-term non-progressors, we were obsessed with the idea of how HIV and the immune system interacted. So, Tony was working on a lot of that work. So from the scientific perspective, there's a sense of admiration. From the political perspective, we felt very strongly that he needed to have some kind of competition for the lifetime role of chief of AIDS research that he had.

SS: Can you explain why you were angry? What is it that you wanted him to do that he wasn't doing?

GG: Well, whether it was from opportunistic infection research or to reforms at the AIDS Clinical Trials Group. Or, more emphasis on long-term non-progressors, or more human immunology, it's just – ever since he came to the NIH, and still today he's got a sort of lifetime appointment, in charge of AIDS research. And so, he was – if things were going to change, it was him. So, he was a lightning rod for a lot of that anger and frustration – especially before there's any good antiretroviral therapy. So all our complaints, all our frustrations, all the things we wanted to have happen, had to go through him.

SS: And how come he wouldn't do them? What was the conflict?

Tape II
00:10:00

GG: It depends, you know? It's very hard not to see the past in terms of the disagreements we have with him today. In certain ways, he was very savvy. He opened the door to let the activists into the ACTG. There was Storm the NIH, but Tony opened the door, and Tony realized that by engaging, he was better off than shutting them out. And a lot of researchers, still today, won't even countenance the idea of talking to a PWA or a patient representative or advocate – whatever you want to call it. So, he brought people in. And certain things – long-time non-progressors – he realized – you know, his lab started working on stuff like that. So, if you had an interest in it, it was fine, but when there were big things at stake, like the ACTG, where there's a huge amount of money, where there are professional relationships with senior researchers in the field. Even though he had a lifetime appointment, you couldn't get him to change things.

SS: Why not? Why wouldn't he do it?

GG: It just entrenched power, surrounded by people who gave him bad advice, in some cases. In some cases, probably things we said were unreasonable. But it's interesting, because the complete split with him came – or just the momentary split – was when we wrote this report on the NIH – which again is when TAG and ACT UP are still co-existing – we basically said leadership has to be taken away from him. And went to Congress and got the OAR legislation passed.

SS: What's OAR?

GG: The NIH has an Office of AIDS research – there are 26 institutes. Tony is in charge of the National Institute of Allergies and Infectious Diseases. But, he was also the head of the Office of AIDS Research, which coordinated all the other 24 programs.

So, he had his own hat within the institute – mostly the Office of AIDS Research, but all these other institutes, as well. So, in '92, '93, we said the OAR needs to be run by an independent person – somebody else, and have power of the purse strings over all AIDS research, including his budget. And, he was livid. But, it was at the beginning of the Clinton administration. Kennedy and Waxman supported it, and despite him calling up his friends in the big professional societies and getting the scientific community to – including Harold Varmus, who was then going to come in and be the NIH director – to oppose it, we were able to push it through Congress.

SS: How would the T&D get a bill pushed through Congress? Can you explain that?

GG: I think it's more TAG – but it was definitely – that analysis and thinking – I mean, Mark and I read through all the grants, looked at it and said, this is an uncoordinated mess. There's stuff that's redundant, there's stuff that's missing. There's stuff that's unaccountable to no one. And the Institute of Medicine had come out with a report that said that in much more sober, conservative terms, a year or so before.

SS: How did you learn how to write a bill? Who did you call?

GG: Well – so, we wrote this report. I think it was the Amsterdam Conference. We wrote this report, we did a press conference, and Patricia Fleming, who was with [Representative Henry] Waxman's office then, and Tim Westmoreland, who was also with Waxman's office – no, she was with [Representative] Ted Weiss – Patsy was with Ted Weiss, and Tim was with Henry Waxman. I remember being at GMHC with David and Mark and me and maybe Peter, and Tim Westmoreland said, "Well, this is our report, this is what we found." He said, put it into – what are the recommendations? So, we put

Tape II
00:15:00

in the recommendations – this needs to happen, this needs to happen, this needs to happen. We give it to Tim, and Tim drafted it into law. We went and talked to Mike Iskowitz who was with [Senator Edward] Kennedy’s office, who also worked closely with Tim, on AIDS-related stuff. And they were supportive of it. [Senator] Orrin Hatch’s office – who worked closely with Kennedy on education and some healthcare stuff, supported it. And, we were able to galvanize Derek Hodel who used to work with the PWA Health Group had just come down to DC to work with the AIDS Action Council – they had the first sort of AIDS research person. And Derek took this on as his big project, so he was on the Hill all the time. I remember Elizabeth Glaser, who was still around, signed onto it. So, we had all these people. We had supportive legislators, we had supportive scientists. Tony was running a monopoly – not a monopoly – a little bit of a dictatorship. There was enormous frustration. David Ho had just gotten his job at the Aaron Diamond [AIDS Research Center] and David Ho and Arthur Amman used to be at the Pediatric AIDS Foundation were supportive and galvanized a bunch of scientists to support us. This was one of the moments where the scientists and the activists, all of a sudden, have a common agenda. So you had David Ho, TAG, T&D. You had Congress people, and you had the new Clinton administration all sort of move in the same direction to challenge Tony’s authority.

