

# **A C T U P O R A L H I S T O R Y P R O J E C T**

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Interviewee: **Charlie Franchino**

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Interviewer: **Sarah Schulman**

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ACT UP Oral History Project  
Interview of Charlie Franchino  
January 11, 2010

**SARAH SCHULMAN: Okay. So if we could start with your name, your age, today's date, and where we are.**

CHARLIE FRANCHINO: My name is Charlie Franchino. I'm fifty-two. We're at 155 West 19<sup>th</sup> Street at my office, and it's January 11, 2010.

**SS: Right, and there's construction going on upstairs.**

CF: Upstairs, yes, unfortunately.

**SS: Through the whole thing. So let's start with you. Where were you born?**

CF: I was born in West Nyack, New York, which is the suburbs of New York City in Rockland County. That's where I grew up.

**SS: Was it small-towny or more suburban?**

CF: It was when I first started when I was first born, but I guess when the Tappan Zee Bridge opened, it opened up that part of the suburbs and it just grew. We lived in a big suburban monstrosity most of my life.

**SS: Your parents, had they grown up in the city and moved out there?**

CF: No, they grew up in Jersey. My mother's family's in Englewood. My father's family's in West Patterson. Their parents came from Italy, and that's where they settled.

**SS: So they came from small towns.**

CF: Yes.

**SS: So when you were growing up, what were the messages or the values of your family regarding community and responsibility to other people?**

CF: Well, actually, it was pretty strong. I went to Catholic school, and my nuns were Dominican nuns. They were Sisters of Charity, so it was all about charity. Our school trips weren't to Radio City Music Hall or anything like that. We were always going to Washington or Albany. We were always lobbying. A couple of anti-war rallies I remember going to. We went to anti-hunger rallies, certainly anti-abortion rallies, too, they dragged us to. Our religion classes and our last two years of high school weren't sitting in there studying religious books or reading the Bible; we were sent as volunteers into homes for the aged or mentally ill. It was all about volunteering. It was all about charity.

**SS: And your parents were that way as well?**

CF: No, not necessarily, no. I think they just wanted us to have a Catholic school education, so they just sent us there. If they were Brothers or a different set of nuns, that's where we would have gone, but they certainly supported that. They loved the fact that we did that and we were being taught that. That Catholic Church doesn't exist anymore.

**SS: No?**

CF: No.

**SS: What happened to the Dominicans?**

CF: They're still around. Back in the seventies when I was in high school, they were one of the first orders to start coming out of habit. We used to refer to it as kicking the habit. Nuns would go into lay clothes, and some of them actually left the

sisterhood. I remember some of the nuns when we were in school, it was a big deal, but they still taught at the school as well.

**SS: So you were trained to be an activist in a sense?**

CF: Yes, I guess I was. There was always that sense of justice with people who had less than you, and that's who you always had to watch out for.

**SS: So when was the first time you got involved in any kind of social movement outside of class assignment?**

CF: I guess that was right after I came out. I was nineteen. I just started chiropractic school, and I started dating a guy. He took me to the city, and we came to Greenwich Village and we were on Christopher Street. We were holding hands, and then we went over to a different part of the Village, I guess over on Thompson Street, over on that part. He goes, "We can't hold hands here. This is the straight part of the Village," and that kind of pissed me off. I got interested in doing something, but I was in school at that time, so I didn't really have the time.

But when I graduated chiropractic school and I came to New York, I was looking for office space in the summer of '81, and I said, "You know, I want to do some volunteering." So I started volunteering at the Gay and Lesbian Task Force, which was at that point not in Washington, but here in New York at Fifth Avenue, 80 Fifth Avenue and 14<sup>th</sup> Street. It was just a night where you stuffed envelopes and met other people. Ginny Apuzzo was the executive director at the time.

**SS: Bruce Voeller, was he still there?**

CF: Yes, he was there. I hold her entirely responsible for outing me to my family, because she said to me – Jerry Falwell was going to be in town. He was going to

be on the show *Midday Live with Bill Boggs*, which no one watched. It was this talk show on Channel 5 at the time, a local talk show. She goes, “I need someone to go on.” I was twenty-four years old. I was so young. She says, “I think you’re articulate and you’ll do a great job.”

So I went on the show, and we met Falwell at the Green Room, and he was a really charming guy. There was someone from Planned Parenthood, as all the usual suspects would be in the audience. Then she grilled me about how to handle him. Part of his literature he was putting out there, she claimed, we were going to claim was causing violence against gay people.

So I did the show, and then I got a phone call from my sister-in-law, who had just had a baby, and my mother had taken off from work to help her out. I guess she had it on and my sister-in-law says, “All I heard from the living room was your mother go, ‘Oh, my god, it’s Charles.’” *{LAUGHS}*

So I had to call her up that day and say, “Yeah, here I am,” and so it kind of outed me there.

But after that, I noticed that there – I don’t know if *The Native* was publishing them, but it was a gay newspaper at the time. They were looking for volunteers at the St. Mark’s Clinic, which at that time had moved from St. Mark’s Place to Barbara Starrett’s practice on University Place. I said, “I don’t know what I can do for you. I’m a chiropractor.”

She goes, “Well, I can train you to do anything.” So she trained me to burn anal warts and to do pap smears, so for a few months I would.

**SS: You were trained by Barbara Starrett?**

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CF: Yes, to do burning of warts, which was not what a chiropractor does. But I loved working there. We would open the clinic at seven o'clock at night. Usually when I finished my practice, that's when she would finish her practice, and it was packed all the time, and we'd finish at one or two in the morning sometimes. It was five dollars on a sliding scale. If you didn't have the money, you paid what you could.

I guess that's when we first started seeing – I know you've asked people in interviews, "When did you first hear about AIDS?" I didn't hear about it; I saw it first. We didn't know what we were seeing, but some of these guys who were coming in were pretty ill, and we had to send them to the emergency room at that point.

**SS: So can you describe what kind of symptoms you saw?**

CF: There were a couple, definitely, clearly were pneumonia. We sent them to the emergency room. Some were just very sickly, low energy, high fever. Barbara was like, "There's something going on." We were seeing too many of them, a handful, but that was a lot. Then, of course, there's the article about the "gay cancer," which I guess came out in the *Times*, I guess in July that year. But it was about cancer, not necessarily about pneumonia and some of the other things that we were seeing.

**SS: But were you aware that these patients died?**

CF: No. We had no contact with them. A lot of these people, we really didn't have charts on necessarily on these patients like you would now. They just came in for treatment. A lot of it was anonymous. A lot of women were sex workers. They just wanted to come in for STD testing, and so we really kept no information on them. If I was treating someone for anal warts, I had a chart which I drew a diagram each time what I saw, but that was about it. We didn't really keep much information on them.

**SS: Did you see KS?**

CF: I didn't see KS. When I opened my practice; the first time I saw that, I opened my practice in January of '82 and there was a gentleman in the building came down and he said, "Can you look at something for me?" He rolled up his pant legs, and from the knees down they were just solid masses of KS. I was like, "Oh." I'd never seen it before. I'd heard about this was the "gay cancer." So I suggested he see a doctor. He hadn't seen a doctor. I'm sure he passed away since I didn't see him since then.

That's when I went to GMHC, which is at that point at 22<sup>nd</sup> Street, just in this brownstone which had no heat—and it was cold; it was like early part of spring—to get some information. I met Mel Rosen, who was the unpaid executive director at the time, and he developed a bit of a crush on me. I was a twenty-four-year-old kid, and he said to me, "You're going to work for me." And I wasn't very busy, so I did. I started volunteering there too. I'd go in the middle of the day for three or four hours answering phones, doing what they needed. I got involved in some of the fundraising activity there. It was really kind of an exciting time to be a part of, and I was meeting lots and lots of guys, none of whom who are here now. It's just such a tragedy what we lost.

