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Interviewee: **Kevin Robert Frost**

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Interviewer: **Sarah Schulman**

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SARAH SCHULMAN: The way we start is you say your name, your age, today's date, and where we are.

KEVIN ROBERT FROST: My name is Kevin Robert Frost. I'm forty-nine years old. Today is August 23rd, 2012, and we are in the offices of amfAR, the Foundation for AIDS Research.

SS: Yes, and we are surrounded by photos of you with your husband and President Clinton, ACT UP, Joan Sutherland. I mean, it's a very fabulous place in here.

KF: A rather eclectic mix, yes.

SS: And a beautiful corner office looking over the river.

KF: Yes.

SS: So where were you born, Kevin?

KF: I was born in Tripoli, the capital of Libya.

SS: And how did that happen?

KF: My father was in the military. He was a military man. He served twenty years in the United States Air Force, and he was stationed in southern Italy. The Air Force base where they were living, my mother and father, had a hospital, but it didn't have a maternity ward, so the nearest military hospital that did have a maternity ward was in Tripoli. So my mother, about a month before I was born, flew to Tripoli, stayed in the hospital there, basically, until I was born, and then within four or five days after I was born, she was on a plane back to Italy.

SS: So did you grow up in a military environment?

KF: For the most part, yes. I mean, my father was in the military. Four of my brothers have served in the military. We were a military family, which meant we moved around a lot. Every few years he was restationed until, really, I was in about the fourth grade, and then they settled in Texas. So I spent most of my formative years growing up in Texas.

SS: Where in Texas?

KF: In San Antonio.

SS: So, I mean, you are very community-oriented person.

KF: Yes.

SS: And you have been all your life.

KF: Yes.

SS: Did any of that come from your family or was it in spite of being isolated and moving around?

KF: My parents are—my father's dead, but my mother is still alive. And they were, and are, Irish Roman Catholics, and in addition to that, my father was in the military, and the one thing that you learn from both the Catholic Church and the military is obedience. So I have five brothers, four of whom went into the military. I knew that I was never going to be able to go into the military and I'd never be a Catholic priest because obedience just wasn't my thing. And you learn, or you're taught, at least, not to question authority in both of those. And my father was a strict disciplinarian, I mean really strict military man, and I guess I was pretty rebellious at a fairly young age.

I think my work in the community probably comes more from my own sort of desire to break outside of those restrictions. So I always knew there was more out there than what the military or the Catholic Church was telling me, and so moving to New York and being a part of everything that is New York was probably a reaction to the environment in which I grew up in, which was very strict, very Catholic, very military.

SS: When you started to come out to yourself, did you start to become aware that there was a gay culture or a gay scene somewhere out there?

KF: Not at all. In fact, what little I knew about the gay culture were the marches in San Francisco on Gay Pride, which, in the seventies, if you were looking at Gay Pride marches in San Francisco, you were seeing something that looked, from the perspective of somebody that lived in suburban Texas, looked like a hippie parade. It was long hair and beads and flowers and all those things. So it didn't look anything like the existence that I knew.

So even as I came to an understanding about my own sexuality, which I did fairly young, I didn't relate that to a gay community. I didn't see that as being part of the gay community, at least as I knew it. I didn't really get a sense of what community meant, of what gay community particularly meant until I moved to New York, and really until I became part of ACT UP. That was when I really began to understand what it meant to be part of something bigger than just yourself.

SS: Now, had you ever been involved in any kind of politics before ACT UP?

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KF: No, not at all. Not at all. And I think that there were—my political awakening, if it were such, started to happen—really coincided with the emergence of the

AIDS epidemic. So the epidemic emerged while I was still in Texas, mostly while I was a college student, and I started to read stories about it and understand what it was now, the mid-eighties. And if you were living in Texas, the epidemic was something very far away. It was something in New York. It was something in Los Angeles and San Francisco.

But nonetheless, by the time I was in college I was going to gay bars, and certainly, I was sexually active at that point, so I was aware of what was happening, but it was an evolution over time. It wasn't a wake up one morning and, aha, this is what we're dealing with. I was reading stories about gay-related immune deficiency and the gay cancer and HTLV-3, all these crazy things, but didn't really relate them to my own life until I saw *The Normal Heart*.

I went to college in Austin, and I was a music major in school, and then after I left Austin, I moved to Dallas, where I worked for a theater company called the Moving Target Theater Company. And there was a production in Dallas of *The Normal Heart*. They came to Dallas. They did it, and I saw it, and all the pieces came together. I suddenly realized, I think, in a more cogent way what was going on, and at that point I knew that I couldn't be just an innocent bystander. I wasn't infected, but I was gay, and I knew that this was affecting gay men, and so I knew that I was going to have to do something. I had no idea what that would ultimately turn out to be.

SS: Had you ever met anyone who was HIV-positive at that point?

KF: I had two friends who both died of AIDS. One was a very close friend, Robert Caudio [phonetic], who was a part of our circle of friends, but none of us knew he was sick until he died. We got a phone call one day, and Robert was dead, that

sort of—Robert never told anyone. We never had any awareness of it. I think he developed PCP pneumonia and died.

Also while I was living in Dallas, I worked for the Dallas Opera. I was a singer in the Dallas Opera chorus for a while, and the stage manager of the Dallas Opera was a man named Kevin Hurr [phonetic], and Kevin was my roommate. We lived together, we had an apartment together in Dallas, and we were great friends. We did a lot of things together. And then one day Kevin got sick and he went into the hospital. It was so sudden, it was so quick, that it kind of caught us all off guard. And I remember going to see Kevin in the hospital and going to his hospital room and seeing the signs on the door with the big hazard warning signs, and the nurses who were going in and out of his room were wearing gowns and gloves and masks and all of this protective gear. We were enlightened enough then, even, to know that that was more than—I mean, we weren't going to put on gowns and gloves and masks to go see Kevin. We went into his room.

But Kevin never said he had AIDS. He never said that he was dying of AIDS. He never said he had AIDS. He told everybody that they had diagnosed him with some rare blood disease, and he also died very, very quickly before anybody really had a handle on it, and he was just gone so fast.

SS: Now, were you afraid that you were infected at that point?

KF: No, I don't really remember being afraid that I was infected at that point. I mean, later, obviously, when I moved to New York everybody was afraid, but at that point, it still seemed very distant. In Dallas, Texas, to meet someone who was dying of AIDS seemed really quite extraordinary.

SS: It's interesting, because here's your roommate dies.

KF: Yes.

SS: And you decide to go right to the epicenter. How do you understand that decision now?

KF: You mean move to New York?

SS: Yes.

00:10:00 KF: I didn't move to New York to be an activist. I didn't move here because I was outraged about the AIDS epidemic and wanted to be involved. I moved here because I was a musician and I wanted to make my life as a musician. So I moved here thinking I'm going to be in the city, and I'm going to have a musical career. So I moved here and I started doing auditions and I started doing all the things that people do as musicians, but I didn't come here because the epidemic was here. What I found was something very different than what I expected, but it wasn't the reason, really, I moved here.

SS: What year did you move here?

KF: I moved here on February 14th, 1990.

