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P R O J E C T

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Interviewee: **Garance Franke-Ruta**

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Interviewer: **Sarah Schulman**

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ACT UP Oral History Project
Interview of Garance Franke-Ruta
June 6, 2007

SARAH SCHULMAN: Okay, so we start, and you just say your name, your age, where we are, and today's date.

GARANKE FRANKE-RUTA: My name is Garance Franke-Ruta. I'm 35 years old. I'm sitting at my home in Washington, D.C., and it is June – Fifth?

SS: Sixth.

GFR: Sixth, of 2007.

SS: Okay. And I just want to say, we've been really looking forward to talking to you.

GFR: Likewise. This is, I think we've planning this for about a year now, or something?

SS: Yeah, right, that's right. So let's just start a little bit with your background. Your last name shows a lot about you already. You're probably from the first generation of hyphenated last names.

GFR: Actually, I am a third-generation Franke-Ruta.

SS: Really.

GFR: Yes. And I actually have a blog of my own now. And part of the reason I created it is in fact to just provide the whole entire story of my name, because so many people ask about it. And so it just goes through it in complete detail. But my grandfather was Walter Franke, and he was a German writer living in Italy in the 1930s. He left Germany very early with my family, my dad's family, who is Jewish, or half-Jewish. And then after it became increasingly difficult for Jews, or someone who was married to a Jew, to publish in Germany or in Austria or anywhere in the German world, and as fascism intensified in Italy, he wanted to sort of distance himself from Germany,

and he took Ruta, which is the town he was living in in Liguria in Italy as part of his last name as well. And he stopped being Walter Franke and became Walter Franke-Ruta.

SS: Oh, okay. So your mother, Suzanne Ruta, that's her married name.

GFR: Yes.

SS: Oh, all these years, I thought that was her maiden name.

GFR: No. In fact, conveniently enough for her, though, her maiden name was Frank. Which was shortened from Frankenthaler –

SS: Oh, okay.

GFR: – who was this other group of German Jews who came over in the 1840s. So basically the family narrative is every time there's a convulsion of anti-Semitism in Europe, some new wave came over. It was primarily German and some Russians.

SS: So you're from like a long line of educated intellectual –

GFR: Yeah. And in fact, I'm very unusual in that both of my grandmothers went to college.

SS: In Europe.

GFR: My German grandmother was the first generation of women to go to university in Germany. I think she graduated, or started, in 1911. And she was also, I think, the first generation of Jewish women to go to college then. And my other grandmother went to Hunter College in New York City.

SS: Oh, wow. Okay. And so these are your father's paintings.

GFR: These are my father's paintings. And this, in fact, is the town where I was born.

SS: Which is what?

GFR: It's in Cavaillon, in France, which is this tiny little village in Provence. And this and the painting on the other side of the room are paintings he did the summer I was born. And then this painting, on the other side — I don't know if you're going to get any shots of these — is of San Chapas in Mexico, where I lived till I was six and a half, with my parents. And that's what he painted there.

SS: Are you the only child?

GFR: There's three of us.

SS: And you're the oldest, or the —

GFR: I'm the middle.

SS: The middle. Because I just want to say, your mother was a writer, your father was a painter — and I believe you grew up in Westbeth. Is that—

GFR: I did grow up in Westbeth —

SS: Okay.

GFR: — partly. When we weren't in Mexico and New Mexico, I was in Westbeth.

SS: So what school did you go to?

GFR: I went to PS 41.

SS: Oh, me too.

GFR: Yeah.

SS: Okay. So you're, West Village —

GFR: You went there?

SS: Yeah.

GFR: Oh. I didn't know that.

SS: At a very, very young age.

GFR: Well, of course, all of us, right?

SS: And where did you go to high school?

GFR: I was in high school in New Mexico at the time. I went to freshman year at Santa Fe High School. At the time, there was only one public high school. There was a public high school, private high school and a Catholic high school. And so I went to the public school. And then sophomore year, I transferred into the private high school. And then I skipped junior year, and then went back to the public school. And then, for complicated family reasons, wound up dropping out in, I think, the first or second month of my senior year; and moving out, on my own, in New Mexico, when I was, shortly after I turned 16.

SS: So how old were you when you came back to New York?

GFR: I was 17 when I came back to New York. So I spent the year when I was 16 living on my own in New Mexico. And then my parents moved back to New York when I was 17. And at that point, I moved back in with them, in New York.

SS: Okay. Now, obviously, your parents were intellectuals and you were aware that there was a social world. But were they politically engaged?

GFR: Um, yeah. I think they're more politically conscious than politically engaged. None of, neither of them were involved in electoral politics. But they were very heavy readers. And my mother was a great follower of politics and a writer of

letters to the editor. And she wrote a book of political satire, actually, in the mid-'80s, called *Stalin in the Bronx*. Which was well received, and since then, she's done a lot of book reviews and so on. And she's always been interested in international politics and international relations, especially. But neither of them were ever engaged in electoral politics at any kind of level, although my mother will occasionally write letters to her congressman.

SS: But did they ever take you to demonstrations, or anything –

GFR: No.

SS: No.

GFR: No.

SS: So there you're 17. What landed you at ACT UP? Was that your first political involvement? You came at 17, right?

GFR: Yeah.

SS: Yeah.

GFR: Yeah. It was, in fact. I remember Derek Link and I used to joke in later years that we were the unofficial chicken caucus in ACT UP, because we were so young. He and I were roommates for a while; I don't know if you knew that.

SS: Before you came to ACT UP?

GFR: No.

SS: After.

GFR: When I was 19, and he was, I don't know; 23 or something.

SS: But I do remember; I think he had green hair and you had something going on with your hair.

GFR: Yeah, I know. I had, I went through this phase of multicolored hairs. I went through just about every color. But I've had this color since I was 19, pretty much.

SS: So did you come to ACT UP together, or did you meet him there?

GFR: No, I met him there. How did I get to ACT UP?

I was involved in groups in New York that were recruited for the FDA demonstration in, I guess it was October of 1988, right?

SS: How did you get recruited?

GFR: I think there was a speaker from ACT UP — Neil Somebody.

SS: Broome? Neil Broome?

GFR: Neil Broome, right? Who had like that floppy '80s New Wave haircut and shaved his hands?

SS: That's Neil.

GFR: Yeah, right. Is he still around?

SS: Oh yeah. We interviewed him. He's a social worker. He lives in Northampton.

GFR: Yeah. I think it was him. He came to a meeting at the Center — the Gay and Lesbian Community Center in New York — that I was going to for teenagers — and — and spoke, and invited people down to the FDA demonstration. And so at that time, my involvement was simply in the role of warm body in the background. And I went there, and it was — Washington was still much more the South then it is now. And it was the first protest I'd ever been to. And it was very — exhilarating and, and just the community aspect of it was very appealing. But —

SS: Did you know anyone who was HIV at the time?

GFR: I – I knew a lot of gay and lesbian teenagers in New Mexico; most of whom, like myself, wound up living alone as teenagers, because they had problems with their parents on account of their sexuality. And, and there was always – this was New Mexico, there was – if you think of how New York was in the late '80s, mid-'80s, in terms of gay rights and stuff; and you think New Mexico, is, I don't think they'd even had their first gay rights march, or any of that stuff. And it was – it's also this fairly Catholic state.

And I actually wound up living, as a roommate, with this guy Michael Ortega, who was a friend of mine. He worked as a waiter at a Italian restaurant in downtown Santa Fe. And now, he's known as Mistress Formika in New York City.

SS: Oh.

GFR: But he was my old roommate when I was 16 and he was 19, in New Mexico. And – and then eventually both wound up in New York. But he came several years after I did. And some of the other people I knew in New Mexico also came up later.

And so it was, it was sort of one of these issues, and my best friend my sophomore year was this guy who was gay, and it was just sort of this question, because nobody really even knew about safe sex. There was this, I remember getting the pamphlet from C. Everett Koop at my apartment, I think in, was it '87 or something like that? And it was like, what is this? And you just throw it out. And so it was, it was just a very disconnected environment, although, not disconnected from homophobia, certainly.

SS: So just Neil was so persuasive, you decided to come?

GFR: I don't know. I just, I had friends, they were going down. They were like, why don't you come down? Okay. It's an adventure. Right? And then I got there. And I remember –

SS: Did you do CD training?

GFR: I don't think so.

SS: Okay.

GFR: I didn't do CD down there. I remember – people seemed to think I was very cute and naive. And I suppose, in retrospect, that I was very naive. Because I remember, there was someone — and I don't remember who at this point — said something to me about, you know, being worried about the police; what if they charge us or shoot us, and like that. Oh, they'd never do that. And he's like, well what about Kent State? And I was like, what's that?

