

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: **Karen Ranspacher**

Interview Number: **094**

Interviewer: **Sarah Schulman**

Date of Interview: **July 13, 2008**

ACT UP Oral History Project
Interview of Karen Ramspacher
July 13, 2008

SARAH SCHULMAN: Tell me your name, your age, today's date, and where we are.

KAREN RAMSPACHER: Can I remember my age? Karen Ramspacher's my name. I am forty-three. And we're at my house at 219 East Second Street, Apartment 2E.

SS: And today's date?

KR: Today is July 13, 2008.

SS: Okay. Great. Karen, where did you grow up?

KR: I grew up outside Philadelphia in a town called Havertown, and then we moved around pretty much every year when I was little kid till I was ten, and then we lived in Rye, New York, in Westchester.

SS: Was your family community oriented at all?

KR: Well, Catholic, so usually involved with the church, and my parents were both very progressive politically, so, very Democratic. Solid Democratic working-class was their background, and so they talked a lot about caring about people. It was a lot about caring, and they talked a lot about elections. I remember being a little kid in the seventies talking about McGovern and Nixon and the war, Stop the War. We used to pray to stop the war in Vietnam.

SS: Did you believe it would work to pray to stop the war?

KR: Yeah. I think power of positive thinking. I still believe that works. I also think political speaking works, so, I guess, without knowing it, speaking truth to power was very important in my household. My mom stood up to the Catholic Church.

She used to teach catechism, and one of the students in eighth grade asked her if after Jesus was born was Mary still a virgin, and my mother was a biblical scholar and she said that some scholars said that indeed Joseph and Mary had other children, and she was kicked out of teaching CCD [**Confraternity of Christian Doctrine**] because of that point of view.

SS: Wow. So then was she removed from as a teacher permanently, or did she get back into teaching?

KR: She did not get back into teaching. {LAUGHS}

SS: Wow. How was that handled? Was that like a big trauma in your family when that happened?

KR: No. I mean, she just said, “They’re wrong and I’m right, and I’m going to keep telling them they’re wrong.” I think it was traumatic for her, but it didn’t shake us up.

SS: What did your father do for a living?

KR: He worked for IBM, which in the seventies stood for “I’ve Been Moved,” so that’s why we moved a lot to different locations, which is actually really good for a kid, I think, because you make new friends and you learn how to socialize really well, and it prepares you for being in different circumstances and handling yourself, teaches you some basic etiquette and the ability to get along, a little bit of politics.

SS: So when you were in high school, were you involved in any kind of organized politics?

KR: No. I went to a Catholic all-girls' school, so, in a way, by its very nature, it felt political because girls did everything. And, actually, my mom raised us—I have another sister and a younger brother, and she raised us all to think we could be whatever we wanted, and I decided I wanted to be the first woman president. Okay, that's not me, but we had one running. So I think in the all-girls' high school, the girls ran Student Council, they did the yearbook, they organized the parties, they did everything, and I was a big part of that. So I wasn't political in terms of political parties, but always very active and a leader.

SS: What was your relationship to people who had fewer rights than you had? Did you see yourself as a person who was standing up for people when they were being victimized? Was your politics a politics of empathy or were you seeing yourself as a constituency that you were concerned with?

KR: Both. I mean, I know I keep talking about the religion, but in the way I was taught Christianity, a lot of Christ's teachings are similar to many of the ethics, where you care about people, the poor, the hungry, the homeless, and you're supposed to look out for people who are in a bad circumstance, bullies. So, yes, I was the kid in the neighborhood who was standing up for the kid being picked on, because that was the sense I was getting from home and from church, that that's what we do and that's how we make the world a better place.

I remember the Bobby Riggs-Billie Jean King tennis match, which was a seminal feminist moment, and I was a little kid, and I was rooting for her and I was telling the boys, "Girls are just as good as you, and we can play sports." So it was both,

empathy for those who were in less circumstance and understanding that, as women at that time in the seventies, we were seen as a lesser class.

SS: So where did you go to college, or did you go to college?

KR: Oh, yes, I did. I went to Cornell for a year, but it was too far from a city, because I grew up in Westchester, and I was a club kid and missed dancing in the nightclubs. So I transferred to Wellesley, which is a suburb of Boston and a women's college.

SS: Let's go back to the club kid. What clubs did you go to?

KR: Oh, I went to the Peppermint Lounge. It was my favorite.

SS: Oh, god.

KR: You're my contemporary.

SS: I'm older than you, but yeah.

KR: The Pep was big. Oh, god, what were they called? I went to Studio 54 before it went under, and I wore my prom dress and went with a gay guy in a tux. Seemed apropos. Spent a lot of time at CBGB's, listening to very bad punk bands, although I did see the Tom Tom Club there, which was a lot of fun. So, places like that.

SS: When did you start socializing with gay men or hanging out?

KR: Oh, Danceteria, too, spent a lot of time at Danceteria. Started socializing with gay men? Well, in the all-girls' high school, we were friends with the all-boys' high school, and I was in the theater group and, you know. So I had a lot of boyfriends who I would date, who then would tell me that they had feelings for other boys. So I felt like the steppingstone to gayness for some of my high school boyfriends.

SS: Oh, that's depressing, can be depressing.

KR: A little bit. {LAUGHS} I was like, “What is it about me?” But, actually, in my family I have a gay great-uncle, who was living with his partner back in the fifties, and they were together for like thirty years till my Uncle Frank died. So when I was growing up, I remember I was about five years old and I asked my mom, “If Uncle Eddie is Grandma’s brother, but Uncle Frank isn’t, who’s Uncle Frank?”

And she said, “Uncle Eddie and Uncle Frank are married, just like your daddy and I.” So I just assumed everybody had gay people in their family, so when somebody would say, “Well, you’re gay,” I’d say, “That’s not a bad thing.” So I think probably I projected that, and that perhaps drew some of these gay boys who weren’t out yet to me.

SS: So given that you’re hanging out at all these places and you’re having this sophisticated New York life, why did you decide to go to women’s college?

KR: Well, I never have trouble meeting men, so it didn’t really matter. It was a good college, and when I was transferring, I just wanted to be closer to Boston, and I didn’t want to go to Boston University; it’s too big. I didn’t want Boston College; it’s Catholic. So Wellesley was a great school, got in. Tried Harvard, didn’t get in so—

SS: So, no prejudices?

KR: No. But I knew that I could handle being in an all-women’s environment and it wouldn’t cut down my social life, which some people might think it would.

SS: So when you were at Wellesley, did you become more politically involved?

KR: Not exactly. The movement at the time that I was in Wellesley was against pornography, and there was that whole movement in, I guess it was the early eighties timeframe, which pornography is evil. That's not my relationship to pornography, and I think that was actually seen in ACT UP. You could actually be into sex and into porn and a feminist at the same time, and so it's about the type of eroticism. So my goal was to make eroticism better for everyone.

SS: So that was not your calling.

KR: It wasn't my cause. So that was the cause of the day, that and animal rights. I like animals, but I figure we should take care of people first, and then I'll get to the animals.

SS: So when did you first become exposed or hear about AIDS?

KR: Well, I was working in the art world. I have a degree in art history, and I thought I wanted to be a curator. So I was a curatorial assistant at Dia Art Foundation.

SS: After you graduated?