So I was involved with that and doing St. Mark's, and then I dropped the NGTF. I just didn't have the time to volunteer there anymore. I felt like, stuffing envelopes or treating patients and trying to find information, I felt that was more important.

**SS: So when a patient came in to your office and you saw KS or certain kind of obvious symptoms, what would you do?**

CF: I would ask them if they were seeing a medical — most of them had medical care, were seeing medical doctors. As far as I thought to myself, “All right, if casual contact is going to — I’m already infected. Whatever it is, I have it,” because I was also going to the St. Mark’s baths. I had a very active social life, too, that most men at that time had. So I didn’t really have that fear. There were plenty of other chiropractors who had that fear. Once they got wind that I was in the Village — and I gave a little speech to the Manhattan Chiropractic Association, and they all came up to me wanting my card because they were going to send these patients who were gay or they thought were gay. They didn’t want to touch them. They were terrified. We’ve come a long way.

**SS: What happened when you gave that speech?**

CF: It was just very brief. I had some information from GMHC, and they all were listening very intently, and afterwards it was just very brief. What could I tell them? There really was no information. We didn’t know anything about it. I was giving them basically what to look for. “These are the symptoms people have who have—.” We didn’t call it AIDS back then. I think it was GRID. I don’t know even what it was called at that point. But they were very stone silent. Then it was afterwards all the business was done in the meeting and then a lot of them just came up to me after the meeting and said, “Give me your business card so I can call you.” But really what they wanted was to send those patients to me. They didn’t want to treat them.

**SS: You must have ended up in some kind of counseling role. I mean, people must have been completely freaked out.**



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CF: Well, GMHC started something. I was one of their first buddies that was trained in the first session, and basically they trained you to go in — a lot of these guys, when they got sick, they went to the hospital. The families didn't know they were sick, didn't know they were gay. Everyone was finding out everything, and everything was moving so quickly too. When you got the diagnosis, you didn't live very much longer, much longer after that. They needed all kinds of care. There were hospitals which were treating them very badly. So, yes, I became a counselor, but it was tough when you were a counselor and really didn't have much information to give these people. It was really, really hard, and especially their families when they eventually came. What could you say? You didn't have much more information than the doctors did. They didn't have much more information than you did, is what I should say. It was just so early in the epidemic.

**SS: Okay. We're going to stop. I'm going to go upstairs and yell at these guys. Excuse me. Because this is too important.**

**SS: These were the first buddies trained at GMHC?**

CF: Yes.

**SS: Do you know who started that program?**

CF: Oh, god. The only person I can remember who I was in it with was Michael Shernoff, because he used to always tell me years and years — He was a psychotherapist. He's deceased now. But he'd say, "We're the only two left alive." He used to tell me that from after our days at GMHC. Mel Rosen had a master's in social work, so I imagine he had something to do with setting that up as well. I don't remember exactly who it was.

**SS: What was the training? What did they tell you?**

CF: Basically what a patient's rights were in a hospital, how to deal with the family. We sort of role-played that out. Family comes, they're extremely hostile or they're upset. We kind of played that out, see how you should react to those people. Basically you just had to be very neutral, very calming, just keep explaining the facts to them and make sure they understood what was going on. But also you're trying to run interference, because they were over at Cabrini Hospital. That had to be one of the worst hospitals for people with AIDS in the early parts of the epidemic. There's food outside the door all the time. People would not go into the rooms. They were not getting care. So you had to go and intervene there, too, and raise all kinds of holy hell, and we did, a lot of us.

**SS: Do you remember your first buddy?**

CF: I don't remember his name. I remember he lived on 16th Street right off Seventh Avenue, because I met him, he was hospitalized. I went to visit him and tried to work things out with him. Usually at the hospital at that point, they didn't get out, but he did. He got well and got out, and then he had terrible back problems too. He was right across the street from my psychotherapist, so I would go to her once a week and then I'd go across and give him a treatment at home as well. I don't remember his name, though.

**SS: So you were seeing all these sick people.**

CF: Yes.

**SS: In your practice, in your volunteer work.**

CF: Yes.

**SS: What was happening with your friends?**

CF: Well, it's interesting you say that. I was twenty-four. They were all really young. I'll tell you, guys my age at that point felt, "Oh, it's the older guys who are getting it. They went to the Mineshaft and all that. We're immune to that." It's sort of how I got into ACT UP, because 1987 was the worst year. So many of my friends died that year or got sick, the later part. I heard about ACT UP at the demonstrations. "I want to go check it out." Because at that point I wasn't part of GMHC anymore. I wasn't really in any volunteer work at that point.

A friend of mine, Mark, my close friend Mark Kowanski, his boyfriend was sick and dying. His roommate was sick and dying. He decided he wanted to go to Europe for a month because he'd never been there, and he felt like he more than likely was infected as well. He was going to spend the first two weeks in Paris, and I was going to meet him in Milan. I met him in Milan. I saw him there. He had a KS lesion on his face, and he goes, "What do you think this is?"

I said, "It's a pimple. Let's just have a good two weeks."

I remember we were in Florence and we were leaving that morning, and his arm started to twitch. He goes, "Look what's happening." He ended up having a grand mal seizure, and he had toxoplasmosis, was the diagnosis he eventually got. It was a brain infection. I wanted to immediately get on a plane and go back to New York. He said, "No. I met this guy in Paris. I want to stay. He's going to come and meet me in Rome," where we were heading, "and that's what I want to do."

I said, "Mark, you're sick."

“I don’t care.” He just wanted to do it. He progressively got more and more paralyzed on his right-hand side. By the time we got on the plane, he really wasn’t moving very well. We were about an hour outside of New York, and he got up to go to the bathroom, pulling himself along. Looking at the guy, you’d think, “He’s injured. Something’s wrong.” He got back to the seat. I was sitting in the aisle seat. He was sitting in the window. He says, “I want to stand for a bit.”

This woman started yelling at him from about two or three rows back to sit down. He was blocking the view of the movie, which had just ended. It was some Mel Gibson film. I remember that. I still remember these stupid details. So he sat down. But she was loaded. So was her husband. They had been drinking. And she got up to give him a piece of her mind.

I said, “Can’t you see he’s injured?” I’m looking up at her.

She told me to go fuck myself. So I got up and said, “Well, fuck you.” Then she slapped me and I slapped her back, and then her husband got up, and we got into a big brawl on the plane. All I remember, I ended up on top of him, holding his throat with one hand and just punching away. I wanted to fucking kill him, and I had never been in a rage like that before or since.

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When we landed at Kennedy, they told everyone to sit down, that the Port Authority Police were coming to remove us from the plane. Everyone had seen what happened, and I wanted to prosecute, press charges against these people, but I had to get Mark to the hospital. They said, “Well, either he stays or you’re not going to be able to do anything. What’s your choice?” Well, the choice was I had to get him to the hospital, and I had a friend meet us there.

That was a Sunday. Then on Tuesday I was seeing my therapist, Rosemary Caggiano, who ended up seeing a lot of people in ACT UP. I sent them there. She has a great history, herself, if she could talk about her patients and what they've told her. On the way there, I was crossing 10th Street, and this cab came. I had the light. I'm crossing the intersection, and he kind of slams on his brake in front of me. I was furious. I had an umbrella with me, and I took it and I carved this big scar right in the front of the car. I was saying, "Get out." I was going to go into another rage.

When I went to Rosemary and I told her what had happened, she said, "You've got to find a way to channel this anger. You should go to this group ACT UP," and I did. And it did help. I often say it saved my life in many ways. It really was just an amazing experience for me, a place where I could really channel anger and find a place where actually here was some people were actually doing something, I felt. The first meeting I went to, the acronyms were flying. I didn't know what the hell anyone was talking about, but I knew that's where I belonged.