SS: Valentine's Day.

KF: Valentine's Day.

SS: Okay. So you're moving to New York absolutely at the height of the AIDS crisis.

KF: Yes.

SS: How did it affect you personally? Did you feel threatened? Were you afraid of having sex with people with AIDS?

KF: No, never, and I think that partly that was because I had educated myself enough to know what was going on. By 1990, we knew it was a virus. We knew it was sexually transmitted. We knew a fair amount about it. So by the time I moved to New York, I don't think I was afraid in that sense, but certainly as a young man in the eighties and being sexually active, certainly when I lived in Texas, despite what we were reading, nobody used condoms. Nobody did. I mean, it wasn't really clear that that's what was going to protect you. By the time I had moved to New York, we understood this was sexually transmitted, you had to use a condom, you had to do all of those things.

So, yeah, I dropped into the epidemic's ground zero, but by that point, I knew enough about how to protect myself that I wasn't afraid in that sense. I didn't know if I was negative or positive either, because it was very unclear about the value of being tested at that time. So a lot of people, myself included, really didn't get tested. I never got tested at that point because why would you? Why would you want to and bring all of that on to yourself? So it was a few years before I was willing to sort of go and get tested and figure out whether I was positive or negative and all of that.

SS: I want to ask you kind of a weird question, but—

KF: Sure.

SS: You're an AIDS professional, you're the director of an enormous AIDS organization, and here we are, so many years ago your roommate died under these tragic circumstances. He couldn't even say that he had AIDS. Is there something about staying in AIDS all these years that keeps the trauma going on some level? I mean, some people run away from it and some people come towards it.

KF: I would love to tell you some grandiose story about why I have done it for all these years and why I've been in it so long, and service and all of those things, but the reality is when you peel away the layers and when you get down to the onion itself, for me, a big part of it, I always believed that I was fighting for my own life. I always believed that on some level we were all going to die. I understand my own nature, and I think I understand enough about human nature to understand risks, the risks that we take in our lives, and there have been times in my life when I've been more risky than others. I always believed this fight was my fight as much as it was anyone else's, and so on some level I would argue that I was doing it more for myself than anything else.

SS: Right. But now you know that you're protected.

KF: Yes, yes.

SS: Some people stick with it, and some people let it go or run away from it or—

KF: Yes. Well, maybe part of that is because I've always been involved in the research. From my days in ACT UP, I was part of the Treatment and Data Committee, and I always had this belief that research could bring us the answers we needed and that there are a lot of things you can do to fight AIDS. Right? There's a lot of stuff you can do, from giving out needles to helping people—delivering meals to people who are homebound, to volunteering in hospitals, all of those things. But I always believed that research was going to end the epidemic, that that was the only way, and there's a certain unfailing optimism about people who are in research, and we are constantly surprised, which is part of the joy of being in research, is that you're

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constantly surprised by the progress you can make, and sometimes depressed by the setbacks.

SS: Sure.

KF: There's a negative side to it, too, but the optimism is unfailing. So perhaps if I had done some of those other things, it might have been different and my commitment to it might have been different, but because I was on the research, always, I mean, at ACT UP and then at NYU and then eventually at Bellevue, and finally at amfAR, I always saw the potential for research to solve problems. So for me, I've always had this very sort of optimistic approach to what we can achieve. If we just had a little bit more money, if we just can convince the politicians, if we can just get the right research done, we can bring the answers to those things. And for the most part, I think that's been borne out true.

SS: Yes, you're right. Okay. So how did you get to ACT UP? What got you to that?

KF: The last job I had living in Dallas, Texas, before I moved to New York was I was working in the classical music section of a record store, and I played in piano bars at night to pay the bills. The first job I got when I moved to New York was in the classical music section at Tower Records in the East Village, the old store that was at Fourth and Broadway. I knew I could get a job there. That was not going to be an issue. My background in music, my degree, I knew a lot about classical music. So I walked in and I got a job right away, and I started working there.

I had worked there for a few months, I guess, and I knew Larry Kramer's work. I had read *The Faggots*, his first novel. I'd seen *The Normal Heart*, which had

really had an effect on me. And one night he walked in. So it was very late at night; it was like eleven o'clock at night. In those days, Tower was open 365 days a year, 24 hours a day. So it never closed. And he walked in very late one night. I knew who he was immediately. So there were only a few of us in the classical department, anyway. So after a little while, I sort of got my southern gumption up, and I went over to him and asked him if I could help him find something. And he was looking for an opera, some obscure opera recording, and I told him I'd help him see if we had it.

After a few minutes, I finally said to him, "Listen, I just want to tell you that I saw your play, *The Normal Heart*, and it really, really moved me."

And Larry being Larry, looked at me and said, "Oh, that's great. So what the fuck are you doin' about it?" [laughter]

Now, being a southern boy from Texas, we don't exactly talk that way, and I was really just sort of taken aback by it, and he must have seen it right away, because whatever anybody else ever says about Larry, he's the biggest teddy bear in the world. He saw the reaction on my face and he immediately said to me, "listen, if it really moved you and you really want to do something about it, there's a bunch of us that get together on Monday nights over at the Gay and Lesbian Center. You should come over and join us."

The very next Monday night, I went to my first ACT UP meeting, and I walked into this room full of people who were fiercely dedicated to actually doing something about the epidemic, and I knew the very first time I walked in that this was what I wanted to be doing, that I needed to be a part of this, that all of that about standing

on the sidelines and being an innocent bystander—that this was what I should be doing and I got involved right away.

SS: So who were your first friends in ACT UP? Who did you first meet?

KF: Well, Eric Sawyer, Andy Velez, of course Larry. Larry kind of looked out for me for a little while till I got my sea legs. I started going to Treatment and Data Committee meetings, so Bill Bahlman and George Carter and, of course, Mark [Harrington] and Gregg [Bordowitz] and Derek Link, and all the folks of Treatment and Data in those days were people that I started to get to know in the organization.

SS: What were they working on when you came in?

00:20:00 KF: They had just come out with a report called “Countdown 18 Months,” which was a report Garance Franke-Ruta and Derek Link were, I think, the big architects of the report. But it essentially was an attempt to look at all of the opportunistic infections that people with HIV get, and god knows there was a broad spectrum of infections that people got. The goal was we would have treatments for all of those opportunistic infections in the next eighteen months. It was incredibly ambitious document.

What happened in the context of T&D was that people were sort of assigned different diseases within T&D to look at, so different pieces were sort of being assigned to people. And Iris Long was sort of a mentor, and she started telling—she would work with us, different people, to figure out areas that you could work on and what were the different areas that you were going to work on.

So coincidentally, while I was working at Tower Records one summer, a young woman came to work at the store. She was on her college summer break, and Abby Friedberg [first name is phonetic, last name confirmed via Dorothy Friedberg] was her name. Abby and I became very good friends. She lived in Chelsea and I lived in Chelsea at the time. One day Abby because she knew about my ACT UP work and she knew about all of that, she said to me: “My mother is starting a research program over at NYU, and she needs somebody to help her. Would you be interested in a part-time job at NYU?”

