

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

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Interviewee: **Esther Kaplan**

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**ACT UP Oral History Project  
Interview of Esther Kaplan  
September 7, 2012**

**SARAH SCHULMAN: So, you look at me, not at the camera. So, you just start by saying your name, your age, today's date, and where we are.**

ESTHER KAPLAN: I'm Esther Kaplan, I'm forty-seven, and it's September 7<sup>th</sup>, 2012, and we are in my apartment in Park Slope, Brooklyn.

**SS: Where were you born?**

EK: I was born in Claremont, California.

**SS: I didn't know that.**

EK: Yes.

**SS: Why was your family there?**

EK: Well, my dad claims he moved out to California when the Brooklyn Dodgers did. That's his version of the story. But my mom got her teaching degree at the Claremont Graduate School, and my dad worked in aerospace in Southern California, so that's where they settled and had kids.

**SS: Your mother was still in graduate school when you were born?**

EK: No, she was a young schoolteacher.

**SS: Let's wait. It's Brooklyn.**

EK: Methodist Hospital is not too far from here, so —

**SS: How long did you stay in Claremont?**

EK: We moved. My parents were back-to-the-landers, so when me and my sisters were little, we all moved to rural Oregon and became subsistence farmers.

**SS: So that's a big difference from aerospace to subsistence farming.**

**When they had this revelation, how old were you?**

EK: I think I was six.

**SS: So, you just went along with it. You weren't in a place to —**

EK: Oh, no. But it was the greatest. We were the only Jewish family in this dirt, poor evangelical farming community, but it was beautiful. It was western Oregon, and we grew up raising animals and running around in the fields and the streams.

**SS: What was the name of your town?**

EK: Kings Valley, Oregon.

**SS: What did they want to get out of that? What were they looking for?**

EK: Well, it was a failed collective endeavor. They planned originally to move up there with two other young families, I mean two other families with young children, and they were going to — they had schemes of starting an alternative school, and no one else came but them. So, I think for my parents it ended up being kind of an isolating experience, but for us kids it was pretty great.

**SS: How long were you there?**

EK: Until high school, and then we moved back down to Claremont, to the suburbs.

**SS: Not only is that a really significant period of your life, but it's also through a time of a lot of social change in the United States. Were you alienated from that, or were you aware that that was happening? Were you guys watching television? Were you reading?**

EK: No, we weren't allowed to watch television.

**SS: Did you know that there was a Women's Movement and that there was a Gay Movement?**

EK: My mom actually was involved in a tiny little product of the Women's Movement, this little women's journal called *Calyx* that was published out of

—

**SS: Oh, I remember that.**

EK: — Corvallis, Oregon, or somewhere sort of within reach of us. So, yes, the Women's Movement made it into our household. I don't think I was aware that there was a movement. And then we moved to Southern California right when it was disco versus punk rock in — I guess it was like 1979. Sadly, I chose the punk rock side, so I really missed — I never really learned about disco until my adult years because of that.

**SS: What did it mean to be a punker in Claremont, California?**

EK: I was more of a punk hanger-on. But we were the Inland Empire's, like, Black Flag country. We would sneak into clubs when we were underage and see bands like X or the Clash play, and I definitely think, like, Exene Cervenka of X was my female role model at that age, so it was positively formational, I would say.

**SS: When did you start thinking about or noticing that there were political movements or activist movements around you?**

EK: I think I just had a protestor personality. In my high school there was so much else going on, that this became my cause. This is kind of ridiculous, but we had this flexible structure in high school called the modular system that allowed you to take

long lecture classes and short other classes, have more like a college structure to your day. And they were trying to eliminate it while I was there, and me and my friend Naomi led this campaign against it. Then we got involved in anti-nuke stuff too. That was sort of probably my teen activism, and that's what I did when I first went to college, too, was anti-nuke work. I was that generation where I spent my teens having apocalyptic nightmares about the end of the world.

**SS: Also California, it was really big there, the Anti-Nuke Movement.**

**It was huge.**

EK: Yes it was. There were nuclear facilities there.

