

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

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

Interviewee: **Garry Kleinman**

Interview Number: **165**

Interviewer: **Sarah Schulman**

Date of Interview: **March 3, 2014**

ACT UP Oral History Project
Interview of Garry Kleinman
March 3, 2014

SARAH SCHULMAN: So you just look at me. So you start by telling us your name, your age, today's date, and where we are.

GARRY KLEINMAN: Okay. My name is Garry Kleinman, and I'm sixty years old, and the date is March 3rd, 2014, and you're in mine and my husband's apartment.

SS: And you just got married. Mazel tov.

GK: And we just got married.

SS: Right. Very nice. So where were you born, Garry?

GK: I was born in Passaic, New Jersey.

SS: And where were your parents from?

GK: My mother, I don't know that she was born in Passaic, but she grew up in Passaic. And my father, he died a long time ago. My father died when I was eight years old, but I always just think of them from Passaic.

SS: Did they meet in high school or something like that?

GK: I don't know. If I knew the whole story, I probably forgot it, unfortunately, but I don't really know the whole story.

SS: In the fifties, was Passaic still like a town or was it really a suburb?

GK: Well, it's a town. I mean, it's still a town. I have a friend that — one of my best friends actually still lives there right across the street from my high school. It was a good place to grow up. I was sort of in the Passaic Park area. There's Passaic Park and then there's downtown, the other side of the tracks, and definitely was almost like in

some ways, like, segregated, you know, but then in school everybody came together.

SS: Segregated like white and black or Jewish and black?

GK: Yeah, kind of, yeah. Yeah, when I was there, yeah, yeah. I mean, they were very — like in the area where I lived, it was predominantly white, and then you sort of walked as you got to downtown, and then across the tracks it all of a sudden became people of color and, you know, whatever, Puerto Rican and —

SS: Was it Jewish or white?

GK: There was always a large Jewish population, and now I think there's actually a large Hassidic population, I think. Now it's actually the whole — like, in fact Passaic Park is very, very Hassidic, I've heard. And when I've been there, I've seen — you can tell, they're walking down the street with the long *payess* and stuff.

SS: Because I always thought of, like, Passaic or — where is Allen Ginsberg from again?

GK: He's from Passaic. I went to high school with him. The last time I saw him was in — Allen Ginsberg, the poet, you're talking about.

SS: Yeah.

GK: No, there's actually another Allen Ginsberg who is from Passaic who won an Emmy Award for writing something. That's the one I'm thinking of when I think of Allen Ginsberg.

SS: No, he's from Paterson.

GK: Yeah.

SS: Then there's like Elizabeth, Passaic, Paterson, Newark, was this whole kind of like working-class, middle-class Jewish population after World War II.

GK: Then there was one section that was a little wealthier than the rest, and they called it Pill Hill, which was where all the doctors lived.

SS: So would you say that it was liberal? You were growing up during the sixties and Civil Rights Movement, war in Vietnam. I mean, how were those issues dealt with in your town?

GK: Well, I was from a hippie kind of — I was getting high and smoking pot and doing everything by the time I was, like, fourteen or fifteen, and I was not political at all. I just basically just went through school smashed, high all the time, and barely graduated high school, and I really didn't get political until, probably until the whole AIDS thing started. In fact, I don't think I voted until I was in my thirties.

SS: So were you gay in high school?

00:05:00

GK: Everybody, yeah, I guess I was gay, but I wasn't sexual. Let's put it that way. I mean, like in junior high school I probably had a couple of girlfriends. I remember having a girlfriend and she always used to say I was gay. But I wasn't having sex. I wasn't a sexual kid at all. It was more drugs I was doing.

SS: Do you think there was a connection?

GK: No, not really. No. I never really — I was sort of medicated when I was a child. I mean, it was almost there was no other — I started doing recreational drugs when I was in junior high school and high school, but even as a child, I had some

stomach problems and was misdiagnosed and was on just lots of like tranquilizer-type stuff as a kid, and it affected my whole life. Actually, by 1980 I put myself into the hospital to get off of, like, like a lot of the like benzodiazepines and things like that, that I was being prescribed on a regular basis by people who didn't know what they were doing. Then I came out of that whole thing very depressed and then went on antidepressants, which I'm still on antidepressants.

SS: Okay, so you know the medical world.

GK: Yeah, yeah.

SS: Pharma is familiar to you.

GK: Yeah, yeah.

SS: So, after high school, did you leave Passaic or did you stay there?

GK: After high school, I got in a van with about four other people and drove to California, planning on staying there, and we went to Berkeley. I was, I guess, eighteen. Went to Berkeley, stayed for about a month, ran out of money, and had to call my mom to send me plane fare home. That was the first time I was on a plane.

And I think I just started — I went to junior college for a while, but I really couldn't handle that. A lot of it had to do — some of it had to do with my stuttering. I was much more of a severe stutterer then, so my participation, it was just very nerve-wracking for me to have to get up and talk and do things like that. In college you're really required to do some of that stuff, and it just was — you know, I couldn't do it.

And then so the following year, we packed up in a van again, drove across Canada for three weeks, thinking I was going to stay in California again, and pretty much the same thing happened, ran out of money and had to come home.

And then when I got back from there, I was always pretty — you know, I came from, like, the hippie days where you all were artists, so I actually had a portfolio and I applied to — I got into School of Visual Arts, and I went to School of Visual Arts for two years. It was before they were even an accredited school. There was no degree. It was just a certificate program. So the first year was okay. I was in, like, the fine arts program, and then the second year I had to go and pick a major, which was media, which I hated, and that kind of fell apart.

Then some factory jobs, and then my friend Judy, both of us, we were — she was someone that lived right up the block from me, was a few years older, and she was a hippie too. She decided she wanted to be a hairdresser, and she asked me if I wanted to go to hairdressing school with her, and I was like, “Yeah, okay.” And we went, and I’ve been a hairdresser since 1974.

SS: Wow. So you started out with the shag.

GK: Yeah, and, like, a mullet.

SS: Wow. So did you ever get into the gay life in New York?

GK: When I was living in new Jersey, pretty much we actually had — in the seventies we had a few really cool gay bars, and we had a gigantic gay disco called Charlie’s. There was no affiliation with the Charlie’s here, but it was Charlie’s West there, but it really wasn’t any affiliation. It was such a big club that people from the city

actually used to come and go there. That was open for several years so I really didn't have to go far. I always liked to dance, and I could actually — it was like five minutes from where I was living at that point.

Every once in a while, we might try to go into the city, but I'd be so high that by the time — I remember driving into New York and by the time I got there, just sleeping in my car under the West Side Highway because I couldn't even get out of the car. I mean, I'd be driving like that also. So I really didn't hang out in New York until after I got out of the hospital to get off of a lot of drugs. Then I started driving into New York and going to the Saint and places like that and discovering those kinds of places. Then I was discovering the bath houses and things like that and Fire Island. So it was after 1980 I actually started to —

00:10:00

SS: So for the people who are very young, can you describe the Saint?

GK: Well, I'm old enough to remember when the Saint was the Fillmore East. So I used to go there all the time as a kid. My friends used to — you know, we were, like, obsessed with Laura Nyro, who was, like, our favorite. So we used to go to — and the first time I saw her was in Fairleigh Dickinson. I was about fifteen or sixteen, and, I mean, we actually were so obsessed that we found out where she lived.

SS: Where did she live?

GK: It was uptown somewhere. I don't know. But somehow we knew someone who knew where she lived, and I remember we were, like, literally tripping on acid, and we, like, we went to her apartment and rang the bell. I think she came to the intercom, and, I don't know, we probably ran away. But, yeah, we followed her. I mean,

we went to Boston to see her. Anywhere we could get to, we would go to see her. We were, like, literally obsessed, like groupies for Laura Nyro.

SS: Well, she deserves it, absolutely.

GK: Yeah, yeah, yeah.