So I said, “Sure,” so she set up an interview for me. I went over and met her mother, Dorothy Friedberg, who was an ophthalmologist at NYU, and I told Dorothy about everything that I was doing and I was involved with ACT UP and all that. Dorothy hired me on the spot. She had established the first research program at NYU on CMV retinitis. So I started working on CMV retinitis trials at NYU. So in ACT UP, in T&D—

SS: Was it DHPG or—

KF: In those days, DHPG, which Ganciclovir, that was the first drug, but there was a new drug coming that through the pipeline called Foscarnet, which was owned by Astra, and they were starting—they were getting ready to start a trial which would compare the two—compare Ganciclovir to Foscarnet. So I started working on that trial for Dr. Friedberg, and that coincided with my work in T&D. So I immediately sort of became the CMV guy in T&D, and I started writing articles about it for treatment issues at GMHC and other places. I was writing about new treatments and what we were learning about CMV retinitis. So those things just sort of lined up.

SS: Can you describe to us what a trial in that era was like?

KF: It was very difficult. Particularly in CMV trials it was really difficult, because most people weren't diagnosed with CMV until they had less than fifty T-cells. So you had to be very sick by the time you were diagnosed with CMV retinitis.

In our very first study, the very first trial we did, we did this comparison of Ganciclovir to Foscarnet, and the average life expectancy for someone in our study was about nine and a half months. So we were bringing these young men into this study to put them on these really terrible, difficult, toxic drugs, which they would tolerate for about nine, nine and a half months, and then die. So it was very difficult and very emotional for the staff and for everybody who was involved in the trials at that time.

SS: Because they administered it through a Hickman, right?

KF: Yes. You had to in those days, both Foscarnet and Ganciclovir had to be infused through a Hickman catheter, and it was a drip. You were hooked up to a drip, but you had to get it so frequently that you couldn't constantly be poking people. So these guys lived with Hickman catheters, which were put into their chest, because it was an easy administration for an IV, and it went, obviously, immediately into the bloodstream that way.

SS: Now, were people desperate to get into the trial? How did you select?

KF: I don't remember a desperation because CMV was still a relatively rare OI, and, frankly, if anything, we were desperate to find people who had CMV so we could get them into this study. It was an NYU study, but our offices were in the Eye Clinic at Bellevue. So we were in Bellevue actually screening patients through the Bellevue program to try and get them into the program.

Most of the people who came into those early studies actually were referrals from primary care physicians, people like Jeff[rey] Greene and Alex[ander] McMeeking and Ron[ald] Grossman. The primary care physicians that were sort of in the NYU circle were referring their patients, and there were gay men that were coming from private practices into the studies, but a handful would come from the Bellevue program. But, honestly, it was a bigger challenge getting people, identifying people, getting them into the trials than it was a desperation to get into the studies per se.

SS: I see. And how did Foscarnet come out?

KF: Well, the study was designed to be a progression study, which meant that it was designed to look at how fast the CMV retinitis disease progressed in one group versus the other, thinking that maybe one of these drugs was better at controlling the retinitis. But CMV is an endemic—it's an infection of the entire body it's not just in the eye, and so people who would get CMV retinitis—it was like you were identifying the tip of the iceberg, because it probably meant in most cases they were suffering CMV disease in other places, like in their intestines and things like that, that you weren't so easily able to identify. But in the eye, you could see it and you could track it.

But even though it was designed to be a study to look at how fast their CMV progressed, it ended up that there was a mortality outcome that was different, and the people on Foscarnet were living longer, three to four months longer than the people who were on Ganciclovir. It was a very controversial finding at the time, and a lot of people argued, well, it wasn't designed to be a mortality outcome, but there it was. You had a mortality outcome. It was published in the *New England Journal of Medicine*, it was considered a really important study, and, of course, the Aster people jumped all over

that to declare Foscarnet the second coming. But Foscarnet was a horrible drug. I mean, it was a terrible drug. It had to be administered more often than Ganciclovir, and it was incredibly toxic to the people who took it, and the side effects were just devastating, I think.

So there was an argument that even though people on Foscarnet might have lived two or three months longer, the quality of their life was lower, and that led to a series of quality-of-life studies, which sort of followed to try and articulate even more clearly what the differences were. But they were both horrible drugs. They were both horrible for the people who were on them.

SS: So did you stick with CMV after that study?

KF: There were several CMV studies that followed in the years after that. Then in late 1993, I left the program. I was offered a job by Bellevue Hospital itself, and the director of the AIDS program at Bellevue then was a man named Charles Farthing, and Charles had asked me to come over. My title at Bellevue was AIDS Inpatient Care Coordinator. Charles, who was a gay man and a friend, said, “What’s really happening at Bellevue is that a lot of people who come into the hospital and are sick aren’t identified as having AIDS. They’re not identified, and they’re not being diagnosed, and they’re going to all of these different wards for different problems, but they’re not being identified, and the doctors aren’t identifying them. They’re not getting tested and identified. They show up with pneumonia, but nobody tests them for HIV.”

So he hired me, and basically he said to me, “Your job is to help us identify these patients. I want you to go to every ward in the hospital and I want you to look at every medical chart in the hospital.” This was in the days before HIPPA, so I

could go and look. “And I want you to find cases that you think might be AIDS and bring them back to me and tell me about them, and then we’ll get those people tested. We’ll go up and offer them tests and see if we can get them tested, and then if they are HIV patients, we’ll get them transferred to the virology ward.” So that was my job.

SS: So what did you learn? That was amazing. What did you realize by doing that?

KF: It was a great experience, but it was a brief one. I was only in the program for about nine months, because six months after I joined the program, Charles announced that he was leaving, and he became the medical director at the AIDS Healthcare Foundation in Los Angeles. So he was leaving New York and moving to L.A.

00:30:00 It was right around this time that I had learned that Ellen Cooper had been hired by amfAR. Now Ellen Cooper, as you know, was the very first director of the Antiviral Division of the FDA, the newly created Antiviral Division at FDA. And Dr. Cooper was hired basically to review the filing for AZT, and she did it singlehandedly in record time, and yet she was also an incredibly difficult person to deal with. And one of the ways that she was very difficult to deal with was around CMV.

So I had gotten involved at the FDA because Dr. Cooper was looking at the application for Ganciclovir for DHPG, and people were going blind. The problem was at the time, because AZT was really the only medicine available, AZT caused anemia, especially in those days when people were getting really high doses. Ganciclovir, which is sort of a cousin, they’re both nucleoside analogues, also caused anemia. So people were having to choose between taking AZT and taking DHPG, Ganciclovir, because the anemia was such that you weren’t allowed to do both. Basically, the choice

was die of AIDS or go blind. That was your choice. So there was a lot of activism around it at that time.

So I knew Ellen. I'd gotten to know her. We called her the Ice Queen back then. She didn't like that very much. But I'd gotten to know her because of the FDA. She left the FDA, and in the sort of incestuous relationship that drug companies have with the FDA, she went to work for a company called Syntex, which was a West Coast biotechnology company which actually owned Ganciclovir, which owned DHPG, the very drug she had worked on as director of the Antiviral Division.