**SS: Did you know people when you walked into the room?**

CF: I didn't know anybody, no. At the end of the meeting, this cute guy got up, Tim Stannard, and he said, "We're going out wheatpasting this weekend. We need volunteers."

I said, "Let me go do that," and met them. So that Saturday night I went out with him and a bunch of other guys from the Outreach Committee, I guess is what it was at the time. There was a drag queen named Bella. She had a big old '67 Cadillac that we got in and we went out wheatpasting and drinking. My sex life was in the toilet.

I forget who I had sex with that night, but somebody on the wheatpasting thing. I was so happy. I was so overjoyed. I was actually, again, doing something.

The meetings, like most of us when we went there, you eventually learn all the acronyms and everything. You start to understand what's going on. You gravitate to what you want to do and what you want to work on. I stayed with the Outreach Committee for a while. It seemed like that committee had been something bigger and stronger, but a lot of the key players had left, so it was kind of moribund. So I eventually became the chair of the committee and then sat on the Coordinating Committee representing that for a while.

**SS: What year is this?**

CF: This is 1987. I got there in October of '87, early November of '87, and things were going great for like, I'd say, the first two or three months. I felt like everything's going great, this is where I want to be. The sex was good. But I was just having more of a social life, because a lot of my friends were gone at that point.

There was one night I was ready to leave my office, a Monday night, for meeting, and I kept thinking about going to the meeting, and every time I thought about it, I got sick to my stomach. I got cramps. I thought, "This is crazy." I made the connection. Your mind does not want you to go to this meeting tonight, so I didn't.

When I saw Rosemary at my Tuesday appointment, I told her, and she basically said to me, "You joined GMHC, and you met all these guys and they all died. Then all your friends died. Now you're meeting all these other great guys, you're having fun, and more than likely many of them are going to die too. Can you handle it? That's really what it's coming down to." It was amazing, how sometimes one statement [snaps

fingers] could just cure you of something, because I was able to go back. I felt pangs of that every now and then, but I just thought, “What choice do I have?” Ultimately, if I don’t go and do this, I felt like I was just going to have this rage where I had no place to channel it.

**SS: What about your own health? Were you concerned about that?**

CF: Yeah. whenever the test first came out, I ran and got it. I know it wasn’t the politically correct thing to do at the time. I was negative, and I was shocked. But I practiced safe sex, and so I really wasn’t that concerned at that point. I was thinking about my history and everything I had done, and I thought, “Well, I just dodged a bullet, so I’ll keep it that way.”

**SS: Can you explain, for people who don’t know, why it was not the politically correct thing to do to get tested?**

CF: I think people felt, well, if there’s no treatment, why get tested? And I think people were afraid that it might create this two-tier between gay men, the infected and the uninfected, and like there wouldn’t be any motivation for the uninfected to do anything for the infected. I don’t know. That’s kind of what I was sensing there about that. But also because if there’s no treatment, why get tested? Or there’s also, I think, the other issue was there were really no protections in place for people who were infected, so if you found out and the government had that information, they could use it against you somehow. I think that was also an argument people were making.

**SS: You decided that that was not the most important --.**

CF: I wanted to know. I absolutely wanted to know. And it was horrible. I remember going for the results, and I’m sitting there. It was at a clinic on Ninth

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Avenue. They hand me this big envelope of paper, pages and pages. Just tell me what the result is. I just want to see that. You had to go through this counseling beforehand, and subsequent, even if you were negative or positive, they'd sit down and counsel you a little bit there too. I forget when the test came out. Was it '87? I don't remember.

**SS: I don't know. Do you know, Jim?**

JH: Yes, it was '87.

CF: It was '87, yes.

**SS: It's also like you're describing this world of volunteers. It's like you're a trained buddy, and then you go to the guy, he's the trained counselor, and everybody's trained and everyone's counseling each other.**

CF: Yes.

**SS: It's kind of like a cycle. It's like a self-help model.**

CF: Yes.

**SS: So when you were the head of the Outreach Committee, what did you guys do?**

CF: Well, I loved the wheatpasting idea, and I wanted to set up, get people doing sort of captains all around the city to get – because I felt everyone should be at these demos. I was so determined that we should have more and more people at demonstrations. They used to call them Charlie's Angels. The word got out that we'd go out, we'd party, we'd wheatpaste, we'd party, sometimes there would be other shenanigans going around, so it made it a pretty easy sell. Also our committee also came up with the idea of let's get the silence equals death on stickers, not just buttons, so we can plaster all over the city. So that was it.



Then when I realized, you know what, we're not really getting that many more numbers of people in, I kind of lost interest in the committee. Where I really wanted to be was looking at what Treatment and Data was doing, which I think originally was part of the Issues Committee and then kind of broke off. That's where I ended up gravitating to.

**SS: So when you went into Treatment and Data, were there any existing treatments?**

CF: Oh, yes, there was AZT. DDI, I think, was in the pipeline, and DDC was in the pipeline at that point.

**SS: So that was the point at which you came in.**

CF: Yes.

**SS: What were your feelings about AZT at the time?**

CF: Well, it was clear the drug was very toxic, and it maybe had some benefit, we thought, and now know it really didn't have much benefit at all. But it was something. It was a beginning.

One of the things that struck me at the first T&D meeting, which really made me want to be there, was basically those drugs were just stuff that was on the shelf that the drugs companies and researchers just threw against the virus to see if it would kill the damn thing. I don't know who, it was probably Mark Harrington, was talking about we need more basic science and that's what we have to start pushing for, to find out really the mechanism and the actions of this virus, and this is the way we can attack it. That made a lot of sense to me, and so that really ginned up my interest in being part of that committee.

**SS: I want to go back to AZT for a second. In hindsight, when you think about all our friends who took AZT, do you feel that people were too cavalier about it?**

CF: Well, it was the first treatment. People were dying to take anything. It was the first government-sanctioned treatment. There was a lot of other stuff out there, AL-271 or whatever the number was, and Compound Q, other things, but people were desperate to take anything. I think that makes people vulnerable to entering into clinical trials and maybe taking a dose of the drug that was way too high. We knew that. These drugs in the Phase One trials are often tested at maximum tolerated dose, how much we can give the patient without killing him, because they want to test it at the highest level, and we know the toxicities, especially in those early drugs, what they were like. They were horrible.

**SS: Why did AZT become the first government-sanctioned treatment?**

CF: The history of that is fuzzy on me, and I think it was the first one that – What was the drug? The company doesn't exist anymore. It got bought by somebody else. I can't even remember the name of the company that developed it now. Burroughs-Wellcome, I think, was the AZT developer. But it was the first thing in the pipeline that showed some activity against the virus, and I think the government at that point felt some pressure to get something out there for people with AIDS. So it just was the first one that became identifiable, but I think everyone rapidly realized it clearly wasn't a very effective drug.

**SS: So as AZT is on its way out and DDI is coming in, you guys decide that basic science is the direction that -.**

CF: Well, one of the directions.

**SS: So how do you pursue that? Once you have a revelation like that, what's the first step?**

CF: I think identifying where that takes place, and our first big action was really against the FDA and the whole approval process, but then we turned our attention, as far as T&D, to the National Institutes of Health and looking at how research dollars were being spent. Mark and Gregg, they went in there, and they gave them access to everything, Mark Harrington and Gregg Gonsalves, and they wrote a report. If I remember from the report besides being a lot of duplicative research being done, the other thing there really wasn't much basic science being done. So that was part of the gist of the report, and that report was eventually turned to legislation, which was through Waxman's office in the House and Kennedy's office in the Senate, which revamped the Office of AIDS Research, made it much more powerful and directed the funds in a much more efficient way.