Because I didn't know. I had no idea about the '60s, or any of that stuff. It was, I was very young; and not particularly well educated about recent American history, as well. Having had two years of high school education, which, even if I had had the complete thing and finished my AP history courses, the semesters always sort of peter out around mid-1960s, and then the book is done, and then suddenly you have finals, and everyone's applying to colleges and so on, so.

SS: That's true. So you came to ACT UP. You had never been to college. You –

GFR: No, I hadn't been to college.

SS: – you were a high school dropout. Yeah.

Tape I
00:10:00

GFR: Yeah. I had, I got a GED before I left New Mexico. Because I'd been an honors student. And was a National Merit semifinalist the same year as my brother was, and he's about a year and a half older than me. There was like a little item about us in the local Santa Fe paper.

SS: So what happened to you at the FDA?

GFR: It was just this big protest, with people shouting; and this huge, raucous community of people, who were all, in one way or another, outcasts, and socially isolated, and who, out of that, created a community.

SS: So did you start going to ACT UP meetings right after that?

GFR: I think I started going after that. And again – sort of remained at the level of body-in-the-background. And then I got roped into the City Hall protest, in 1989, against Ed Koch, with the affinity group the Divas.

SS: Oh, who was in that group?

GFR: God, I can't remember anyone's names. The really big, tall, good-looking guy who's a doctor now.

SS: He's a doctor?

GFR: He's a doctor now. He went to medical school. There was a group of us who later all, like, got science-y, and decided to become doctors, and then some of us did and some of us didn't.

Costa [Pappas], I believe was –

SS: Uh huh.

GFR: – in it. And I can't remember who else.

SS: Is this the group that later became the Costas?

GFR: I think it became the Costas afterwards, yeah.

SS: Was Avram in it? No?

GFR: I don't think so.

SS: Okay.

GFR: No.

SS: I wonder who was.

GFR: I just remember that the night before – was it – or maybe we were Cher, and not the Divas.

SS: Cher!

GFR: It was something like that. It was Cher. And –

SS: C-H-E-R, Cher.

GFR: C-H-E-R. And the night before, we all ironed on these iron-on images of Cher on white T-shirts, and that's how, we all wore them the next day, to the protest. And we were making jokes about what it stood for. And it was, I think people were joking that it stood for Concerned Homosexuals Enduring Reality. So, the high camp spirit of ACT UP was very attractive as well.

SS: Right.

GFR: And then I was arrested at that protest, with a group of other people. And I was still under the age of 18 at the time. And then we were, as you recall, strip searched. And then – in retrospect, I'm like, what the, how were they doing? What was the City of New York doing?

SS: So you were underage. Did they pull you out from the rest of the people?

GFR: No, no.

SS: No, they kept you. So this was the group that was like Catherine Saalfield, right, and Maxine [Wolfe]. It was a whole bunch of women who got strip searched.

GFR: Basically all the women — there was like 80 of us or something like that — all of the women who were arrested that day were strip searched. And I recall — I'm so bad with names. How many years later is it? Sixteen years since I sort of left ACT UP? The woman who had the curly brown hair and dated Liz [Tracy], the — for a while. Do you remember her?

SS: Liz —

GFR: Liz, big Liz? You don't remember either?

SS: Who's Liz?

GFR: With the short blonde hair?

JIM HUBBARD: Yeah, I can see her, but I don't —

GFR: Anyway. See, it was a really big organization.

SS: Oh, it's okay, that's fine.

GFR: Anyway, I just remember she was sort of, I wasn't particularly bothered by the experience, but I remember she was rather traumatized by it. And after that she didn't want to do any kind of direct action things again.

SS: So what was it like being 17 in ACT UP? How did people treat you?

GFR: I don't think anybody — treated me particularly — differently. I think that was the sort of interesting thing about ACT UP, is that there was this real —

democratic spirit about it, little-D democratic. And everything was about, to a large extent, the work that you could bring to the table around whatever it was you were doing. There was a certain amount of it that was about personal charisma. And you could see that; the way certain people just were listened to more intently than others. But that happens in any group.

And all these groups; there was still this little bit of the shadow of the '70s organizing spirit about non-hierarchicalism, and no spokespeople, and all of that stuff, although obviously Jay Blotcher was kind of a spokesperson for a while, and Chip Duckett and all the media people. Although they were not, I mean it was this ideal of the leaderless movement, right? But –

SS: But you were a very respected member of ACT UP. I mean, what did that feel like, when you're 17, you're a high school dropout; you're in this group with, stakes are very high; there's people four times your age, or three times your age; and you're being treated with a great deal of respect and seen as an equal.

What did that do for you? How did that affect you?

GFR: It was, it was fun and scary and – there was a lot of moments where it was scary to do things. You didn't know how people would react. You'd go to these, National Institute of Health hearings, or National Academy of Medicine hearings, and be dealing with all these people with Ph.D.'s and M.D.'s and get up there, in your, little East Village outfit, and ask questions. And it was one of these things where, I don't know why I had the guts to do what I did. I guess I said at one point in something, it's one of those things where if you don't yet have any inkling of what's possible or impossible or proper or improper, then you're much more likely to do things that actually wind up

moving the bounds of the possible. Rather than if you just accept there's those fixed categories.

And I think that was the really cool thing about ACT UP, is a lot of people were just very fresh to social organizing.

There was obviously huge connections with the older new social movements, like the feminist movement and the earlier gay rights movement and so on. It was a great tutorial.

SS: So when did you decide to start getting involved in treatment issues?

GFR: I got involved in Treatment and Data Committee – after the Montreal convention, in 1989; and after Costa died.

SS: Well let's go back then.

GFR: Later that year, right?

SS: Were you involved in his care at all, or –

GFR: I wasn't, I wasn't a close friend of his. But I was part of that group of people. We went to various meetings at his house, and his apartment was on 17th Street or 19th Street; something like that.

It started feeling much more serious after that.

SS: Had you ever seen a peer of yours die before?

GFR: No.

SS: Okay. Now he had died before Montreal?

GFR: I thought he died after.

SS: After Montreal?

GFR: Do you recall?

SS: I don't know.

GFR: I remember it somehow being the winter. Like the new year.

Maybe it was the summer.

SS: So can you just tell us the story of the Montreal conference, in terms of your experience of it and what happened there? How you got up there, and what the point of it was.

GFR: If I can remember.

SS: Okay.

GFR: How did I get there? I don't even remember how we got there.

SS: Okay.

GFR: We might have taken a train or a bus. I mean –

SS: Do you remember who you went with?

GFR: No.

SS: What was the point of the Montreal –

GFR: I stayed at someone's house. I remember staying at some stranger's house. It was one of those things that ACT UP was always doing, where they would always find this community of strangers to house us. And I remember going to some very weird community center. It was like painted floors, and organic food, and it was kind of punk rock hippie. I have vague memories of that.

Again, at the time, I was really much more of a marginal member. So I was not deeply involved in any of the things that happened there. Because I know it was a very significant breakthrough moment in the history of the Treatment and Data

Committee, with Mark Harrington and David Barr being very involved in getting compassionate use going, I think, at that conference. But I was not involved in any of that.

SS: Did you storm the stage?

GFR: I don't think so.

SS: Okay.

GFR: I don't think I did.

SS: So what was it about your experience in Montreal that made you decide to get more involved in T&D?

GFR: It was more of the thing with – Costa. And then just feeling a need to – I don't know.

SS: Well what was the treatment situation when Costa died? What was available to him, or –

GFR: At the time, there was just AZT.

SS: So when you got into T&D, what was the goal at that time, when you first came in?

GFR: A lot of it was around getting medications approved more rapidly; about changing the FDA regulations to allow for broader compassionate use.

SS: Can you explain what that means; compassionate use?

GFR: Compassionate use; the idea that in a situation where there's no approved medication to treat a condition, it's made available even on an experiment-, when it's still experimental, on a compassionate basis, with the idea that once it's been proven safe. I later wound up working at the People with AIDS Health Group, and we

used to call them what-the-hell drugs; can't hurt, might help, what the hell; we'll sell it. I mean, that was the idea that if something, this was, in particular, what we, oral alpha interferon. Right? Which was basically placebos. It didn't do anything for anyone. But it was very trendy for a while. Or DHEA, which was another medication, which was this weird egg paste, it was actually derived from eggs, I believe. It was this yellow paste, and it was sold in these frozen tubes, and probably had no effect, either.

Was that DHEA?

SS: That was –

JH: That was AL 721.

SS: – AL 720, 721.