SS: This is kind of a weird question because it requires you to sort of step back a little, but looking at who you all were at that time – what was it about you guys that enabled you to finesse the government, get bills passed, scientists? How come you were able to communicate with power in such an effective way?

GG: I think ACT UP had built this credibility, a political base for what we did in Treatment and Data. I think Treatment and Data, and our early connections with researchers, trained us in speaking the language of science. So, we had the political credibility of ACT UP, the training through T&D. And I think in '92, '93, we didn't have any drugs that were going to save anybody. Larry's calling for a Manhattan Project Against AIDS. Marty Delaney was calling for something called the Madison Project, which was basically the Manhattan Project, and invited, again, all these different power brokers to a meeting. But, it's obviously – you know, there's not going to be a Manhattan Project for HIV, and we came out with a report and said, look, we're going to re-structure what happens at NIH. So, there was this Manhattan Project thing that was never going to happen in a million years. And then there was, sort of – seems like shuffling around some key players at NIH, but Tony knew what he was definitely going after his power. And also, it was a transition from Bush into Clinton. I think a lot of people like Tim Westmoreland and Mike Iskowitz and others were waiting for years to be able to be under a Democratic administration to do something. The Clinton administration wanted to show that it was going to do something for HIV. David Ho and the new generation of AIDS researchers who weren't these old herpes virologists – you know. David studied under Marty Hirsh, one of the Gang of Five. So, the second generation of AIDS researchers wanted to assert more of their power in the decision-making on AIDS research on a national scale. So, you had all these different things happening at once.

SS: And what did you learn about long-term non-progressors?

GG: It's interesting, because it's not grandiose – but it's a little grandiose, because Joe Sonnabend said, look I have these long-term survivors in my practice. Mark writes letter. We end up getting NIH to do this conference, and then there's all this work going on. But David Ho here, and John Moran, Rick Koup, and my friend Bill Paxton, are looking at long-term non-progressors, and they find people in New York City who don't get infected with HIV, and they go looking for what is keeping people from getting uninfected. They're definitely exposed. They've had partners that are definitely positive and had unprotected sex. And they find out that there's a genetic mutation in one of the receptors that HIV needs to get into cells that keeps a very small percentage of people from getting infected with HIV – one particular of the two big sub-types of HIV. And there is a clear path from those early – they may have done the long-term survivors' meeting maybe three years later. But, from those discussions of long-term survivors to people who didn't get infected, to understanding a bit about – making a major advance about how HIV infects cells – from sort of understanding what's happening to our friends, I think we had some small contribution into what – a deep understanding about how the virus works. We should actually – it would be nice to write it up one day, because I think it's a clear example. And I think the researchers involved would also see the trajectory, too. The clinical reality that basic science researchers might miss often holds some key facts that are going to increase our understanding.

Tape II
00:20:00

SS: What was the AIDS Cure Project?

GG: There was the AIDS Cure Project. There was the Barbara McClintock. Were they the same thing?

JAMES WENTZY: Same thing.

GG: There were these early '90s outbreaks of utopian dreams about ending the AIDS epidemic. One was the Madison Project, which was Larry and Marty Delaney. You know, "We're going to bring everybody to the desert and do what we did for the atomic bomb, for AIDS" – which, you know, was not going to work. So, that was Larry and Marty. This was, again, after T&D – after TAG had formed. I mean, Mark Milano and a bunch of other people who were also in T&D came up with a very similar sort of Manhattan Project idea about, again, curing HIV.

SS: So, you guys had Countdown 18 Months. These guys had Manhattan Project, and these guys had –

GG: Well, Countdown 18 Months is 18 months to two years, three years in the past. It's like, '90, '91. '92, 1993 – it was a pretty bad, bleak time. There's not drugs. People are still dying. There's no antiretroviral therapy. There's a political chance to make some sort of change, with Clinton coming in. And so right around the presidential election, there's the AIDS Cure Project – the AIDS Cure Project seems a little later, but there's definitely Larry and Marty and the Madison Project. There's the OAR legislation that we were doing, and then, sort of – I think after the election, the AIDS Cure Project – starts talking about, again, a Manhattan-like Project, to cure HIV.