KR: Yes, after I graduated from Wellesley. I knew about AIDS in college, HIV, and remember hearing it was sexually transmitted and knew I was sleeping with men who were either maybe using drugs or sleeping with other men, so I kept getting tested every six months. The nurse at Wellesley finally said to me, "You have to stop doing this." She's like, "You have to use a condom." So, okay. She said, "I won't test you anymore if you're having such risky behavior."

SS: How did that feel to hear that?

KR: Like she was right, and if you really think you're having risky behavior, you should take of yourself. But it actually caused me empathy later when I was in ACT UP and met men who were seroconverting, even as I knew them. I could understand how if I were in that circumstance that it might be me too. So it made it very easy to relate. But it did change my behavior. So, you were asking about AIDS.

SS: You were working at Dia.

KR: So at Dia, I was working and it was the first time I was meeting people who were actually infected and would talk about it. And then they were getting really sick, and I just thought, "This is really bad. No one should die from sex, because sex is great." So someone invited me or told me about an ACT UP meeting. I remember, I was at the *Village Voice* Awards.

SS: The Obies?

KR: The Obies, and it was at BAM. ACT UP got an award that year. Eighty-eight. ACT UP got an award and they dropped the banner. Robert Garcia was there, and I was so like, "Silence equals death. Huh?" And I was standing the lobby looking puzzled, and Reno came over to me and said, "Why do you look like that?"

And I said, "Well, I'm trying to figure out what that means."

And she's like, "What rock have you been hiding under?" And so she told me about ACT UP and the meetings at the Center.

So I got a friend, who was gay in the art world, and we went to meetings and we just started going all the time after that.

SS: So do you remember what your first impressions were or what you felt when you first came in?

KR: I thought, what an exciting group of people, a place to make change, and that's just great. I thought it was so great to find a community of people who felt the same way I did, that no one should have to die from this disease. We can do something about this. There are ways to work within the system, around the system, above the system, below the system, and just make change happen. So it was very exciting.

SS: So who were some of the first people that you met?

KR: Well, Robert Garcia I remember from day one. He was there at the banner drop, and he just had such a shining personality that I was immediately drawn to him. I think he was a facilitator at the time or he was variously throughout, so he became a friend.

SS: Can you tell us a little bit about Robert?

KR: Yeah. He's not with us anymore. He died in '93. Robert. Let's see. He had a great mix in his personality, where he was very electric, but at the same time he was very focused and organized. His job, in his day job, he was like a secretary in an insurance company, which made total sense to me because he could be so together and step by step, which also made him a great facilitator at the meetings, and then the other side being so magnetic and really drawing people to him. He was a great party friend. I mean, we went to clubs and danced, and then he'd go off and go to the back rooms, and I'd say, "I got to go find some straight guys." {LAUGHS}

I campaigned hard to be able to live in the loft where he lived with Catherine Gund and Jocelyn Taylor and Robert, and I was the fourth roommate. We had four bedrooms, and then there was an extra bedroom above the bathroom, and some other activists from North Carolina lived there for a while, too. And then at one point, all four

of us had one other person living with us. I had my sister, Robert had his brother, I don't remember, Catherine had somebody, Jocelyn had somebody. It was a very busy loft, and there were a lot of meetings in our loft.

SS: Where was it?

KR: It was at 60 Warren Street, which is between Church and West Broadway, and now it's the super ritzy, upscale gentrified neighborhood. But at the time, it was a fifth-floor walkup, which was really nine flights, because they were the double flights. So I think it was grueling for people to come to meetings there, because there was no elevator. But it was a huge loft space, and it was a commercial space that was supposedly Look Mom Comics, was the name on the door. The fire department used to come and knock, too, because they knew people were living there who weren't supposed to. We'd be real quiet, so we wouldn't get kicked out. But it was a great space.

SS: Why did you want to live there?

KR: Well, because it was really a center of activity and such great energy and such great people, and everybody was doing ACT UP plus something else. Robert was in the people of color group.

SS: House of Color?

KR: House of Color, thank you. And Jocelyn was involved with Clit Club, and Catherine was making documentaries, and I was doing WHAM! for reproductive rights, and they were all doing that, too. We were all doing everything together.

SS: Did you have any concerns about being in a movement house, that you would have no privacy or no way to get away from it, or was that the goal?

KR: I'm not a very private person. {LAUGHS} One of my friends cautioned me about doing the interviews because anybody can read them, but to me, I'm proud of everything I've ever done. I'll talk about anything I've ever done. I think it's important for us to learn from each other. So privacy was never an issue. Plus, you can always find a sneaky quiet place if you want it. But, I mean, we did have code words, you know, in case our phones were tapped. We didn't talk about the things that you didn't want to talk about.

SS: Did you believe that your phones were tapped?

KR: Yes, they were. You could hear the clicks.

SS: Did you do a Freedom of Information Act?

KR: You know, I never did. I should.

SS: So what would be something that you would not say on the phone?

KR: Well, I know how to perform abortion, and should abortion ever become illegal in this country, I will gladly teach and they can come and look for me. {LAUGHS} It's called menstrual extraction, and so that's something that we used to practice at the time, and we were taught by some of the women who were in the feminist health movement. It actually came out of ACT UP. A lot of the very cutting-edge reproductive rights stuff that we were doing—

SS: We as WHAM! [Women's Health Action & Mobilization] or ACT UP?

KR: We as WHAM! Well, it started out there was always parallels. There was always overlays between the Women's Health Movement in the late eighties and

ACT UP, because the principles are the same. It's about respect of your body, control of your body, health of your body, rights of your body. One of the t-shirts that I loved at the time was "Your laws stop where my skin starts." Basically, it's really all that. I mean, it's all about sex. It should be all good stuff, so if it isn't, we need to fix that. So for me, the parallels were clear, and for a lot of us they were. So these women who had been in the feminist health movement were actually in ACT UP, core members and so—

SS: Like who?

KR: I guess I can say it. Risa Denenberg, Marion Banzhaf, those were the two. They brought such a perspective that we actually ended up doing a teach-in. I don't know if they've already spoken about this, about the parallels between the women's self-help movement and the AIDS movement. We did a big day-long teach-in, and we ended up doing a book, *Women, AIDS and Activism*.

SS: What were the parallels?

KR: The parallels are that it's about a self-empowerment movement. It's that you can take control of your own body in so many ways. With the women's health it's about learning your cycle, understanding how it works, treating certain conditions holistically, like a yeast infection. Is it really an infection and there are natural holistic things you can do. And at the same time, those same principles we're applying to people with HIV. There are natural herbs you can take and vitamins and all kinds of supplements that you can take to help with viral load and fighting off infections. Even some of the infections are the same. Thrush is a problem. It's the same thing as yeast.

And then in terms of how you do it politically, I mean, menstrual extraction is about taking your menses out and it's taking over a medical procedure,

which isn't really a medical procedure, and doing it on your own. So the idea that you can wrest healthcare from the health system and beyond the medical system is sort of what ACT UP was doing, too, getting drugs into bodies, making it easier for people to access the care they need.

SS: So ideologically, you did the teach-in because there was a need for this information or a need for this concern. What was missing that made you do the teach-in?

KR: Well, someone such as myself, I was, whatever, ten in '75, when these feminist health clinics were thriving. So I didn't know, but I knew they existed, and I knew I needed to know, and if you went to look for books, there were like two books by the Federation of Feminist Health Centers, and I had them both. {LAUGHS} So how do you learn this stuff? So we just happened to have these resources right here, so we got with them and we did a teach-in. So we started with the feminist principles, and then we built on it about women and AIDS and what were the issues, and then about the AIDS movement with men and where are the parallels. So it just put all the pieces together.