GFR: That was AL 721, that's right, not DHEA. DHEA was the, was the bodybuilding pills.

Right. And then AL 720 was, AL 721 was those weird yellow packets.

Anyway, but these were the drugs that were sort of the category of, well, there's – they're probably not going to hurt anybody. They might help. The placebo effect is potentially powerful. We'll sell them anyway.

But the – the group also – was involved in – getting many more significant and real medications into the United States. And in fact, I would say about my involvement in T&D, and the work that I was doing at the PWA Health Group were very much in sync with each other. Because I started working there, I think, in April of 1990. And they were looking for a publications associate. And so it all sort of blurred together, as one continuum of stuff that I was doing; where the work there is constantly researching new medications to try and see what might potentially help. And they were

the first group of people to import Azithromycin into the United States, and Clarithromycin, which are now standard treatments for various conditions, and FDA-approved. We were importing fluconazole before it was approved in the United States. A lot of different medications that wound up – we were doing — this was probably not legal, but there was a sort of – medication exchange for people who passed away while getting access to ddI through compassionate use, who had excess stocks of it, who would give it to people.

And I remember, for a while, I wound up funneling some of that to Peter Staley.

SS: You did what?

GFR: Funneling some of that to Peter Staley.

Because it was really hard for people to get their hands on these medications, you know. And people had to be very, very aggressive in – sort of pursuing new things in order to – stay ahead of the condition.

SS: Now, you made the decision to start studying science and looking at and reading about all of these new drugs so that you could really understand the science.

GFR: Um hm.

SS: What was it like for you? Because you had no background at that time, right?

GFR: Mmhmm

SS: So –

GFR: I took high school chemistry and high school biology, and I liked them.

SS: So what was it like for you to start reading these high-level documents?

GFR: It was great. It was really fun. It was really interesting. And then you start reading them, and you discover it's not that hard. There was this group of us who did – has anyone talked about Science Club yet?

SS: No, no. Tell us –

GFR: Oh, okay. So Mark Harrington and me and I think Jim Eigo for a while, and Rebecca Pringle-smith, and, oh shoot, what's his name — he worked at Community Research Initiative — Jim – and Peter Staley and a couple of other people; the Southern guy who loved, loved the old '30s movies, and was always quoting Bette Davis. Remember him? Oh, shoot.

SS: Could have been anybody.

GFR: He dated Peter Staley; no, he dated Mark for a while, briefly? Okay. I wish I could remember people's names.

JH: Michael Nesline?

GFR: I'm sorry?

JH: Michael Nesline?

GFR: No, not Michael Nesline.

SS: No.

GFR: And then he worked for AmFAR, and then eventually I think he decided to go to college, or finish college at some point. He was from the South. After

there was this round of new medications, and sort of, suddenly everybody was like, oh, now I might have 20 more years; now what do I actually do with it? I think he went to college after that.

But anyway, so we did this thing at Peter, at Mark Harrington's apartment, on East Ninth Street, called Science Club. Where we would meet once a week, and read medical journal articles. And it was basically like a doctor's weekly sort of rounds-style meeting, where you discuss a particular problem, and we assigned ourselves immunology textbooks, and we read them, and virology textbooks. And – made a goofy little logo for ourselves. The whole thing was, it was this weird mix of sort of East Village – DIY, and high-level science. I mean, it –

SS: What's DIY?

GFR: Do it yourself.

SS: Oh.

GFR: Sort of a little punk rock. I mean, because Mark had been, he was at *Rolling Stone*, right, wasn't he?

SS: I don't know.

GFR: Or he was, he was involved in music for a while before he got involved in ACT UP. And he had one of those very old 286 computers, with the amber screen, and he was always there, formatting these giant documents, and smoking endless rounds of unfiltered cigarettes.

And then, I remember one summer, I think – I can't remember when it was. Maybe it was '91, the summer of '91? Maybe it was 1990. It sort of dissolved into

what we called Tequila Club, where we'd basically just go sit up on his roof and drink Margaritas and talk about science. So –

T&D sort of extended across the spectrum, in terms of becoming this whole sort of group of people who all knew each other. And then I was good friends with Anna Blume as well — and I'm still friends with her — who was involved with the neurology, Neuroscience Committee; and also the Kids Committee.

SS: Now these were subcommittees of T&D? Pediatrics and Neurology?

GFR: I think, Pediatrics, right. And they all sort of got spun off. I mean, that was the thing with, there was always some new committee that was being spun off.

SS: So what was the first time that you actually were in conversation with an official researcher or doctor or government official?

GFR: I don't remember.

SS: Well – okay, well, think –

GFR: I remember I went to some early meeting with Anthony Fauci; some very early meeting with Anthony Fauci and Mark Harrington and a couple of other people. And this must have been when I was still 18 or something like that. And I can't even imagine what he thought of us.

And he and Mark kind of got to be a bit, friends, I think, in later years. And it's funny; a lot of those people who were working at NIH; who were sort of enemies at one point, or there was this real clash between the activists and the scientists; it turned out we couldn't have picked a better group of people to target, because they're empiricists. They're data-driven, and they're empiricists, and they're hypothesis-based.

And so if you bring them new information, they're probably the most likely group of people you could approach who would be willing to change what they're doing or how they're doing it.

SS: Can you give me an example of new information that you guys brought to the NIH?

GFR: There was definitely a sense of urgency that came down. And I recall going to one of the meetings with the – the NIAID, National Institute for Allergy and Infectious Diseases AIDS Group. And it was at some – pretty bucolic, flower-surrounded – glass-walled, glass-windowed building. And the whole thing just was so – suburban and calm and serene. And, people would drive there from their homes in Maryland, and it all seemed very low-key.

And then there was this group of people who were coming down from this crisis center, in the East Village, where everybody they know is dying and in crisis and in pain and grieving and not even allowing themselves to recognize that that's what's happening; and impoverished on top of this, because they're doing activist work. There was obviously a lot of better-to-do people in ACT UP as well, but – the East Village at the time was still much more of the East Village as well.

And so there's this real clash of mentalities, and bringing, I think, a sense of urgency and a sense of – letting the affected communities — as people used to say — direct the course of things was very important, and letting people who had a direct stake in what they were doing have a voice in the process.

Tape I
00:30:00

SS: Well, as you guys started to conceptualize your agenda, what did you start to think or believe were concrete steps that should be taken that were not being taken? What kinds of things did you push for?

GFR: Nineteen ninety, my major project was Countdown 18 Months.

SS: Right.

GFR: And that was partly because I was working at the People with AIDS Health Group, and because we were importing these medications and researching them. And so it was about recognizing that, okay, we're in this situation where there's one antiviral — AZT — there was maybe another one in development, ddI; and people are dying, and they're not dying from, they're dying from the consequences of immune suppression. And if there's nothing that can be done yet about fixing their immune systems, or — or suppressing viral load — which we weren't even talking about at the time — then at least you can treat the five most common conditions that are killing people. And if you can treat them, then you can keep people alive. And if you can keep people alive, then there's hope. And if there's hope, then maybe people will be around long enough for something else to happen, and something else to get discovered. And that in fact was very much what, how things worked.

SS: So when you were conceptualizing this, what were the five basic things that were killing people?

GFR: Pneumocystis carinii pneumonia; Toxoplasma gondii; cytomegalovirus-related blindness; Jesus, have I forgotten them? Do you remember?

JH: Uh, KS?

SS: KS?

GFR: Was it KS? I don't think we did KS because it was a cancer and not a pathogen-based condition. It was a GI thing, I remember right now.

JH: MAC. [Mycobacterium Avium Complex]*

GFR: MAC, exactly, MAC, yes. Which was a – sort of bizarre parasite that caused some intestinal problem, and caused tremendous wasting, and I think Scott Slutsky wound up dying of that, if I recall correctly.

SS: So –

GFR: Or had it.

SS: Who did you conceptualize this with? Or did you just realize on your own that this was where the focus needed to be; on these opportunistic infections?

GFR: This was part of a conversation that we were having in T&D. And I spearheaded the project, and sort of conceptualized how to organize it. And because one of the things I was also doing at the Health Group was doing these fact sheets, and writing articles about medications and so on, it seemed sort of a natural fit to then do this report as well, sort of looking at the medications and the conditions. And it was all very sort of, I guess what you'd call now, explanatory journalism.

SS: But where'd you come up with the idea of 18 Months?

GFR: It just seemed that the drug development didn't need to take longer than that. It could be done rapidly.