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**SS: Can you explain why there was replication of research?**

CF: I think what happens is the National Institutes of Health is a lot of different institutes. You're talking about career scientists here who work for the government. So let's say you have the National Eye Institute doing research on cytomegalovirus, and they find gancyclovir is effective. Well, someone else in the National Allergy and Infectious Disease, "I'm going to do the same trial because I'm going to get the same results," and "I got positive results" just looks good as a career scientist. That's what they got. I really think that's all it was.

**SS: It was that cynical?**

CF: I think so.

**SS: So what was it like for you guys to go in and deal with these types of people?**

CF: Well, I wasn't one who went in. I wasn't researching. The only experience I had with that was when Mark Harrington, myself, and Peter Staley, we went to the NIH. We were planning the NIH demo. We were going to go down and do some spec on the place to see what was going on, and we were going to meet with Fauci that evening. He invited us to dinner as an attempt to sort of co-opt the organization. We got picked up by the NIH police, and they held us for thirty minutes, not any longer than that. We decided that we weren't going to say anything to Fauci about us being picked up. We wanted him to bring it up.

So we went to dinner with him. It was a nice dinner, and we had too much to drink, probably, and then you could tell he was itching to ask us, and we weren't bringing it up. He asked, "Well, what brings you guys down here besides this?"

Mark just laid into him, "Well, we know in about a month's time from now, we're going to have about a thousand activists on your campus, and these are our demands." This heated argument ensued.

I think there's always that attempt from people on the inside, once you get on the level, to try to co-opt you in some way, and I think we were pretty resistant to that. The fact is, we still had the demonstration. Tony Fauci got to lay out his agenda why we shouldn't, but we still had it, and it was a very effective demo as well.

**SS: So let's go through all of that again, because I have a lot of questions. So, first of all, what was the purpose of the NIH demo?**

CF: There were a lot of purposes, so many different issues that came up. I remember when we were planning the demonstration and we repeatedly brought it to the floor and everything was getting shot down, which ultimately turned out to be a good thing. We kept having to go back to the drawing board. But I think, to summarize in one sentence, the purpose of the demo was to make the NIH more responsive to needs of the people with AIDS. We wanted to revamp the way AIDS research was being done, the way dollars were being spent, and we wanted to be part of the people who were making decisions how that money was being spent as well.

**SS: So that was the demand?**

CF: Yes. The overarching – I remember when we wrote our list of demands. There were so many of them. There were just dozens and dozens of individual demands. I remember Mark was writing something as we were doing one meeting. I think as far as a demo's concerned, you had to have one simple thing that people can get their mind around that was wrong. And we were coming off a very successful demonstration at the FDA. We got what we wanted out of the whole idea of parallel track and expanded access. We got what we wanted. It was a little disturbing that the next day the *Wall Street Journal* editorialized in our favor, because they were all for deregulation. But we wanted to turn our attention there next, because that was the next bottleneck for us.

**SS: But had there been any precedent of citizens setting an agenda for a government agency?**

CF: I don't think so. No, I can't think of one.

**SS: So you wanted the NIH to do it your way, to restructure.**

CF: Exactly. Yes. Well, the community's way, not necessarily our way.

**SS: The agenda that you guys envisioned.**

CF: Yes.

**SS: And ACT UP was willing to do this demonstration.**

CF: Yes.

**SS: Do you feel that they really understood what your demands were?**

CF: I think so. There were a lot of smart people in the room, and we would always keep updates on the table in the back where all the handouts were, and do teach-ins. I think people really understood the issues very well.

**SS: So why did they keep sending you back to the drawing board?**

CF: I think it was more logistical than anything else. It was just about the logistics of the demonstration.

**SS: So then how did you get this dinner with Fauci?**

CF: I don't remember how that happened. It must have been through Mark Harrington, because they were talking and he said, "We're going to be there," and so he invited us over. He must have known what was going on. He had to know that after the FDA the NIH was — And we were already firing fuselages over his bow, that there were problems that we wanted fixed.

**SS: So you're having this dinner in this fancy restaurant.**

CF: Oh, no, it's at his house.

**SS: Oh, at his house.**

CF: Yes.

**SS: What was his house like?**

CF: I'm trying to remember. It wasn't anything terribly spectacular. I guess it was what we call a brownstone in New York. I don't know what they call them in D.C. It was very small, very quaint. The rooms were small and tidy and kind of stuffy.

**SS: Did he have good taste, Dr. Fauci?**

CF: Chintzy. I'd call it chintzy. Not chintzy cheap, but chintzy like chintz.

**SS: And who cooked?**

CF: His wife.

**SS: Was she at the dinner with you?**

CF: She was at the dinner, too, yes.

**SS: Okay, that's interesting.**

CF: But I do remember one thing. I don't know if I should say this, but I'm going to tell you anyway. We were drinking a lot of wine, and he got up to go to the bathroom, which was right up there, and I remember Peter and I and Mark were just listening, and he had quite a heavy stream. We were laughing about it later.

*{LAUGHTER}*

**SS: So you got to know him up close in person.**

CF: Yes.

**SS: So you're drinking and you're eating and then Mark says, "Well, we're doing this thing and these are the demands." What was his argument?**

CF: Whatever it was, he was arguing against it. I can't remember what the specifics of the conversation were.

Tape I  
00:30:00

**SS: Was it the specifics demands or the idea that you guys were demonstrating?**

CF: The idea that we had to do a demonstration, he felt was unnecessary.

**SS: Because why?**

CF: Obviously he felt he was being or the NIH was being responsive to our needs and there was nothing that need be done. Strengthening the Office of AIDS Research cut into his power, so I don't think he was going to be too happy with that.

**SS: This is still their argument. We just heard them at Harvard a few weeks ago. They still claim that they were doing everything right and we were too abrasive. It's amazing, historically.**

CF: Well, without the abrasion, we wouldn't be where we are now.

**SS: Absolutely. It's interesting that they can't accept that, even at this late date.**

CF: Well, history. They've got their eye on history.

**SS: Yes. So then we did the demonstration, and what happened as a consequence? How did you guys get in?**

CF: What do you mean in?

**SS: Into the NIH. Did they call you the next day and say, "Okay, okay"?**

CF: No. I think people started showing up. It wasn't just that demonstration. There were also zaps like the ACTG meetings in Washington. People were showing up and refusing not to be let in and demanding to be part of it. It was a continuum. It was the major demonstration to bring media attention to the issue, and then



these individual zaps and pressure and putting pressure on. I think once they had the demonstration, look, when anyone's sitting at the table, debating across from Fauci or anybody else, the specter of a thousand people at their front door again is always sitting behind them. You call it good cop, bad cop. I would refer to it as bad cop and less bad cop. "If you don't deal with this and these are our demands right here, you're going to face that again." Or individuals asking sometimes are even more effective. Just two or three or four, half dozen people can really zap someone and really humiliate them in front of the public.

**SS: So they were willing to change just because they didn't want to be yelled at, basically.**

CF: The way I look at it is we were maybe trying – Maybe like you said, they still don't recognize that and they felt they were doing everything right. So maybe if we change the institution, they just have to change with it or they're not going to be a part of the institution anymore. I really think that was more the goal. We're not necessarily going to change them, but change where they work and how, through regulation and law change what happens, and then they just have to change with it.

**SS: I want to get into the ACTG thing and then back to the NIH. So when you say, "Let us sit," who was sitting at these ACTG meetings?**

CF: See, I never went to them, so I'm not going to be able to fill you in on that. I just didn't have the wherewithal, being in practice, to travel, and my role in T&D when I got there, I wanted to educate myself, but then I found myself all of a sudden facilitating meetings because I guess it just seemed like a natural thing for me to do. I remember Herb Spiers sitting next me, wanting a meeting, and Ken Fornataro was

running it. Ken's a very talented guy, but he can't run a meeting. He said, "You should run these meetings."

So I went up to Ken afterward and said, "You know, maybe I can facilitate the meetings. You mind if I did that?"