SS: Let's talk a little bit about the pharmaceutical companies. Let's get away from the government. When did T&D start to build relationships with the pharmaceutical companies?

GG: Again, I think, it's hard for me to know what preceded me, but some of the first things I remember doing is coming down from Boston to meet Garance and Derek

and stuff at Pfizer, to talk about fluconazole, and talk about fungal infections. So, it's early on there, making connections with the drug companies.

SS: Can you describe what that was like, to go to Pfizer? And how it was different from the ACTG?

GG: Yeah, I think it was probably the first drug company thing I ever did. I assume it was about fluconazole, and maybe some drug they had in the pipeline for fungal diseases. And, it was the night of the first Gulf War starting, and I remember going with Derek, and I think Mark and Garance and Chris DeBlasio and some of the Countdown 18 Months people, and you go into their headquarters on 42nd Street, which is a little bit imposing. Rich Lynn, from T&D, worked for Pfizer.

SS: What did he do for them?

GG: He was in computers or something. He's on TAG's board. He's still involved, but he works for Pfizer, so it was a little bit different feeling, because we knew somebody who was there. But again, there was a bunch of people who really never had any interaction with people with various afflictions, except in sort of a charitable way. And then, people wanting to know, what they were going to do and when.

SS: How did they respond to you? How did you get the meeting, do you know?

GG: Again, remember, this is in a period where Peter has barricaded himself at Burroughs Wellcome or whatever, and things are starting to wane by '92 or so in terms of direct actions against drug companies. But, this is in the era where you don't get a meeting – or, even if you do get a meeting, you're still going to be demonstrated against. So, I think there's a little bit of fear of God, going on.

SS: Let's talk about that period for a second. How would that work?

Who would decide that there needed to be an action against a pharmaceutical company? How would they bring it to the floor? And then, who from the floor would do the action? What was the structure?

GG: The one that I clearly remember the most is a late one – the one against Hoffman – La Roche Nutley, in the freezing cold, and we had our arms in these tin sleeves that Peter and others had used against Astra, up in Massachusetts, and we're all hooked in these tin tubes, and then we had these big cement – barrels filled with cement – that we rolled out of the truck. It's a nightmare. Stuff generally got proposed at T&D. And then it went to the floor for acceptance or not.

SS: Do you remember what the demand was?

GG: From Roche – it was around ddC, but God knows what it was about.

SS: So, if T&D came to the floor and said, we need to do a CD or something – a direct action against this pharmaceutical company, everybody would do it, right? I mean, was there any question?

GG: Yeah. Those meetings were – there were a lot of opinionated people in ACT UP, and so there's always these long debates about what we're doing or why. There's always a period of – when describing the action, there's a little bit of a teaching component of it, where, this is the drug, this is the issue. It was sort of substantial, sort of an educational effort for the floor, about any given issue. Then, tactics would be discussed, and generally, a working group would go off and figure out how to work on the action.

SS: Would there be people who would do direct actions against pharmaceutical companies, who were not the same people who would be involved in setting the research agenda?

GG: Yeah, I mean, there were people who actually ended up – like Joy Episalla and Barbara Hughes – who were interested in the science, but didn't want to get involved – actually all the Marys. There was a group of people in ACT UP who were very sympathetic, but didn't come to the T&D meetings, per se. But if something happened around treatment, they were – Barbara, Joy – I'm trying to think of who else. So, yeah – there was a group of people. And Bob Rafsky – I don't remember him being at T&D when I first got there, but then he started coming, I think, as he got sicker. But, your key people – especially the PWAs who showed up for demonstrations – then there's a group of people who definitely would show up, as well.

SS: What was the dynamic inside T&D between people who were negative and people who were positive?

GG: Well, I was negative then, so it was interesting being on that side of it, and hearing David and Mark and Peter and everybody else talking from sort of the position of being positive. I didn't feel particularly like sero-status was being used as a weapon, to claim some sort of greater access to truth. Then, there's Derek Link's "HIV-negatives get out of our way."

SS: That was his slogan?

GG: No, he wrote – I just remember there was some conflict about meeting with drug companies or with the NIH, and this was when the relationship between the

floor and T&D are getting really nasty. I remember Derek doing a screed “HIV-negatives get out of our way.” In retrospect, it was just insane.

SS: And at that time, you were negative?

Tape II
00:30:00

GG: I was negative.