*The five infections targeted by countdown 18 months were: Pneumocystis pneumonia, CMV retinitis and colitis, toxoplasmosis, mycobacterium avium-intracellulare, and fungal infections cryptococcosis, histoplasmosis, and candidiasis. See pages 33 & 34

SS: So okay, so then you had this idea for this massive campaign; for ACT UP to be focused on developing treatments and meds; to address these five conditions, over the next 18 months, with the goal of being able to treat them successfully at the end of a year and a half. So how did you present this to the floor? Did you have to politic beforehand, or did you just pop up one day and say, Countdown 18 Months?

GFR: All T&D was behind it. I remember; there was this fellow Chris, who — do you remember Chris [DeBlasio]?

SS: Leon?

GFR: I'm sorry?

SS: Was it Chris Leon? No?

GFR: No. With a mustache? And Jerry Jontz was involved with it, and Scott Slutsky was involved in it. And there was about, and we four were the people who worked on it most. And so that was our little project. And then I guess we just had the support of T&D and brought it to the floor, but I don't have any recollection of how.

SS: So did the floor just say, okay?

GFR: Your guess is as good as mine. I don't remember!

SS: Well, it's kind of amazing to go to a room of 500 to 800 people and say, okay; for the next 18 months, we're going to be doing this thing. And people just saying, okay.

GFR: But that's how it was.

SS: That's right.

GFR: It was like Athenian democracy. And after I went to college, and started reading these books about the origins of democracy, and I was like, you know what? I experienced direct democracy in ACT UP in a way that is so rare in American life. Because it was a thousand people who came together once a week, every week. And everyone had a vote. And everyone was equal, and everyone had a voice. And – it was a different thousand people every week. So you never really knew where things were going to go, because you didn't know who was going to show up and who wasn't going to show up.

And it was just, you know, it worked by Robert's Rules of Order. Facilitators in miniskirts and big hoop earrings.

SS: That's the men.

GFR: That's the men, yes.

SS: Yeah!

GFR: Oh, of course! And – yeah. So –

SS: So let's talk about --

GFR: So basically there was an agenda, and you had to get on agenda through, the Coordinating Committee did the agenda every week, right? And I was on the Coordinating Committee for a while. And I used to, because the ACT UP offices, when they got offices in the West Village, were close to where I was living. I used to spend a lot of time there, and I learned how to use a, I taught myself how to use a computer there, and I used to just do a lot of work on the computers at the ACT UP offices; and was on the Coordinating Committee.

And so it seemed like it was just – I don't know. It just didn't seem like anybody had to do a huge amount of politicking to get anything done. It was basically just – anyone who had an idea that seemed like it could possibly help, and that had any kind of validity behind it, seemed to get their idea approved. You came up with a budget for what you wanted to do. And Countdown 18 Months did not require a large budget.

SS: Why was that?

GFR: Because it didn't involve demonstrations. It was not a demonstration-based project.

SS: So what did it involve?

GFR: It involved a lot of meetings with scientists.

SS: So in other words, you guys in ACT UP would do the research, and see which drugs and treatments you recommended be pushed forward quickly; and you would meet with scientists and show them why those drugs should be put, those treatments should be pushed forward? Was that basically the strategy of Countdown 18 Months? Can you give me some specific examples?

GFR: It was also about talking to them about what their strategy, their research strategy was, and thinking more intentionally. Because if you have a – and Mark Harrington was, you've probably talked to him already. He was really the sort of central figure in the Treatment and Data Committee, and just had a phenomenal amount of energy, and also personal investment.

It was about trying to make the research process more intentional. Because if something's driven by principal investigators, and so you have ideas that come to a committee that then evaluates the ideas through a peer review process, and then you

approve them. Well, that doesn't necessarily get you exactly where you want to be, from a research perspective, where you need to say, okay, these are the things we need to get answers to, fastest. And we're going to solicit people to send us proposals for how to do this, and design trials specifically to do, to deal with these particular problems.

And so you just, it was about trying to make the whole process more intentional and directed and very results-oriented.

SS: So can you just take us through one of them; one of the OIs and which treatments you recommended, who you spoke to, how the trials got redesigned?

GFR: You might have to pause here while I recollect this.

SS: That's okay.

GFR: And it wasn't just me. It was a bunch of us, were doing this. And we actually divided it up so that we each took one of the infections, I believe.

SS: What was yours?

GFR: I don't remember.

SS: Well let's say, for example, pneumonia.

GFR: Right.

SS: Because I think at that time, sulfa drugs were the issue, and a lot of people couldn't tolerate them. And people were looking for alternatives.

GFR: Right.

SS: Do you have any recollection of what treatments you guys were in favor of, or who you met with?

No.

Of the people you were working with, who's still alive now?

GFR: Mark.

SS: And who el—

GFR: And Chris, I believe, is still alive.

SS: Okay.

GFR: Scott died.

SS: Scott died.

GFR: Jerry Jontz died.

SS: Um hm.

GFR: Phil Zwickler. I remember – he was – worked at a organization, I think, that was in a building next to where I was working, at the PWA Health Group. I remember talking to him the day after he got his diagnosis with CMV, and he was just – like it was – yeah. And he was going to lose his sight, and he was going to die, and just – remember him saying – he was never going to see another Democratic president. This was what was upsetting to him at that particular moment.

Summer of '91 was very, very difficult for me. Because Jerry Jontz was dying that summer, and his care, I was very involved with, as were a lot of people from T&D. And –

James Wentzy: Maybe we can pause here –

SS: And change tapes? Okay.

JW: Change tape.

GFR: I wish I remembered –

Tape II
00:00:00

GFR: I'm going to go on your Web site, and I'm going to see if I can remember people's names based on looking at the pictures.

SS: Okay.

GFR: That's ACT UP Oral History?

SS: Yeah.

GFR: {TYPING}.

SS: Dot org. Hey, Garance is looking at our Web site to see if she remembers anybody.

GFR: Yes, I'm looking at the Web site to see if I can remember people's names, because it's been 15 years since I was in ACT UP.

SS: Okay.

GFR: I'm sorry, 16 years since I was in ACT UP –

SS: Okay, s–

GFR: – and I don't remember a lot of things.

SS: But you just remembered Bill Snow.

GFR: Well, no, I was going to say, yeah; well, Bill Snow. Well, Bill Snow and I are still in touch, actually. And I mean, this happened after ACT UP, but we stayed – because of the friendship that we developed on the Treatment and Data Committee – and in the early '90s, we developed an interest in HIV vaccines. And he was one of the few people on T&D who was HIV-infected who was really interested in prevention of future HIV infections and not just in treatment. And so there was a little sort of small subset of people who were interested in vaccines. And then he and I and David Gold – and – a couple of other people started a group called the International – I'm sorry – called the AIDS Vaccine Advocacy Coalition, in 1995. And we were all living in different cities, and the Internet was this brand-new funny tool that we were using, and we organized this virtual organization by e-mail, using these sort of primitive e-mail systems, and used the same sort of model, of the Countdown [18 months]. But there was supposed to be 10 years, but those 10 years have come and gone, and there's still no vaccine. And they're all still working on it.

And this is what I mean, when there's this – I mean, the people who were, back in the day – like Peggy Johnson, who was at NIH, and who was in charge of their basic science division for a time; and then she went to the International AIDS Vaccine Initiative, and ran their science programs as well. So she's sort of been involved in – and Pat Fast, who's such a sweetheart, at NIH. She was involved in running their vaccine programs. And a couple of other people who were – mainly the women scientists, actually, wound up being really close to a lot of the activists in later years.

Because the activists stopped being activists; they started being advocates. And that was the transition. And I think T&D was really the forefront of that transition. And that was part of the sort of ongoing tension between T&D and the rest of ACT UP, which is that ACT UP was this very in-your-face direct-action-based institution. Whereas T&D was this sort of nascent science-policy advocacy group embedded within it. And ACT UP, just as it was constantly forming these committees, was constantly spinning off organizations, which is why you have – Housing Works, as well, which used to be the Housing Committee of ACT UP. And then you have the Treatment Action Group, in New York, which was where a large number of people from the Treatment and Data Committee left, in the early '90s.

SS: I just want to ask you some more about Countdown 18 Months.

GFR: Okay, Countdown 18 Months.

SS: Now, at the end of the 18 months, had any new treatments come to be?

GFR: I think so.

SS: Or subsequently? Were there new treatments for those OIs that you can attribute to Countdown 18 Months, that eventually emerged?

GFR: Well, a lot of the things eventually got approved.

SS: Like what?

GFR: Like Clarithromycin and Azithromycin, and some of the things that were being imported at the PWA Health Group. There were new drugs that were approved for PCP treatment; there were, Azithromycin especially, I think, and Clarithromycin, for MAC. I remember, I think MAC was the — it's coming back to me now — I think MAC was the OI that I was involved in working on.