**SS: Right and it involved civil disobedience on a mass scale.**

EK: Yes.

**SS: But you must have been a brainiac, because you went to Yale, so you were doing your homework.**

EK: Yes, I was a smarty-pants. I tested well.

**SS: You were a good girl despite —**

EK: Very good girl.

**SS: You get to Yale, and where did you put your energy?**

EK: Well, Yale at the time was kind of a gay Mecca. I kind of entered Yale straight and left Yale queer or bisexual, as I defined myself then. There was a great kind of growing political gay community there. There was a thriving Women's Center. I became a feminist there, wrote for a journal, a women's journal there called *Aurora*. The Anti-Apartheid Movement was big on campuses at that time and big at Yale, and I got involved in that. I was a work-studies student, obviously, and so I was involved with the

union. There was a big strike my sophomore year the entirety of the year, and we all organized to get our professors to move their classes off campus to honor the picket line.

**SS: That strike, was that the grad students' strike or was that the kitchen workers' strike?**

EK: This was the kitchen workers, and everyone went out in solidarity with them. Or it may have been the clerical and technical. I was a dining hall employee, and I think we were out in solidarity with the clerical and technicals, actually, but everyone who was unionized on campus was on strike, and then we all got our classes moved off. So, we spent the whole school year eating off of hotplates in our dorms and having our classes meet in churches and movie theaters.

**SS: Help me understand this, because I've heard a few people talk about Yale this way, and when I think of Yale, I think of the Bushes and the ruling class and all the people that have been hurting us.**

EK: That is Yale.

**SS: And then to hear you say or other people say Yale was so great for gay people, but the people who were killing us were also from Yale.**

EK: The good thing about Yale is just that it was big and it was big enough to have strong subcultures. I went to a Yale reunion recently, and I was reminded that the experiences I had at Yale and the friendships I brought from Yale were not what Yale was about. That was a place where you met people whose last names were the names of the buildings you were living in, I mean Vanderbilts, and it was ridiculous.

**SS: How did those two things coexist at the same time? Is it a progressive force or is it a negative force?**

EK: Yale as an institution is a force for reproducing the power structures of American capitalism, there's no question. It's just that I think people's undergraduate years are sort of a pause. People break out of their class structures temporarily and interesting things happen. Again, it was just large enough that there could be subcultures within it that were quite strong.

But I think Yale was a politicizing place and partly because one became very clear-eyed about how power really worked. My idea about wealth was from my experience in Oregon and in the L.A. suburbs, where rich meant you had a big house maybe or you had more land or you actually had some employees on your land or something. I finally figured that all out when I got to Yale.

**SS: What does rich mean now to you?**

EK: The kind of serious wealth that, like, owns buildings, that owns companies, that owns the government.

**SS: And do you have an insight into the psychology of that level of power from being there?**

EK: Well, I feel like one thing — saying that Yale was sort of a pause or a play space for people where there was rich people and poor people, working-class people, as many as there were at Yale, got to interact for a while. I think it's been notable, I would say within five to ten years of graduation, that everyone walked back into the class track that they came from and that the people, many people who seemed to be counterculture types or barefoot hippies at Yale were running hedge funds or working on Wall Street within a half a dozen years.

So, I think it's a little bit of an illusion, the kind of experience of class mobility or something that one has at an elite space like that during that cloistered time that you're there. But it made me — it radicalized me. It made me very angry. I spent a lot of time there being very angry. Made me very angry at the United States, made me angry about how power worked.

**SS: Did you emerge situated in the queer community?**

EK: Yes.

**SS: By the time you graduated, what did that mean? What was the consequence of that?**

EK: Well, I think certainly AIDS was at the periphery of everything. While we were undergraduates, it was that weird time when no one even knew how HIV was transmitted, and I felt like all my gay male friends were having very different strategies about how they dealt with that. Some people just didn't even want to exchange saliva. It really affected people's sexual exploration and experimentation as young gay or proto-gay people. But that was New Haven. That was at some distance from a metropolitan center that was being hit horribly like New York. So, once me and a lot of my friends ended up in New York, I feel like it became —

**SS: What year did you move to New York?**

EK: The fall of '87.