SS: So you already used to go to the Fillmore East and then you went to the Saint.

GK: Went to the Fillmore East, yeah, yeah We went there a lot, actually.

SS: So can you describe the Saint a little bit for younger people?

GK: It was very minimal, really. The downstairs was just an open space with places, like sort of bleacher-type sitting. Everything was gray carpet, as I recall. And you could get wine or beer, and you could smoke pot, so that was, like, great. I mean, I didn't stop doing drugs after 1980. I just changed the drugs I did.

I used to go on Sundays, and since I'm a hairdresser, like, Sunday nights were my favorite night to go out because I didn't have to work on Monday, and I would pretty much go by myself almost every place I used to go, because there just wasn't anybody else that could have — I was never really friendly with hairdressers, so I used to really go by myself a lot. On Sundays I pretty much liked to be almost, like, the first one there and just hang out, because there was this incredible dome that was almost like a planetarium-looking kind of thing, and these lights came up out of the floor and the dome came down from the ceiling and it was just —

SS: And people used to have sex up on the top, right?

GK: Yeah. I never did. I wasn't like — I mean, I really was into — I deejayed for a while, I mean. Even in ACT UP, I used to deejay for a couple benefits and things like that, and I still actually do mixes for, like, Sound Cloud and have a small little following worldwide. For me it was always about the music. It still would be if I were — I mean, I just love introducing, like, tons of new music, which I probably would be retired and have a condo if I didn't spend all my money on vinyl.

SS: Bruce Mailman, who owned the Saint, also owned the baths, the St. Mark's Baths.

GK: Yeah, I didn't even know that. St. Mark's Baths I was only at maybe once or twice. I liked the Club Baths. The Club, those were my favorite.

SS: And were was that?

GK: That was on —

JAMES WENTZY: Second and Second.

GK: Yeah.

JIM HUBBARD: No, First and First.

SS: Lucky Cheng's.

GK: Lucky Cheng's, yeah. Yeah, Lucky Cheng's. That was like a great — I loved the club baths.

SS: What was great about it?

GK: Well, it was big. There was like lots of — I remember the first time I ever went was on Thanksgiving, like, I was by myself on Thanksgiving, and I decided that was there, I decided I was going to go to the baths, and they actually had a pool table

there, where they actually had a spread of, like, turkey and everything. I think I was there for like ten hours or whatever. But it was cozy, you know.

And like the times I used to go, it really wasn't crazy crowded. I was never someone that liked to go in, like, big crowds. I mean, I wouldn't go in a room where there was a million people. I always, like, would usually just meet somebody and hang out and whatever, you know.

SS: What was the difference in the scene between the Club Baths and St. Mark's Baths?

GK: St. Mark's Bath, I don't know, it actually was small. I felt kind of confined in there. The Club Baths, they just had a great downstairs. I mean, they had a beautiful hot tub and steam room, and it was a whole floor of that. It was more walking around, and it was a little bit more like a maze than the St. Mark's Baths. If I saw the whole thing, it seemed very small to me.

SS: So when did you first hear about AIDS?

00:15:00

GK: Well, I was renting on Fire Island in 1984, but I'd been to Fire Island a few times, and it was around that — 1984 just seems — I'm sure things were happening before that, but my awareness, at least right now I can think of, was around 1984 and just, hearing, I guess, hearing about it from people, hearing rumors and things like that, and no one knew how it was being passed along. I don't know. It just crept up, you know. I don't remember, like, thinking and being nervous a whole lot before maybe around 1986, '87, but you just heard stories.

And while I was renting, I was renting with two guys that weren't close friends, but we became close from having lived in the same building before, and they both have died. In fact, the woman — Janet, her name was — she's dead as well. I'm the only one that's alive from those days, from the people I rented with on Fire Island.

You know, just people started getting nervous about even sweat. I remember being in the Saint and dancing and all this, and all of a sudden getting this nervous feeling, like, "Oh, my god." Just nobody knew anything. That was probably around the first time, in that era, that time period, I think I started becoming aware of it, but I didn't really realize what was going on so much until pretty much '86, I'd say. I mean, I didn't know anybody who was sick at that point.

SS: When you were in Fire Island, did you see people who looked sick?

GK: You know, I don't recall seeing that.

SS: So how did it first reach your life? Was there someone you knew?

GK: I never, at that point, I didn't really know anybody. In a lot of ways, I was a loner because of what I did for a living. I used to do a lot of things by myself. And my close friends from high school were my friend Peter, who I'm still very close with. We weren't really sexual. I mean, it's not like I wasn't having a lot of sex, but it wasn't my predominant thing in my life.

SS: Because it's interesting, because a lot of people have had the same story that you have, like AIDS is happening, but it's like kind of out there. But

you're right in the epicenter. You're at the Saint, you're at the baths, you're on Fire Island. This is like where —

GK: But I think because I wasn't in these cliques, you know. When you think of Fire Island, you think of people like in that movie *Longtime Companion* or whatever. That wasn't my experience at all. First of all, I was in Cherry Grove. I wasn't in The Pines. The Pines probably, I think, had a much bigger awareness of it because so many people were living so close together, I think.

I mean, my friend Tony was renting on Fire Island. I think twenty people were renting that house. Our house was like four people, and it was a different experience. I didn't have that. I didn't really like The Pines experience. I was, like, definitely Cherry Grove. I liked the drag queens. It was a different kind of scene in Cherry Grove. So I think I was hearing about it more about people in The Pines, things happening, but not so much in Cherry Grove it wasn't — I think I just was a little more insulated.

SS: So when you decided to join ACT UP, was that unrelated to personal experiences?

GK: Yeah, pretty much. I went to the march in Washington with my friend John that I had rented with on Fire Island, and I think that's probably where I heard about ACT UP, and I went to my — it was like joining the army. I mean, at that point, for whatever reason, I knew that something horrible was happening. Was Reagan president then, I guess? Yeah. I mean, I knew I hated him, and I knew the things that were being said. I was starting to become politically aware at that point.

SS: So what do you think it was that got you to go to that first meeting?

00:20:00 GK: I could see things were horrible and things were — I was just getting angry. I was just getting mad at some of the things that were being said. When I joined ACT UP, I just went by myself and not even realizing or thinking that many people, if not the majority of at least men in ACT UP were HIV-positive or had AIDS. So that part of it didn't hit me, that I was going to become close to a lot of people that may not be here soon, and I didn't know if I was or not. After going to meetings, I kind of assumed I was at that point, just because I had been to the baths, and definitely I probably didn't participate in as much unprotected sex as many other people, but I definitely did. So I was aware of that assumption we're all HIV-positive.

I guess I think very much from the beginning when I joined, I met David Kirschenbaum, and I knew I wanted to get involved in some of the little bit more — like the issues surrounding treatment and things like that. So I immediately kind of fell into that small group of people, like Iris Long and Jim Eigo and, those — that group.

SS: What year did you come into ACT UP?

GK: Eighty-seven. It was like just a few years —

SS: So was Vito still alive?

GK: Yes, definitely.

SS: Vito and Marty —

JH: Robinson.

SS: Marty Robinson.

GK: Yes, everybody was there, yeah. I mean, pretty much everybody was there. Michael Callen. Everyone.

SS: So you came in very early.

GK: Yeah yeah.

SS: That's interesting. So you can explain to us what initially the ideas were about treatment in ACT UP? Like what was the first kind of ideology?

GK: It's going to be hard for me to get really technical and in detail, because my memory is really sketchy about things. So all I remember is AZT coming out and ddC and those drugs, and how expensive things were and how, like, some people were able to get treatment. Other people weren't. I was at some of the meetings even at the NIH and CDC and FDA, but I have such a hard time remembering exactly what went on.

SS: Why don't we go through all your files here.

GK: They're not exactly in order. I just sort of pulled out —

SS: That's okay.