And he said, "Fine." I said we'd alternate, but then after I did it once, he didn't come back.

**SS: What was it like to facilitate those meetings?**

CF: I had to bring a whistle. I had a whistle around my neck. There were a lot of people, very smart people, with a lot on their plate, and everyone would come up to me, and I'd set the agenda. If they weren't first, then I got these glowering looks at me, like, "Why wasn't I first?" Then there were other people. We had a lot of people who came to the meeting. I remember a few doctors coming with — they had a cure in search of a disease they were trying to foist upon us. It was some junk, and people like that I put at the end of the agenda because everyone had to have their say. But we had two hours. If we were meeting at the Center, we had two hours. Eventually, we moved from the Center over to our workspace over on Ninth Avenue that ACT UP had rented. We were meeting there for a while too.

But it was tough. It was tough, because everyone would come in, "I've got to be at the top of the agenda. I've got to be at the top of agenda." You had Mark Harrington, David Barr, and Peter Staley, these are strong personalities, and it was difficult. And no one would walk out happy, which I said, well, I probably did my job right.

**SS: How many people would come to a T&D meeting?**

CF: Thirty or forty people, probably.

**SS: How many of those people were people with AIDS who were looking for treatment?**

CF: There were some people looking for information, but I think most of them just wanted to find out what they could do and what they could work on. There were other people who came, they had stuff they wanted worked on, but they wanted other people to do it, and that became a bit of contention. Then there was the guy from – At that point, Chuck Ortleb, I think he was on swine flu, is that what AIDS was, and one of his reporters, John [Lauritsen], I don't remember his last name, but he would come to the meeting every week and insist to be heard. I just put him at the bottom of the agenda because it was the same ranting and raving of a lunatic.

**SS: He was the HIV-denialist guy?**

Tape I  
00:35:00

CF: Yes. And then at a point, I guess some people were unhappy with the way I was running the meeting. I remember who it was. It was Bill Dobbs, Michael Petrelis and Jim Fouratt, all of whom I think are great. I love them all. I think they're really fun people, and a couple of them I've known for many years before ACT UP. They wanted to be heard, and they said they didn't like the way I ran the meetings, and they asked the committee to vote me out. The committee said no. Then they took it to the floor of ACT UP to have me removed as the facilitator. The person who defended me the most and really settled it was Maxine Wolfe. It really wasn't defense of me, as defense of the committees to really determine how they want to run themselves and a sense of autonomy. So that got shot down.

**SS: What did these three gentlemen have against you?**

CF: They felt I wasn't democratic enough and I was too autocratic, and that I wasn't giving other people – I was just focusing on the people, certain people in the organization, in the group who were the stars, as they put it. I said I wasn't. I was focusing on people who were actually doing work, and they need to report back and get feedback, and that's what was happening. If they were working on something, then, fine, we would do it. But a lot of times it was just kind of a haranguing, "I want you to work on this." Well, everyone who was doing work had enough stuff on their plate. They had room for no more.

**SS: So what were some of the big debates inside of T&D that you recall?**

CF: That's a good question. I'm trying to remember. A lot of it was just reports on what people were doing. I'm trying to remember any kind of big debate that was really acrimonious. I remember something with David Barr. I just remember him being so upset one day and no one siding with him. I can't remember what the issue was, though, but he was easily upset anyway.

**SS: What about HIV-infected people in T&D volunteering for cutting-edge research? How did that all work?**

CF: Putting themselves in clinical trials?

**SS: Yes.**

CF: I don't think they got any special access. A lot of these trials had very stringent criteria. If you didn't meet the criteria, you weren't in. So it was as simple as that. If there were an expanded access, that's what it was approved for, if you're narrowing the list of these people who meet these seven or eight criteria and there's all

these other people who need the therapy, I think many of them probably, if they felt they wanted to go into therapy, just went the same channels everyone else did. I don't think anyone got any special access.

**SS: No, I don't mean in terms of special access. I mean in terms of a person — I think at some point Mark or somebody was doing some kind of gene treatment or there was like a lymph node—**

CF: Mark, he presented slides. You're talking about the slides of his lymph nodes at the conference in Amsterdam, maybe. I think he presented it there. I think that was a plea for basic science, doing some basic science.

**SS: I guess my question is, when people were themselves invested in a certain kind of treatment because they were in a study, was that an issue in how decisions were made?**

CF: I don't think it was an issue. Look, when people are in a trial, they want to believe that, first, they're getting the right treatment and that it's going to work for them. It is going to color your view of things. I can't see how it's not. But I don't remember. I think people may have brought their personal experiences about being in a clinical trial to the group, and maybe that was something that interested them, obviously, to work on, but I don't think it really directed T&D's activities in one direction or another.

**SS: Would people corner you at an ACT UP meeting and say like, "What should I do? What treatments should I take?"**

CF: No. I think Mark got cornered a lot for that, I think, very much so.

**SS: When you saw people deteriorating in the group, did you ever feel like this guy should be on this or that?**

CF: No. That's a thing that I think back on when people did start to deteriorate and I just couldn't handle it well. After everything that happened, going back to that pit-in-the-stomach feeling that I had that one night, I didn't feel like I was someone who had the knowledge, basically, other people in T&D had to advise them on something like that, and I just didn't. I don't know if I could have at that point.

Tape II  
00:00:00

**SS: So after the NIH—I just want to get back to that—what was won at that point? What literally changed after those actions?**

CF: I think we had just more access.

**SS: Can you say literally what that meant? I mean, were you sitting in offices?**

CF: Yes. I think members of T&D and other groups around the country Project Inform were sitting in on meetings and having input. I think that was probably the biggest change after that.

**SS: Were you?**

CF: No, I was not.

**SS: So what were you doing?**

CF: Again, I was just facilitating the meeting at that time and being in practice. I was not volunteering at any other organization. Actually, no, that's not true. Someone who was in T&D asked me if I would join the board of CRIA at the time, Community Research Initiative on AIDS. Marisa Cardinale was the ED, executive

director, at the time, and Joe Sonnabend was the medical director, and the organization was in a state of crisis at that point. So I joined. I think Ross Bleckner joined at the same time. So the organization was a mess, and all of sudden that started taking up a lot of my time, too, and being on the board and trying to do things I'd never done before, like raise money and other things. So, yes, I was doing that as well.

**SS: Why was CRIA a mess?**

CF: I think because they weren't doing any research at the time. Funding was drying up. Joe, he had his own practice too. He was going through an issue, I think, where he had lost his office space. Some key board members had left at that point, too, so it needed help badly. I'm still on the board. It's eleven years later. I can't believe I'm still on the board. But it's doing quite well right now.

**SS: Why did you feel at the time that it was important to save that organization?**

CF: Because I think it was doing the research that — It was always that Drug of the Week Club. There was a rage, all right, it's this compound, that compound, that compound, and I felt those things should be put into a clinical trial quickly to find out if they worked so people weren't wasting their time or money, or if it was something that's actually dangerous, we needed to find that out. So that's why I really — It was just really the whole ethos of like GMHC, CRIA, ACT UP: "Well, if you're not going to do it, we're going to do it or we're going to force you to do it." It was really of that same mold, so it really appealed to me in that sense.

**SS: What treatments do you feel came into being because of CRIA?**

CF: We were part of some of the big pharma trials that we had done. There were a couple of protease trials. But I think we were looking at them — Nothing really. Again, we were disproving a lot of things at that point. There were no — AL721 didn't work, Compound Q didn't work. We were doing clinical trials on all this stuff. Bitter melon, I think, was another one.

**SS: Dextrin Sulfate.**

CF: Dextrin Sulfate, exactly. So to me it would be great if a clinical trial showed like this is an effective treatment, but it's just as valuable to show that it's something that doesn't work and you should not be taking it. You should not waste your time, money, or if it's something that could be quite toxic as well.