SS: What was it that the men were not grasping that was offered by this?

KR: The way that the women had done it were methods that the men could borrow and learn, so it was like this wisdom already exists, let's quickly teach it instead of reinventing the wheel.

SS: Thank you. I just want to ask you a little bit more about Robert and then we'll get back to you.

KR: Oh yeah, sure, no problem.

SS: Were you involved when he got ill?

KR: I was. I was in his primary care group. I was his best friend, at least, like a sister. So when he got ill, I was the person who organized the group, because I knew that I couldn't do it all myself. He had dementia, and he would be walking through the East Village in winter, in his underwear, thinking that he was Jesus. That was a really hard time.

SS: How would you respond to that?

KR: Well, people would call me and say, "Robert's in the East Village in his underwear again."

I'd say, "Well, did you get him inside? And this was before cell phones, so it was real hard. Usually, somebody would go out, tuck him in. Sometimes we would get him to St. Vincent's and we would take rounds, because St. Vincent's was so overcrowded, the hospital, at the time that you couldn't get a bed. So he would be in the hallway in a gurney, and we would sit with him, because we didn't ever want him to be alone. So we would make shifts so that no one person had to do it 24/7, because it could take days to get a bed. And then once you get a bed, what are you hoping for? I don't know. A medication that's going to bring him back to himself? At that point he had seven T-cells. This was before the cocktail. He had some OIs. So we were just trying to make him as happy and comfortable as possible.

He was very clear on what he wanted. He never really wanted to impinge on his life, and I can't say I blame him. He just wanted to keep being the Robert he was, and that meant going out as much as he could and participating as much as he could and

not slowing down, and, as he used to say, not eating right. I mean, I'd go over to his house—we lived together at the loft, and then I moved to East Second Street—no. Avenue B, between Twelfth and Thirteenth, and he did, too. He lived with Victor.

SS: Mendolia?

KR: Uh-huh. And I lived in the apartment below them with my sister. So it was still a house, and he had keys, and he would come in and he would borrow my dresses to go cocktail waitress, and I'd come home, and my best dress would be trashed. {LAUGHS} But, you know, it went both ways. He'd lend me stuff to wear too. I'd wear his leather jacket.

SS: Why do you think that you became responsible for his care, and not a man? That's the question I'm asking.

KR: At the time, he didn't have a boyfriend, a steady boyfriend. He did later. He met Bob Scarpa. I don't know. I guess because we were already roommates and I really loved him. We were really tight, like brother and sister. He knew my family and I knew his family. His brother Danny came from L.A. to live with him. Danny was younger and a little less responsible. I don't know. I'm a caretaker. I don't know. I don't know. It was cool. It worked, and I had the resources. I paid his insurance premium when he couldn't work anymore. It wasn't much; it was like 100. I mean, god, nowadays, that's a great bargain. It was like 180 a month.

SS: So when he died, were you responsible for his body?

KR: No, he was in L.A. with his family. He went home, which I think was the right decision for him, because he was really tight with his family and he loved his parents and his sister and his brother, his two brothers, older brother and younger

brother. He was tight with the nieces and nephews, so he was really right in with his family. I actually wasn't there when he died. Ann was. Ann was a social worker from Community Health Project, which is now Callen-Lorde. He had that kind of impact on people. I mean, Ann didn't even live with him, and she was there for his death.

I remember she called me and she was like, "He's going to pass. Do you want to come out?" But by that point, he wasn't cogent anymore, and so I actually decided not to go, which was a really hard choice. But I wanted to remember him the way I knew him, and he knew I loved him. I talked to him on the phone, when he was there, and I actually went out with him to L.A. when he first decided to go tell his family, because they didn't know, and I went.

SS: Did they know he was gay?

Tape I
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KR: They knew he was gay. He had been out to them for a while, but they didn't know he had AIDS. While he was out there, he had a heart attack, which could have been related to drug use. They don't know. So I went out and stayed for a week. Maybe that was part of it, too, since I was there when he told them and they were kind of looking to me to sort of bridge that gap for them and be them from afar.

SS: Thanks for telling us about him.

KR: Sure.

SS: So let's get back to you. So you got into ACT UP. Besides the women's health stuff, what was a big activity that you got involved in?

KR: I did Treatment Action Committee. Me and Garance Franke-Ruta were like the two chicks for a while. Some of my best memories of ACT UP, for some reason, the women always sat in the front. Do you remember that?

SS: Yes. I thought because they were shorter.

KR: Is that what it is? {LAUGHTER} I always like, “Why do we always sit in the front?” I also kind of felt like a student at class. I wanted to be up front and take really good notes. So we were always up front. I really liked that aspect, because I really felt like I got it all. {LAUGHS} Then also I liked the back of the room where [whispering], go back there because you had to have a sidebar conversation.

So Treatment Action Committee, I did it because I’m kind of a science geek and I wanted to know what was going on, and I loved studying the science. Then I got involved with the Fetal Cell Group, because there was the possibility that fetal cell tissue could be used to help improve the immune system, and there was this ban from the government, which I believe is still in place, to prevent that experimentation from happening. So it was an interesting connection of moving science forward, using something that’s a product of abortion, and figuring out how to make people better. So it was an interesting mix.

SS: Who was in that subgroup with you?

KR: David Lopez, who also died in that early nineties. He was in the Lavender Hill Mob — Marty — .

SS: Marty Robinson.

KR: Yes, Marty. What a character, great guy, character. And there was one other person and I can’t remember. But we looked at all the science and wrote a big report, like 138-page report for ACT UP, and then ACT UP used that with the scientists. So that was sort of my subcommittee of the Treatment Action Group.

SS: And what did you find in your report?

KR: Basically, that there was a lot of valid science for doing this and pursuing it, and it would help not just HIV, but also Parkinson's and Alzheimer's, and it had all this potential, and that it was basically being stonewalled because of the abortion issue. It seemed very shortsighted and reactionary and right-wing. So we tried to bring the science to the fore and put it out there so that the scientific AIDS community could get behind it and help push through the abortion block, which was essentially a religious right block. It was good to do. Somebody needed to do it. I don't think that the AIDS scientists would have touched it, because it would have been too political, but by having us do the research, hopefully we helped move that cause forward. That was the idea.

SS: What did you do with Garance?

KR: Well, Garance was the only other girl in Treatment Action Group, so it would be a meeting with, whatever, twenty guys and two of us. I wasn't in a subcommittee with her. It was just fun to see her at the meetings.

SS: What were some other campaigns that you were involved with?

KR: Art Positive.

SS: Can you tell us how that got started?

KR: I don't remember. How did Art Positive get started?

SS: Because you were still working in the art world for your money job?

KR: Yeah, that varied. I mean, we're talking a number of years. So in '88 and '89, I was still at Dia, and we did a lot of things at Dia. We had a lot of meetings at Dia. We did teach-ins at Dia. We did reproductive rights screenings at Dia. God bless

Dia. We made lots of copies at Dia. I don't think they realized how much paper was liberated, how much their machines were used. So that was a great resource.

Then I was working with Group Material, which is an artist collaborative, and we were doing social and political art projects. That wasn't exactly a paid gig. We were paid honorariums. But we traveled around the country, around the world. They were already famous when I got to join them, and that was through Dia. God bless Dia.