So she went to work for Syntex, and she wasn't there very long. They were trying to develop an oral formulation, a pill formation of Ganciclovir, and she was part of that and was navigating those waters with them. Eventually she fell out with Syntex. Syntex was bought out by Roche; they became part of Roche. Ganciclovir became part of Roche, and she left and was hired by amfAR. She came to amfAR as the vice president of clinical research, and at the time amfAR didn't have a clinical research department, so she was basically hired to come on board and create a clinical research department for amfAR, and she did that by setting up offices in Rockville, Maryland, right next to the FDA, where she lived.

When I heard that she was coming to amfAR, I wrote her a letter. At that time I was at Bellevue, I was working at Bellevue, and I wrote her a letter and I said basically some smart-ass remark along the lines of, "I understand you're coming over to the light." "You're leaving the dark side," I think is what I had said, and said, "If it turns out you need help in the program down there I'd be willing to help you." I was basically

offering my services. I knew Charles was leaving Bellevue at that time, so I reached out to Ellen and said, “You’re creating this department—if you need help.”

Well, she called me, like, right away. I guess right when she got my letter, she called me up and she said, “I want you to come down here and meet with me and meet the team that I’m assembling,” and so I did and she hired me, and that was where I went to work for amfAR.

SS: Okay. So the Ice Queen brought you over.

KF: The Ice Queen brought me.

SS: I just want to get back to the Bellevue thing, because I’m still interested in the hidden epidemic issue.

KF: Yeah.

SS: Where did you find AIDS? Did you find it in pediatrics? Did you find it in—

KF: I found it everywhere. Not pediatrics. That wasn’t our purview. That was really separate. So it was all adult AIDS. But I found it everywhere. People would come in with things—like I remember a young man who had a cryptococcal meningitis infection, right? Now, when you have cryptococcal, it’s a fungal infection, basically of the brain, of the neurologic system. When you have an infection like that, it’s pretty rare. It’s not unheard of, but it’s fairly rare. But it was an infection that people with AIDS who had compromised immune systems would get. And so he shows up on the neurology ward. They assign him to the neurology ward because he has terrible, terrible headaches, which is what happens with crypto. He’s in a bed there, and they do a

spinal tap. They eventually diagnose him with cryptococcal meningitis, never do an HIV test, never did an HIV test.

00:35:00 These were the neurologists. I think it's fair to say that there was a certain willful blindness at the time. NYU was not a very welcoming place to people with AIDS in the early years of the epidemic, and Saul Farber, who was an oncologist and was head of the hospital at that time, was even quoted, I think, as saying that he feared if "those people" started coming to NYU, that the more traditional patients, i.e., the older oncology patients, would stop coming. So he made it very clear that he didn't want AIDS patients at NYU.

And I think a fair amount of that—remember, NYU has a teaching relationship with Bellevue, so the very doctors who are the physicians at NYU are also the doctors at Bellevue who are teaching young residents in the Bellevue system. So there was a certain willful blindness. There was a certain willingness to say, "He's got cryptococcal, we'll treat him for cryptococcal, and then we'll get him out of here." So they didn't really—they weren't terribly interested in looking for HIV/AIDS.

SS: That's so ironic, because so many significant people died there. Vito [Russo] died there, and [Emery] Hetrick and [A. Damien] Martin died there.

KF: Yes.

SS: Phil Zwickler

KF: Well, if you were HIV-positive and you were poor, that's where you ended up. Bellevue was the place you went because it was the city hospital. Vito died nearly penniless at the end of his life, and I remember Larry raging about it at the time. Vito died in late 1990. I remember he—because I got here in February of 1990, and Vito

died in November of 1990. I met Vito several times during that year because he was close to Larry. But I remember Larry saying that Vito had to spend down his assets to qualify for Medicaid so that he could get care at Bellevue, because that was the only way Vito could get care at Bellevue, was by spending down his assets so that he had no money. And then he could qualify for Medicaid and then he could get treated.

So that's where you sort of ended up. You ended up in Bellevue. If you ended up in Bellevue in the AIDS ward when Charles Farthing was there, you got great care, because those doctors were AIDS doctors, and they were there because they knew what the—and Charles was gay and he knew what this was about. If you ended up on any other ward at Bellevue, the likelihood that you would even get diagnosed with HIV was fairly small. There wasn't a concerted effort to diagnose AIDS patients, because they were much more difficult and, I presume, in the terms of hospital-speak, they were much more expensive to deal with and all those other things.

So Charles knew that, he understood that, and that's why he hired me, to go and look at these other charts and find out what was going on with patients and try to figure out who might actually be HIV-positive that the hospital was missing. Then if they were, he would transfer them into the virology ward, and they would take care of him in the AIDS program.

SS: Now, what finally happened with CMV?

KF: CMV, like a lot of opportunistic infections in this country, anyway, diminished rapidly, and it diminished rapidly when we ended up coming up with cocktails which would essentially improve people's immune systems, right? If you could drive down viral replication to the point that their CD4 counts would recover, they would

become at lower, lower, lower, lower risk for all these opportunistic infections. So pneumocystis, Kaposi's sarcoma, CMV retinitis, cryptococcal meningitis, all of these opportunistic infections started to diminish at a very rapid pace in the aftermath of '97 and protease inhibitors. So it changed, and it's not unheard of today. It still happens. There's still diagnoses of people with CMV retinitis, but they're fairly rare, and we have better treatments for them today than we ever had before.

SS: So the concept behind Countdown 18 Months, which was to go after the OIs, basically became irrelevant once the cocktail was in place?

KF: Yes, except that it didn't happen in that kind of a timetable. Countdown 18 Months happened in the early nineties, and protease inhibitors didn't come on board until '97. Countdown 18 Months was an incredibly ambitious project, of course, and it didn't work out the way it was planned, but it sure galvanized a whole lot of work around opportunistic infections, which was not really happening at that point.

SS: So help me understand a little bit. Pharmaceutical companies, they were all looking for the magic bullet because that was the largest market, and they were hesitant to research for OIs. So how did they get pressured into making that transition?

KF: Some of them did earlier than others. Burroughs Wellcome, for example, had a drug called Acyclovir, which was a drug for the treatment of herpes, and a very effective drug for the treatment of herpes, a drug with very low side-effect profile.

00:40:00 So they cornered the market on herpes treatment pretty early on and showed that you could make money at it, right? You could develop treatments, even for these other kinds of infections and make money at it.

The problem with most of the other opportunistic infections is that they basically fell into the category of orphan drugs, because they happened so rarely. By drug company standards, they happened so rarely that it was very hard to develop a drug and make money on them, which is part of the reason why Ganciclovir and Foscarnet eventually, when it was approved, were so incredibly expensive. I mean, Foscarnet must have at the time broken records for the cost of a drug, because it was astronomical what its cost.

SS: Do you remember how much?

KF: It was near \$15,000 a year or more. Remember, when AZT was introduced, AZT, I think, came onto the market around 12 or \$13,000 a year, and that caused a big uproar. Well, fast forward ten years. By the time Foscarnet comes onto the market, \$15,000 was a big deal, and there were many a protest in Massachusetts as Astra's headquarters, but they didn't budge. They were absolutely intractable about it. It was an incredibly expensive, incredibly expensive drug.