**SS: Did people on T&D ever really believe in a drug that did not pan out?**

CF: No. I think there was always a high degree of skepticism about everything, very, very skeptical about everything. It wasn't like Larry Kramer dancing in the streets in San Francisco Compound Q. Never. It was a deeply cynical group, deeply, deeply cynical.

**SS: So when did the idea of some kind of compound medication start to be conceptualized?**

CF: You mean Atripla, drugs like that?

**SS: No, protease inhibitors.**

CF: Oh, protease inhibitors. I guess David Ho was the one who originally did the work on that, and that was probably — My timeframe is so bad. It's '91, '92, I don't remember.



**SS: But when did you guys conceptually jump from the idea of AZT as the cure to –**

CF: I think that was probably when TAG was probably forming at that point, Treatment Action Group. So it was probably around '92, because that was the next horizon. Everyone's looking for the next horizon, like "What else do you got? What else is coming down?" So that's what I think. It's probably around that time, same time.

**SS: Do you remember discussions about just having to conceptualize the idea of a multi-drug approach?**

CF: I'm sure we did, but I don't remember anything like that.

**SS: So was there anything else really significant in T&D before TAG was formed?**

CF: No, I mean other than leaving ACT UP. That was a very, very difficult –

**SS: Yes, that's where I'm going right now.**

CF: That was very difficult for everyone, I think. I'm trying to think who early on was really advocating. I know it was Peter and myself. I don't know who else, but I remember Peter and I having a lot of discussions about it, because it just felt like an organization where we couldn't really do our work in anymore, and it was becoming too hostile. The tensions within the group were kind of tearing it apart. Really, my thing was it's probably better for both groups if we left and formed our own group and did our own thing and started our own organization, focused it narrowly on what we wanted to work on.

Tape II  
00:05:00

**SS: So when did you first start to feel that? What were the first issues that –**

**Jim Hubbard: Actually, could I go back to the NIH briefly?**

**SS: Sure.**

**JH: There's a lot of footage of these meetings that I think took place in your apartment.**

CF: Yes, those are the planning meetings for the NIH demo. They took place in my apartment because we could meet for as long as we wanted. It was fairly large by New York standards, but not that large because it was so packed in, so we held them there. Yes, it really was just a matter of logistics of where we could meet easily. It wasn't anything more than that.

**JH: Were those just T&D people?**

CF: No, no, there were people from the Action Committee there too. It was a mixture of people working on that, and it was a fairly large group. I remember, I'm picturing it now, people standing around because I didn't have enough – And sitting on the floor, two or three deep, so probably thirty people sitting in my living room for those meetings.

**JH: You let people smoke in your kitchen?**

CF: Yes, well, I had a balcony too. They also went in the kitchen. There was a window in there, too, so Mark Harrington and Gregg. What could I do?

*{LAUGHS}*

**SS: Before we get to the split, I just want to get into the thing about alternative treatments. So there would be Jon Greenberg standing up talking about garlic.**

CF: Right.

**SS: Then there was the Alternative Treatments Committee, Bob Lederer.**

CF: Right.

**SS: What was your relationship to that?**

CF: It wasn't great. They felt because I was a chiropractor and was an alternative therapist that I really should embrace these treatments, and I felt, well, they should be held to the same standard that we do with what traditional medicine has to throw at it. I was all for researching all these things and seeing what kind of benefit they could bring to people, but they just had to meet the same rigorous standards as everything else, and they didn't like that.

**SS: Did you feel that any of those treatments were helpful?**

CF: No, I honestly think not.

**SS: Really?**

CF: Maybe a placebo effect. I know when a patient believes in what I'm doing, they're going to get well a lot quicker than a patient who's very skeptical of chiropractic care. If you have someone who's very devoted to alternative therapies and they're taking those therapies, you cannot discount that placebo effect.

**SS: So you don't think there was any of the nontoxic or whatever non-pharmaceuticals?**

CF: Yes, I don't think any of them were — At best, they may have helped a little. At worst, they did nothing at all.

**SS: So were you involved in conversations with that committee about these things?**

CF: I never went to the meetings, but people like Bob Lederer, he would pigeonhole me quite a bit at the general meetings and try to get me interested in coming to this. He was a really great guy. He was very well-intentioned, very smart. Who else? Mark Milano, a little more aggressive with it. But it just didn't interest me. I didn't see where any of that was going to be — I just felt the answer was going to lie more with traditional medicine.

**SS: What do you think was motivating that?**

CF: Being a chiropractor, I can tell you, and being an alternative practitioner, a lot of us feel besieged by the medical profession, and there's a little bit of conspiracy theory with alternative practitioners, like "Medicine is always trying to thwart what we're doing, and the cure is out there, but they're just trying to hide it." There was always that, and that was part of that committee too. That kind of turned me off. I don't feel that way.

**SS: [In reference to construction noise] What should I do? Should I go upstairs and yell at these people?**

CF: Maybe they're not on the other side now.

**SS: Let me go talk to them.**

[Move to another room]

**SS: Let's go back to the question of the split. By the way, we're now back in your office. {LAUGHTER}**

CF: Okay.

**SS: What was the first issue that started to create conflict and make things hard for you?**

CF: Well, I think the issue that started coming up was there were people in the organization who felt we should never be on the inside, I guess, and never be meeting, so we were having lots of meetings at that point. I remember there was an issue over 076, a trial of AZT in pregnant women, and there was some disagreement between the Women's Committee and some members of T&D how that should be carried out, I think. Then I think the Women's Committee went down to a hearing on the committee, and they kind of shut the meeting down and created this big brouhaha.

I remember that specifically, because that Monday I got to the meeting and Marvin Palmer came up to me. He was a member of the Majority Action Committee. He says, "You'd better come to the back of the room and hear what's going on back here."

I'm going, "What are you talking about?"

So basically what was going to be presented on the floor was that the women from the Women's Committee went down to this and did their action, but they're undercut by Mark Harrington and other people from T&D because they were having meetings with Tony Fauci at the same time or maybe that weekend prior to that, I don't know what it was, but clearly it was a political blunder, I think, the way they handled that meeting. Here is an opportunity to reach out to communities of color, and they kind of

shot them down, and I think a lot of those other women who went to the meeting were pretty pissed off at what happened there. But just the fact — that was kind of an inkling to me. Why would you try to turn this around into something else when you really want to talk about what really happened at that meeting? That was kind of like a heads-up.

Then at some point –

**SS: Wait, slow down. What was the conflict?**

CF: The conflict between?

**SS: What was the conflict about 076?**

CF: I think the women felt that -

**SS: And who were they?**

CF: Maxine Wolfe, Tracy Morgan, Heidi Dorow. I don't remember the other women on the committee necessarily right now.

I think their issue was a general issue about the way women's access to clinical trials — First of all, they didn't have access, they weren't having enough clinical trials for women, and now here was a big clinical trial coming up and it really was focused on the unborn child, and I think that was their issue there. I think that was a valid issue. It was how women are treated in clinical trials. Medical is very male-centric in many ways, and that was a completely valid issue. I just think the tactics they used to go about raising that issue weren't great, which is fine. We all make mistakes.

**SS: What were the tactics exactly?**

CF: They went into the meeting and they basically shut it down.

**SS: But which meeting?**

CF: It was a meeting of the ACTG [AIDS Clinical Trials Group] over 076, and there were other people at the meeting, too, women who had a vested interest. They were the women who were really going to be affected by this clinical trial. I don't know if they were from some particular group or if they were just individuals, but the meeting was essentially what we do sometimes with things, we shout everyone down and don't let anything happen. I think that's what happened there.

**SS: Why do you think they did that?**

CF: I don't know. You'd have to ask them. I'm surprised they did it, because I think it was just a blunder. It doesn't seem like – They're all very smart women, and I don't know why they did that. I really can't say.