**SS: When did you first become actually exposed to AIDS? When did you first meet a person who was infected or have it enter your realm?**

EK: Oh, that's an interesting question. I'm not sure I can answer that. By '89, I think, I was living in a collective household in Fort Greene that I lived in for



many years, and one of my housemates was HIV-positive. I think that's when it became part of my real routine of life, and that was during the period when the treatments were so awful. He was having to do aerosolized pentamidine which was just brutal.

**SS: Is he still alive now?**

EK: No.

**SS: Can you say who it was?**

EK: Kevin Kennedy.

**SS: What happens when it's real and you're living in a house with someone you love and they're suffering? What did you do?**

EK: Well, I had already joined ACT UP. I joined ACT UP in that sort of winter of '87, '88, or early spring of '88, so I already had a political context for it. One of the amazing things about ACT UP was having access to people who were following treatment developments, including drugs that were still in trials, very closely. It actually put me in a slightly vexed situation, because Kevin was someone who was very private about it. It wasn't something that he liked to talk about a lot. I was always sort of trying to butt in and be really clear on what medications he was on and dosages and trying to crosscheck that with people who I trusted. There was a little bit of a dance around that in terms of I really wanted him to be getting the best treatments possible. I also wanted to be supportive of whatever approach he wanted to take as a person living with HIV.

I came to New York for an internship at the *Village Voice*. There were people on staff there who were HIV-positive, who weren't necessarily intimates, like Robert Massa, who I think might have been one of the first beat reporters, and his beat was AIDS. He also has died.

But Kevin definitely was kind of the person that I was living and breathing that with.

**SS: Just looking back with hindsight now, what do you think was his hesitancy about getting information?**

EK: I feel like the world has changed so radically since then, and I actually attribute a lot of it to ACT UP, but people were still very closeted then. Gay lives were so suppressed, and part of what was so intense about ACT UP's presence in the streets was just all these gay people being gay in public and not apologetically so. And there was so much panic that that triggered, in police and media and everyone else, and so much emotional intensity for the people involved.

But I feel like those early years, Kevin's parents hadn't really acknowledged that he was gay. I think that made it hard. It's like to try to build a positive gay life, he just moved to New York when he moved in with me, to build a positive gay life in New York at the same time that you're trying to struggle with an HIV diagnosis in that really dark time when that was a pretty scary and hopeless diagnosis. It's a bitter pill, and I understood that he just wanted to try to not have that dominate his consciousness and his social interactions and his identity.

It's funny, because both of my housemates at the time were black gay men. My friend Bernhard [Blythe] is still HIV-negative and thriving. But I feel like they were both really in the midst, in their twenties, of trying to find themselves as gay men and still negotiating openness with their families, and that's the context in which HIV infection was happening.

The fact that there were so many people in ACT UP who managed to be really forthright about having HIV and trying so hard to be open and shameless about it, it's incredible. To me, the opposite, like Kevin's experience where he didn't want to be front and center with that, that makes sense to me completely, given the time. I think the exceptions are really what's remarkable — that some people managed to do that.

**SS: One of the things we've really been thinking about in the eleven years we've been doing these interviews is it's such a special group of people. I've interviewed 140-something people, and it's an amazing group of people. And one of our questions is what do these people have in common or what enabled people to be so out there, coming from the same backgrounds as most people who couldn't be? Do you have any insight into that?**

EK: Well, some of my responses are going to be shaped by my experience of having just watched *How to Survive an Epidemic* or *How to Survive a Plague*. But I think ACT UP was really an ecosystem, and it was the combination of these forces that made this happen, that there were these super experienced activist radical types, the Maxine Waters people and —

**SS: Wolfe.**

EK: Oh, my god. Not the congresswoman. She was not in the room. Oh, dear. Maxine Wolfe. And Aldyn McKean I think of as one of those people who already had a deep radical history combined with a lot of people with an incredible sense of play and joy, and people with a strong sense of entitlement, like the handful kind of, I think, overemphasized, possibly, group of people that came off of Wall Street or whatever who were in ACT UP who really had been leading quite privileged lives until AIDS smacked

into their realities, that there was — I don't know. There was just something mutually reinforcing about all of it, I think, and the urgency of it.