But to get back to your question, the reality was in that period of time from the late eighties, early nineties, Countdown 18 Months, until protease inhibitors came on the scene in '97 and until they really began to saturate the market, if you will—that's a horrible way to say it, but until enough people started taking protease that you started to bend the curve on mortality, a lot of people's lives were made better by the effort to develop these drugs for opportunistic infections.

I think the vast majority, in my opinion, were developed by smaller biotechnology companies like Syntex, like Chiron who could afford to invest money in a particular disease area, even if it was an orphan drug area. They could afford to do that,

because they were narrowly focused on that and they were raising investor money to do that. But as we saw over time, almost all of those companies got bought up by big pharma. So once you sort of prove that you have a product that you can actually market, big pharma is more than happy to come along and buy you out and buy the drug. And that's what happened with a lot of OI drugs.

SS: Okay. So now you're at amfAR. Did amfAR and T&D have any kind of differences in terms of research agendas?

KF: By the time I joined amfAR, it was September of '94, and ACT UP had really changed a lot by then. In fact, TAG [Treatment Action Group] had been created a few years before that. A lot of the people from T&D had jumped ship and gone to TAG. I was one of a handful of people probably you could count on one hand who remained in T&D and became members of TAG. So I did both.

T&D would meet on Wednesday nights, and TAG would meet in Marvin Schulman's apartment on—I don't remember—Tuesday nights, whatever it was. So I was doing both, and I did both because I continued to believe that there was value in the kind of work that ACT UP could do, but also understood that the very front edge of research work was being done in TAG. So I put a foot in both camps and I stayed in both camps until I joined amfAR.

At the point I joined amfAR, I moved to Rockville, Maryland. That's where the research office was, and so Ellen relocated me to Rockville. I left New York, I went to Rockville, and I worked there for exactly one year and then moved back to New York and we closed that office, and that's a different kind of story.

But, yeah, so I kept a foot in both camps, but I stopped, essentially, when I joined amfAR.

SS: Can you explain to us why T&D split into T&D and TAG?

KF: It wasn't a T&D and TAG split; it was an ACT UP and TAG split.

SS: Okay. Can you explain it?

00:45:00 KF: Yes. I can give you my perspective, which was that ACT UP changed and began to suffer from the same kind of intra-organizational, infighting politics that happens to a lot of organizations, unfortunately, and maybe not surprisingly. I mean, I recently saw a documentary about Vito, actually, and the Gay AIDS Alliance. The Gay AIDS Alliance, of course, preceded me. That was in the early seventies in the aftermath of Stonewall.

SS: The Gay Activist Alliance?

KF: The Gay Activist Alliance. What did I say, Gay AIDS?

SS: Yes.

KF: I do that sometimes. So the Gay Activist Alliance was in the early seventies, and it was like déjà vu, watching this documentary and seeing what happened to the Gay Activist Alliance and how the factions within the organization began infighting, and ultimately the group had sort of run its course in a matter of four or five years.

You can look at ACT UP and say that its heyday, the real force of its work, happened really in a fairly narrow window, a fairly short period of time, a limited number of years. And the guys in Treatment & Data, Mark and Greg and others who were part of that, they became targets for some of that infighting, and they ultimately

decided, for better or for worse, that they could no longer do their best work within the confines of ACT UP. They were science nerds, they were geeks, and they wanted to focus on the science, they wanted to focus on the research, and they didn't want to have to deal with all of the other issues around the organization and the fighting and all of the other stuff that went on. So they decided to leave and form their own group. So Mark and Peter Staley, they formed TAG.

SS: I just want to talk a little bit about the ACT UP experience.

KF: Yes.

SS: So did ACT UP take over your life? Did it take over your social life?

KF: Yes. It was all-consuming. There's no question about that. It was all-consuming. My social life was ACT UP. That was what I was doing for a social life, and the people, my friends in ACT UP were the people that I socialized with and I went to actions with and I went to meetings on Monday nights with and I went to T&D with on Wednesdays and all of those things. So for that period of time, for those years when I was involved, yes, it was entirely all-consuming.

SS: Did you have a good time?

KF: Yes, it was incredibly empowering. My Catholic military upbringing taught obedience, and I left that because I knew always that I was going to be a person who was going to question authority. But ACT UP taught me that questioning authority wasn't enough, that you also sometimes had to challenge authority, and that was not something I learned at home. It was not something that I understood until I got into ACT UP, and I understood immediately the value of challenging authority, and that was an

incredibly empowering experience. That experience taught me that you really can make a difference. It's that Margaret Mead saying. Never doubt that a small group of individuals can change the world; they're the only ones who ever have. That was ACT UP for me. I learned in that experience that we could change the world, and, in my opinion, we did.

SS: Okay. I just want to ask you a few questions about AIDS right now, if that's—

KF: Sure. Sarah, you get to ask me anything you want.

SS: All right. Is prevention possible, successful prevention?

KF: Except that. You can't ask me that. [laughter] That is a very difficult question, it is a very complicated question, and it is one that I have struggled with my entire life. The simplistic answer is, yes, prevention can work, right? You give people knowledge, you give them condoms, you give them clean syringes. Yes, you can help people to protect themselves, and so, yes, prevention can work.

00:50:00 Where I struggle with it is that at the end of the day, we're talking about for the vast majority of infections, we're often talking about sex. The very nature of sex and the very fragility of the human condition, in my opinion, means that prevention is only partially successful. It can only ever be partially successful. It can never really fully succeed.

I don't think that we can end the AIDS epidemic through prevention only. I just don't, because I know human nature, and, of course, that's colored by my own human nature. I've known, throughout my adult life, periods when I was successful and periods when I was not successful with prevention efforts. And when you think about the

complexity of sexual behavior and then you multiply that by a desire to change behavior, which is enormously difficult to do—we know that. Look at things like obesity and smoking in this country, and you understand how difficult behavior change is, and then you add sex into that mix and it becomes incredibly difficult to do. So I think that we cannot end the AIDS epidemic through prevention alone. That is not what's going to get us to the end of the epidemic.

SS: Just to go a little bit further with this, I mean, we see that no matter what new prevention strategies come into play, the same percentage of people are getting infected, and there's something about seeing prevention as a private problem instead of as a social responsibility.

KF: Yes.

SS: So gay people still don't have rights, we still have racism, we still have all these things, and then we're asking people to transcend that somehow.

KF: Yes.

SS: But what if it was reconceptualized as a social issue instead of as an individual issue, if it was politicized? I mean, the prevention industry can't politicize because they're all funded and everybody's co-opted now. But what if there was a politic around prevention?

KF: Well, you're talking about changing culture, which I think can be even more difficult than changing behavior. But let me just say that I do believe that the prevention world has changed dramatically in the last five years. We have seen an extraordinary change in our understanding of prevention and our knowledge of prevention, and I would argue we haven't had success yet, or perhaps not even enough

time yet, to be successful at figuring out how to implement everything that we now know about prevention.