GK: Everything I have there, I myself got involved in city issues because nobody was doing that. I got involved in some really kind of what most people would consider really boring stuff, and in some ways I didn't have a lot of support on that except for maybe David and Jim, because people really were focusing on the whole national level, like Peter Staley and everybody, and nobody was looking at the Division of AIDS Services in New York City and people's access to Medicaid and how difficult the system was to get through, especially if you were sick. That's sort of what, when I'm

looking back at everything and some of the letters that I wrote and some of the things, it's like I don't even remember doing it. I don't even know how I did it then because I didn't really have any education or anything when it comes to all that stuff.

I didn't have a computer. Anthony — Tony Malliaris gave me his old computer, which I just used as a word processor, and that got me able to, like, at least write and print some things. But I became pretty much I was the committee for city services.

SS: Let's definitely go into that. Let's just do the background. I mean, it's hard sometimes for people to understand how much New York City government opposed us —

GK: Yeah, oh yeah.

SS: Because when you look at San Francisco, they had the cooperation of the city government. But it's stunning to think about how much we had to fight our own government here. So what was the center of the problem?

00:25:00 GK: Well, when I look through my files, the thing that I always seemed to be dealing with, and I'm looking, like, it goes back to, like, 1989 all the way to, like, 1991, that they were actually denying food. There were these budget cuts under Dinkins and Cuomo, and Peter Vallone, I think, was the head of City Council in those days, and they actually came up with a flawed formula of people being — there was a formula for people that they had to meet, like, a prerequisite to get food stamps, Medicaid, nutritional supplements, things like that. And I don't know if intentionally or whatever, they came up with this flawed design where people were losing access to — people who were dying

were losing access to nutritional supplements. Then they came up with this thing saying that Carnation Instant Breakfast is as nutritionally — you know, without any basis in fact at all.

Those are the kind of things that I was getting into finding out about, and sort of with — even though I didn't get a lot of other people interested in it, the fact that we were doing all those larger demonstrations, it always seemed like people always seemed nervous that if I wanted to, I could call, like, four hundred people at any given moment, which probably wasn't the case. Maybe I could get like ten. But they didn't know that. So they saw the St. Patrick's Day demonstration, all those things, and I always was able to get a meeting with somebody. I mean, I was always getting people to write back to me and put themselves on record saying this or saying that.

So that's where the greater group came in for me, was able to just kind of like it was that threat was there. So for a couple of years, I was able to really deal with stuff, and I actually had a caseload of people myself, like people that my number was out there and they would call me, and I would go to arbitration with them at the Medicaid offices, I believe. Somehow I understood all the lingo. Now I couldn't. I don't think I could get myself through anything that complicated, but somehow I was able to get people through the system and help. And some of them were not gay. I even had a few people who were Hassidic Jews who had AIDS and families, like five, six, seven kids, and were not able to get services. So I would talk to people on the phone. They'd call me and I'd meet them downtown. I only worked three days a week at that time, which I still only work three days. So I had a lot of free time to do all that stuff.

It got to the point where I was having so many caseloads that actually at GMAC they wanted to hire me as the ombudsman, the head ombudsman there. I thought about it, but I declined. I could not have handled it. I mean, it wasn't something I could do. So, really, for most of the time I was in ACT UP, that was the stuff that I personally got involved in.

SS: Let's go through your pile and just see what you've got there.

Just pick anything and tell us what it is.

GK: This was like — we actually got this headline into the *Daily News*.

SS: Can you hold that up for the camera?

GK: “A Paper Chase for the Dying.” It says it was so difficult to get through. I mean, you had people who were so sick and couldn't — and very often they would get a termination of services somehow. I don't know if it's true, but we had heard from somebody, I don't remember who it was, that was in the state level that said that arbitrarily they would — it's hard for you to believe, but I really believe it's true, that arbitrarily they would just send out cancellation notices of services because they knew a certain amount of people would not be able to make it back into the system because it required them to go stand on lines, and at that time, not everybody had someone that could do that for them. In fact, most people didn't. And the city was so strapped for cash, and the state, that they would do that, and so people would actually just not be able — I'm sure people just died in their homes and people not even knowing. So, I mean, it was horrendous to hear that and see that.

Let's see, this was the — I just have articles on the human resources chief. There was some kind of scandal going on in the City Council, and I don't remember. I mean, I'd have to read every —

SS: Who was the head of HRA at the time?

GK: Barbara Sabol, she was the chief. I had face-to-face meetings with her that, to be honest, I can't even remember. I just can't.

JH: Can you hold it up for the camera? What's the date on that?

00:30:00 GK: The date on this was November 18th, 1990. It was in *Newsday* magazine.

SS: Was it Laurie Garrett? Who wrote it? Clara Hemphill.

GK: Hemphill, yeah.

SS: Because I remember Laurie Garrett was the *Newsday* person.

GK: *Newsday* was like a more supportive kind of newspaper out of any of the newspapers that were going on. We just had some kind of relationship with them.

This is an example. This was a handwritten letter from somebody that — I was getting stories from people, and somebody who was asking me to help them get through the system, and this is somebody's whose services were cut. His food stamps went from —

SS: Do you want to read it to us? What's the date?

GK: There isn't even a date on this. It was just a handwritten letter. "As per our phone conversation, here are copies of my budget, as you requested. Included is my first budget, which was \$678 bimonthly and \$265 in food stamps monthly for a

family of five, with a \$700 amount rent. I applied for SSI as I was instructed, and when the DAS, Department of AIDS Services, found I was getting my SSI benefits, they adjusted my budget.

“The other copy is my new budget. I receive \$409 monthly for SSI. The Department of AIDS Services has adjusted my cash allotment by \$204.50 every check to compensate for the \$409. I have no problem with that. I expected it. But what they did was cut my food stamp allotment from \$265 to \$89, saying SSI is income and that changes the formula,” which they were including their benefits as income, as if they worked for it, as if it was work and they were required to pay taxes or something.

“I did not ask to apply for SSI. I was told I had to. I am getting the same cash allowance as before. My budget and living allowances are the same, but they are taking \$180 a month in food stamps away only because I followed their instructions. And this is not an isolated case. I’ve spoken to several people this has happened to, who did not fight it and just accepted it. I will not accept this. The DAS is the only department in the welfare system that allows people to collect SSI benefits along with income maintenance. As a matter of fact, it insists we do. However, they aren’t doing us any favors, as the cash grant is adjusted and food stamps are then taken away. It is impossible for me to feed a family of five on \$89 a month.

“I’ve already spoken to an attorney at Legal Action Services, also to the Human Rights Commission on AIDS Discrimination. We may be filing a complaint. In GMHC’s ombudsman’s office, I have also requested a fair hearing and will be notified by mail of my hearing date. Any help your organization can give me will be greatly

appreciated. We must correct this flaw in the system so myself and others are not discriminated against. I've also enclosed a computer printout of the budget breakdown and phone numbers of the various people I have contacted.

“I will call you by Friday with any information. I appreciate your time and consideration in this matter. Thank you. Martin Negin. My caseworker is —,” and gave me the phone numbers of the caseworker and various agencies.

SS: Do you remember this person?

GK: No.

SS: It's amazing because you're an activist, right? Everyone else's person is dealing with this on a salary. You're a hairdresser in ACT UP who's working as trying to help somebody through all these salaried people.

00:35:00 GK: Right, and I do remember going to these hearings and speaking, and I do believe that some of the people we were able to help, but this guy was pretty eloquent, really, and did some, had all the phone numbers. I mean, he was able — but for everyone that was able to do that, just think about how many, you know, would not be able to write a letter like that to even get the help or ask for help because they're so sick or — you know. So he's just, like, he was lucky in some ways because he still was well enough to do that much, like, prep work for me.

SS: And you had a face-to-face with Hassidic Jews who were —

GK: Oh, yeah. Yeah.

SS: So what was that like? What were these guys like?