I've been in a lot of activist organizations since then where there's a lot of people just getting caught up in their political positions, and knuckling down in their stances on things, and just getting paralyzed and unable to move forward. I feel like that was never true in ACT UP. There were huge, rip-roaring conflicts over things, but it was always very, very fluid because everyone wanted something to happen and to happen very quickly, so no one was going to be patient with grandstanding or with people staking out inflexible positions.

**SS: Do you think there's a link between what you call staking out an inflexible position and not really needing things to change?**

EK: Well, there's a kind of activism in this country that I think you can see mostly clearly with, like, the Catholic worker folks, some of whom are in ACT UP, which is sort of about bearing witness, and it's really up against this unethical corporate machine or government machine — these cruel policies. "We're going to make our stand and say this is wrong."

I remember I was working with Coalition for the Homeless for a while with this StreetWatch project, and we were trying to observe and interrupt police violence toward homeless people. One time we got this call in the middle of the night that Giuliani was going into this encampment with a bulldozer and laying it low. This one guy who was involved in the project who was a Catholic worker, a guy, Felton Davis, who was also in ACT UP —

**SS: What's his name?**

EK: Felton Davis. Went by himself to stand in front of the bulldozer. And I think that's beautiful. It was incredibly moving to me that Felton Davis did that on his own at one in the morning, but that's not what ACT UP was about at all. It wasn't we're just going to — we're just going to show that that government is disregarding us, and we're going to show how morally bankrupt they are, and we're going to show Burroughs Wellcome that they're unethical. That wasn't anybody's goal was just to show that they were right. It was always, always to make shit happen, and that just was like this hot knife that just cut through everything.

**SS: But that's the question that's facing us right now in 2012. There's so many people who want change, many, but they don't know how to do it.**

EK: Yes.

**SS: I'm trying to understand what is the relationship between being able to be effective. Why are people not able to be effective?**

EK: Yes, because they don't believe they can be. So, then the question is why in ACT UP did we all have that leap of faith, that mutual leap of faith that we were absolutely going to be effective? I think that absolute conviction about that just fueled everything. It meant the targets kept changing, you were pushing on NIH, and then you realized it was a drug company and then you shift to the drug company, and then it's an insurance company, so you shift to the insurance company. It didn't matter if it wasn't a customary political target. It was just whoever was creating the problem that you identified that week, it was time to roll.

I think the non-ideological aspect of ACT UP really helped with that. It wasn't like everything necessarily had to be anti-capitalist. At times people worked with

private, whether it was insurance companies or drug companies, to try to advocate change at times they were targeted. Government, private sector, international bodies, media outlets — anything was a target if it was creating problems.

I think, I don't know, having spent a lot of time in community-organizing circles, I also think there's this problem that's created by the funding structure, the foundation funding structure where people have to design campaigns, and they get that campaign funded, and they have to have plans that go over years, and there's this kind of taming of people's strategies and ambitions. People choose the campaigns that are more fundable. There's all this stuff that nips creativity and effectiveness and nimbleness in the bud, and ACT UP never had any of that.

**SS: No, we avoided that. All the money was grassroots fundraising.**

EK: Yes.

**SS: There was no 501(c)(3). Nobody was paid. The only person who was paid was Sean Strub for his mailing list. But nobody else was paid.**

EK: But it was also like at times ACT UP had a ton of money, because people like Keith Haring were helping raise money, and at times ACT UP was broke, and either way things happened. Yes, there was a period of years when we could do big actions in Bethesda or D.C. and buy blocks of hotel rooms, and later that was unaffordable. But it almost didn't matter in terms of, like, the strategizing. You do it with money. You do it without money. You just do it.

**SS: So, what is that moment when people decide that they want funding? From what you're saying, that's a very key moment where you give up a lot of possibility.**

EK: Yes.