So I think if we could figure out how to implement everything we know about prevention today, we could radically alter the rate of new infections in this country. We could drive new infections down to really low levels if we could implement everything that we know.

So we've learned about a microbicide to protect women in the last five years. We've learned that circumcision can prevent men from acquisition in the last five years. We've learned through HPTN 052 that treating people who are infected can make them less transmissible in the last five years. We've learned through iPrEx and other studies that if you give people who are negative a pill once a day, you can prevent their acquisition of HIV. We've learned all of these things which have the potential to radically reshape the prevention agenda. We don't have anywhere near the understanding or the tools or the money or the political will to implement all of those things.

SS: We don't have a healthcare system today.

KF: We don't have a healthcare system that supports those things. That's right. So unless we're prepared to radically alter that landscape we're still just nibbling around the edges of prevention. We're still going to have 50,000 people infected every year until we figure out how we really effectively implement those things.

Take one example from that, the Gardner Cascade. I don't know if you're familiar with the Gardner Cascade.

SS: No.

KF: It was a study that was published that looked at AIDS in America, HIV in America, and it asked the question, okay, how many people have HIV, and how many people are at the point where they are virally suppressed, meaning they're on treatment and their virus levels are undetectable, which is what you need in order to achieve the outcomes in HPTN 052, which showed that if you put people on treatment, and they were treated effectively, and they were virally negative, that if they had undetectable viral loads, that they were unlikely to transmit virus to their sexual partners. Okay?

So in order to get from where we are, which is over a million people in this country living with HIV, what do we need to do? Where are we in terms of getting people to viral suppression? And what the Gardner Cascade showed was, in fact, less than 30 percent of all people living with HIV in this country are actually at undetectable levels of virus. So the other 70 percent of people living with HIV in America today have the potential to transmit virus in sexual encounters, in the sharing of needles, although in 00:55:00 New York State, we've been incredibly successful and that doesn't happen, but through any of these means.

And the Cascade is a Cascade because it starts with the question, well, how many people are HIV-positive in this country? We know that. More than a million. Of that, how many of them even know it? So how many are living with the disease and don't even know they have it? Of the ones who know it, how many of them are then referred to care? And of the ones who are actually referred to care, how many of them stay in care?

SS: Or how many of them have care to be referred to?

KF: How many of them can even get into care? Then the ones who do, how many of them actually stay in care? And each time you ask one of these questions, the number gets smaller and smaller and smaller and smaller. And you ask the question, okay, the ones who have been referred to care and stay in care, how many of them go on treatment and stay on treatment, right? And that's a percentage. And then you say of that number who are in care, on treatment, and successfully staying on treatment, how many are virally suppressed? And you get down to about 28 percent. So you go from 1.1, 1.2 million people living with HIV down to only 20 percent of them being virally suppressed.

SS: And that's why we still have 1,600 AIDS deaths a year in New York City, because people are coming into the ER.

KF: Because people come in too late, because they're not getting proper medical care, because they don't have access to the kind of care that would help them to return to care, to stay on treatment, to do all the things that they need to do.

SS: It's so interesting, because there's a real parallel between the condition of people with AIDS and gay people, because there are some gay people who basically have all their rights and are fine.

KF: Yes.

SS: Then there are some gay people who are profoundly oppressed, and they could live right next door to each other. It's so uneven—

KF: It's incredibly uneven, yes.

SS: —the experiences of being HIV-positive.

KF: It's incredibly uneven. There's another problem, though, too, in the way we've approached prevention in this country. We started out, for obvious reasons, in the early years of advocacy by saying everybody's at risk, right? We started out by saying everyone's at risk. It could be your son. It could be your daughter. It could be your uncle. We said this, and so the response to that was, "Well, we have to tell everybody. We've got to get the word out. Everybody's got to know." And arguably, we diluted our resources by saying everyone's at risk and spreading the resources as widely as we could, when, in fact, not everybody is equally at risk. If we had targeted our resources more effectively to the populations that we knew and understood to be at risk, I think we could have made strides much more quickly in the fight against it.

SS: Right. But it was a strategy because the people who were really at risk were people that nobody cared about.

KF: We did it for valid reasons. We knew that if we went out and said it was just about hookers, junkies, and whores, nobody would listen, right? Nobody was going to hear that argument. So we had to say it's not about fags and junkies; it's about your daughter and your son. It was a political strategy, and it made sense at the time. I'm not arguing with that. But as we got smarter about the epidemic, we didn't get smarter really about how we spend our resources to prevent new infections.

The other problem is there are about 1.2 million people living with HIV in America today. There are 320 million people living in the U.S., right? And our strategy for too long was, well, we have to tell the 329 million who don't have HIV how to stay negative. We have to focus on their behaviors. Use a condom. Here are the things that you have to do. Don't share needles. Don't do all these things. We tried to reach the

329 million, and we essentially ignored the 1 million. We just said, “Well, they’ve already got HIV. What good is prevention? We can’t talk to them about prevention. We’ve got to talk to the people who aren’t infected.”

If we took all of the resources we had for prevention and instead of sharing them across the board on the 329 million who live in this country, and focused on the 1.2 million and said we’re going to spend that money helping them to get tested, getting them into healthcare, buying health insurance if they need it, if we took all that money we spread trying to keep negative people negative and focused on how we keep positive people healthy and in care and on treatment, we could radically alter the course of the epidemic. We could drive down new infections overnight. But we spend way too much time on the 329 million and not nearly enough on the 1.2.

SS: And who is the 1.2?

01:00:00 KF: We know who the 1.2 are. The vast majority of new infections in this country still happen in gay white men, and if you look at the top four groups of people who are getting HIV today, of the 50,000 new infections, you see that gay white men are first, black MSM are second, black women are third, and gay Latino men are fourth. Those are the four big categories if you look at it. Yet here in New York State, Don DesJarlais, who is one of the leaders in syringe exchange, will tell you that for the year 2011 we are reporting zero new infections in injection drug users. We have driven it down to zero by focusing on that population, and we did it, by the way, over the last twenty years spending about 1.5 to \$2 million a year. That’s all it cost to implement the kind of syringe exchange programs, the prevention programs to drive new infections to zero.

So we know that gay white men, gay black men, black women, and Latino men make up the vast majority of infections. If we would focus our resources on the populations that are in the 50,000, if we would focus on the 1.2 million that have it now, we could radically alter prevention in this country. But it's difficult to do.

James Wentzy [speaker?]: Prisons?

KF: Prisons? Absolutely. But these remain uncomfortable populations for a certain segment of the population. So we don't have the political will and we certainly don't have the resources that we need to do that.

SS: I want to ask you about the new category of undetectable.

KF: Yes.

SS: It's a very complex category socially and emotionally and historically. We don't have the kind of public realm in which to discuss things that we once had. So, for example, somebody who was infected in the nineties who has been through every hellish medication, who all their friends have died, who's traumatized, who's now undetectable, is the same as someone who is just infected and is now undetectable. But it's not the same experience.

KF: Definitely not.

SS: And a lot of people view undetectable just means they can have unsafe sex now. So what is undetectable really?

KF: Well, there's a biological definition of undetectable.