SS: He was negative, but he pretended he was positive. How did you feel when he said that?

GG: I knew it wasn't directed at me. I'm sure you've heard this from others – but there was this huge tension between T&D and Maxine and Heidi and some of the women in ACT UP. There's a cadre who felt like T&D was making too many compromises by talking to the government or meeting with the drug companies. That's when Derek was definitely going after Maxine and sort of a faction on the floor was aligned with her, and so I didn't feel like it was a particular – a blunt, political weapon that Derek used – really, that was much more specifically directed at people in the organization.

SS: Why do you think he pretended he had AIDS?

GG: It's really sick, but David and I were joking that Derek's going to show up – we said this back in 2001 – was going to show up and say, you know, “I've lost my entire family in the World Trade Center.” I think Derek was young and wanted to feel part of a historical moment, and I think there was so much – his identification with – a lot of us were obsessed and into the work, but I think Derek's identification just went sort of that one step that, you know – his identification with the work and the virus became really superimposed. He's a little pathological because of the other details of his life that have nothing to do with AIDS. Maybe it was just anxiety about being negative and being

afraid of sero-converting, or seeing everybody else around him getting sick and dying. But I think in a weird sense, it's an over-identification with the people around him. It's hard to explain.

SS: This is a naive question on my part, but when you sero-converted, did you have insight into your own relationship to AIDS when you were negative?

GG: No.

SS: It didn't change your relationship to the material?

GG: Not to the material, it's strange – to my own mortality it did. My cousin had just died a few months earlier, in '95 or '96, but I didn't feel – I'd done a lot of work. I'd done five to six years of work before sero-converting. So, I didn't feel any different.

SS: When T&D was still ACT UP, did you have instances of people who were very sick coming to you or asking you what they should do?

GG: There was this one guy – I remember very clearly at a Monday night meeting, in the hallway, where all the papers were – coming up to me, and he was extremely gaunt and wasted and wanted to talk about cryptosporidiosis, and what was available. And, I just remember very clearly not being able to say that there was very much out there for him. I said these are the alternatives. Nothing seems to work very well. It was clear that he was going to die soon of this, and he did. But, I also remember going to Jerry Jontz's hospital room with Garance. It was such a desperate time. Jerry was part of Countdown 18 Months – banging on the table for opportunistic infection drugs. And Garance and I and maybe Derek were in this hotel room, spraying Peptide-T up his nose, while he's just raving like a madman. He obviously had AIDS-related dementia or some brain infection, and we're like, going day after day to give him

Peptide-T – which, you know, in our saner moments we knew that it had no hope of working for him, but he had fixated on it, at some point.

Tape II
00:35:00

SS: Do you think a lot of people in ACT UP made treatment decisions based on what you guys recommended?

GG: There weren't a lot of treatment decisions to be made back then. I do think – I just remember – I think a lot of people came to T&D because – I was HIV-negative. Maybe it was a bit about – I was interested in the scientific side of things. But a lot of people came to T&D because they were scared to death. All the other issues that ACT UP worked on were important to them, but this was the issue that was going to make life or death for them. And I think people who were in Countdown 18 Months – Chris and Jerry and Rich – not Rich he's negative – came because they were going to get information about opportunistic infections. A lot of people were in that room, because it was the way they would have access to the latest data – not that often, that it really helped that much. We were dealing with AZT and some opportunistic infection drugs and the dual combination therapy by the end of the heyday of T&D. But I think people were really looking for information, and that's what sustained it. It got a little crazy.

SS: In what way?

GG: I remember being at a meeting with Bob Rafsky – and again, this was during the transition period, when T&D – that group of people in T&D went to TAG – that Bob was like – he would go on these tirades. And somebody said something and he just turned and said, "No, these people are going to save my life." In retrospect, there was just such desperation. Bob was sick and there was a lot of faith put into what was happening at T&D.

SS: Did you feel the burden of that at the time?

GG: No, I don't think I did. I think probably Jim and Mark and others maybe felt it more acutely. And I think, probably the other positive people in the room. I think, maybe Garance and Derek with Countdown 18 Months. It was clear that there were not many answers in the room for people. That's why we started going to basic science. There's not an answer here. We're in really bad shape.

SS: One of the things we've been doing for historic record is that everyone we interview who's positive – we ask them if they would tell us what treatments they are on now.

GG: I am on AZT, 3TC, nelfinavir – since 1996 or 1997.

SS: So, I just wanted to get back to the pharmaceutical company thing, because this became an issue of contention later. How did that relationship develop? Which pharmaceutical companies were more open to ACT UP? Which ones were not open?