And CMV, there were sort of improved treatments for that as well. I'm just looking at this here; see if I can find a copy of it. Everything's online now; it's kind of awesome. It's one of these problems where if the Internet becomes like collective memory, then you wind up just forgetting everything yourself.

All right. So we were looking at PCP, CMV retinitis and colitis; Toxoplasmosis; MAI or MAC; and fungal infections, which was cryptococcus, histoplasmosis and candidiasis. And Derek Link was also involved in that; Derek Link was very involved in that. And I guess it was released in the end of 1990. And so I guess we worked on that in '90 to '91. And I was most involved in it in 1990 and 1991; up until the summer of '91. And the summer of '91 just, I don't know, everything went to hell.

SS: What happened?

GFR: I just, that was the, remember, that was when things got really divisive internally within ACT UP. I think the tensions of activism just were really

eating away a lot of people. There was that horrible newsletter, *Piss and Vinegar*. It was like an early blog. And was Michael –

JW: TITA?

SS: Tell It to ACT UP, is that what you're talking about?

GFR: I'm sorry?

SS: Was it called Tell It to ACT UP; TITA?

GFR: TITA. There was *Tell It to ACT UP*; but there was also *Piss and Vinegar*. *Tell It to ACT UP* was, I believe, the official newsletter, informal internal newsletter. And *Piss and Vinegar* was the alternate, anonymous newsletter, where people basically just dropped dimes on each other, and said nasty things about each other, and it was pure gossip. And I believe Michael Petrelis was involved in doing that. Michael Petrelis and What's-his-name, Dobbs, who runs the protest in New York now? Was it Michael Dobbs?

SS: Bill Dobbs.

GFR: Bill Dobbs, Bill Dobbs, yes. Bill Dobbs and Michael Petrelis. And it's funny that they're both still so involved in activism, because, you know, Bill Dobbs was, is involved with United for Peace and Justice. I get press releases from him all the time. He's involved in organizing the huge antiwar protests in New York and against the Republican National Convention when it was up in New York. And I remember, he was always much more, a regular liberal than a lot of the other people in *ACT UP* who were there completely just for issue-based reasons. He was always interested in the war against Iraq, the first war.

And this was like a big debate in ACT UP, about how involved to be in these other causes and issues. And I think the group always, or almost always, came down on the side of, we're an issue group. It was a 501(c)(4). So – it was officially nonpartisan. And I think it wasn't –

SS: But that was controversial, getting the 501(c)(4).

GFR: It was.

SS: Because people were afraid that that's exactly what would happen.

GFR: Yeah. But at that time the Democrats were so bad on most of the stuff, too, that – why would you say that they're your people? That they're definitely the people?

I mean, obviously, once Clinton got elected, things changed tremendously. And I remember Bob Rafsky going around, while Clinton was running for president. And there was this project to sort of target Bush, and to have people in ACT UP. Because it was all around the country at the time, basically people shadowed George Bush when he was running for reelection, and pop up in all his speeches, and raise AIDS as a question. And then Bob Rafsky got up and stood up at some forum with Bill Clinton in New York City, and this got written up in the *New York Times*, and asked him a question about what he was going to do. And I remember, he just had these, the huge, the Kaposi blotches all over at that point, which is, I think, what he eventually died from.

And it was, it was very powerful. And the *New York Times* called us ubiquitous.

And I have this, these –

SS: Careful, you're plugged in.

GFR: Oh, oh, I'm sorry, I'm plugged in. Right. Okay. But I have these CDs, these tapes, still, on the other side of the room. The raps; do you remember the raps?

SS: Oh, you mean Tony [Maliaris]?

GFR: Yes, Tony's raps!

SS: Yeah!

GFR: You know? And I remember, I still have all these CDs from that time. And – not CDs, tapes, because there were no, you know, CDs yet. And I remember, he had those one-line – we're unique, we are ubiquitous. Something-something-some — and if you stick with us.

SS: {LAUGHS}

GFR: And it was just, it was really funny. And that's the thing – it was this whole, it was this huge community. It was art and you know, all these people who were, you know, in the Whitney Program in New York City; it was fashion and design with Avram, who basically gave America sideburns, basically. I swear to god, he was responsible for the sideburn trend in the late '80s and early '90s, because he was also a hairstylist at Vidal Sassoon. He was gorgeous; he had sideburns. Men would come into ACT UP without sideburns. They'd see him. They'd think, I want to look like him. And then they'd have sideburns!

And then you had this core group of people, that's like in the middle of, the center of the cultural ferment in New York City, spreading these ideas out. And there was a lot of art as well.

Oh yes, him.

There was this, this other guy whose name I'll try and find again. And you know, he did this great thing where he was – Gacey Felts. It was this character that he developed. And he did this thing at – some of these little places on Fourth Street, the little theaters, where they only showed works in progress. And he did this one – one night – he also did the thing where he dressed up as Barbara Bush.

And it was Barbara Bush sings songs of the Great War. And it was so moving. Because it was about, until the boys come home again, and all this stuff, and there was this sense of being in this sort of wartime community, where people were just – dying all around you. And I wrote about this somewhat later on, when I was in college, and looked at a lot of the use of the war metaphor, and a lot of people who were writing about AIDS at the time talked about it as being in this sort of weird war zone, where the bombs only dropped on you and the people you knew, and nobody else could hear it.

SS: Let me ask you just one thing about Countdown 18 Months.

Looking back, do you think that that strategy was the best strategy; to go after the OIs? Or do you think that – was that agenda what eventually led to the kind of meds that we have now? Or did we have to revert back to doing basic science that had never been done, about –

GFR: It all had to happen. It was, Countdown 18 Months was never envisioned as a solution. It was always a stopgap. It was basically, a lot of people who are alive now don't have the time to survive these things if they're going to die of them. It was about just keeping people alive until something better came along.

And it's not like it was the only thing T&D was doing. And people were very involved in pushing virology research forward and they were very involved in work on immune stimulants and antivirals and all sorts of other things. It was just, it just happened to be what I worked on.

SS: Okay. Looking back, in terms of where we're at now, in terms of medication and treatment; what was the work of T&D that you think ultimately paid off – which projects ultimately were the most beneficial?

{LONG PAUSE}

GFR: I think at the time some of the FDA reform stuff did; the speeding up the drug-approval process had a huge impact. It also created an incentive for the pharmaceutical companies to do research. It lowered their research costs, in a way. I don't think that we realized at the time that this was part of the broader gutting of the FDA that we've seen since; that there was a lot of political agendas that we just happened to be in sync with.

SS: Oh, okay. Can you say that more explicitly? You mean we didn't just win it because we were so great? You mean that it actually fit in with –

GFR: I mean the pharmaceutical companies wanted a weaker FDA, too. And so do a lot of political figures. Our FDA, right now, is sometimes, acts as a complete politicized joke. And it's sad. And one of the reasons we've had a lot of problems with medications in recent years — like Vioxx, or whatever — is we just don't have adequate research controls. Sometimes it seems like it's gone too far in the other direction — and not just for AIDS — where you really had a crisis situation, where it

made sense. But there's a really strong pharmaceutical lobby against the FDA as well that I don't think we were aware of. I know I was not aware of it, at all.

SS: Right. No, but was Pharma actively involved when we were going after the FDA? Or did they just back off, and let us do it?

GFR: I don't know.

SS: Okay.

GFR: I just know that in later years, I realized that this probably had something to do with the fact that a lot of other people wanted it, too.

SS: I see. Okay.

GFR: But that did have a huge impact. And then, I can't speak to a lot of the stuff that's happened recently. I couldn't even tell you what the treatments are today. I really, I stopped being involved in AIDS issues entirely in 1997, so that was 10 years ago. And I live here in Washington, and I have some gay friends, but -. And I'm in touch with Bill, still. But I'm just not part of that world anymore.

SS: Why did you stop? Just out of curiosity.

GFR: Well, I was involved with AVAC in '95 through '97. And -

SS: Can you say what that was?

GFR: AIDS Vaccine Advocacy Coalition, I helped start. And I stopped because I got a job as a journalist, and to be a member of the press corps and get a congressional press pass, you have to not be part of any organization that has business before Congress. And we had business before Congress.

SS: Right.

GFR: So I stopped.

SS: Okay. I just want to ask you: when you were in T&D, and you were surrounded by a lot of sick people; were people coming to you and asking you for treatment advice, you personally?

GFR: Yes.

SS: And how did you handle that?