**SS: Why does that happen?**

EK: I don't know. People have to pay their rent, I guess. During the years — like in my early years of ACT UP, I was much more of a foot soldier, and I just participated in a ton of actions and got arrested a lot. I was just like an eager student and participant. But in the later years when I was taking a lot more leadership and just really — I look back on those years and I mean I was living in New York City on \$10,000 a year during those years. I happened to be living in that collective household where we were paying next to no rent, which made it all possible.

I couldn't have done that if I was paying market-rate rent or if I'd had a kid or if I — you know. I think people just hit a crossroads where they were like, “well, if I want to keep doing this work as the primary thing I do every day when I wake up in the morning until I go to bed at night I have to get paid.”

**SS: But that's a big theoretical obstacle, because it's like when I see people who say, “I want writing to be thing to be the thing that pays my living,” and I'm like being an artist and earning money are two separate endeavors.**

EK: Yes.

**SS: And being part of a political movement and earning money are separate.**

EK: Right.

**SS: But where is this idea in people's minds that those things are supposed to support them financially? Where does that come from? It's a fantasy, really. I'm just wondering, do you think is there a propaganda machine? Are there**

**messages people are getting that politics and art are supposed to support them?**

EK: We're all existing in the context of American capitalism and I think that it takes a lot of consciousness to resist that. You look at what passes for counterculture in this city right now, and it's all about marketing things. It's all about creating your little marketable pickles or crafts or whatever. I just think that there's this way where I think Americans lose track of how much they just think everything's supposed to be monetizable.

**SS: But if you're trying to build political movements that are effective, that's the obstacle, isn't it, cutting through that?**

EK: I think it's a big one. But I think the question of sustainability remains. How do you — or maybe things don't need to be sustainable. ACT UP is an interesting lesson in that. It's like it was super effective for seven years, eight years, and maybe that's enough. Maybe you don't need to try to make something sustainable for twenty-five years. Maybe movements need to rise and fall based on the political moment. But now that I'm middle-aged, I think the question of how to continue to be an activist, how to continue to lead an activist life — it's challenging.

**SS: One of the things we've been talking about is the whole AIDS Inc. phenomena and how so many people came into ACT UP not knowing if they were going to live or die, put everything into it, changed the world, and then were unable to earn a living and ended up being employees or participants of AIDS Inc.**

EK: Yes. I was.

**SS: Okay. Who did you work for?**

EK: I worked for *POZ* magazine. It's an HIV/AIDS magazine.



**SS: And now AIDS Inc. is the problem, right? AIDS Inc. is the thing that keeps things from moving forward, especially in prevention and stuff like that.**

EK: But AIDS Inc. does great things, too, in people's lives. It's not — it's a mixed bag.

**SS: Well, some of those agencies do.**

EK: Yes.

**SS: Some of them are very highly funded and don't do anything.**

EK: Yes.

**SS: Certainly, the treatment has done much better, but prevention is nowhere. I think we all know that.**

EK: Yes.

**SS: And yet there's all this paid infrastructure and huge amounts of money and global AIDS also is a money eater.**

EK: Yes.

**SS: So, what does an individual have to tell themselves when they're authentically in the process of changing a society so that they don't become the problem?**

EK: I guess it's a sense of ethics. I remember when I took the job at *POZ*, I was very conscious of that, because in ACT UP we defined ourselves so strongly as against AIDS Inc. We were not wearing red ribbons around ACT UP.

**SS: Right. We didn't have Pharma ads.**

EK: Right. *POZ* was funded by Pharma ads. But once I was at *POZ* and the editor-in-chief, Walter Armstrong, I think was probably arrested more than possibly anyone else in ACT UP — I mean, Sean Strub — it's kind of amazing what we got to do with pharmaceutical money there. We were the first ones to start reporting on the nasty side effects of protease inhibitors, long before anyone was even bothering to study it. Obviously, the drug companies were getting these reports back and not doing anything public with them.

But I think there was just like an ethics of this is absolutely about people living with AIDS, and I actually feel pretty proud of what we accomplished at *POZ*, which was not how I thought I would feel walking in the door. And pushing for stuff that those pharmaceutical companies — pushing for research into unpatentable substances like vitamins. There were a lot of things that we did in *POZ* that were pretty much biting the hands that fed us, but for at least a period of years until they switched their marketing strategies, we had what they thought was the audience they wanted to reach.