We did the AIDS Timeline, which is the social and political history of AIDS in this country from 1979. The first time we did it was 1989, and we did it in '90, and then we did it in '91. It was first at UC Berkeley and then at the—was that at the Whitney? No. It was at the Whitney, but it wasn't in the biennial. Then it was in the Wadsworth Atheneum.

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SS: Who else was in Group Material?

KR: Julie Ault, Doug Ashford, and Felix Gonzalez-Torres when I was a member, but the membership changed throughout the years. There were thirteen at the start, and then it was two more later after I left. At one point, Tim Rollins was in it.

SS: Had you been making art before that?

KR: Not exactly, but I've always been a researcher, and kind of my role often in things was researcher, whether it was in the women's movement. I would read the Supreme Court decisions and then help bring them down to a one-page fact sheet. Or with the fetal tissue issue, I would read a lot of stuff and then synthesize it. It's the same principle. So in the AIDS Timeline I read a lot of stuff and then helped write the timeline. Now I'm a researcher in television. It's a good cause. So, I don't know. So I did that for a job and then I worked at Community Health Project as a fundraiser, had no

experience, but they just liked me because the guy who was head of development was in ACT UP.

SS: Who was that?

KR: Oh, god, what's his name? I can't remember. Then I ran the Women's Health Project at Community Health Project. At first it was Women's Health Project, but in truth it should have been a Lesbian Health Project, so we renamed it, sort of rejigged it, and then I stepped down because I'm not a lesbian, and I thought it should be run by a lesbian. Dana Greene took over. She was definitely in WHAM! She might have been in ACT UP too. I don't remember. So I did that job. Then I went and worked in advertising and liberated many corporate resources for ACT UP in my position in advertising. I was also part of YELL, Youth Education Lifeline, which was a subcommittee of ACT UP that worked on safe sex in schools.

SS: Let's get back to that, but tell me about Art Positive.

KR: Art Positive. So Art Positive was a lot of artists who wanted to draw attention to the HIV issue through their ways. There was Gran Fury, which was great, big, doing stuff, and Art Positive was like the local grassroots version. We did t-shirts and—to be honest, I don't even remember.

SS: Who was in it?

KR: I can't remember.

SS: Was Lola Flash in that?

KR: Sounds like she probably was, yes. I'm going to say yes.

{LAUGHS}

SS: So what were your t-shirts?

KR: It was a plus sign. Sorry, too many activities.

SS: Let's talk about the different AIDS arts collectives. Gran Fury was, like you said, the big one.

KR: It was a big one and it was a closed system. It was more like Group Material in that it was an ongoing collaboration, and they did mostly, in my opinion, graphic and design projects that had a specific goal or purpose in mind. Art Positive, I think, was more of a loose affinity group, and you could come or go as you pleased, and it was an open group. But here I can't actually remember what we did, so I'm not sure the impact was as great. Then Group Material was more like Gran Fury, and it wasn't AIDS-specific, but because Felix Gonzalez-Torres was living with AIDS and I was in ACT UP, vehemently in ACT UP at the time, a lot of our projects incorporated AIDS whether it was the focus or just a part of it.

SS: Was there a jealousy between the different organizations?

KR: Not that I knew of.

SS: So, Art Positive, when you say it was more of a grassroots collective, what do you mean by that exactly?

KR: Well, it was really an offshoot of ACT UP where there would be an announcement, "We're going to have a meeting, and if you want to come, you can come." So it was much more the way an open affinity group would function in ACT UP, where we would tell you what we were doing and invite you to join us if you wanted.

SS: How did YELL get started?

KR: My memory is that YELL was started by Steve Quester. I don't know if he started it, but this is who I remember, Steve Quester, who was studying at

Tape I
00:35:00

Banks Street College to become a teacher, and Jonathan Berger, who was a high school student, and Kate Barnhart. I think she was a college student at the time. Those are the three people that I really remember. I'm sure there were other members. I think the Macy's Santa—what was his name? Help me out. I don't know. The Macy's Santa was part of it too. So it was like, again, an open affinity group. Their goal was Youth Education Life Line. It was twofold, to talk directly to students about safe-sex issues and to interact with students in whatever ways were needed, and also to work on the Board of Education to either improve the curriculum where possible, but even enforce the AIDS curriculum, because the AIDS education curriculum in New York State is one of the best. They don't enforce it. So there are set lessons that are age-appropriate throughout the years a child's in school, but if they're written on a piece of paper and the teachers don't teach it, it doesn't help.

So a lot of what I did was apply my professional research skills to bring this issue to the fore. So we did a multi-school survey where members of YELL went out and did a paper survey and asked these kids questions. It was a one-page survey at a bunch of different schools around the city, a whole variety of types of schools. What we found out is that very little of the curriculum was being implemented. Kids didn't know condoms were available, all that kind of stuff.

Then we took that to the Board of Ed. So I'm up there as a researcher saying, "Here are the findings," and then the kids are behind me with the posters saying, "We need AIDS education."

Then other times we would go to the Board of Ed and go incognito and protest something that was being discussed, and we'd be dragged out, and you'd see a

shot of me on TV, you know, “High school student arrested.” I’m like, “Yeah, that’s nice. Thank you. I’ll take it.” {LAUGHS}

SS: Can you talk about working multi-generationally inside ACT UP?

There were people who were minors. There were people who were grandparents.

What was that relationship?

KR: It was great. I mean, you didn’t even think about it. I couldn’t believe that Jonathan Berger was thirteen. You didn’t know. You didn’t know. And I wouldn’t know that one of the grandmas was a grandma. I’m being polite and not saying. Or one of us could have been a grandma. Or I could have been a mother, you know. It was so cool because it was so many different perspectives and that’s what you valued, but at the same time, you didn’t judge. The greatest thing was that these ideas were popping up from all these different places, and a good idea is a good idea, and that’s what it felt like at ACT UP. Sure, you could see cliques and the influence of cliques, but I didn’t think it ever really squashed a good idea, and so it felt great. Sometimes there’s infighting, but if you don’t have that, it’s kind of like the group isn’t alive. We had it at WHAM! too.

SS: Were you ever concerned about getting arrested with minors?

KR: No. Should I have been? {LAUGHS} If we didn’t make them do it, I don’t – actually, he had an easy time, an easier time being arrested, because they would call his parents and the parents would come get him, and he was out. And the rest of us had to sit there for the six hours till they decided to give us desk appearance tickets. I was never fully put through the system, and I think probably being a young white girl helped.

SS: How many times were you arrested for ACT UP?

KR: More than two dozen.

SS: More than two dozen.

KR: Between ACT UP and WHAM!

SS: Did you ever go to trial?

KR: No, and that was a decision. With WHAM! we never considered going to trial. The only time that I ever would have gone to trial was if it had something to do with teaching abortion and teaching menstrual extraction, which some would consider an early form of abortion. Then I would take that to trial. But anything else with WHAM! seemed like it didn't make sense. But I certainly have friends who took their AIDS issues to trials, and it was always discussed. It's an option, but it didn't seem worth it.

JAMES WENTZY: We should maybe change tapes.

SS: Change tapes? Okay.

SS: You're saying about your busts.