GFR: That's what we did at the Health Group. It was about providing fact sheets; it was about giving people information, and letting them make decisions about how they wanted to handle things. It was about sort of the whole patient empowerment movement that extended later to people with breast cancer. We had meetings with breast cancer advocates who came to us, and said, how did you do this? We want to do what you did. We want to have the same kind of involvement in our care and the research around our condition that you people have.

SS: How come they can't? How come ACT UP could do it, and other illness models can't achieve it in the same way?

GFR: I just think in ACT UP, it wasn't just about AIDS. And if AIDS had not hit a group of reasonably empowered, well educated, extremely talented gay men, in the center of the media universe, in New York City, it would have been a very different national experience. Even if it had only hit San Francisco and not New York. But New York is a unique culture. And it's been much harder for heterosexual African Americans to get attention directed towards AIDS than I think it was for gay men. And also because homosexuality was so stigmatized, still. There was, there was, it was just – it was just different. And so people had a lot less to lose.

They weren't embedded in families, either. So it was easier to create – an organic alternative community.

SS: Do you think that a community of married gay people in privatized family units would be able to respond to a crisis in the way that gay culture of the time was able to?

GFR: That's an interesting question. I think it's harder for anyone who has children to be involved in an activist organization.

SS: Right. The reason I ask you this thing about sick people coming to you and asking you: There's an emotional burden; there's a personal responsibility in that. How did you handle that?

GFR: I don't think I realized it was as much of a burden as it was, because so many other people were experiencing this. This is what I was going to say before you changed tapes, was like, one of the reasons I can't remember things is because I have 15 boxes full of material from this period in my parents' house, and my parents have been desperately fighting, get me to get out of their apartment in New York City for like more than a decade now. And I tried once, because I was going to go through it and sort through it and donate it to the New York Public Library's archives. And I started, I just opened the boxes, and I started going through it, and I was like – I was, just so many of these memorial service things, and just – all these memories just totally came flooding back, and I was like – okay. Just close the box and stick them back in storage!

And so I just like --.

SS: Do you think you'll ever write a book or a memoir of that time?

Why?

GFR: [No] Because I can't remember it well enough. It would be so much research.

SS: Okay. I want to ask you — this is a weird question, but — did you oppose the AIDS Cure Project? The Barbara McClintock Project?

GFR: I don't remember what that is.

SS: It was – okay. It doesn't sound familiar?

GFR: No.

SS: Okay. Okay, let's go to the AIDS conferences. Now in Amsterdam, I think we have footage of you with somebody's ashes at the Amsterdam conference. Can you tell us what that was?

GFR: Yeah. I have pictures of that, actually, in my – in storage up there.

That was '91 or '92; '92. Gedalia Braverman was part of that, also. And that skinny little blonde girl, Brenda, from San Francisco.

SS: Sounds familiar. Is that Anne's [d'Adesky] roommate?

GFR: No. She lived in San Francisco. She was part of Project Inform.

SS: Okay.

GFR: The thing was, is T&D was not this standalone institution; it was part of this whole universe of people. There was Project Inform in San Francisco; and then there was the Health Group; and then there was the Body Project; and there were all these other institutions and organizations and people in different cities, or people in Chicago and San Francisco and Los Angeles and New York, all working together on these projects.

SS: So what was this ashes event in Amsterdam?

GFR: I think this was during the era of the public funeral. Remember those?

SS: Um hm.

GFR: I think the first one I went to was Jon Greenberg's.

SS: Can you describe that event?

GFR: It wasn't the first one that happened. It was the point, I think, where everyone was starting to go crazy without realizing it, in a way. It was this idea that, again, this idea of invisibility; that the world couldn't see what was happening. And so people wanted the world to see what was happening. And so – and it was this idea that by holding the, instead of, it was moving from the mock funeral, with the cardboard caskets and the little fake tombstones and all that stuff, into actually, when someone actually did die, to sort of giving them a public funeral procession. And I know Jon Greenberg wanted that.

And he and Risa [Denenberg] were really good friends, and they were on the Alternative Treatments Committee, along with Anna Blume. And they held a sort of memorial service for him in Tompkins Square Park. And it was just – this public memorial service in this public park in New York City.

SS: With his actual body.

GFR: With his actual body; and with us going and saying our goodbyes in the park.

And there were several other ones. And the ashes thing was because someone wanted his ashes to be distributed at Amsterdam, because he couldn't go.

SS: So what did you guys do?

GFR: I think we threw them into a canal and lit candles. I think it was the first time I'd ever seen ashes. They're not really ashes; it's more like granular. It's very – pebbly.

SS: Now what was your role at the Amsterdam conference?

GFR: I think I might have had an abstract at the conference. I don't remember.

SS: When you dealt with pharmaceutical companies or when you dealt with government agencies or with doctors, did they treat you with the same respect that you experienced in ACT UP?

GFR: Well, they didn't treat any of us with the same respect. It wasn't personal to me. It was, we were obviously these outsiders. And usually we had some demand for something that they didn't want to do, because otherwise they would have done it already. And usually it was something that was going to make them less money, and lead to embarrassment for someone, who made a lot of money, and had a very high-status social position, and didn't like being embarrassed. So it was –

I don't know. After a while, I think the pharmaceutical companies realized that this could actually work for them. We'd go to meetings at Bristol Myers on Park Avenue, and they'd put out these spreads of food for you, and sort of chat with you and – where did it hurt them to have a conversation. They would get more buy-in for their drug when it went to market.

SS: Right.

GFR: I just remember, Mark [Harrington] was always smoking at these meetings. And it was one of these things where he just like, he was such a fidget. And

he was always smoking. And that raised eyebrows. Because people could still smoke inside at the time, but even so, it was not common. And he'd be just like getting up and down, and smoking, and wandering around.

SS: Were you involved at all with the campaign to change the CDC definition?

GFR: Yes.

SS: Can you tell us what your role was in that, and how that played out?

GFR: I don't remember.

SS: You don't remember.

You know, there's a famous story — and we're trying to find out if it's you or not — where there was a demo, and it was raining, and Mark and some woman — but we don't know if it was you or not — were meeting with some officials. And when they stepped outside of the hotel, there was this demonstration in the rain of Women with AIDS Network, to try – was that you? Do you remember this event?

GFR: Keep going with the story.

SS: It was just that, it was kind of an awkward coming together of these two different approaches. Because one hand, there were these people outside, doing this demonstration. On the other hand, there were these people inside, having a meeting.

GFR: I don't recall that being me, but it doesn't mean that it wasn't.

SS: Okay.

GFR: It could have been Rebecca Pringle-Smith. Mark and Rebecca were really good friends, and did a lot of projects together. And then she eventually went to medical school, at Brown. And she's a doctor now, as well.

SS: Okay.

GFR: And then there was Community Research Initiative also; it was another institution I should mention. A lot of us were involved with helping them with their clinical trials as well –

SS: That was Joe Sonnabend's group, at the time?

GFR: Joe Sonnabend, right.

SS: Yeah

GFR: Yeah.

SS: And which drug – so were you involved in designing trials?

GFR: I wrote a lot of informed consent forms. We talked about medications that were worth studying. I mean, I don't think I was involved in the actual research methodologies, no.

SS: Do you remember the 076 argument?

GFR: Vaguely.

SS: This was about informed consent.

GFR: Right.

SS: Yeah. Do you remember where you sat on that at the time?

GFR: No. I assume I came down on the T&D side of things.

SS: Did you ever dissent from T&D?

GFR: I'm sure I did. There was always dissent, in every faction of ACT UP.

SS: But nothing stands out in your mind. No. Okay. Let's talk about Derek Link. So we've got the whole story on tape, from a number of sources, including David Barr, and all this stuff, about what happened with him, and this sort of thing. But you guys were very, very close –

GFR: What happened with him?

SS: That he turned out to not be HIV-positive.

GFR: Oh, really?

SS: You don't know that?

GFR: No! I told you, I haven't been involved in this stuff for 16 years!

SS: Garance!

GFR: Oh my god, that explains so much!

{ALL LAUGH}

SS: What does it explain?

GFR: It explains: there was one time I was in San Francisco. And they were selling, like, ddC through the buyer's club in San Francisco. And I think I brought some back for him, because he couldn't get it in New York. And then there was some issue where he got this dog from the pound, and the dog ate his ddC, and then the dog died. And so then there was no dog.

But I don't know if I even met the dog. It was just suddenly, like, there was none of this medication.

I don't know; I didn't live with him very long. I remember that he had a lot of issues.

SS: But you guys were like best fri-, there was a point where you were together all the time. I remember you guys coming in together. Of course, you said you were roommates, but –

GFR: Yeah, we were roommates. Um – honestly, I don't think that my personal friendships at the time were very personal.