**SS: So the fact that they did something that was a blunder and had a negative consequence, why would that – because that happened in ACT UP all the time, people made mistakes.**

CF: Right.

**SS: Why would that mean that you guys couldn't do your work?**

CF: No, it wasn't that. That was sort of a sight to me, the fact that they were having this meeting and they were going to try to shift this blame somehow to Treatment and Data Committee, it just seemed wrong to me. It was bad politics.

**SS: And why were they mad at you or why would they want to do that?**

CF: I think some people felt that we were getting too cozy with insiders and that politically they felt that you should never be on the inside, you should always be on the outside agitating for change.

**SS: But why would they feel that way?**

CF: I guess that's just their own political — The way they feel, the way they want to operate. Some people had an identity as an activist, and the activist is always someone on the outside. All of a sudden there are people now on the inside and they felt that might have undermined the stuff they were doing or their identity in the organization. We had taken the organization into a different place where it originally was, where they had a lot of their identity focused on.

**SS: So you think it was ideological?**

CF: Yes.

**SS: This is a real serious question, because I've obviously interviewed a lot of people about the split. Do you think those people would have ever had a place as insiders?**

CF: I think they could have if they — Yeah, sure.

**SS: You think that Maxine could have been an insider in Washington?**

CF: No. *{LAUGHS}* No, not necessarily. Individually, no, but anyone could really have been if they wanted to educate themselves on the issues. Again, sitting at a table across the table from a government bureaucrat or some drug company official with the specter of a thousand people behind them, sure. Anyone could do that if they wanted to, if that's the way they viewed themselves. I think in T&D we viewed actions as what's going to be the most effective action? Is it going to be a big action? Is it going to be a zap? Is it going to be sitting across the table from somebody? Whatever we felt



was going to be the best way to attain our goals, that's what we were going to do. We weren't married to any particular action.

**SS: But I'm just going to be really on the table with you.**

CF: Okay.

**SS: You honestly believe that someone who wasn't like a Mark, someone who had gone to Harvard, could have had the kind of access that he had?**

CF: But there were people who didn't go to Harvard who were. There were a very lot of smart people in T&D, no doubt. But there were other people who didn't have that education, maybe they weren't to get up to the level that Mark Harrington did, but if they focused on one narrow issue, they could. I really do believe that.

**SS: Was this ever a concern of yours that other people in ACT UP be included, or was that just not —**

CF: I think that T&D was a very Darwinian structure, and it was like whatever rose to the top rose to the top. Because we didn't have much time to get meetings done, to talk about things, if you were doing work and you were making progress, well, that's where the attention naturally flowed. So, yes, some people were excluded because of that, absolutely.

**SS: What about, for example, the campaign to change the CDC definition?**

CF: I really wasn't involved in that.

**SS: So do you think, looking back, that there was anything that T&D could have done differently that would have been positive in that circumstance?**

CF: Well, I remember when the whole issue came up, the Women's Committee put forward a proposal to essentially what we viewed as shutting T&D down for six months and not having any meetings with anybody, government officials, drug company reps. I remember the discussion was up on the floor, and it was the kind of thing where in ACT UP we had Robert's Rules of Order. You had to vote to end discussion, then vote on it. We never could vote to end discussion on this issue, it seemed, because the organization was really kind of torn apart.

It almost seemed like a divorce to me. T&D and Women's Committee were the parents, and the kids were everyone else in the organization. You were asking them for their allegiance in this horrible, wrenching thing. I think people recognized that that it was really causing a big rift in the organization.

At one point, I think they asked, "Why don't you guys get together and try to work it out?" So I remember a meeting was put together at the Center on a Saturday. Not many people came; it was a handful. The only thing I remember about that meeting was Bob Rafsky, who was very articulate, very smart guy, with a deep, sonorous voice, making the case, "I don't want to wait to level the whole playing field before I get access to drugs." He was very honest with them. And some of the women on the other side, "Well, we just feel you have to." And to me, that was such an impasse.

**SS: What do you mean, level the whole playing field?**

CF: In other words, I think, "You're a gay white man. You're a man of privilege." And he acknowledged that. He goes, "I don't have to worry about housing. I'm not a substance abuse user," all the other things that people may have other concerns about before they can even deal with their HIV infection. He goes, "But I'm still here

and I want to live.” I think he viewed it as, “You want to stop everything for six months.”

I made a point at the meeting, I thought it was kind of a cruel irony that we were going to stop for six months, because six months seemed to be the average time when someone got their first infection till the time they were dead. So it really was a lifetime for a lot of people in the room.

**SS: Why do you think they made that proposal, Maxine and Tracy?**

CF: I ask myself that, and they had to know it was going to be very divisive. I don't think that was necessarily their goal, to get rid of us. I don't think a lot of the women really wanted that proposal, frankly, from subsequent conversations I had. I think that when you have someone who's ideologically pure and wants to enforce that and they have a strong personality, they're going to control a lot of people. I think they felt that that was the best way to go, that we were going to get more by being on the outside and not meeting with these people inside, that the danger was we were going to get co-opted and sell all the people out who weren't us. And that wasn't the case.

That was a discussion we've always had inside T&D. Are we getting too close? That always came up, and we challenged each other in the group. Remember at some of the meetings people talked about that, “Do you feel you're getting too close?” It was something you always had to check. Yeah, there's always the danger of that. It's inescapable.

**SS: Now we have a global access crisis, so there's somewhere along the line from that day at the Center when ACT UP started to where we are now where access fell out as a priority.**

CF: Right.

**SS: Where do you think that happened?**

CF: Well, I don't think it ever really became that big a priority for the organization. I think that the organization, when we talked about it, there was an Insurance Committee, whatever, it broke up in different factions. I think it was just recognized as too big of a thing for just ACT UP to just handle.

**SS: But still at the level of the FDA action, with compassionate use and all of that, it was still integrated.**

CF: Right.

**SS: But after the NIH, access really ceased to be integrated into the priority. Would you think that that's accurate?**

CF: I don't think that's accurate, no.

**SS: Okay. What do you see?**

CF: I see, look, if you're getting a drug approved, the first people who are going to cover it are going to Medicare and Medicaid, and then the private insurance is going to follow after that. So for just not even global, just talking about the United States, you're going to get a lot of people who are going to have access to drugs through those programs. Then, also, the ADAP Program as well, which began here in New York, and that's a fantastic program, and that's spread to other states as well. So I always think that that was part of a issue. That was always talked about and considered, that there would be access to these drugs once they got through the approval process.

**SS: So where along the line did everything fall so out of joint that now we have treatments that people around the world can't access and it's not built in? How did that happen?**

CF: I don't know. I can't give you an answer for that. I don't know how that happened. I think once T&D left ACT UP, it did suck a lot of energy out of the organization, and I think that organization, even if that didn't happen, at some point direct action group how long is going to hold together and not be a victim of its own success too. A lot of people probably felt, "All right, we've got the drugs in the pipeline. We're getting things."

Right now we have a situation in the United States where gay men feel they have a lot of access to drugs, a lot of them feel that's a chronic manageable disease. I think that's why we're seeing safe sex go right out the window now for a lot of the younger generations as well. They don't view it as a threat that we viewed it before. So I just think a lot of the air went out of the movement because a lot of the initial things we were clambering for we attained.

**SS: I just want to say one more thing on this, and then we can move on. But, honestly, having now talked to over a hundred people about this, I'm not sure it was ideological. I think it was more characterological, like there were a couple of really intense personalities who had particular character things. When you said "the parental structure," that appeals to me as a way of looking at it. But I'm not so sure it was ideology.**

CF: Well, it seemed that way to me. It did at the time, and I'm certainly open to that interpretation as well. Again, because I had to think they had to know this

was going to be very, very divisive, and they were willing to push it to the mat like that over this issue. If you really, strongly believe in some ideology, yeah, you're talking maybe if you put Tracy Morgan and Mark Harrington in a room together, it's like matter and antimatter. If that's what you're referring to, yeah, I would agree with that too.