KR: Most of the arrests were probably with reproductive rights. I mean, if I had to count them out, probably the majority are reproductive rights, but the most interesting ones were with ACT UP, and that's the ones where there was this whole thing about a dentist with HIV and the desire to bar dentists who have HIV from practicing. So we demonstrated at the ADA, which I guess is the American Dental Association, and the way we got into the building was somebody pretended to be a FedEx delivery person, and we followed them in. Then we're in the ADA's office and throwing papers around and handing out fliers and calling the press and doing press interviews, and those were the

Tape II
00:00:00

more interesting, whereas with reproductive rights, we were protesting the Health and Human Services ban on saying the word “abortion,” and federal funding, so we took over the HHS offices, and they didn’t care. They were like, “Go ahead. Stay as long as you want.” And we were like, “Oh, this is so bad.” {LAUGHS} We ordered pizzas. They didn’t care.

SS: Why didn’t they care?

KR: I think because the people in power weren’t at the office at the time.

SS: Who were the people in WHAM! and in ACT UP, both?

KR: Oh, there were a lot, and I’m actually still friends with the Church Ladies for Choice, which was an affinity group of ACT UP men who went to Buffalo in ’91. I think it was in ’91 when Operation Rescue hit Buffalo heavy, and they, on the bus ride up, formed this group, and it was Brian Griffin and I think Donald Grove, and I can’t remember who the third guy was who was an original Church Lady. But they decided to do bad drag in order to be the USO of the pro-choice movement. So they sang songs. They took traditional songs like “God Save the Queen” or “This Land is Your Land,” and they rewrote them to be pro-choice, and they would take hymns and make them “hers.” They’re still around.

Now that there’s been the Catholic scandal with altar boys, I’m actually a Church Lady, and my name is Tad Loose. I’m the altered altar boy, so I can do drag the other way. And I have a child who’s Demon Seed. He’s in the Church Ladies too. So the Church Ladies was a big core affinity group that didn’t come to the WHAM! meetings, but they would come to the WHAM! events. There was a lot of blockades back in the late eighties and early nineties by the anti-choice groups, and they were

getting a lot of attention and they were on the street a lot, and there was a lot of movement for them. So we were kind of right in their face, and we tried to bring street theater there. I was in WHAM! The WHAM! organizers could be vociferous and loud, you know, loud and proud and out and very pro-choice, and then the Church Ladies would come in and provide us with humor, because some of the chicks can get kind of serious. That's not going to look good in print. Some of the women. {LAUGHTER}

SS: You know that's your pull quote.

KR: Some of the women can get very earnest, so it's nice to be able to always balance what you do with a sense of humor so that you can maintain your own level of interest and the public's level of interest in what you have to say. So the Church Ladies did that for us. Those guys today are Steve Quester, Donald Grove, Brian Griffin, Luca Torregiani, who's a Church Lady from Rome who's joined us, Elizabeth Meixell, who is – I hope I can say this. She's Sister Mary Cunnilingus. Yes, always in good taste. And—oh god, I'm blanking.

JAMES WENTZY: David Buckingham?

KR: David Buckingham, absolutely, and Coe Perkinson, who's Sister Mary Mucho Foreplay. And who else? There were others, other women. Sabrina Jones was in for a while. We had another woman, who was Cardinal D. Eadly Sin.

SS: But separate from Church Ladies, what about in terms of activists?

KR: Oh, a ton. There were a ton of people. There was a core group of WHAM! who would also go to ACT UP. So like Diane Curtis, Julie Clark, me, Tracy Morgan. It was mostly women. And then also a lot of us would also go to ACT UP, and

then there were extra women in WHAM! who didn't go to ACT UP, and then there were extra ACT UP guys who didn't go to WHAM! but would show up at the demos. So like one of the WHAM! demos we had was 5,000 people strong, and certainly there was a huge ACT UP turnout for that.

SS: What demonstration was that?

KR: I don't remember. We were on Broadway. {LAUGHS} It was successful. It was probably related to a Supreme Court decision. Certainly, actually, one that I remember very well with Robert Garcia there taking a bust with me was at the Holland Tunnel, and that was a very covert action where the planning was very secret and there were lots of affinity groups, and the point was that all these different affinity groups got in front of the Holland Tunnel from different directions, so you had your group of twenty people and you knew exactly what you guys were doing, but you didn't know what everybody else was doing. That way if any one group couldn't get there, there were about two hundred people who laid in front of the Holland Tunnel that day and messed up traffic really well.

SS: I want to talk about that action, because there's a lot of things that converge on that action. What year was that?

KR: I want to say it was '92, and I think it was the *Webster* reproduction rights decision, but it could have been *Casey*. I don't remember. Do you remember which year? See, this is when I should have studied for this.

SS: Because there's two Holland Tunnel actions, right? There's one in '95 and there's—

JIM HUBBARD: No, there's the Holland and there's Midtown.

SS: Okay. So this is '92, I think.

KR: '91 or '92.

JH: Casey's '91 and Webster's '92. Or the other way around, right?¹

KR: Right. I want to say it's *Casey*, because I don't know that we had our – I don't know. I remember getting arrested on the steps of the Supreme Court with Marion Banzhaf and a very much smaller group during the arguments for *Webster*, but I'm not sure that we had it together to do that. I think it was *Casey*. I'm going to go with *Casey*.

SS: Now, this was unusual action, because did it ever come to the floor of ACT UP?

KR: No.

SS: Because this was a top-secret action, which was very unusual. That was never how we operated before.

KR: Right.

SS: Why was this action done differently than every other action?

KR: Well, I think at the time it was contextual, because I think at the time there had probably been a number of actions that had been intervened, perhaps.

SS: Do you have any examples?

KR: Not off the top of my head, but there had been actions where people were trying to do things and couldn't do them. So the thought was, let's keep this really quiet and do it in affinity groups, and, therefore, one affinity group's going to get it done. It was more of an ACT UP issue than it was a WHAM! issue, because I don't think

¹ *Planned Parenthood of Southeastern Pennsylvania v. Casey*, 505 U.S. 833 (1992).

anybody was paying attention to what WHAM! was doing from a legal perspective. We had done some great affinity group actions like dropping a banner over the face of the Statue of Liberty, which I know Steve Quester talked about, right? I think he did. And it said “No Liberty, No Choice,” over the face of the Statue of Liberty, and then there was a banner at the bottom that said “Abortion is Healthcare. Healthcare is a right.” We did it. No busts. And I was back at press central answering calls, so if you Google my name and Statue of Liberty, you’ll find me talking to the AP about it, even though I wasn’t there, because you’re never at the action if you’re doing press. Note for future activists.

SS: I’m trying to get at something larger, which was that this action took place at a time in which ACT UP had a fear of infiltration or that there were discussions by some people in ACT UP that perhaps there was some kind of infiltration.

KR: Yes.

SS: Do you know any of the details of that? Did you ever have evidence of that?

KR: No, and it was one of the things that tore ACT UP apart at that time. I mean, I think certain aspects of ACT UP healed, but it was tough time, so it was great that this action was able to be pulled off, but there was definitely a sense among the major organizers that it be very, very covert and quiet.

SS: Looking back in hindsight, do you believe that there actually was infiltration?

KR: Yes.

Tape II
00:10:00

SS: Or do you think it was paranoia?

KR: No.

SS: But you don't remember any of the evidence for it?

KR: Well, the reason I think there was infiltration was because there had been a couple of actions that were attempted that were known about, so whether it was as simple as there's a cop sitting in the meeting who isn't identifying, or there's a piece of paper or whatever, they know, and it's easy to know.