I think I had a lot of people who I did a lot of activities with. But I don't recall having a huge number of direct one-on-one, heart-to-heart conversations. We were all so work-focused and so activity-oriented, and it was all guys. And gay or not, they were not hugely necessarily forthcoming about their lives. People will talk about sex endlessly, and they would talk about politics, and they would talk about science, and science politics, and they'd talk about the work people were doing in ACT UP. But they did not talk about themselves and what they were feeling, or their backgrounds, or even, really, their families that much.

SS: So did you ever socialize with the women in ACT UP?

GFR: Yeah. I was friends with Anne D'Adesky; and Anna Blume, who like I said, I'm still friends with. And Joy Episalla.

SS: But you kind of stayed away from the whole Women's Committee and all that kind of stuff.

GFR: Well, Maxine didn't like me.

SS: Oh. How did she let you know that?

GFR: She was awful to me. She was very mean to me.

SS: So that meant that you couldn't be part of that.

GFR: Well, it meant I didn't want to be. I just felt like, well, okay, she's the queen of the Women's Committee, so I'm going to go do something else.

SS: And, okay.

GFR: I mean, they always accused me of being male-identified.

SS: Somebody literally said that to you?

GFR: Yes!

SS: Who?

GFR: I don't remember.

SS: Oh, okay.

GFR: But I remember that this was like one of these things. There was all these stupid sexual politics, also.

SS: Like what?

GFR: I'm sorry?

SS: Like what?

GFR: Well, like that. Which is like a total '70s thing to say. It's like a '70s feminist thing to say. Who talks about these things anymore? Male-identified. – anyway.

SS: So ACT UP took over your entire life, right?

GFR: Yes.

SS: You were living and breathing ACT UP.

GFR: For four years.

SS: Right.

GFR: From '87 through '91. And then I couldn't take it anymore. And then we all left, and we started the Treatment and Data Group.

SS: We're going to get into that in a minute.

GFR: Okay.

SS: But just for you personally. So, I mean, you were very young, and you weren't, you didn't have, like, friends outside of ACT UP; you weren't dating people outside of ACT UP; ACT UP was your entire world. Is that right?

GFR: Yeah, pretty much.

SS: And –

GFR: I was – in the earlier years, I was also involved in some, you know, fashion design stuff. I was an assistant wardrobe mistress on Whit Stillman's Metropolitan.

SS: On Whit Stillman's Metropolitan.

GFR: On Whit Stillman's Metropolitan.

SS: Okay.

GFR: In fact. And I was involved in theater design for a variety of Off-Broadway publications, and involved in some theatrical productions myself. And I was, I made hats.

SS: Oh, okay. So you were doing other stuff. You did have other –

GFR: Yeah, I was doing stuff.

SS: – communities and other friends.

GFR: Yeah. it was like this, it was slightly more artistic communities. Because there was this huge sort of, there was still this sort of East Village arts scene,

also. And Zoe Leonard went on to become this very well known artist, and Joy Episalla is an artist, and Anna was an art historian by training, and David Wojnarowicz was in the group, and Keith Haring was in the group, although briefly.

SS: So would you say that most of the parties you went to, most of the things you did on weekends, were ACT UP–related, or were through people that you knew in ACT UP? I mean, I’m not just asking you personally. Many people say that.

GFR: I’m just trying to remember.

SS: Yeah, yeah.

GFR: I’m just trying to remember. Right. Because I was in New York City. I didn’t have any base of friends I knew from high school.

Another thing is basically, everybody I knew was at least five, 10, 15 years older than me.

SS: Right.

GFR: So I just pretended I was their age.

SS: {LAUGHS}

GFR: And because, it was pre-Giuliani, pre-crackdown, pre–all these laws. And no one ever carded me, so –

SS: Right. Nobody ever carded you.

GFR: I went to Times Square, like a typical teenager in New York, and got my fake ID, and that was the end of that question.

SS: Okay. So what happened to you? Did you go to college after you left ACT UP?

GFR: I did. Like I said, I left ACT UP in late '91, during the period of tremendous division over the debates about action, and action for action's sake versus action for a specific end.

SS: What was the issue? Specifically, what are you referring to?

GFR: In the early history of ACT UP, there was a series of demonstrations, which I came in afterwards. It was the Nine Days of Rage, or Nine Days in the Rain, as people used to call it, because it rained continually. And – and there was the Actions Committee, which dealt with planning protests. And – I think, I remember Heidi was organizing this huge protest in New York City. There was the protest around – Grand Central. I think it was the Grand Central protest.

SS: Day of Desperation?

GFR: Day of Desperation, that's it, exactly. And we were, in T&D were, okay; what is the goal of the protest? What are you trying to accomplish?

And they couldn't come up with anything, as I recollect, other than sort of — again, this was the moment where everyone was going crazy — other than just saying, hello, we exist, this is an issue, deal with this. And in T&D, everything had become so goal-oriented and so focused and very specific. We would have, we wouldn't just do protests. To do a protest, on its own, seemed like an extremely inefficient strategy of creating change.

First thing you do, is you figure out exactly what you want; what the changes are that you think need to happen. You write a letter to whoever is the highest-ranking person who you think can effect those changes. You send them all your

demands. You ask for a meeting. You have a meeting. You don't get what you're looking for.

Then, you hold a protest. After that, again try and meet with the person.

So there's this ongoing process, where everything was very targeted and goal-oriented. And T&D was also, so sort of scientific at that point, and sort of – specialized. It was divorced from, I think, the mainstream of ACT UP a bit at that point. And there was these questions about whether we were all sell-outs, and this, that and the other thing. And all of this stuff got – discussed in Piss and Vinegar.

Anyway, so around that time, a group of us — including Larry Kramer and Peter Staley and Mark Harrington and a variety of other people — started a new group, that was going to be more of a advocacy organization, and also, after a while, people needed to get paid. ACT UP was entirely volunteer. And if people were going to devote their lives to this, for more than a couple of years; at some point, it would be easier for everyone if they were actually getting, able to survive while doing their work; survive economically.

SS: So how did TAG fund the salaries?

GFR: It didn't have monies, often. It didn't have much. It had two staff employees at first. I don't remember how they got funding.

SS: So when you went to TAG, you just left ACT UP?

GFR: Yeah, that was pretty much it.

SS: And how did that feel for you?

GFR: I remember, I was so stressed out. I went with Anna, we went to Spain and Morocco for three weeks in late '91. And she was, oh, if you're going to go to

Europe, you can't go for less than three weeks. And I just remember getting to Spain, and going with her to the Park Güell in Barcelona, and just, being so completely stressed out, about the whole thing; all these arguments and conversations that were going on at the time, and still being in my head, and just trying to sort of use that as a three-week period to sort of transition out of that way of thinking, to transition out of engagement with those voices and to just sort of recognize that people were going in their own way, and I was going in my own way.

And I was also working at St. Vincent's Hospital at the time. I was working as the clinical trials coordinator for their AIDS center. And so I was responsible for writing informed consents and coordinating the clinical trials; and dealing with a lot of doctors on a regular basis as a hospital staffer. And at that point, I just started thinking about myself as an individual again, outside of the institution; thinking about my own life, and thinking about, maybe I should be a doctor. And then realizing that I needed to go to college first, heh heh.

SS: So what did you do? Where did you go to college?

GFR: I started out at Hunter College, which still had an open enrollment policy at the time. And I went there for two years. And then I transferred to Harvard. And I went to Harvard for two and a half years, and finished up there.

SS: So what was it like for you to go to college, after all of that?

GFR: I discovered that college was so much easier than ACT UP.

SS: {LAUGHS}

GFR: But also, you have to remember that my primary experience of life up until that point was you work and you work and you work and you work and you work

and you work, and nothing does anything, because people are still dying. And – and college was very different, because there was this actual effort; there was this actual correlation between the work that you expended and the outcome. You had actual control over outcomes? And I did very well in the sciences, and , I thought I was going to be a biology major, but then I discovered William Blake and a variety of other, of the sort of – Romantic and radical enlightenment figures, and decided to be an English major instead.

SS: So what was the difference for you between Hunter versus Harvard, in terms of what you had experienced in ACT UP?

GFR: Well, Hunter is, it's an urban commuter college; it's primarily minority; it's very low-income; it's very New York. And Harvard is Harvard. And – people came from much more sheltered and coddled and wealthy backgrounds than I did.

SS: And at which one do you feel that you were best understood?

GFR: I don't think being understood was ever my goal.

SS: Okay. What was your goal?

GFR: To understand.