GG: A lot of it's the same – Abbott, Roche, Astra – monsters still are. Bristol-Myers had the parallel track for ddI, which is really an activist invention to give people drugs before they got their drug approved, for free, for over 30,000 people, and to collect data at the same time. So, that was a collaboration – at least of ideas between Bristol-Myers and T&D and other people who were calling for expanded access to drugs. I think Merck – they didn't have anything until Crixivan, but they were always more – are still interested – they seem to have more of a public health focus than a lot of the other drug companies. The ones people always had trouble with were Roche and Abbott.

SS: What did they make? What were their products?

Tape II
00:40:00

GG: Abbott had clarithromycin, and later it would have ritonavir/Norvir, one of the first protease inhibitors. Roche had ddC – they always bet on bad drugs. Astra had Foscarnet, which was for CMV. They were in Boston, so in Boston we had huge fights with them. But, I don't remember – there were actions against Glaxo, there were actions against Roche. I don't know if anybody demonstrated against Bristol-Myers.

Tape III
00:00:00

SS: So, how did T&D people start to become formalized as advisors to pharmaceutical companies? How was that relationship built?

GG: It's interesting, because for the FDA and the NIH, ACT UP or Project Inform people would sit on advisory committees or the Community Constituency Group. But, for drug companies, there was never an advisory capacity. You went in and you had meetings with them. You had demands. Letters would be written. It's only more recently that the drug companies have tried to sort of corral the community into being their – the Community Advisory Board for Glaxo, or something like that. Back then there was much more – you could advise the government, but drug company meetings were much more – a letter goes out, these are the demands, you go meet with the companies. If it gets really nasty, you end up chained to their gates. With the NIH it became more of a partnership, with certain components like the ACTG. And then, the seats on the advisory committee meetings and stuff like that, at the FDA.

SS: Well, now the pharmaceutical companies fund POZ or whatever, with their ads. How did that relationship switch?

GG: My sense – and I have to research it, to see if it's true – is that in 1996, when they all started having products to sell, I think we became something to market to, and that's when I think the money started flowing to a lot of community-based

organizations. ACT UP, TAG – none of them took drug company money, at least in the beginning. But I think in 1996, as soon as there were drugs or marketing managers became – now, it's all pervasive. Drug companies fund a lot of AIDS organizations. They have their own community advisory boards. They bring community leaders together. It's much more insidious.

SS: Do they fund ACT UP now, by the way?

GG: No. I wouldn't think so.

SS: Can you explain what parallel track is?

GG: So AIDS drugs came out. The normal time for approval of a drug could be a decade or more, and one of the things that ACT UP, T&D and Project Inform in California – were big proponents of is that people don't have time to wait to get access to AZT or ddI or ddC. And so, there has to be some other way to do it. And Marty and Project Inform pushed for something called accelerated approval, where companies could get early approval by the FDA based on surrogate markers, like CD-4 viral load for their drugs, and then they could do the clinical endpoint studies that showed an effect on disease progression, or death, later. And, what T&D proposed was the idea of parallel track. It's that while you're waiting for your drug to be approved while you're still in later clinical studies, do parallel track. There are several hundred slots in a drug trial of ddI, so there are a lot more people with AIDS who need access to it, so why don't you open up a parallel track. So, you have your clinical trials track, but here's a parallel track, where you'll give away the drug for free, and you can collect safety data on it. So what Bristol did was to give away the drug to over 30,000 people, and collected safety data on it.

SS: Which drug is this?

Tape III
00:05:00

GG: ddI. And, I think that's a high water mark of T&D. No other drug company has really done it, since. And, it gave them important safety data for the FDA and for their new drug applications at the FDA because there are certain events that, because they are less frequent if you do – if you give it away to a thousand people, you're not going to see it, because one in 10,000 are going to get it. So, some of the pancreatitis and some of the other rarer side effects of ddI got picked up in the parallel track. Yet, 30,000 or 35,000 people got the drug before it was approved, or during the approval process.

SS: How were they persuaded to do this?

GG: Again, I wasn't in the parallel track negotiations. But, my sense is that, again, it was the sort of political power of ACT UP. I think Bob and Rebecca and Mark and Jim – I think there's always a crowd in T&D that is thinking about how do you get information about drugs – which would later come back to create political difficulties with Project Inform and others. How do you get information about drugs? We don't just need access to it, we need answers as well. And so, I think that that idea that you needed clinical information – the companies knew – we need to know what the safety profile of this drug is. Well, we can get PR out of giving it out to a lot of people. We can also seed our market with 30,000 people who will be taking ddI. So, there's probably commercial considerations in terms of – ddI is widely dispersed before it even gets federal approval. They get a big PR bump, and they also can collect data. But now – we argue with companies about getting a hundred slots in an expanded access program, so nobody else has really done it since.