SS: So when you do a secret action, in terms of the structure of ACT UP, prior to that action, secret actions all took place within affinity groups.

KR: Right.

SS: The meeting was the public face of ACT UP, and the private face was the affinity group.

KR: That's right.

SS: But when you do an entire action in secret, what changes?

KR: Well, it isn't an entire action. It's affinity group actions that are strung together. That's all. That's what it was. There was never a big pre-action meeting. There is no pre-action meeting. Basically, you have to collect your legal paperwork from within your affinity group, and there's one person who takes it to the legal team, who's going to make sure they have all the sheets in case people actually do get arrested and know who they are and where they belong and who needs to know. So it's that level of organization. So it's more like a covert cell. It was cells.

SS: What was your affinity group?

KR: I don't remember what it was called.

SS: What did you do?

KR: We approached the Holland Tunnel from a series of internal tunnels and came out a door, and there we were. I didn't actually even believe it. I mean, I believed that it would work, but I couldn't visualize it until I'm like in this little tunnel and I'm about to open a door, and I'm like, "Oh, my god, we're on *this* street. I didn't know this door was here."

You really had to have trust in your cell leader, which is unusual for ACT UP structure. You felt excited. You felt nervous. But it wasn't the kind of cohesion that you felt in the typical ACT UP action where there's a pre-action meeting and the chanteuse is leading us in the chants we're going to do at the big legal march, and there's CD training in advance. All of that was missing. So the way that that action was different was you didn't have the sense of community coming together, even though there were lots of people from both communities there. It was also made up of a lot of hardcore, for lack of a better word, very committed activists who you looked around and you're like, "Oh, I know all these two hundred people that I'm arrested with. I've been arrested with them before." So it's a lot of familiar faces.

SS: I want to talk about the WHAM!-ACT UP coalition around Stop the Church, but I just wanted to say something first. One thing that we've noticed in doing these interviews, and it's really interesting—I'm so glad that we're talking to you because you are the key lynchpin person in all of this—ACT UP, which argued about every single thing, there was one thing they never, ever questioned, which was that the only non-AIDS issue that ACT UP came out for was abortion. It

was never debated on the floor. No one ever objected, ever, and it's so odd, considering that we debated everything else. I mean, why is that?

KR: Well, the reason why ACT UP never debated abortion is because, I believe, it was crystal-clear that it was exactly the same sexuality issue as gay rights, as HIV. It's the same parts. The activity is so similar. The thing which puts you at risk is so related, and in either way the outcome is not something you want. You can look to prevent it, which is what safe sex is about and what contraception is about, but once it's happened, you have to have equal access to the care that's necessary. On the one hand, that's AIDS healthcare, and on the other hand, that's abortion if that's what the woman needs. So there was a complete understanding of that, and, I mean, it was crystal-clear from the moment we walked in the room. It's all about sex. There was that hip-hop song, "It's All About Sex, Baby." That's what this is, and so that's what drew me to both groups. It's the perfect confluence.

SS: So how did WHAM! decide? Who approached who in terms of working together to do Stop the Church?

KR: It was all at the same time. In terms of Stop the Church, that's a particular thing. But the history of WHAM!, which is a different history, was out of the Reproductive Rights Coalition, which was out of the Center for Constitutional Rights, and then the direct offshoot of that group, there were a lot of people from ACT UP who were in that group who were women. We knew the direct action principles, so we started WHAM! so that the CCR didn't have to be involved in direct action demonstrations.

So Stop the Church, I'd have to say it was Victor [Mendolia] and Tracy Morgan. Those are the people I most remember talking about it. But, I mean, it was

perfect. The church was doing so much, and even later there was an affinity action that we did where we dropped the banner from Saks Fifth Avenue while the pope was in town, similar idea, "Condoms save lives. Condoms are birth control. Get on the bus." So Stop the Church, made a lot of sense to do it. I'm glad we did it. I know it's a big point of contention for some people, but I'm a Catholic and I'm glad we did it.

SS: Just before we get into the actual action, so did WHAM! vote to have a coalition with ACT UP or was it just organic?

KR: WHAM! voted. WHAM! voted. I mean, we knew ACT UP was going to do it, and then WHAM! talked about it and said ACT UP's doing this big action. A bunch of us, Diane Curtis, Julie Clark, myself, Tracy Morgan, all the same people, Elizabeth Meixell, were all talking about it. "ACT UP's going to do this action. Let's do it. Yeah, let's do it." Because ACT UP's whatever, 2,000 people, typical meeting, 700 people. WHAM!'s meeting, 100 people. So, yeah, let's do it. But because the issues were the same, it was easy to put them all in the same fact sheet.

SS: So what was your experience of that day?

KR: I didn't go in the church. That was a choice. I thought about it, but I was like, "Oh, I think I'll have flashbacks from Catholic school." So I decided to stay outside and I was supposed to be part of Operation Ridiculous, which were the clowns. That's kind of a Church Lady feel, you dress like a clown and you talk about how Operation Rescue is ridiculous, so safe sex becomes safe fish, save the baby whales. It was very tongue-in-cheek, making fun of some of the words that Operation Rescue was using in the anti-choice movement and the anti-safe sex movement.

But instead, I missed the timing, so I didn't get to dress like a clown, and I ended up in the street demonstration, laying down in the street. I remember I was with Hunter—don't ask me the last name. And I was with a bunch of the guys I knew, and we took a bus and I ended up on a big school bus full of people I was busted with, for disturbing the peace or whatever it was. Not trespass. It would have been disorderly conduct. And I did go limp, so that's passive resistance. I weighed all of 105. I'm sure it was really annoying for them to have to carry me on to the bus.

SS: So I want to get to the NIH. We have footage of you in leadership at the NIH, talking into a megaphone, people listening to you. Can you just explain to us what that action was about?

KR: Storm the NIH, the National Institutes of Health held the key to so many things that we needed in the AIDS movement. They were the key to research budgets. They were the key to access to drugs. I was part of an affinity group called Invisible Women, and we wrapped ourselves in gauze to look like the Invisible Man. Not mummies, but loosely wrapped in gauze. We were storming the NIH for all the people that couldn't stand up for themselves, so it's the poor who weren't getting access to care, and women who were being denied participation in clinical drug trials because they were women and they might actually reproduce, and they were seen as this major stumbling block. But I hope people know by now that if you don't test drugs on women's bodies, it's a huge misstep, because the chemistry is entirely different. So it should be mandatory that drugs are tested on women, but it's not. So that was part of what we were protesting. I don't even remember what I was talking about that day, but I'm sure they were good demands.

SS: What did your affinity group do?

KR: We weren't the ones who went up on the ladder, I know that. I think we were all trying to get in the door and storm the NIH. I don't know how many hundreds of us were there, 300, 200, and three busfuls of people. We were on their campus. Like that never happens. It was a very private place that's very staunch. I remember that there were people who were basically supporting us inside, and they would hold signs up to the window, and then some people looked very pissed that we were there. And there was a group who got in a door. Was I in that group? I can't remember. I know we got in the CDC once.

Tape II
00:20:00

SS: I want to do something we've never done before. Can we just stop and show Karen the NIH footage?

KR: That would be great, because I can't remember. There's too many actions.

SS: Let's watch.

[Camera turned off.]

SS: So we just watched this NIH footage, and you made two comments to me. One was about the Women's Committee on the ACTG. Do you remember?