**SS: What is their new marketing strategy?**

EK: Well, they shifted a lot to marketing directly to doctors, sending doctors on junkets, giving them free samples. I think they kind of realized that that was where a lot of the decisions were being made.

**SS: That's so interesting, because most Pharma now is doing direct patient marketing through television. You see all those ads all the time, so it's interesting that AIDS would take a different route. Do you have any insight into that?**

EK: Well, the direct-to-patient marketing, I mean, HIV was one of the first arenas where that was pioneered. There was massive amounts of that. Those were the ads that fueled *POZ* during its heyday. I think managing HIV treatments is extremely, extremely complicated. It's not like just deciding you need a sleep remedy, and "I'll take Lunesta." Especially in the age of combination therapy, like a patient walking in and just saying, "I think I'd like to try Kaletra." It's just too complex, and I think they kind of realized that it wasn't really — as educated as people with HIV generally are, compared to other patients in that context — even for very sophisticated, very experienced doctors, managing these combinations is complex — complex art form.

**SS: That's really an interesting point, because early on when there was only AZT, it was so easy to market it.**

EK: Yes.

**SS: Then when ACT UP's research agenda actually became reality and meds were so much more complex, I can see exactly what you're saying, and the marketing had to change.**

**Okay. So, let's talk about your involvement in ACT UP. So, who brought you to ACT UP, or what made you decide to come?**

EK: Mark Gevisser, who was a friend from college, another friend from college who ended up in New York, a South African political reporter, went to a meeting, and he bounded into the *Village Voice* one day. This is probably when I was still an intern and waiting tables at night to pay the rent. And he was just like, "Esther, Esther, you must come!" And I did. It was just like I think he walked into one of those meetings and just couldn't believe what was going on in there.

I started going to meetings, and then I think very — it was in the lead up to the Target City Hall action. I was already kind of pissed off at Ed Koch for various other reasons, and I very quickly just — I got trained in civil disobedience. Gregg Bordowitz led the training that I did. I thought he was just unbelievably glamorous. I got arrested probably within a month or two of my first meeting. That was the first political arrest in my life.

**SS: Let me ask you a couple questions about that. When you walked into the room, had you ever been to the Center before?**

EK: Yes, I'm sure I had.

**SS: Were there people there that you knew in the room besides your friends from college?**

EK: Oh god, I don't remember. I went to that first meeting with Mark. I don't know. There may have been. There were certainly people in that first year I was involved in ACT UP. There was certainly a number of people there that I knew from outside of ACT UP, but not most of them. Most people I got to know through ACT UP. I had probably a smattering; half a dozen people maybe I knew from outside.

**SS: So, when you took CD training, did you have a commitment to nonviolence before that time?**

EK: Yes. I think my commitment to nonviolence lessened during the course of my time in ACT UP. But I think I did at the time.

**SS: Why did it lessen?**

EK: Because of my experience with the police. I've just been thinking a lot. A lot of images have been coming up for me, knowing that I was going to do this

interview, and I think the most intense feeling of rage I've ever had in my entire life, and, really, I think it would be fair to call it murderous rage, was at our efforts to give Tim Bailey a political funeral in Washington, D.C. And when the police surrounded the van and took the coffin out and tried to take the coffin away from us, I — it was so awful.

**SS: Did you have a relationship with Tim?**

EK: No, not a close one.

**SS: Right. So, it's larger than just Tim.**

EK: Oh, yes.

**SS: That moment.**

EK: No, it wasn't even — I felt like I was more of a bodyguard or something in that situation. It was all of the Marys who were trying to honor their friend.

**SS: How did you understand the way the government was reacting to us? Not then, but now — when you look back, what was all that?**

EK: Well, so much of it was just fueled by homophobia. Homophobia is not quite the word. I think it was fear of gay people. It was also hatred of gay people, disgust. It was disgust at gay people. When you think of the stuff that came out of William F. Buckley's mouth or Jesse Helms' mouth — just the interactions with police. The way the police were generally so brutal, but also always wore latex gloves. There was just this feeling. It was so clear that you were a piece of shit that they didn't want to touch, a contaminated piece of shit.