**SS: So then you guys separated.**

CF: Yes.

**SS: You left ACT UP. What did that mean? You never went to ACT UP meetings again?**

CF: No, I think a lot of us went to both. I didn't. I felt like I just wanted a clean break. Those were just sort of prolonging their agony, and they all eventually left ACT UP. It really was for me a clean break at the very beginning. I think for Peter maybe not so much, because he had three things going on. He had Treatment Action Guerillas. He had a couple things going on at the same time. But I think Mark would still go back. But eventually, I think within six months, probably, no one was really going back to the ACT UP meetings.

**SS: So once you were no longer part of ACT UP, you no longer had a mass civil disobedience component, you could only do small-scale civil disobedience.**

CF: Yes.

**SS: So then how did you guys proceed from there?**

CF: Well, I think there was definitely a strong impulse in the beginning to prove that we had some activist bona fides. I think Peter, he had a demonstration he put together, of putting a condom over Jesse Helms' house, and I think we went after Roche again at that point. I can't remember some of the direct actions we did, but you can see

where we were trending. It was trending away from more direct action and more to being on the inside and trying to make those decisions and issuing our reports and studying. And that's really, I think, when you look at, to me, one of the greatest successes of TAG was the NIH report that Mark and Gregg had written, because that got turned into legislation in the early part of the Clinton administration when gays in the military was going down in flames. I think you can really point to what that legislation did to the NIH, to strengthen the Office of AIDS Research, and really looking at where AIDS dollars are being spent, that that saved lives.

That was the whole point of ACT UP for me. Obviously, the story I told you of me getting there was I don't want any of my friends to die. I don't want to see any more people die. That was the whole point. So that's what appealed to me about it, and that was, I think, the greatest success of TAG. You just can't say TAG. We all came from ACT UP, and the direct action that that led to the writing of that report was also part of that too.

**SS: You just brought up about the crisis of prevention. Is there any kind of prevention that works in this scenario?**

CF: I think when you go back to early '83, maybe '84, when it was really information getting out there, this is sexually transmitted, fear was probably the only thing that worked. People were terrified, and so they were very open and amenable to safe-sex education. I mean, there were plenty of walking sticks walking around Chelsea. In the Village, you saw sick guys all the time. When that started to change, especially with the advent of protease drugs, you don't see safe-sex education out there anymore. You go to a bar, there's nothing. You used to be bombarded with it. You see nothing out

there anymore. Just talking to patients of mine, young ones and friends of mine who are dating out there, he says, “You know, I go out and no one’s having safe sex.” I’d say maybe 10 percent of the partners they meet even discuss using a condom. They just go right into it without using a condom.

**SS: What do you feel about that?**

CF: It’s sad in a way. I understand it. Condoms suck and who wants to use them? These younger guys, they didn’t experience what older generations did, so it seems natural that they’re going to want to have sex without any kind of barrier. But it’s also sad. I think they’re trying to serosort in some way. That was never thought to be politically correct back in the ACT UP days, but I think a lot of positive guys are serosorting because they don’t want – “If I’m positive, I want to just have sex with positive guys. I don’t want to have sex with a condom.” I understand that. That makes perfect sense to me.

But I think the danger is, a lot of these guys, if they’re newly infected, they don’t know they’re infected, they’re shedding gobs of virus, and they’re very, very contagious at that point. I don’t know if we’re going to eventually see an increase in numbers. Certainly just from the practice here, I see the medical practice, there’s a few guys that come in that seroconvert, but I really don’t have any hard numbers on that. It would be interesting to see it.

**SS: Do you think it’s worth it?**

CF: Safe sex?

**SS: To give up safe sex and be infected in this environment?**



CF: No. I think one of the studies that we're doing at ACRIA, looking at AIDS in an older adult population, and I think the second-highest infection rate in the city for men is over age fifty-five. So I think they're doing the math. "Well, if I get infected, maybe it will be seven, eight, ten years before I have to go on meds. Now I'm sixty-five, and then if the meds have their effects." They're really not worrying about it. But what they don't understand is that HIV in older population is very different than someone who's twenty-two or twenty-three.

**SS: So how many AIDS organizations are you involved with now?**

CF: Oh, my god. Just ACRIA right now. *{LAUGHS}*

**SS: That's it?**

CF: Yes.

**SS: And your practice.**

CF: And my practice, yes. I'm a chiropractor, I have a part-time practice here in a medical office, and he's a great HIV physician. He's fantastic.

**SS: Is there anything important that you think that we've missed?**

CF: No. Going back to ACT UP, it really was a very special time in my life. I really feel that the organization accomplished a lot. I don't think we'd be where we are talking about gay marriage or any of that if it wasn't for the AIDS crisis, and it's a terrible price to pay, that we paid to get this far.

**SS: What's the relationship? How do you think the AIDS crisis led to gay marriage today?**

CF: I think it seared gay men and women into American consciousness. We exist. We're no more different than you. We became so much more visible. It

became that much easier, I think, for people to start accepting the civil rights that we're clambering for. You look at all these younger generations, like I look at my nieces and nephews, they're in college or just out of college, they all have gay friends. It's like no one cares. It's no big deal. It's very refreshing.

**SS: Then why are we losing all the ballot measures?**

CF: Oh, I think, just naturally it's the give-and-take of politics, and the Democrats are notoriously spineless. You'd think we have both houses in New York State, and we can't pass a gay marriage law. It's just ridiculous. I just think we should completely boycott the Democratic Party at this point. No votes, no money, no volunteers until they make do on their promises. What's the point if we spent all this money and time and energy putting them in office and then stab us in the back?

**SS: That's the clip that's going to go in the movie, Charlie.**

*{LAUGHTER}* **I want to ask you two more things, and then we're done.**

CF: Sure.

**SS: What do you think is the emotional price that our generation paid for having gone through that entire nightmare?**

CF: Well, I think it's emotional. It's the great sense of loss, all those people. I have a list of all the people who have died, and I haven't added to it in a long time, which is great. But I recently moved and I was packing and I saw it. My legs went to rubber. I still haven't processed it. I don't know if I ever will. I still have nightmares, the AIDS nightmares. It's just something that's always going to be with us in our generation, and we're never going to get over it. I've just accepted I'm never going to

get over it. I'm never going to totally process it or deal with it either. It's going to come in fits and starts.

**SS: My last question is—this is what I ask everybody—what do you think was ACT UP's greatest achievement and what was its biggest disappointment?**

CF: I think saving lives. Everything that we did, whether it's getting drugs into bodies or getting people shelter, whatever it was, safe sex to younger people, we saved lives. To me, that was the ultimate goal of the organization, and I think we did it. We seared AIDS into American's consciousness too. We really brought it into focus.

I think its greatest disappointment was that it couldn't go on forever and be totally harmonious when it was functioning like that and when we were truly a coalition. Because I remember my first meeting, Maxine Wolfe and Peter Staley were standing in front of the room, and I'm like, "This is truly a coalition if these two people can be in the same room at once." Peter was still on Wall Street at that time, wearing a suit without his tie. And maybe that's the gist of any activist organization. It just never really can last. Eventually it's going to fly apart. But I just like that those first three years, four years, that intense camaraderie, we really can depend on people, that was pretty awesome, because even the people I disagreed with vehemently over the split between T&D and the Women's Committee, I look at Tracy and Heidi, I did a couple of zaps with them. We needed to depend on each other. They were there and I was there for them, and it was great. And just to see that kind of dissolve like that was a little upsetting.

**SS: Thank you.**