KR: No, I don't remember what I just said to you. It spurs my memory that it was the AIDS clinical trial group was excluding women from drug trials because of the reproductive issue, the fact that they might possibly get pregnant. And that's been

something, obviously, if you're a woman with HIV, especially in that time frame—and I haven't studied in the past few years what the cocktail does to women, but the idea that we don't know, women weren't even getting access to the experimental drugs, so they were just automatically dying.

The other action that we were doing at the same time in the same time frame was getting the CDC to redefine AIDS to include diseases that women were dying with, so that if you're an HIV-positive woman with pelvic inflammatory disease, that's considered an opportunist infection and you have an AIDS diagnosis, which allows you to get into drug trials, because they were being blocked from drug trials on two counts. One is the fact that they could possibly get pregnant, and the other was they only had HIV, not AIDS, because they didn't have the same OI as men, because Kaposi's sarcoma, for example, is very infrequent in women and more frequent in men, obviously pelvic inflammatory disease is not an issue for the guys, and that's what a lot of women were getting. Even though it's extremely treatable, it was much worse in a woman with HIV and actually could cause death. So that those things were kind of tied hand in hand.

The CDC we worked on for three years, going back each year and doing lots of actions and zaps in order to get them to change the definition. The NIH we were working on to get the AIDS clinical trial group to recognize women as a set of people, okay, half of the population, who needed to be included in AIDS drug trials, and that the drugs need to be looked at in the chemistry of women's bodies.

I'm not sure that still goes in. I read in the news stories of how drug trials are conducted and, if anything, it seems that it's worse, because they're conducted to get the rubber stamp of approval so that the money that they've spent is worth it, and,

therefore, it's probably not being tested on a full swath of people. What Keith [Cylar] talks about with racism and really classism, it's a money issue, because if you don't have access to appropriate healthcare, you don't know about your options for drug trials and you don't have the base level of care that would make you a good choice by the medical establishment. I'm putting "good" in quotes, because if you're healthy, so to speak, except for your HIV, you're a good candidate in their standards to be part of the trial because you might actually do well, whereas if you don't have access to care and have a number of other problems, diabetes, whatever a typical low standard of living can cause, you're not, in their eyes, a good choice. So I think that is what we were there for, the poor and the women, two groups that were incredibly excluded.

SS: So what did we win at the NIH?

KR: What did we win? I don't know. Can you remind me? I don't remember. What did we win? We won expanded access, and I know at the CDC we won the definition to be expanded. There was an Office of Women's Health that was established, I think it was in '92. Maybe it was '94. It was definitely under Clinton, where they actually put money into doing research on women's health, and it didn't include just breast cancer, but it didn't last long. It lasted less than five years, and then it was de-funded, and they said it was due to lack of interest, which leads me to believe that actually the change that we wanted didn't actually take. I think it took on the surface level, and then I'm not sure. Because of the way that drug trials are seen as moneymakers now, I'm not sure. Do you know?

SS: No. We're trying to find out. We've asked a lot of people and we can't get an answer.

KR: Well, see? We need to reinvigorate the group to look into this, because that's exactly the kind of thing. From my perspective as an ongoing activist, because I'm still active, you personally have to change your tactics. So I'm not still the one doing the treatment research, but it has to happen. My husband—I'm married. I was married when I was in ACT UP, which is probably unusual. I think my husband will say you have to let the kids do it now, and that's his way of saying that the next generation has to come along and I need to move along and progress as an activist, because you can't keep doing the same thing. You'll burn out. You'll stop being as effective.

So I look at these problems like spokes on a wheel. The issue in the center stays the same, but the way that I attack it varies over time. Jill Harris went on to be on the Board of Ed, the School Community Board, and those are the kinds of things I'm thinking about now. So when they go to look me up, they'll get to see my point of view and know what they're getting. But I think that the work needs to happen, and I encourage those who come now and after me to carry the torch in whatever way they see fit. In many ways we have access to more information than we did when we were doing this because of the Internet. So figure out ways, guys. We've got to get these issues covered.

SS: You had mentioned something about press function.

KR: Yes, I wanted to make a point. One of the great things about these actions, one of the reasons they were successful wasn't just all the street planning and the organizing among the people; it was the way there was always a dedicated committee to get the press out. Even when you look at the footage from the NIH action, you see an interviewer from 1010 WINS talking to one of the protestors live on the scene. That

means that the press alerted them to the action and enticed them to come. I can't emphasize enough to every activist that that is one of the main reasons you do your action, because if you get the press to see it, then you get the public to see it.

[Telephone interruption. Camera turned off.]

SS: Is there any other realm of activity or action that we haven't discussed that you think is important?

KR: The press is an important function. Any other action or activity? Well, the CDC is the one that I think I'm the most proud of because it's change that will last forever. So the idea that we changed the definition of AIDS to include the diseases women die from is incredible. Then just meeting all the people.

What else? I think the emphasis on local New York City issues is important, too, even though it might not seem it, because so many things around the country go the way New York City goes. So what the health level is here, what the government does from a health perspective, the kinds of regulations they make, the funding that happens, the groundbreaking programs that are often started here, like Needle Exchange, I think the local emphasis was great, and it might not be appreciated when people look at it from a 5,000-foot view, but it is.

SS: One of the reasons that AIDS became a crisis was that straight people did not see gay people as fully human, and there were a few straight people in ACT UP, not many. We've interviewed like three or five. One of the things that I found in those interviews, and you are very consistent with that, is that there was somehow exceptional people in that they actually saw everyone as a human being, which was counter to the cultural trend.

KR: Oh, that's so sad.

SS: But it's really true.

KR: Is it?

SS: Yes. We interviewed Ray [Navarro]'s mother.

KR: Patricia.

SS: Yes, and we asked her, "Hundreds of people came to ACT UP and died and their mothers never came, but you came. What was different about you?"

And she couldn't really give us an answer because she saw it as such a natural thing to do. How do you understand all of that?

Tape II
00:30:00

KR: My mom came. I know Steve Quester talked about this in his interview. She was the mom in the Saks store who was having the birthday party to create a "Hey, look over here" smokescreen effect so that they would all come over and sing "Happy Birthday" so Steve could get on the balcony and drop the banner. Meanwhile, I'm somewhere else with I can't remember who, one of the other women, dropping a banner somewhere else in Columbus Circle that says something else about the pope and AIDS. I think it said the same thing, "Condoms Save Lives." I think we were consistent in our message. And there was actually a pro-choice march around Columbus Circle at the time, so that's why we dropped it there.

So, for me, I had a gay relative, and it was embraced in my family. I don't know. I mean, Jesus Christ said we're all people and love us all and love the lepers and love the hungry and love the homeless and love the shoeless and love the short man and love the blind guy and the guy up in the tree. So, I don't know, did these people not read the book? I'm not sure.

SS: I don't know, but I'm sure you thought about it because you were one of the few straight people for many years. How do you understand that you and a few other people were able to identify with people that other straight people could not identify with?

KR: Well, it's really two different questions, because when you talk about people not seeing gay people as fully human, that's a different talk as opposed to can I take an ACT UP meeting. I always joke that I'm a gay man trapped in woman's body, because my sensibility is very fabulous, very over the top. Steve Quester and I joke, when we go in drag we try to get a size 6 dress and a size 16 dress and the same wigs, because we're actually twins separated at birth, but we don't look a lot like.