It's not like I had warm feelings toward the police before that. There was a lot going on in terms of police brutality in the city at that time, and I remember going to some of the public services and funerals and protests and stuff around various victims,

African American victims of police violence. This is when Al Sharpton was first taking on the issue. It's not like I thought these guys were — I had no illusions about the NYPD, but I think that having that experience again and again and again with the cops, and how repulsed they were.

I remember we did this action up in Kennebunkport at the first George Bush's vacation retreat, the Bush family compound up there, and, like, the whole town shuttered. It was all of Main Street, this cute little, like, Mayberry Main Street, unbelievable. You wouldn't believe it existed, this beautifully manicured white clapboard, golf course manicured lawns. And they were so afraid of a couple hundred ragtag AIDS activists coming to town, that they literally locked down the entire commercial district — that was the mood. I think that was the mood of the elected officials too. They generally were a little more circumspect about it, I guess.

**SS: But given that and given how many of our friends died horrible deaths, it is amazing that ACT UP never committed an act of violence.**

EK: Yes, I guess. I guess it is.

**SS: Why is that?**

EK: Well, we were really disciplined. We were trained really well. I'm sure at that incident I was talking about where we were trying to deliver Tim Bailey's body, I think, to the White House and got stopped, and when I was losing my shit, I'm sure there were three people that were holding me back. No one ever wanted the police to have to be policing us, so there were always people whose job it was to keep their cool and keep separation between activists and the police and make sure that we were the ones controlling the situation, not the police.

I learned a ton from that. That discipline was so profound in ACT UP compared to other organizations I've been in. I think of Amy Ralph like this, just profoundly unflappable person always inserting herself.

**SS: Amy Bauer?**

EK: Amy — oh, my god.

**SS: That's okay.**

EK: Amy Bauer. Where did Ralph come from? Amy Bauer and BC Craig, too, and a different, slightly different temperament, but just being able to be completely —. And that was just so impressive to me, and I learned a lot from that. I think over time I slowly became that person who could do that, who could be experiencing intense emotions and still really stay focused.

**SS: But I think what I'm asking is, like, nobody said, "I'm going to die anyway, so I'm going to assassinate this CEO of this..."**

EK: Yes. People talked about it.

**SS: They talked about it, but it never happened.**

EK: That's true.

**SS: Do you have any thoughts about why?**

EK: Well, I think that period of time in '92, '93, which was some of the worst years of the epidemic, got the closest, because that's when all the political funerals started happening and the Ashes Action, and that's where people were starting to use their actual corpses or plan that their own corpses would be used politically. I don't know. ACT UP had a reputation. I mean, not a reputation. People's fears — people had these phantasma — what's that word?

**SS: Phantasmagoric.**

EK: Phantasmagoric fears of ACT UP, but I think we so much knew that there was such a strong — that it was the most ethical place any of us had ever been, so I think that really drove everything, everyone was so straight up. I think — I don't know. Part of it may be strategic, like we wanted to win, and committing violence wouldn't have really helped with that, but I think you're asking about something else, which is, I think, a harder — which is something temperamental about the organization. We were all seized profoundly by the righteousness of our cause, and therefore all our actions were righteous, all of them.

**SS: So, let's talk more specifically about some of the things you did in ACT UP. Is there any particular campaign that you worked on that you remember better than others that you'd like to focus on?**

EK: I don't know. I feel like you should — maybe I should tell you some stuff —

**SS: Tell me.**

EK: — and maybe there's ones that other people haven't spoken to or something, I mean.

**SS: Okay, great.**

EK: There's the Invisible Woman Action at CDC, which I'm sure you've had other people talk about.

**SS: No, we haven't. Let's talk about that. Let's start with that, and then we'll go on to something else.**

EK: Okay.