GK: Really, like, scared. First of all, a few of them — I mean, there weren't a lot, as I recall, that I had, but I can recall at least one person that comes to mind, and it could have been him, I don't remember. But I don't even know that the family — that everybody — they knew he had AIDS. He had to really hide that because in that community, it's probably one of the most, like, conservative. It's hard enough maybe being gay, but can you imagine having AIDS and then having a family? Because there were a lot of, I think, closeted Hassidic Jews and they all had families, but obviously —

SS: It's amazing that this guy found you.

GK: Yeah. I don't even know—I mean, my name was out there. Some of the social services were so overtaxed that my name would come up, and also Liz Krueger at the time, Liz Krueger, I think she's a state senator now, but she ran the Community Food Resources Center in New York, and I met with her.

There's a letter somewhere in there from her, as I was looking through. We were in communication. Her organization dealt with issues around nutrition and hunger in the city. So I think they might have gone there because they didn't have food stamps and needed some resource to find a way to get food. So I had been in contact with her and told her I was helping people. I think it's possible that's how they found me was through her, because we had somewhat of a relationship, me and Liz Kruger at the time.

SS: Did you have an actual committee in ACT UP, or were you just doing stuff as an independent?

GK: It was a small committee. It was just —

SS: What was it called?

GK: I'm terrible. I can't even remember.

SS: You're not City Action?

GK: Yeah, something like that.

JW: City AIDS Action? Do you have a contact sheet?

GK: I have—it was handwritten. No, this is for the Albany Action.

SS: Who else was on it with you?

GK: Actually, it was just a few people from the Treatment and Action because that's what I was originally —

SS: So it could be called Treatment and Action.

GK: Well, that was TAG. That turned into Treatment Action Group.

SS: Well, later the Treatment Committee became known as Treatment and Data. But when you first came in, when it was Vito and Marty and Iris and all those people, I think it was called something else. It was called Treatment.

GK: Treatment and Data, that was the original, yeah. So like Jim Eigo, I always got support from Jim. David Kirschenbaum and David Falcone — I'm still friendly with David Falcone, who was involved and he did more action work, but he was always there if you needed someone to demonstrate. Debbie Gavito, I think was probably. Sally — Sally. I can't remember her last name.

SS: I know who you mean. She was Rebecca's girlfriend.

GK: Yeah, yeah.

SS: What was her last name? Brown? No.

GK: No. Not Quinn. Sally — no.

JW: Sally Greenberg, maybe?

GK: No.

SS: No.

GK: I'd know if I heard it, yeah. And it was just a few people from the original Treatment group would help support me. But when I would go to meetings, 90 percent of the time I'd be by myself.

We had a demonstration over the nutritional supplements. I was able to get about twenty-five people at the demonstration. But like I said, there was always that threat that I could get — like, I didn't really get a whole lot of support, because they didn't see that — they used to talk about certain issues being sexy. It was not. Like it was not a sexy issue, so it just didn't — we did get some media, which was great. We were able to get some — like we got that one headline, *Paper Chase*. That was like —

SS: Do you remember how you got it?

GK: I don't. I don't.

00:40:00

SS: Okay. Let's keep going through the papers.

GK: Actually, there was a New Jersey ACT UP as well before I — I mean, I was doing straddling in New Jersey and New York, and this is like New Jersey ACT UP. Here's a letter that I wrote to *Newsday* that actually got in.

SS: Read it to us. The date?

GK: This was December 4th, 1990. They named it “Food for Thought.” “Next Thanksgiving, the editorial ‘Got an Extra Plate’ might be more appropriately titled ‘Got an Extra 100,000 Plates.’ If the Dinkins administration has its way, by this time next year there will be vast increases in the number of people with nowhere to turn for food. Included in the mayor’s Contingency Reduction Plan for fiscal year 1991 is a decrease in funding by 50 percent of the Emergency Food Assistance Program, which serves 456 emergency food pantries and soup kitchens and the elimination of the Office of Food Programs and Policy Coordination.

“Included in the latter is the Hunts Point Produce Program, which distributes 2 million pounds of surplus produce per year. Hundreds of community organizations that provide food for the needy but do not rely directly upon the city for funding will also be adversely affected. The city plans to reduce funding for storage and transportation of food by cancelling the Food for Survival Food Bank contract. This nonprofit organization contracted by the Human Resources Administration stores and delivers more than 12 million pounds of food to hundreds of community groups, homeless shelters, and daycare centers.

“Among the 456 city-funded emergency meal programs in New York City, 19 specifically provide nourishing meals for people with AIDS. The Momentum Project sponsors 8 sites and serves more than 500 people with AIDS a week. These facilities are already stretching their resources to the limit and will be ill equipped to handle the increased caseload in the face of drastic city reductions.

“While Mayor Dinkins saves \$1.5 million by taking food from the hungry, Governor Cuomo will attempt to balance his budget by cutting Medicaid, thereby reducing healthcare services for the poor, many of whom rely on food pantries for their primary sources of nutrition. Both Mayor Dinkins, Governor Cuomo, and their respective budget offices realize that these reductions could cost many lives. Is there really a difference between the death of an individual caught in the crossfire of gang warfare or the death of that same individual through willful governmental neglect?” The writer was me, a member of ACT UP City and State Actions Committee.

SS: Great letter.

GK: And I don't remember writing it.

SS: You know what's so interesting? It's like when we look back, we always hate Koch.

GK: Yeah.

SS: This is Dinkins.

GK: Yeah, right, yeah, yeah.

SS: Yeah, and I think that's been blipped over a little bit, how much damage was done.

GK: Yeah, I think so too. Like I said, it amazes me when I read stuff like that that I wrote, because it's not — like I said, I didn't go to college. And I remember researching, but it's just so vague out there.

SS: So the committee was called City and State Actions.

GK: Yeah, ACT UP City and State Actions Committee.

SS: Was it a subgroup of the Actions Committee or was it its own thing?

GK: I don't know. I don't remember. Everything, as far as the research and all of that, I did it pretty much all, because I really didn't have — people just didn't really get into these issues. These things I think people thought were just being handled by GMHC and other nonprofits. And everybody's caseloads were so stretched to the limit that any help anybody could get was — and I guess I realized that at the time. And people within ACT UP, who many were clients of Departments of AIDS Services, so I was getting stories from them also. So, I mean, that's where people helped me a lot was in getting their stories, because they weren't able to make sense of it either. So I tried to start making sense of those systems, and whatever information I could get could help somebody else within the organization as well as other people that were just coming to me out of the blue. So, yeah.

00:45:00

Let's see. These were — I wrote for a newsletter for New Jersey, newsletter for — we had like about six or seven people in ACT UP New Jersey. But we actually did some good work. We were able to have meetings at the University Hospital there, and there were some different issues in Jersey. Like policy issues in the hospital had to do with more like discrimination in treatments, because at that time people were really scared they were going to touch somebody and have AIDS. So there was a lot of discrimination issues within New Jersey and the hospitals. So I'd use whatever stuff I'd learned in New York ACT UP and brought it back to New Jersey, so I was there — for a couple years I was doing that. Then I moved to New York and that was — you know.

Then also through one of my clients who I still see, her name is Mary O'Malley, she's, like, a wonderful person. I don't know if you remember the AIDS Treatment Registry which started the —

SS: Could you explain what that is for people?

GK: There was no coordinated, like, list or way to find out about clinical trials for new drugs in New York City or anywhere, really, I don't think and so a lot of these places, what we found out through Treatment and Data, we found out that there was no oversight of a lot of the grants that people were getting to do research, and they weren't given any budget to recruit people for trials. So there were so many drugs being tested with, like, hardly anybody on the clinical trials because they didn't know about them. There's no way to find out about them. Hence, like some of the grants, we got information about grants and where the money was going, and some of that money was going for, like, office furniture. I mean, it wasn't even going to — there was no oversight. It was like they'd get these grants and then that's it. They got hundreds of thousands of dollars, if not millions, and nobody was keeping track of where that money was going.