SS: What was the tension between prevention and cure, inside ACT UP?

GG: I don't know if there's a tension between prevention and cure so much, as there was – I do think there was this HIV-negative, HIV-positive issue. I feel like a lot of people came to ACT UP out of the fear of God that they were going to die. And, a lot of people came looking for treatment information to T&D. A lot of people were in great fear. I think a lot of other people sort of came out of progressive political histories and different movements over their lifetimes. And, I think – my sense of when things started getting crazy – when Derek Link wrote, “HIV-negatives, get out of our way” – it was like, we're not going to – and Derek was channeling something really important, which is freakish, in retrospect – is that, people felt like getting better treatments was more important than anything else, because it was a life or death matter for them. But, ACT UP was growing into a broader social movement, and people felt like it was getting pulled in other ways. Stop meeting the drug companies, with the NIH. No, we need to get this information. And, I think there was this sort of broader social movement that sort of got alienated from the very specific survivalist mentality of a lot of the PWAs who were in T&D, or who were around T&D.

SS: Let's try to be specific. Let's talk about the split and try and get as specific as we can. Something I'm realizing as you've been speaking is that you guys were in this – having this very special experience together. You were together all the time, you were traveling back and forth, you were meeting with the government, you were meeting with pharmaceutical companies. How did you convey to the rest of ACT UP exactly what you were experiencing?

GG: Well, two ways. First of all, we had to convey back to the rest of T&D. Lots of people in T&D were active in various different projects, but the T&D meetings were very well attended and there was a lot of – if you went to a meeting, there was a lot of talking beforehand about what to say, and then, there's a lot of de-briefing and pulling apart what happened afterwards, in T&D. And then, generally T&D would do an update on the floor, and report back on various issues. But again, in the context of those Monday night meetings, they were overly long. The agenda was filled with all these different issues. Except on special occasions, T&D wasn't going to get – especially in the later years – got a certain portion that could do the quick version of the issues that had been discussed fairly in depth at a T&D meeting. People from T&D generally did go to the main meetings and reported back on the floor. And, I remember there was sort of – I feel like we congregated at the main meetings at the right side, at the edge. And, you know there was –

Tape III
00:10:00

SS: At Cooper?

GG: At Cooper Union. I just remember all of us sort of being down there, and stuff would come up around treatment, and it was definitely very clear physical space that T&D sort of occupied at the Monday night meetings. And there was interaction, and people would stay to the end, and take questions and have very strong opinions. But, people were very invested in what was happening to the organization as a whole.

SS: Do you think that T&D, in any way, made themselves apart from the rest of the body of the group?

GG: Only in the sense that it was very specifically focused. It was. ACT UP was becoming a much broader social movement.

SS: What do you mean by that? You've said that a few times. What does that mean to you?

GG: It was taking on things that, you know – it was taking on larger social issues around housing. I can't remember all the different committees, but we had a huge panoply of social issues, related to AIDS – some very intimately, some sort of further and further out. Meanwhile, you had these PWAs who were like, I don't want to die, I want to get access to treatment. Yes, housing and all these other things were important, but they were very mono-focused on, I've got to figure out how to stay alive. And, in a certain sense, maybe a lot of them were middle-class white guys who didn't have to deal with housing, prison issues or all these other issues. And in that sense, there's some sort of class anxieties, and other things that played out. But, I do think they were very focused on – I just want to get my drugs and figure out how I'm going to stay alive. And as ACT UP became more and more sort of a vehicle for all these other social movements, I think there was a little bit of tension there.

SS: Let's talk about housing, because that's the one that you brought up – when do you think the Housing Committee started in ACT UP?

GG: I can't remember. Again, most of these things were there before I got there. And, I think of housing in retrospect because of Keith [Cylar] and some of the people I do housing stuff now with, and that I work with.

SS: I'm just sort of getting into this with you, because you positioned it as though ACT UP was now expanding into these other areas. And then, the area that you suggested was housing. So, I'm wondering if in your perception, housing was a new area of work for ACT UP?

GG: No. I think to be clear, I think people in T&D – the people I felt most extremely focused on personal survival, and who invested in the treatment issues because they thought that was the number one for them. If we can't solve this issue, the rest is afterthought. It's not a question of that ACT UP got broader, but I think other people came to the organization with a more diverse set of priorities.