SS: Okay. And which one helped you best understand?

GFR: Harvard.

SS: Why?

GFR: Well first of all, the teachers were just fantastic.

SS: Oh, I see.

GFR: It was just a really good education. And I made a lot of friends there who are still friends –

SS: Okay.

GFR: – I'm still friends with.

SS: So you had like a normative college experience. You lived in a dorm, you smoked pot, you – no?

GFR: No, I didn't – smoke pot.

SS: Okay. I'm sorry.

GFR: I'm just saying.

SS: {LAUGHS} Or whatever.

GFR: No, I didn't –

SS: You were a normal college student. You had that normal experience that you hadn't had before.

Tape II
00:40:00

GFR: Uh, no, I was like, actually, it wasn't normal. Because, if I was a normal college student, I would have smoked pot in the dorms, and it would have been this very low-key thing. But for me, I was like, thinking about the people I'd seen through the Lower East Side Needle Exchange Project, and I developed this totally anti-drug attitude. Because I'd just seen drugs in New York City destroy so many people, and also destroy young people. All these young people; you'd see them, they'd come to New York with this vision of being artists or writers or whatnot. And several years later, they'd just be alcoholics or whatever. And they'd think that they were living these sort of interesting, creative lives. And in reality, I don't know. I got kind of judgmental.

JW: We have to change tapes.

SS: Okay.

Tape III
00:00:00

SS: Is something jarring your memory there?

GFR: No, I'm just reading e-mail.

SS: Oh, just reading an e-mail? Okay. We're almost done.

Okay, we're rolling.

GFR: So, where are we now?

SS: I just have a few more questions. We'll be done soon.

GFR: Okay.

SS: Do you want to answer your e-mail?

GFR: No, I'm just checking to see what I have to do.

SS: Okay. Can you talk about how Clinton's election affected ACT UP?

GFR: I think that it made people – feel like some of the responsibility had been lifted from their shoulders. And I think in that they were somewhat correct, and that there would be – Act up was a reaction against Ronald Reagan. It was partly a reaction against Reagan's approach to AIDS, which was continued, to some extent, under the first George Bush. And – under Clinton – there was no more talk of rounding up gay people for camps, or anything like that. It was much more a question of, would people be coopted, and there was all these questions about that, and there were a lot of the things that seem normal now, or are the new frontier for political debates around gay rights questions, such as gay marriage and so on. Nobody was even talking about gay marriage at the time. There was people who were together, and wanted to have kids together. But there was – it was only the gay conservatives and the gay Catholics who were really interested in marriage questions.

SS: That shows you how far to the right the gay movement has gone, really; in a certain way. That that's become the dominant discourse. Because what was the other side of it? If the gay Catholics and the gay conservatives were the pro-gay marriage people, what were the other gay people in favor of? What was the other vision?

GFR: I think the other vision was – things as they were. Which is probably, frankly, still things how they are. I don't think gay marriage is ever going to, I don't know. I'm not part of gay culture anymore, so I don't know what the debates are.

SS: Okay. That's fine, then. All right. Well, let me just ask you a big question, and then I have a little question, and then I'm done, unless you think there's something that we haven't covered.

How did you adjust out of the ACT UP way of doing things; the ACT UP way of dealing with people, the ACT UP level of expectation; into real life, or the way people exist in bourgeois society, or the status quo of behavior?

Should I be more explicit?

GFR: Yeah.

SS: In ACT UP, somebody had AIDS, and they needed meds; other people would fight for them; other people would have a third-party intervention. They would say to the government, you can't treat my friend this way. In life as we live now, that is no longer the case. There's no structure like that. There's no – the idea, what you laid out before; that you become informed, you make a demand that somebody could actually give you. And you force them to do it, because your agenda is moral and right. There's very little model for that today. That's not even considered, sometimes that's considered almost antisocial, that type of behavior.

So there had to be a huge adjustment, of things that we believed at the time to be true and right — and we may still believe them to be true and right — but we're not living in a time where they're viewed that way, or where that's acceptable behavior.

How did you personally transition from one mode into another?

GFR: Right. But it's not like we were making these demands on our own, or that people were – unusually rude in their interactions with other people on a day-to-

day basis. So there was, it wasn't like there was a huge – the big shift was from being part of a community to not being part of a community.

SS: Okay.

GFR: And to existing for other people and for a cause larger than yourself, to just figuring out what you're doing with your own little life. And that was the big shift, for me.

SS: And how was that for you?

GFR: Well, I decided ultimately that I didn't want to be a doctor. I think especially after the new antiretrovirals were approved, and things really did seem less urgent; and when even the people with AIDS I knew were starting to think about themselves as individuals again, and to stop thinking in just a crisis mode, and were starting to think about the future, and plans. And maybe I should open a bed and breakfast, like I always wanted to do. Or maybe I should finish that degree that I stopped when I was 23 and I got my diagnosis and joined ACT UP. You know.

So people were – were reevaluating the idea of having individual personal lives, where they existed for themselves and not for something larger.

And – I work at a liberal publication now. And over the past few years, we've seen the rise of the sort of left-wing political blogosphere. And in some ways, I felt like as a reporter covering, that I understood it instinctively; because I understood what social mobilization looks like, and what its power is. And I really do believe in democracy, and I think that's the one thing that ACT UP really taught me, is that in a democracy, change comes from the outside. Politicians are lagging indicators. And

whoever works hardest wins. And it's just a matter of figuring out how do you organize things.

So what's been really interesting in the left has been this sort of resurgence of, this idea of institution-building, and movement-building.

So I feel like it's been a very useful sort of history to have, in terms of being able to look at what's happening now, and also – sometimes I get impatient, watching people do things. I'm like, if you're going to keep complaining about this, and you're not going to sit down and do a targeted campaign about it; just do something, and figure out how to do an action that's targeted and focused and specific. And sometimes things are so scattershot, and people shoot so wide. And I'm like, media matters for Americas resident. Here in Washington, D.C., criticizes a lot of media institutions and so on. They've been complaining about certain TV shows for years.

And I'm like – if you were ACT UP, we would fixed this, like, six months. It's just a matter of sort of an impatience with people who are not effective activists.

SS: Right.

GFR: Because ACT UP was very effective, because it couldn't afford not to be. And that's the critical difference between it and probably any other organization I'll ever be involved with, is that – it's like having an antiwar group where everybody in the group is also the frontline soldier. And you just, you don't see that. Everything's very – people have their own broader agendas; they're trying to position themselves as intellectuals and as writers, and trying to get jobs with candidates, and – it's just, it's just different.

But it is interesting, and there is a kind of community aspect to the sort of new resurgent left that's been interesting to me.

Sometimes I still feel like the most useful thing I ever did was when I worked at the Health Group, because I was actually helping people directly. And everything is very much at a remove now.

Politics is so much at a remove. You're a writer. You can write something, but what does that do? Right? Like –

SS: It's true.

GFR: It doesn't do anything, really. Maybe it'll provide a basis for someone to ask further questions, and – but writing isn't activism, it's just writing.

SS: I agree with that. Last question. So looking back, what would you say was ACT UP's greatest achievement; and for you, what was its greatest disappointment?

GFR: It was a lot of people coming together with this idea that this crazy, literally crazy idea that if they, as a group of lay citizens, got together, and organized in a particular kind of way, they could save their own lives. And then they did, a lot of them did. And I think that was a huge achievement. And it wasn't just for them; it was for everybody. And now you look at AIDS, and the religious right is interested in it, and Bono is interested in it, and everybody talks about it, and it's this huge big thing, and it's, and it's not stigmatized at all, really, except socially, where, but none of the people who do the work on it, or the political work on it, are going to be dealing with the people on a day-to-day basis who, who are actually affected, so there's no question there, right?

I don't know.

Its failures were the failures of every movement and every activist group, which is the kind of turning inward and people being unkind to each other. And obviously, – I sometimes wonder if there had been less of that, if certain other things could have been accomplished more effectively, or if it could have gone on at a high level for longer, or something like that, but it provided an education for a whole generation of people in New York City, you know. It was, I used to joke, when I thought I was going to get a biology major in college: I used to say I was going to go for a basic B.S., since I'd already got my advanced B.S. degree, with ACT UP.

And it created a whole set of institutions in New York City that still exist. And artistic and community services and research-oriented and advocacy and policy. And it was just – I don't know – it was like the last of the great new social movements of the 20th century.

SS: Okay, thank you, Garance. Was that okay?

GFR: Yeah. Was it okay for you?

SS: Yeah, it was great. Thank you.

GFR: Yeah. I just, I wish I could remember more. But like I said, it's all

–