So, anyway, we had an idea to start this thing called AIDS Treatment Registry, which was going to be a comprehensive list of all clinical trials going on for any drug for AIDS and HIV in the city area, even in the tri-state area, and we needed start-up money. One of my customers at the time, and still, she was the vice president of the Prudential — the sort of altruistic branch of Prudential where they give out grants for various things, and she was able — we went and met, me and Jim and Iris, I think, met

with her at Prudential at her office, and she was able to get us \$10,000 to start AIDS Treatment Registry. I think Ken Fornataro was involved with that as well. Ad that really was the first time that anyone had ever done that, so we were able to — I don't remember how effective it was, but I think it actually turned into another organization, I think.

SS: How did you get the information?

GK: Well, David Kirschenbaum was, like, a genius, and Jim, and I think probably — and Iris. And we did have some kind of relationship with Anthony Fauci at the National Institutes of Health, so I don't think it was difficult for us to find the information where the clinical trials were. It was about getting people on to the clinic, I mean, and a lot of people didn't even have ways to get to the clinical trials. I probably wasn't involved in finding out what clinical trials were going on. I was more involved with getting people on to the clinical trials.

SS: I remember that initially it was, like, this huge, huge book. Right?

GK: Yeah, yeah.

SS: It was, like, mimeographed or something, and then you would send out, mail out supplements, right, or updates?

GK: I think so, yeah. I mean, I didn't really — I mean, I was not there on a daily basis, but I was, like, proud to have gotten — been able to assist in getting money to start the program. And Mary, also, in New Jersey, she was able to get us \$10,000 in New Jersey to set up New Jersey's version of the Community Research Initiative, where it was really, really vital in New Jersey, because people just didn't have access to
00:50:00 healthcare in general, because everybody who was on these clinical trials had to have a

baseline of healthcare. So it got basic healthcare, plus they would get on a clinical trial for new medications.

That organization still exists, and that actually is — I don't know what it's called now. The first two years of its existence, I was on the board of directors there and I would be able to sit in on the meetings. That was, actually I went to, just a few years ago, it was like an anniversary of that organization, and Mary took me as her date, and we got little plaques. It's a while ago. Maybe ten years ago. It seems like yesterday. But that was really, really great, and I really feel great about that, because that's still there.

SS: It's still there?

GK: It's still there. Its own organization, I don't know what — and this is like years later.

SS: Who else was in ACT UP New Jersey?

GK: The only one that I remember is this guy Bill Orr, William Orr, who sort of was the head of it. We used to meet at his house in Hackensack or something. There were just a few other people.

SS: Is he still alive, do you know?

GK: As far as I know. I mean, he was actually—he was like the CEO of that community group. He became very involved in that. I know that he's not involved anymore, but he for many years was involved with the New Jersey's CRI, and I just don't think he's involved in it anymore, according to Mary, because I still see Mary. I just saw Mary on Saturday. She gets her hair done. I've been doing her hair for thirty-five years.

SS: Great. Let's see what else you have there. It's a real treasure chest.

GK: Most of them are just copies of the same thing.

SS: That's okay.

GK: Here's another article from the *Daily News* about red tape jamming up food. Most of the things are about food.

SS: What's the date on that one?

GK: This was Monday, October 30th, 1989. So it must have been when I started. This must have been in the beginning when I was just looking into it. I don't know what we had to do with getting the article in, but probably something, probably otherwise I wouldn't have had it.

SS: It's interesting that the *Daily News* picked up the story. I mean, that's rare, because their coverage wasn't the best.

GK: Look what I found. AIDS Treatment Register. Wow. And, actually, this is the board of directors was —

SS: And who were on the board of directors?

GK: There's probably another page to this, but Nancy Adams — was that — no. Nancy Adams. Michael Cowing was the president. Jim Eigo, published writer and scholar.

SS: Who's Michael Cowing?

GK: Michael Cowing.

SS: C-o-w-i-n-g?

GK: C-o-w-i-n-g. He was really prominent in ACT UP, actually did a lot of speaking but under the radar at the same time, you know. But me and David and Michael, we're trying to get together a dinner, actually, because David is, I think, in touch with Michael Cowing. He was just there all the time, and he was very smart, and he was kind of a Wall Street person, I think.

SS: So we should interview him.

GK: Yeah. Oh, yeah. I could tell you at that time he was director of Micro Computer Services for the New York City law firms. Let's see. He was the program director of the chapter Services Division for the American Society of Interior Designers, maybe he was an architect, here in New York City, and from 1982 to '94 he was on the staff of the School of Law at New York at NYU, where he served concurrently as publications manager and microcomputer support office.

I wish I could find the rest of the board of directors.

SS: It's interesting, right, because that's a typical ACT UP coalition. It's like you were a hairdresser, Jim Eigo was a playwright, this guy was corporate, Iris was a scientist, and you're just doing all this together. It's beautiful, yeah.

GK: There was some things — the more probably organized stuff that I had, I had donated to Mimi Bowling. Who actually was — she was involved with the archives, ACT UP Archives at the New York Public Library.

SS: So it means they're sitting in a box.

GK: Somewhere, yeah.

JH: They're available; they're processed.

SS: They're processed? Okay.

00:55:00

GK: I must have been very impressed with my letter to *Newsday*, because there's like a zillion copies of it.

JW: It was a great letter.

GK: Oh, god. There's so many papers with just statistics and things like that. Oh, this is interesting. This was a demand poster for, to the sick and poor. Medicaid says, "Eat Pudding."

SS: "Medicaid Says 'eat pudding.' Department of Health policies starves people with AIDS and other chronically ill people."

GK: So this is something I was totally involved in.

JH: What's on the back of it?

GK: Demands, which our demand at that time was Medicaid must automatically approve all applications for prescriptions of nutritional supplements deemed necessary by a physician as life support for chronically ill patients and resumption of approval by telephone, because you had to actually go down. You couldn't like go — and the lines, I mean, you're sick to begin with. Can you imagine, like, going and waiting in line with some life-threatening opportunistic infection and then having to go down there to just get your food supplements?

SS: You know what's so interesting about your demands is that they're so reasonable.

GK: And they're so few.

SS: And they're so doable, right?

GK: Yeah, yeah.

SS: They're completely normal, reasonable.

GK: And just thinking that when they're cutting a budget, that's in a city that's devastated by a disease and people are literally dying with no treatment. I mean, there's not even a treatment. They're thinking that it's appropriate to deny food. I mean, it's like it's —

SS: You wonder who these people are.

GK: Well, I did know who they were at the time. I wish I could —

SS: How did you feel about them, like when you would sit across the table from someone like that?

GK: Well, I mean, I was fun to insult them, you know, and I felt, I think for all of us, any of us who would go to meetings, I mean, no matter, and we educated ourselves so much that it's like they were so intimidated, they just couldn't —and it felt good to intimidate them, because look at what they were doing to people. You just wanted to make them feel as bad as possible, and that would make you feel good. And I know —

SS: Did you have any insight into them, like how —

GK: They're just bureaucrats that don't — I mean, I don't have insurance now, and I go to Bellevue for my healthcare, so, I mean, if it weren't for having been in ACT UP, I mean, I don't think I would be able to — I would have healthcare now. I mean, I'm able to talk to doctors now, and I'm having an issue now with getting pain killers for my back, that they're just being so completely ridiculous about because they

turned my Tramadol into like a Schedule C drug because some people are crushing it up and snorting it. I mean, I take six of these pills a week, which is like nothing, and they want to cut it out. And I'm having this issue. I have to go to patient advocacy and all that stuff. But at least — I couldn't do that if it wasn't for this.

I, myself, like, I don't know — since the very first time I was tested, and I was negative in 1988, I've never been tested since. I've declined a test every single time. I just never wanted to know. So far, so good, you know, in terms of that, but I have a lot of other healthcare issues, between my back — I just had some thyroid problems, and since I don't have insurance, I've had to really, really work — like, I see people at Bellevue, I don't know how they get through it, because it's massive amounts of people. But since I have this little bit of education and still that ACT UP mentality, I've been able to get my healthcare there and pretty much hardly pay anything.