SS: I'm just going to go at this with you for a minute, because everyone's got their take on this. Did you have any exposure to people in ACT UP who had been in prison? Or who were low income?

GG: No.

SS: Did you know homeless people? People who were in housing for homeless people with AIDS?

GG: No.

SS: Because you said personal survival, and obviously that is a personal survival issue.

GG: I understand that. I also said that T&D is also – remember, it's a large core of men who are white, middle-class gay men, who – housing, incarceration, other issues are not –

SS: So, would you say that they did not see the experiences of other people in ACT UP as primary to what they were experiencing?

GG: A little bit. I can give a contemporary example, which tries to – we do work with the Treatment Action Campaign in South Africa, and they had this competition case hearing against the drug companies in South Africa. And they just wanted to cut a deal for a low price for Glaxo, Bristol and Boehringer Ingelheim drugs. Jamie Love from

Consumer [Project on] Technology in DC is like, “No, we have to get a compulsory license. We need to push this, and push this further.” It’s all about reforming intellectual property in the sphere of public health. And they’re like, “No, it’s really about us getting a cheaper price of the drug.” And so – because I do think there are people in T&D, and in ACT UP, who worked on issues that dealt with broader topics. But there’s something fundamental about a lot of the stuff that was happening in T&D that was about – the drugs were central and it was. Maybe in retrospect, it’s myopic.

SS: Did you know that there was a contingent of women with AIDS who came into ACT UP from Bedford Hills, and they were mostly in the Latino Caucus?

GG: No, I can’t say that I do.

SS: Do you know any of their names?

GG: No.

SS: Where do you think the conflict began? Where T&D began to get alienated from the rest of the organization?

GG: Again, it’s really fuzzy. I mean, I remember there was contention about whether T&D could go meet with X. And, it’s either pharmaceutical company or NIH whether we wanted a moratorium on meetings – I think, with the federal government.

SS: And who proposed that?

GG: I just remember on the floor, Maxine being very vociferous about it.

SS: Do you remember what her reason was?

GG: In detail, no. It was more of a sense – I had the feeling that we were being positioned as, sort of, collaborationists – that people who went to negotiate with the

government or talk to the government were somehow betraying an oppositional role, that ACT UP wanted to hold.

SS: Did you think it was just ideological? Or were there concrete, specific things that were going on?

GG: Back then, I felt like it was completely ideological. I felt like – I’m just putting it out there Maxine, you have no idea what we’re talking about. We discussed the details. We’re not collaborating with the government to get this or that. It’s just – this is part of the work we have to do. And again, it was around outsider/insider status. There’s a lot of things going on.

SS: Were you guys involved in the changing the CDC definition of AIDS – that campaign?

GG: I didn’t personally work on it. I remember someone was doing work on opportunistic infection. I remember some discussions of it happening.

SS: And so, when this proposal came up – to control whether or not you guys could meet – did you sit down with any of those people, and talk to them individually? Or, did you rely on the T&D analysis of the situation to understand it?

GG: I don’t remember talking with people directly. But I remember talking, in the context of a Monday night meeting in terms of the debate on the issue. Remember, my social circle is very T&D focused. And so – and then, there are the issues about when we decided to split off, because there were some members of T&D who were like, “No, we shouldn’t do this.”

SS: So, personally, why did you decide to split off from ACT UP?

GG: I remember having a very clear sense – but, again, I was very interested in the scientific, clinical stuff and felt like that was what made it, in the end – as somebody said to me, recently – I can eat and eat and eat, if I don't have the drugs, I'm going to die. It can be about nutrition, it can be about housing. In the end, if we don't have drugs, people are going to die. And that's all I could focus on, and I did feel like everything else was becoming a distraction. And, the emotional climate of ACT UP – it was just fraught – it just felt painful. I don't know where it was coming from, or who was driving it, but there was definitely this welling of tension, that made it very painful to go to the Monday night meetings. It felt very besieged, in a certain sense.

SS: Looking back on it – because now it's been a long time, like 12 years – with hindsight, do you see any way that T&D contributed to that?

GG: Yeah.

SS: How?

GG: It's clear. First of all, think of the personalities involved. Mark, alone – you know? It was very confrontational. There were huge egos at play in T&D and in the general membership, and other committees, as well. So, there were the personality issues that were going on which were extremely potent. I think there is – I think T&D developed an egotism about the importance of its work and the importance of individuals within the committee, which I think, again, definitely contributed to the alienation from the rest of the membership. I also think, you know, the fact that we're dealing with mostly well-off, gay white men – largely. To be fair, it's more diverse than that, but those issues are pretty clear. I think Larry was a fulcrum in this, too.