SS: Okay. Socially, I mean, what does it mean?

KF: But you mean socially.

SS: Yes.

KF: There was a study published just this week, really interesting study, which looked at there was a period of time where people who were negative and positive, gay men who were negative and positive, employed a prevention strategy called serosorting, and serosorting meant that you tried to identify people who you thought fell into whatever category it was you were looking for. So presumably if you were negative, you were looking for a negative partner. If you were positive, presumably you were looking for positive partners. So this social phenomenon developed called serosorting, where gay men would try to serosort, and they would do that whether they met someone in a bar or increasingly online, through chat rooms and sex hookup rooms and all those things. And yet there was a fair amount of behavioral research which suggested that serosorting was of limited utility. It had limited effectiveness in its ability to sort of discern whether somebody was actually negative or positive in the groups that you were hooking up with.

Now there was a study that—an online survey that looked at gay men's behavior and found that gay men are actually asking their partners what their viral load status is today. Are you undetectable or not? That's become part of the lexicon in the environment in which gay men are meeting today. And I think it's a reflection of men—gay men are absorbing the information that O52 and other studies are providing about how the risk of transmission with an undetectable partner is diminished. So it's working its way into the social fabric of the gay community in interesting ways.

What does it mean? I'm not really sure. I'm not sure if it has long-term value, because a lot of these phenomenons, in my opinion, are just bridges, right? We're just bridging to the next development. And for me, although the bridge has spanned

twenty years of my work in AIDS, the bridge has always been to get to a cure, right? Ultimately that's what I saw at the other side of the bridge, and all these other things, whether they're prevention strategies—and arguably that's a bridge to a vaccine—or they were treatment or other things for people who were positive, that's a bridge to a cure.

01:05:00 So I think that if you're looking at the prevention bridge, there are things that people have done along the way to affect their prevention behaviors. I think undetectable is just another phase, to be honest with you. I think it's just something we're going through because that's what the latest information is telling us and that's what people are absorbing into their behaviors, but it won't last long before we will be on to something else.

SS: Well, I only have one question left. Is there anything else you think we need to cover?

KF: Oh, my god.

SS: Like the time you jumped naked into a swimming pool at the ACT UP party? No? [laughs]

Jim Hubbard: You answered, I think, specifically about when TAG left ACT UP. Why did you stay to do the work in both places?

KF: Yeah, I mean, I want to be careful about how I describe this period, because it was a difficult period, and I certainly don't want to offend any of my friends from that time about why certain people left and why certain people stayed. I stayed because I continued to believe that there was value in what ACT UP was doing. I stayed because I knew that if we wanted to do an action, that I could marshal the troops of ACT UP to an action, that I could get them involved, and that they were still prepared.

Whatever the infighting that was, was going on at the time, I knew I could still get them to come and be part of something important. And by leaving, I think TAG gave that up. Now, TAG did smaller actions, they did smaller targeted actions which were very effective, but they couldn't marshal the numbers.

I also knew that there was value, there was continuing value in being able to sit down at the table with a pharmaceutical company, which I did a lot of in those years, and say that, "I'm here as part of ACT UP New York," and that had incredible weight at that point because there was enormous credibility with ACT UP, and pharmaceutical companies feared ACT UP. They feared us showing up at their doorstep like we did in Meriden, Connecticut. I remember there was a biotechnology company that was developing an AIDS vaccine in Meriden, Connecticut. They were a relatively new company, and they had gone and gotten Congress to give them an earmark for money. James, you might remember this.

JW: I have footage.

KF: You probably have footage of that action. We went to Meriden one morning. We rented a U-Haul truck, and we all piled into the back of this U-Haul truck and we drove up to the—you had to go through the gates, which we did, at seven in the morning, and drive all the way up to the front to where their building was. And we jumped out of the truck and we chained ourselves to the front doors of this company's offices, and we yelled and screamed, and the police came and the fire department came, but we had used these metal tubes so that they couldn't see—we told them we were handcuffed inside, but in fact we'd used those little carabiner hooks, but we didn't tell them that. So they were threatening to come and bring the saws and cut us out, but they

were worried about cutting us. There was a whole negotiation. We knew it would never come to that. We'd done the same thing at Roche. I mean, my hand is inside a metal pipe there. I'm chained to Peter Staley.

JW: Roche went ahead and started sawing.

KF: Roche did, but this company didn't. So we eventually said—we negotiated to say, “Okay, we'll give up, we'll turn ourselves in, as long as you allow the television news crews to come and film us giving ourselves up.” So they did. So the police agreed, and the television film crew—we made the news that night, “ACT UP storms this biotech company”, and that was our goal, ultimately, anyway, was to bring attention to this issue.

So we went to the jailhouse. They took us to jail in Meriden, Connecticut. And we had spent a lot of time talking about Meriden, small-town Connecticut, what are the police going to be like. We were really nervous about it. We had a pro bono lawyer from Yale coming over from New Haven to represent us, but, nevertheless, we were nervous about it. ACT UP was committed to nonviolent action, but that didn't mean the police were.

01:10:00 So we go to Meriden and we do this action. They take us to jail. They arrest us, and they take us over to the jailhouse. And the police could not have been friendlier, couldn't not have been friendlier to us. Turns out a lot of them had advanced degrees from Yale. They were working in justice in this small town, but it was part of what their work was while they were working on degrees at Yale. They were terrific. We were going into the jail cell. They opened the door, and my friend Andy Velez, who

I hung out with a lot, he and I stupidly had bought tickets that night to see Bette Midler at Radio City Music Hall.

SS: So faggie of you, Kevin. [laughs]

KF: Yes, it was so gay. And I just remember as they opened the jail door cell to put Andy and I in the cell, Andy turns to the sheriff, the police chief who's standing there escorting into the jail cell. Andy turns to him and says, "Listen, are we going to be in here long? Because Mama's got tickets to Bette Midler, and I ain't missin' that show for nothin'." I thought the police chief was going to have a heart attack on the spot. It was hysterically funny. Everybody just broke up laughing.

Well, they were so terrific to us. They sent out for lunch. We spent the day in the jail cell. They went to McDonald's for us. They gave us lunch for free. We waited to get processed.

Eventually when we went back for our court date, which was probably a month or two later, turns out that the district attorney from Meriden, the attorney for the city of Meriden, was a black lesbian. So, like so many other ACT UP actions, we got off with just a little slap.

SS: Big Mac.

KF: We, ACT UP, had to make a donation to an AIDS charity in Connecticut. That was our punishment, which we did, which was easy enough.

SS: That's a great story.

JH: Did you make it to the concert?

KF: And we did. We actually made it to Bette Midler, yes.

SS: Amazing.

KF: We did. We actually had to get on the train. We couldn't ride back in the U-Haul because we didn't think we'd get back in time, but we managed to get on a train and get back to the city in time to get to Bette Midler's concert that night at Radio City Hall, yeah.

SS: Happy ending.

JH: So my other question is from James' footage, too, it's footage of you at an international AIDS conference screaming at some pharma guy. So I was kind of wondering about ACT UP's relationship to the AIDS conferences.