SS: I'm still interested in your — on the human level, what kind of human being makes these kinds of decisions? I mean, you've looked these people in the eye. What is it?

01:00:00 GK: I think they get through it by saying they're not making the decision. There's always someone higher than them that they can blame, that's telling them to do it, you know. You could get up as high as, let's say, the assistant to the mayor, and he's going to blame the mayor. So they never take responsibility. They never make it sound like it's their decision. They're all just pushing the buck and saying, "Don't blame me. Blame this person," and it ultimately will go as far as whoever is at the — and the mayor

will blame the governor, then the governor will blame the president. It's like it's no one

—

SS: Now I'm remembering that Marjorie Hill was the liaison person.

Wasn't she the —

JW: Yeah.

SS: Did you ever deal with her?

GK: I feel like the name I know. Was she blonde or —

SS: No, she was a black woman. She was the daughter of Stanley Hill.

GK: I know the name, but I — I'm sure I did.

SS: She became the head of GMHC, and she was the liaison. Okay.

So you didn't deal with her.

GK: Not that I can remember. I very well might have, but, you know.

SS: Interesting. Interesting. It's like a character issue. Like you have a certain kind of character and you rose to the occasion of history, and these other people have a different kind of character and they become the obstruction.

GK: Right, but they don't see themselves as that. They'll never take that — you'll never hear them take that response — nobody in government ever — it's so rare you ever hear anybody admit they're wrong or take responsibility. I can barely think of anybody that — I mean, and during those days, I mean, they just blamed the budget. It always came down to money. But, I mean, the issue, when it comes to food, I mean, how much more basic can you get than that? I mean, how much money are you really saving by denying food supplements? There's certainly other things you could cut back on.

SS: It's a mental health —

GK: Yeah, it is, and it just doesn't make sense, I mean, to anybody.

SS: Do you have anything else there?

JW: Think of how many people died.

GK: I started collecting these articles for some reason. There's like a clinic tied to \$1.3 million Medicaid fraud, pharmacist charged in Medicaid scam. For some reason, I have these, but I don't know exactly why.

SS: What's the newspaper?

GK: This was the *Newsday*, 11/18/90. For some reason I was collecting all these. I was making some kind of connection with this and that and I don't —

SS: "There's a special place in hell for the person who designed Medicaid. What a disaster."

GK: Here's one. Let's see. "Mayor Dinkins to hungry people with AIDS: Eat garbage." This was a demonstration at City Hall. I vaguely remember me organizing that. It was at City Hall. I believe we —yes, this goes back to the letter that I wrote to *Newsday*. This was all connected to that. I think I remember actually it was the only time ever I actually spoke on a bullhorn, I think, and — I remember that, and there was something with Peter Vallone also, that DAS losing money. It was all connected, all the food and food stamps and —

SS: What year is this?

GK: Well, the demonstration was Monday, December 24th, which was Christmas Eve, I guess, 1990 at twelve p.m. I do kind of remember that demonstration.

SS: That's amazing that ACT UP could pull off a demonstration on Christmas Eve.

GK: Christmas Eve, yeah, yeah.

SS: That is really incredible. Did you remember winning anything?

GK: Yeah, definitely. I do. I do. If we didn't, I would remember. I'm sure we helped. I'm 90 percent sure that we absolutely did something, where they were able to do something with the food supplements. I wouldn't have stopped — I mean, I'd still be doing it today, I think. So I think we did. It's, like, sad that I can't say for sure. But this is actually a whole file of letters to the mayor and everything. I mean, this would be something to go through too. You might be able to get more of a —

SS: Okay.

GK: But I spent a lot of time on that. I mean, it's a couple of years working on just that.

JH: That's a letter on ACT UP stationery?

GK: Yeah. I had ACT UP stationery, so I was using the stationery too.

01:05:00

JH: So you just wrote it on ACT UP stationery? You didn't go to the floor to get —

GK: I think I had sort of this — because so few people were doing this, I think I had carte blanche to do what I wanted. I don't think —

SS: I don't remember people going to the floor for permission to use the stationery, no.

GK: I think anything — I don't know whether you had to go through the floor or you had to go through some committee. There was, now that you mention that, I think — people didn't want just anything going out on ACT UP stationery because people could be sending letters anywhere. I'm sure every single person —

SS: But, I mean, you were a known quantity. I have many, many memories of you in ACT UP.

GK: Right, but I think because this particular issue, I don't think I had to do that. But I definitely think people at times, for specific — I mean, if somebody was writing a letter to the National Institutes of Health or FDA, that had to go through. I mean, there was no way that a letter — that would be counterproductive, because it could be somebody contradicting what the group as a whole was saying.

SS: Right. You had no competition for this territory.

GK: Right. There was no — I mean, I don't remember really having to go to the floor. I would remember because I would have been so nervous to get up there and say anything that it would be — you know, I would remember that to this day.

SS: So I just want to move on to some other areas. And thanks for all of that really incredible information. Were you involved in any care groups in ACT UP?

GK: Not with a group, but I — do you remember Brian Damage?

SS: Yeah.

GK: He lived in the East Village, and I spent a lot of time helping take care of him and wheeling him in the wheelchair around the city and making sure he had

food. I used to spend a lot of time with him. I remember it was my first experience seeing how difficult it was to maneuver the city in a wheelchair. And getting a cab, I remember literally having to get a cab and I remember standing in front of the cab and banging on the hood of the cab because he pulled over and then he saw the wheelchair and then he went going. I think it might have been on Christopher Street or somewhere, but he got stuck in traffic and I chased him and I made him — I took the license plate. I made him take Brian home. I mean, I came with him, but I made him. I remember that.

I remember when he was very sick in the hospital, and I remember all the protective gear people were wearing. And the last time I went to visit him — well, even before that, I remember going to — he was in Beth Israel, which has always given me a horrible feeling about Beth Israel there. I went to go visit him. Since I had a lot of time, because I could just pop up anywhere anytime without notice, so I went to Beth Israel Hospital to go see him. And he needed someone to change his bedpan, and I got there and he had taken it and literally thrown it into the hallway because nobody — he was screaming and yelling and nobody would come. And I just happened to get there at that moment, and there were, like, four, five, six people around the front desk where they had the computers and everything, laughing and saying, “It’s not my job, not my job.” Everybody is — nobody’s job, you know.

And I, like, let loose screaming at them, and I immediately — I called the—I got in touch with the patient advocate of Beth Israel, the ombudsman there, and I saw her that day and told her exactly what happened. And from that day on, she would

call me to make sure everything was okay. If that was happening to him, it was happening to millions of people or thousands of people.

SS: We interviewed somebody about him. Was it Lei Chou? Who did we talk to about Brian? Who was he living with?

GK: I don't remember him living with anybody down there in the East Village. We would work on shifts. It was our wave group. Wave 3, I think we were.

SS: I think he lived on Lei Chou's couch. Where did he die?

01:10:00 GK: Well, he died in Beth Israel. I went to go see him, and I actually—I walked into the room and I didn't know he was dead. I didn't even know. I went over and I started talking to him, and he was already dead, and nobody — they just let me walk in. Nobody said anything to me, nobody, and it was horrifying, like it was — you know.

SS: Do you remember his real last name, by the way?

GK: No.

SS: It's funny, because we've talked to a number of people about him, and nobody knew his real name.

GK: I kind of thought it was — I guess.

SS: No, no, that's his — because there was no family at all involved. He was a typical case in that regard. It was just ACT UP people and — right. Was there a memorial service for him?

GK: I'm sure. There's so many, you know, it's hard to remember. I was very close — do you remember Anthony Malliaris, Tony?

SS: Sure. Tony.

GK: He was like the love of my life. He was like my best — I deejayed at times, so he did a whole rap thing and I did the music in the background. We did it in a recording studio and all that. Yeah, we were very close.