So I think it's a sensibility, and, for me, the fabulous sensibility of the gay culture, *Paris is Burning*, matches my internal sensibility, but I don't think it does for most straight people. I think most straight people like Yankees games. Not that you can't be a fabulous person who enjoys Yankees games. You can be.

SS: I'm going to challenge you, Karen, because even if you're going to say that you responded aesthetically to gay tastes, you started a lesbian health project.

KR: No, I didn't start it; I worked for it.

SS: You directed a lesbian health project.

KR: Right. And I was a closeted straight woman, so I had to get out of the role because I felt that a lesbian should run it, so I organized it, I got it together, and then I passed it on.

SS: It's very unusual that a straight woman would become an advocate for lesbian health. Let's just face it. It is. It's unusual. Who are these like ten straight people who were in ACT UP? What was it?

KR: The magic sauce? I don't know. I don't know. Maybe gay pixie fairy dust came on us when we were asleep. I don't know.

SS: You really don't have a—

KR: But, again, it's a different circumstance. The project at CHP, Community Health Project, needed organizing. I am, by nature, an organizer. Put something in front of me, I'm going to make it work. So that's what they did. I was an evening screener, and they were like, "Hey, want to run the project?" And I'm like, "Sure. Let me get it together and then I'm going to pass it on, because it doesn't really belong to me." So that seemed natural. What you're saying is, most people aren't that cool to be cool with all types of people. Well, Community Health Project, more than anything else, teaches everyone that comes within its purview to be nonjudgmental. No judgments. That's actually, I think, something that some people had an issue with in ACT UP, too. Some of my best friends seroconverted while in ACT UP, right? Could be a problem. We're supposed to be preaching safe sex. But, you know, life is complicated. Life is already hard. My major philosophy is, life is hard, why make it any harder? So I don't have to beat that person up. They're getting beat up enough by themselves.

So I don't know if I'm answering your question, but I think probably what you're looking for is that these people must have a very nonjudgmental gene inside their heads where they're like, "You know what? There but for the grace go I. I might do that, too, if I were in that circumstance, so let's just all be cool about it." Does that help?

SS: It does help, but you actually are proving my other theory, that all the people in that position, in that exceptional position, don't see it as exceptional and so don't have an explanation for it.

KR: Because it shouldn't be exceptional. It should be the norm, and so then the rest of the time we act as brokers to explain gay culture to the rest of the people, like, "Don't you see how this is fabulous?" And in truth, they do. Well, let's put it this way. Everyone I work with thinks I'm a vegetarian because I care about people and I do AIDS activism and when somebody's in need, I help them out. Therefore, I must be a vegetarian. I love a good steak. I love a good burger. I'm not a vegetarian, and I actually shave my legs and get my bikini wax and I'm not crunchy. So you know what I mean? There are these assumptions that go with this stuff. So we have to build bridges all along the way. But it was hard for my then boyfriend, future husband. He came to ACT UP and he totally believes in the cause, but it's a hard space to be in.

SS: Why? What was difficult? I'm not asking you to speak for him, but—

KR: I think that there were judgments among the guys towards him, either they were trying to pick him up or they were like, "Why are you here? You should be watching the Yankees game," which, truthfully, now he'd rather do. {LAUGHS} So it's a hard space to be in.

SS: Because of his discomfort?

KR: Sometimes if you don't totally match, it's hard the other way around, because it's an über gay space and it's seen as an über gay safe space, and so for straight to come in, it was kind of like "Hmm." So they used to tease me that I was a baby dyke,

which means you just haven't come out yet. Mercilessly. I was like, "Guys." So I actually went on a date with a girl just to see. I was like, "Maybe they're right." No, they're not right. Poor girl. She was very nice. Thank you, Tracy. {LAUGHTER}

SS: So when did you leave ACT UP?

JH: Can you talk about the CDC?

KR: The CDC, the Centers for Disease Control's definition of AIDS is lynchpin or was lynchpin in many ways because it was access to benefits like ADAP, AIDS Drug Assistance Program, housing in New York City, healthcare for a lot of people. It helped you get your Medicaid. It helped to get all kinds of services and access to drug trials. So what was happening was women in the late eighties, early nineties, a lot of the women with HIV, and there weren't a lot, the proportions were out of sync, many more men, but there were women, were getting diseases. They're opportunistic infections. They were dealing with thrush on an ongoing basis, vaginal thrush, and they were dealing with pelvic inflammatory disease, and that was actually turning out to be quite dangerous. They were spiking a fever. It was a bacterial infection. It was incredibly difficult to fight and some were dying from it, and they weren't getting any services. They just had HIV.

So it was like, oh, man, we've got to change this, and so it was another issue that ACT UP embraced and saw it universal. So we worked on changing the definition to include the diseases that women get, and it took three years and a lot of phone zaps, three times going to the CDC, and getting in their office, actually. And one of those times was one of those were the Fed Ex guy and thirty people, fifty people, are in the back door, and suddenly we're in the Centers for Disease Control. Eventually they

did it, and it was the right thing to do. I'm very proud of ACT UP for exerting that pressure and making that substantial global change to AIDS.

SS: So when did you leave ACT UP?

KR: Well, let's see. I didn't exactly leave. I focused more on other parts of ACT UP. So I focused on YELL and I was also part of Women's Health Education Project with Darren Britton. That was a project that focused on women with HIV. We worked with women with HIV, to write medical education materials in easy to access language. So that was a lot of what I attempted to do, like with the kids, with Youth Education Lifeline, it was a lot about writing about HIV prevention in a zine with kids, to get the word out to that community, and WHEP was the same thing to women with HIV, for women with HIV, with women with HIV. So I kind of just moved tactics. As I mentioned before, maybe I didn't go to as many big meetings, but I did these more focused things. So that was probably like '93-ish, '94-ish. So I just did that more.

Then I think—I don't know. I can't remember what I did. I may have taken a break for a couple of years. I think I did take a break for a couple years, and then I got involved with work, because I started to work at Oxygen, which was supposed to be this do-gooder TV network for women. So I did that very heavily from '99 for a couple years, and then I got back into the Church Ladies pretty good, and then I had a baby.

Tape II
00:40:00

SS: So our last question is, just looking back, what do you think was ACT UP's greatest achievement and what was its biggest disappointment?

KR: ACT UP's greatest achievement was bringing together all these people who had the energy and the awareness to want to make change, greatest achievement ever, and I wish for every generation that they should have that, and I pray

Tape III
00:00:00

for every generation that they have it, starting now and on into the future, whatever their ACT UP is. With my son, I have a two-year-old and I wonder what his issue will be, but I hope to heaven he has an issue, because that's how we move forward and we make the world a better place. So, to me, that's ACT UP's greatest achievement. It provides a model for future behavior. Not to kiss your butt, but projects like this actually can help show how to do it, provide roadmaps.

I think my personal greatest achievement was changing the CDC definition of AIDS and the ability to apply the actions and activities I learned in ACT UP to reproductive rights at that time in the late eighties and early nineties when President Bush was fully under attack to overturn *Roe v. Wade*, and I think that our public outcries placed some pressure on that, and so I'm proud of that ability personally.

The biggest disappointment, that it couldn't last forever. And it can't last forever because, as my husband points out, the players need to change, and every time the players change, the issues will change slightly, the techniques will change slightly, but the point is that as a culture, we should be moving ever forward and continue to care about each other and express it in new and ongoing ways.

SS: Thank you, Karen.

KR: Thank you, guys.