KF: I screamed at so many of those, I'm not sure which one it would have been, but it's very likely that it was either Astra or—

JW: That would have been maybe Berlin?

KF: Yes. Yes. Berlin was '93. I actually think it was Geneva in '90. Geneva would have been '94, '95, something like that. It was after Berlin.

JW: After Yokohama.

KF: After Yokohama. Yokohama was '94, because that was the year I joined amfAR. So maybe Geneva was '93. And then it went every other year, because '96 was Vancouver or something like that.

Yeah. It was either Astra or Roche. Eventually Roche became the target for ddC [Hivid], and then they had bought Syntex, so Ganciclovir was a Roche drug. I remember being particularly angry at Astra because I knew more about Astra's drug development with Foscarnet than most people knew, because we had participated in that at NYU. So I had worked on the study that helped Astra file their application for approval with the FDA, and it was a pivotal study which showed a mortality advantage to

Foscarnet, and yet that study in its entirety was paid for by the National Institutes of Health. It was paid for by the NIH. It was paid for by the National Eye Institute, which conducted the study. And Astra had the audacity to introduce their drug at a price which was unheard of. And I confronted the company publicly at the AIDS conference to say, “How do you justify charging us this outrageous price for a drug that the taxpayer paid to help you develop?” It was one of those, “Have you no shame?” kind of moments.

And the answer to that was no, they had no shame. They absolutely had no shame whatsoever. They were unequivocal about the fact they believed they were doing the right thing and that it was their right to charge whatever they wanted to charge, and they did.

SS: So here’s my last question. So just looking back, what would you say was ACT UP’s greatest achievement, and what do you think was its biggest disappointment?

01:15:00 KF: ACT UP’s greatest achievement, in my opinion, was that it changed the way research got done in this country, and there’s a long spectrum within that. But really and truly what I mean by that is it changed the way NIH and drug companies did drug studies and simultaneously changed the way FDA reviewed those drug studies. It just radically altered the way a drug gets developed, and some of that is not great. I mean, some of it changed in ways that we didn’t predict and allowed drug companies to do things that we didn’t necessarily want done. But when you are arguing for getting access to these drugs as quickly as possible, doing these studies as humanely as possible, but as quickly as possible, and then telling the FDA, “You have to review these as quickly as possible,” some of the side effects of that process were that drug companies

took advantage of those loopholes. Okay? So without question, changing the way research got done in this country, in my mind, is by the far the single greatest achievement that ACT UP—measurable achievement that ACT UP achieved.

ACT UP's greatest disappointment for me was that the way it declined, the way it ran its course, and maybe that is the way these things happen. Sure, it's what happened with the Gay Activist Alliance, and ACT UP—the parallels in the way that they sort of fell apart and the infighting that happened in the organization was incredibly painful. Because I was so invested in what ACT UP was doing, because it was my social life and it was all those other things to me, it wasn't easy for me to walk away from it. And that's probably part of why I kept my foot in it and kept going even when others didn't. It was very hard to completely separate myself from that, but the infighting was mean and it was ugly and it was harsh, and I never wanted to be a part of that. I always tried to find humor where I could in those days, sometimes probably in ways that I shouldn't have. The Barbara McClintock Project may not have been my best moment. I don't know if you know the story of the Barbara McClintock Project, but—

SS: Tell us.

KF: This was late now, so this was probably, '93, '94. There was a movement in ACT UP to something called the Barbara McClintock Project. There was a faction within the organization that felt that if we could replicate the effort that went on around the Manhattan Project and create an institute that's sole purpose would be to focus on finding a cure for AIDS, if we could assemble that kind of brain power and that kind of think tank, that we could achieve enormous things.

They wanted to do that, and they named it the Barbara McClintock Project. They pushed really hard within the organization to do that, and reasonable people could disagree about these things. There was another—there were a lot of people in the organization who felt that was a misguided effort, that we, in fact, benefited from the diversity and the wide array of people who worked on different parts of the epidemic, and that if we tried to centralize all of that, we could end up starving those other parts of the response because we were focusing all our efforts into a singular project. I was one of those people who felt at the time that we weren't—that the McClintock project wasn't the right way to go, but there were others, Mark Milano, people like that, who felt very strongly that it was.

One of the ways that we communicated at ACT UP meetings on Monday nights is that people would bring articles that they had written, information they wanted to distribute, and we would lay it out on a big table. So you'd come into the ACT UP meeting, and the first thing you would do is you would go through and you'd pick up all the flyers, and you would learn about a new action or you'd learn about an article on this, you'd learn about an article like that, and whatever.

01:20:00 So I wrote a piece, which I'm not particularly proud of, and it was meant to be satire. It was meant to sort of articulate the arguments that were going on at the time about the Barbara McClintock Project, and I wrote a proposal that ACT UP change its name to ACT BABS and it was kind of a play on Barbra Streisand and people calling her Babs and everything. And then I wrote a series of sort of satirical things that we would have to do at all of our ACT BABS meetings singing the song "People, people who need people," whatever.

Anyway, some people found it hysterical, all the wrong people, probably, found it hysterical, and others found it insulting. And in retrospect, it probably was to the people who were dedicated and working hard on the Barbara McClintock Project. I was trying to find humor in it, but they didn't take very kindly to it, and I certainly understand why.

JW: The alternative was the Office of AIDS Research?

KF: The Office of AIDS Research, which really was a TAG initiative.

The Office of AIDS Research existed within the NIH. Not many people knew this, but there was an Office of AIDS Research, and the reason not many people knew it is because it was Tony Fauci. So Tony Fauci was the director of the National Institutes of Allergies and Infectious Diseases. He was also simultaneously the director of the Office of AIDS Research. And so a group of people—I wasn't one of them, but a group of people decided they wanted to take that out of Tony, and they wanted to empower it as a separate office that would have cross-institutional power, to move money around among institutes and thereby try to achieve the kind of synergy that they were looking for across the twenty-four institutes of the NIH.

They succeeded, and the Office of AIDS Research was created, OAR, and yet I don't believe in the history of OAR—and they've had three, at least three different directors—that although they do have authority with the institutes and although they do theoretically have the ability to move money around among institutes, to my knowledge, they've never once exercised that authority. Rather what happens is, is that they get their own pot of money and then they distribute that back to the institutes to work on projects that OAR deems worthy and valuable, I mean among other things. They do other things,

certainly, but they never exercised the very authority that they were created to exercise.

So that didn't work out so great.

SS: Right. It didn't work out.

KF: Yes.

SS: Okay. Anything else? Thank you. Can I tell you that almost everything you told us is new to us.

KF: No, that's impossible.

SS: I think you have the highest quotient of new information.

KF: Is that true?

SS: Yeah.

KF: Really?

SS: Yeah, it's been really great. It's been really helpful.

KF: Thank you.

SS: Thank you so much.

KF: That's nice to hear.

SS: You are an expert. You already knew that, but you actually are.

KF: I've just been around long enough.

SS: Yes but you also remember.

KF: And fortunately I remember some of this stuff. It's not that I'm a particular expert I just remember it.

0:1:23:34

SS: You've got the big picture. Thank you.

[End of interview]