SS: You should see our movie, because we have a lot of footage of him.

GK: I've seen a lot, yeah.

JH: David Kirschenbaum was angry at me because I didn't put you in the credits for preserving Tony's rap.

SS: So what happened at the end there with Tony?

GK: I mean, I was really — I was like I was in love with Tony. I was absolutely, and we sort of got together. I think it was during the CDC action or something. We were in the same room, and it was like once or twice we made love, and it was, like, great. I thought he was in love with me, but it was a friend thing, so I was very devastated after that, but we remained really close friends. Then he started seeing someone from Amsterdam. He wound up moving to Amsterdam, and we actually went to Amsterdam together for two weeks, although while we were there, we barely saw each other. He was there to see this other guy. And then he moved to Amsterdam and we corresponded a lot.

Towards the end, I didn't realize — he wasn't sharing with me how sick he really was, and his last letter to me was vicious. I mean, it was just as hard—I mean, I'm sure he was really sick, but it was just this terrible, terrible letter. We'd been corresponding, and I don't know what happened, but I don't know what I said, what I did.

I think all I can remember my last letter to him was, “If you need me to come, I’ll be there in like two seconds.” His last letter to me was basically — I mean, I found out later he was blind at the end. But his last letter to me was basically that he has so much to live for and in some ways that it should have been me that was, like, dying instead of him. It was just horrible, horrible. It was devastating.

I remember the day I got that and I opened it up. I didn’t keep it, because if I kept it, I’d just keep looking at it, looking at it, looking at it. And his last words to me were, “I know your dramatic ass will want to get the last word, but after you do, please don’t ever contact me again.” It was one of the most — still to this day, and that’s like how many years ago? I still search to find what possibly I could have said or done that would have —

SS: No, it’s the David Feinberg syndrome. There were a few people who just took it all out on us.

GK: It was so devastating to me, and to this day still is, because he was absolutely the love of my entire life, and I always pictured me taking care of him at the — I had this whole — you know. And he got sick so quick, it was just so — like he went from no symptoms, nothing, to within two years was dead, and it was, like, ridiculously fast. I don’t know if he was taking a lot of treatment at the end, I don’t know, but it was just brutal.

SS: But that’s part of the experience. It’s like it’s not just that we were watching people get sick and die, but we were watching people act out, be cruel, just try to destroy the people in front of them. Sometimes it’s the biology of

the illness and sometimes it's people's own characters emerging in that way, but it's part of the special experience of being in ACT UP.

GK: Yeah. It was, like, insane. We did a lot. We collaborated a few times. We actually did an ACT UP benefit at the Gay and Lesbian Center, and I rented equipment, I deejayed, and we set up a — we got a smog machine, a smoke machine. We set up a Berlin Wall. I forget what the fundraiser was called, but we made it to look — literally we had a Berlin Wall in the middle of the floor.

SS: Was he trying to have a professional career?

GK: No, I don't —

SS: It was for fun?

GK: Yeah. I don't think he was ever — I mean, when he was in New York, he worked for — for the years I knew him in New York, he was working for the — it was like the Helen Keller for the Blind, like it was right down the block. I was living in 15th Street at the time, so I used to —

SS: The Lighthouse?

GK: Yeah, something like that, but it's there. It's like a Jewish Center historical thing something now, but when he was there it was a blind — I used to hang out there all the time with him and go there. He had access to a computer there too.

SS: That's funny, because I remember Jim saying, when David Feinberg was being cruel — I remember, Jim, remember you saying, "He doesn't realize that he's not — he thinks he's the only person losing something." So many

people just like scarred everybody before they died, and then they didn't take into account that other people are having an experience.

JW: Going blind is a disease of the brain so —

GK: I think I'm absolutely sure that it was — I mean, as I understand it, he suffered horribly. I never was angry at him. I was just so hurt.

SS: No, I understand. When did you leave ACT UP?

GK: By '94, I kind of, it was — between '92 and '94, I was still in ACT UP, but at the same time I started doing — like every single weekend I was doing like three, four hits of Ecstasy, Ketamine. I was going out, like, really, I mean, self-destructive. My career was, like, screwing up. I just was so bummed out and just miserable, but every single week. Since I only worked three days a week, I would leave work Saturday, and then by Saturday night I'd be tripping till Monday, and then I needed a few days to recuperate. Each time I did it, I would be more and more depressed after, no matter — the better I felt on the Ecstasy, the worse I felt, and I did that literally every single weekend for two years.

I had hundreds and hundreds of hits of Ecstasy, and it had a huge effect. I mean, by 1996, I was pretty much getting into, like, full-blown depression. I suffered from depression my whole life. So I started — I went into emergency clinics to get help, and really until around — in 1996, I met Rogerio, my husband. I met him and we had a one-night stand, and at that time I was just — the real depression hadn't hit me yet. It was like really about a year later after I stopped. I stopped doing Ecstasy. I remember the day I stopped, because I woke up in this apartment with literally amnesia, and I was

tripping my brains out, and I couldn't remember — I couldn't remember leaving the house. It did come back to me, what happened, but I woke up in here tripping my brains out, but I didn't know I was tripping.

And I didn't remember taking anything, so I thought I had like an aneurism or something. I mean, literally at one point I was going out in the hallway, I was thinking we had like — like it was radiation poisoning or something. I couldn't figure out why I was so spaced out, and then slowly it started coming back to me. I had been out that night, and I was at the Roxy dancing, and, I don't know, I took how many hits of Ecstasy, and then I complained that it wasn't good enough. When I looked at my t-shirt, there was actually blood on it, and it looked like a puncture wound. I swear to god somebody shot me up with something, and I remember them — it was the middle of winter, and they threw me out. They took me out a back entrance, down a fire escape, into — and just threw me in a cab, and I was in the cab for like forty-five minutes, I couldn't even speak, until finally I could speak where I lived. And it all came back, but

01:20:00 when I first woke up, I didn't remember it. That was the first time I did Ecstasy.

So that was, like, 1995 maybe, or '[9]4, and then I started suffering from really severe depression, like about a few months later, a year after, and then I happened to meet Rosario and we had this one-night stand, and for three years we wrote letters to each other and talked on the phone. I really didn't let him know about my depression or anything, but by the time we decided jointly that he would come to live with me in 1999, we'd give it a shot, and we'd only met each other once, but we had these, like, in-depth letters, like hundreds of letters and phone conversations.

So I knew that if he came, I was not going to be able to handle this relationship if I didn't get on medication. So from 1999 on, I've been on SSRI. It's like Celexa and things like that. And thank god, they did the trick for me. They helped and I've done medication again ever since then.

I just gave up ACT UP. I couldn't remain there. I mean, things had changed also. So many people were gone, and it wasn't really the same organization and there was too many other issues going on. It was that whole controversy over that whole thing of if one person isn't free, we're not all — there's so many other political — towards the end there, there was like every other — there was like twenty different organizations coming to the meetings, and everybody wanted their issue this and that. It became not exclusively about AIDS anymore, and I just couldn't find it — I couldn't see a place for myself in there anymore, and I needed to evolve with my life.

JW: You had the demonstration in December of 1990, and just a month later was the Day of Desperation on January 23rd. Do you remember what you did?

GK: During the Day of Desperation? I'm not sure. I mean, I don't remember. I remember getting arrested at — I must have gotten arrested about nine times, so I don't remember all of them.

JW: At Grand Central?

GK: No, not at Grand Central. Was there a group at City Hall? I think I was at a group with City Hall. I always remember the Day of Desperation. There's that

one postcard with David Falcone is on top by the clock. I see him once in a while. He's had a rough — he is — have you interviewed him?

SS: No.

GK: I don't know if he'd want to be interviewed, but he's a survivor.

SS: He had an intense presence in ACT UP, even.

GK: Well, he has had, like—I mean, what a life. This is the way I recall it. Can I talk about —

SS: Yeah.