SS: Because he opposed the split, right?

GG: Yes and no. It depended on what day of the week it was. He's extremely volatile, and I think after five, six years of ACT UP, he's getting antsy. He's a central figure in T&D, helping to be a voice for the kind of work it needed to do, but also fostering a self-importance that only Larry can sort of –

SS: He told us, when we interviewed him that he opposed the split. He said he was still angry with Mark. That was on the tape.

GG: No, he was against the split, but he was very cranky by the time the split came up. So, while he may have wanted us to stay, Larry was throwing tantrums, around what was happening again and again, leading up to those 18 months.

SS: It's just kind of mysterious, because we've interviewed 41 people now, and there were women who supported TAG and went with TAG. There were women who stayed in the organization. There were people who were negative who supported TAG. There were people who were negative who stayed in the organization. There were people who were positive, who totally opposed the split, and opposed T&D. So, none of that – none of these identity categories seemed to be the thing that determined where somebody went. It seems to be something else.

GG: I think it's also just – in hindsight, it doesn't translate, whether you're black, white, woman, gay, straight, positive or negative. It didn't necessarily say where you were going to fit on – I just think, at a certain sense an organization starts to – I don't understand how you expect something to be cohesive over a long stretch of time, and people spin off. I think people spun off in lots of different ways in ACT UP, whether it was around housing, or other issues, to do work that was very specific to what they were

doing. And as ACT UP broke up, people went off and did specific – it just happened that T&D was a noisier part of the disintegration of the organization as a whole, I think.

SS: Okay. Enough on that. So, you went off into TAG and you were there for three years?

GG: No.

SS: How many years?

GG: Oh God, like ten years.

SS: Before you went to GMHC?

GG: Eight years. I can't remember when TAG formed – when was the split? So 1992 until 2001.

SS: Why did you leave TAG to go to GMHC?

GG: It's the same thing. Things have cycles, and I wanted to do work in a different context in a different organization. Working with your ex-boyfriend and being with the same people for eight years – it's time to do something else, and feel a little – again, these are people who I came from T&D with. I spent a decade or more with these people, and it's time to – I need to do something that I don't feel is part of this tiny collective. And so I talked to Ana [Oliveira] and Ana said, come and do this work. And in a certain sense, it's liberating.

SS: What is your title at GMHC?

GG: Director of Treatment and Prevention Advocacy. So, I do everything from treatment access to NIH and drug company stuff to prevention stuff now.

SS: Some people, after ACT UP, they never did another socially minded thing, and you've spent your whole life in AIDS – why do you think that is?

GG: I can't think of doing anything else. I've toyed with going back to school, and a lot of my friends who are in ACT UP – even in TAG, have gone off to do other things – often, sort of tangentially related – like, go to work for the government or go to work for a drug company PR company. But, I don't know – the whole experience radicalized me in a way that I feel like I can't go back. It's hard to conceive of going back. And, I wasn't that young, but I was fairly young when I came to ACT UP. And, I'd gotten to see a lot more, and the more you look, the more horrific – it's hard to explain. The more you look, the more problems you see, and it does – the whole discussion we had about mono-focus on treatment, it just – I've met more people, seen more things. It becomes this web of injustice and just horrible things. Even if it's not going to – even if nothing is accomplished at the end, I just would feel really horrible if I went and sat in academia, or went and worked for some profit PR company. It's like, everyday – I don't know.

SS: I have one last question for you. Looking back on your ACT UP years, what would you say was ACT UP's greatest achievement?

GG: We did a meeting last March in Capetown, where we had 125 activists from 67 countries, talking about treatment advocacy and education. These are men, women, straight, gay – mostly straight – from all over the world – Soviet Union, Asia, Africa, Latin America, the Caribbean – talking about taking a role as PWAs to say that we demand the drugs we need to save our lives. And we demand the information to know how to use them, and how to advocate for them. And none of that would have happened, except for what happened in New York 12, 13, 14 years before. There's a global treatment advocacy movement in places where the prospect of success is a lot

more remote. There's the stuff that comes from national liberation movements, but a lot of it is based on the culture that ACT UP created in New York in '87, '89, '90, '91. It spawned a global public health movement based on the needs of people with the disease, which has never been replicated since.

SS: Thank you. Great, thank you so much Gregg.

GG: It's just fascinating.

SS: You told us a lot of really important things.

[END OF INTERVIEW]