GK: I mean, it's very personal. I don't know how he would even feel about me, like, saying some of the things I'm going to say.

SS: Well, just say it, and I'll ask him if he wants to be interviewed.

GK: Okay. He was pretty much my first friend, like, in ACT UP, and when he was diagnosed, I think he was given sort of like a six-month-to-live kind of thing. This is how I recall it. He probably tended towards getting high a lot, anyway, but he just started drinking, smoking crack, I mean really, really tons of stuff. At one point from drinking, he had a kidney removed, and he was smoking crack in a hospital.

He was beautiful, he was really handsome, a great-looking guy, and he's had just horrible health situations. He had mouth cancer from smoking. I think a lot of the things that he had, I don't even know that they were actually, like, HIV-related. But he had mouth cancer, he had radiation on his whole face. I mean basically they had to graft bone from his legs into his chin area, and they did horrible surgery. He's really — they disfigured his face, like, so badly. But at the same time, he has survived, and he's

— yeah, we go out for lunch maybe every few weeks. He's gotten kind of spiritual. He's into like — I think he became a Muslim.

SS: Will you ask him if he wants to be interviewed?

01:25:00 GK: I will, yeah. He texted me just yesterday. We see each other every once in a while. We just go out to eat and touch base. We don't really hang out, but he has a boyfriend that he's had for like, I don't know, twenty-five years who helps financially with him. But he was the muscle. He didn't really get into any of this stuff or any negotiations, this one or that one. He was always there for a demonstration. He was always ready to, like, break through a window or anything like that, or take risks like jumping up in Grand Central. He's an interesting, interesting guy.

SS: You were talking about The Split and how you understood it as people bringing in issues that were not related to AIDS. Do you have any particular examples of that that you remember?

GK: I remember there — I mean, you could almost relate anything to AIDS. It was like legalize marijuana for people with AIDS. There were a host of—I mean, even some of the women's issues, I think, at the time, I think people thought maybe weren't related to AIDS, but it just seemed like every game in town, everything. I think it just seemed like there were so many issues, that you couldn't really — there was no way to deal with all the issues.

I mean, it was hard enough just to deal with some of single issues that we had around treatment and access to medications and things like that, that it just seemed unwieldy to — I mean, you could bring up all these issues, but who's going to work on

them? I mean, what's the point in talking for hours on end about this issue and that issue when nobody wants to really do the work on it? It's like people would bring up an issue but then expect the entire group to go work on it. It takes work. It takes time. I mean, what I did with this obviously took, like, years of work on a single issue, and so it's just impossible, I mean, in a volunteer situation where people have their lives and have other jobs, to actually focus and spend time with an issue that may be very important, but what's the point in even talking about it? It's an action group, not a talk group, and there was no way to split, to spread yourselves that thin and then make a wave.

SS: Do you remember a specific issue besides marijuana?

GK: Even homelessness. Keith Cylar, I think, started dealing with some of those issues. I mean, I was so focused on treatment and life things that needed for individuals to actually stay alive —

SS: Like food.

GK: Yeah, yeah. Right. So I kind of saw some of all those other issues as, even though they're, like, incredibly important, there needs to be another group for that. I just remember, like, going to Cooper Union. I remember one of the meetings we had, there was like a thousand people. I'm like, how can you get anything done with a thousand people? It seemed like everybody wanted to get on stage, and some of these talks and speeches went on forever and ever. And it just became like—ugh. Like your head would spin.

Like, the first few years I was in there, we really got a lot — we were really getting things done, and then I just felt like it just — and that's why I guess certain

groups split off, like TAG became — you know, I mean, things like that happened. Had I continued, I probably would have split off to deal with specifically city issues, but I wasn't capable of doing all that, I just couldn't, and make a living. I had to live. I had to pay my rent.

SS: So I only have one more question. Is there anything else —

JH: I have a couple.

SS: Oh, go ahead.

JH: One is, did you have anything to do with the 076 trial?

GK: 076, I don't think so. What was —

SS: That was the pregnant women.

GK: No.

JH: Because I thought maybe New Jersey.

GK: No.

JH: So you were in ACT UP starting in 1987, and then a lot of things you talked about were in 1989, and I'm wondering about that period before that.

GK: Well, I was living in New Jersey from '87 to '89. I didn't live in New York. So when I moved into New York, I moved into New York to get more involved. When I was living in New Jersey, I was driving into New York literally every single night, and I needed a place to sleep, basically, and I was starting to deal with this while I was still living in Jersey.

01:30:00

I remember the day I moved in. I was like—David Kirschenbaum came to New Jersey, and I sold my car to one of my customers, and we took a train back in, and I

haven't driven since. I haven't driven a car since that day. I don't even have a driver's license.

But I was dealing also with New Jersey ACT UP between '87 and '89, and those were the years that we got money for the community research thing in New Jersey and for ATR, for AIDS Treatment Registry. So I was sort of straddling New York and New Jersey at that time. So that's pretty much what I was doing. And I was attending, like I was involved — I testified at the Food and Drug Administration also for DHPG. It was the drug for, I think, for cytomegalovirus.

SS: CMV.

GK: Yeah. That was my — like we were all given sort of projects. I was the representative for that drug. I remember also nervous. My hands were shaking. I was sweating. I think I was in the bathroom like all night, so nervous.

SS: How did you become an expert on DHPG?

GK: I just researched it, like everybody else, you know. There was information. I don't know how — don't ask me how I did it without a computer. I mean, I didn't have an Internet. I didn't have any access, if there was an Internet. I don't remember.

SS: There wasn't.

GK: Don't ask me how I got all this information. It was like somebody else. I don't know how I did it, I got it, but, yeah.

In '89, also, right after I moved into the city, we had the Montreal AIDS Conference. I remember that. That was amazing, going there. If you have a good time

at an AIDS conference, that was one of the best times I ever had in my life, because I had been communicating with people all over the world about certain issues, and I got to meet some of them. I remember hanging out that night with a guy from Tasmania. We stayed at McGill University, and it was just a ball. They spared no expense for that. They had the party afterwards at the Botanical Gardens. It was decadent. I couldn't believe the government, like, they were spending money on that. It was like everybody, all of us from ACT UP were simultaneously appalled and having a great time. It was like there were ice sculptures, and everybody had their own bottle of champagne. It was, like, ridiculous. It was obscene, really, I mean it really was, because there were so many issues.

I was talking at the AIDS conference about poor countries and this and that, and then they must have spent millions, it seemed like. Tents, giant tents everywhere, and they didn't separate the activists and everybody from the dignitaries and people that were there, and we were just mingling. It was like we were the black sheep of the family, but somehow we did have a good time.

JW: It was Pharmco money.

GK: I guess so. I mean, that was insane, just insane.

SS: Someone we just interviewed was talking about how ACT UP would also go and eat all the food first and do the action.

GK: That was a crazy memory.

SS: Do you have anything else, Jim?

JH: No, that's it.

SS: Okay. So I only have one more question. Is there anything that we haven't talked about that you want to bring up?

GK: Probably, but I couldn't offhand —

SS: Just looking back, what would you say was ACT UP's greatest achievement and what do you feel is its biggest disappointment?

GK: I think its biggest achievement really was early approval for medications. It set up a situation, and I remember going — we went to the National Cancer Institute to talk to people and basically said — trying to get them to do the same thing for cancer, and I still to this day don't understand how every disease doesn't have an ACT UP. I mean, it just seems like everybody's just so complacent about disease in this country. To me, that was, like, our biggest, as a group, getting to actually push them to actually get drugs approved earlier. I feel like anybody probably — it gave a certain amount of hope, I mean, to people at least that there might be something that might work.

01:35:00

Greatest disappointment. I don't know. We couldn't save everybody. That would be it.

SS: Thank you, Garry. This was a great interview. We learned a lot.

GK: Oh, thanks.

SS: Thank you so much.