**SS: How did that happen?**

EK: Well, I wasn't a central player in that, but what that was, was a joint — it was very unusual. It was a joint action by all the women's committees of — maybe not all the ACT UPs, but several different powerful ACT UPs in the country. That didn't typically happen. The ACT UPs functioned quite autonomously. But this was like ACT UP LA, ACT UP Chicago, ACT UP Philly, ACT UP New York. There's still women that I know today from working on that one action with, because, first of all, so many of them are such amazing people. But, yes, I'm not sure I'm going to be very good on the details of the planning, but we must have just done a lot of conference calls, because we really did plan it with all the different ACT UPs, and it was the first big, big women-led action in ACT UP. You might remember the year. But the basis of it was at that point there'd been certain victories. There were certain benefits that you could access if you had an AIDS diagnosis. But the Center for Disease Control had put out this — god knows what their process was — had put out this definition of what an AIDS diagnosis was, where you had to tick off certain opportunistic infections. This is the day of opportunistic infections when there were no good drugs against the virus. It was all about drugs to prevent pneumonia and everything, and people were walking around with KS or bouts of pneumonia and all these OIs.

So probably almost 100 percent of women with HIV had vaginal thrush, right, aggressive vaginal thrush, really, like, impossible to vanquish, and that wasn't on the list. What was happening is women were dying of AIDS without having ever been able to access any AIDS services.

So, the idea was to go to CDC and try to get them to change the definition, which they ultimately did. They didn't add women-centered opportunistic infections, but they just changed it to if your T-cells dropped — what were then called T-cells — dropped below a certain point, then you were considered to have AIDS, and so women got swept in under that.

But I remember it just being kind of amazing, because the CDC was one of those agencies that was not accustomed to being a target of political protest, and there was the big action, but there was also a lot of satellite actions that happened in regional CDC offices. And those were kind of the most hilarious, because you'd go in and there'd be this bureaucrat who was just like, "Excuse me, but I've been an invisible bureaucrat my whole life. What the hell?" We would, like, just walk into their desks and start sending faxes from their fax machine and making calls to the media from their phones, and they just were like, "Oh, my god."

**SS: Like where? Where would you do that?**

EK: In the New York regional office. I can't remember now where physically it was located, but I just remember this guy being like — and, of course, he called his boss, which was exactly what we wanted him to do.

But then the big action, which involved men and women in ACT UP, but under women's leadership, an exceptional circumstance, was great. It was really — it was such a fun thing. It was like all the big actions down in D.C. and at NIH in Bethesda and so on. Some people got inside, some people were scaling the building, some people were protesting outside. It was just a great spectacular thing and —

**SS: We actually have footage of you.**

EK: Oh, yes?

**SS: Going in and occupying the office.**

EK: Oh, that's funny, because, see, I would not have even remembered what I particularly did that day. But we were stuck in jail for a really long time, and I just remember being in jail, because normally in ACT UP, as a woman going to jail — the men would be — there'd be like hundreds of men off somewhere having fun, and there would be, you with the twelve other women. But this was like an army of women that we were in jail with, and I think they kept us at least a night, maybe two nights, and I just remember it being really fun.

**SS: What was your demand?**

EK: Changing the definition.

**SS: Okay. So that particular action of occupying that office, that was part of the campaign to change the definition.**

EK: Yes.

**SS: But Invisible Women was also at the NIH as an affinity group.**

EK: Is that the footage you have, was from NIH?

**SS: No, we have both.**

EK: With NIH there were a lot of issues around — the big women-run campaign was around the CDC definition. That was the big national women campaign. There was certainly a lot of activism around the way drug trials were conducted, that women were excluded from trials, that women of reproductive age, which is like every woman with HIV were excluded from trials, that trials were not being designed around

the way AIDS played out in women's bodies. There was definitely a lot of treatment activism on that front as well, but I was less involved in the treatment activism.

**SS: Let's go back to CDC and then we'll go to the NIH on this issue. So, everybody says that ACT UP was 100 percent behind this campaign, the CDC campaign. It's interesting, because there was always sexism in ACT UP.**

EK: I don't know that ACT UP was 100 percent behind it.

**SS: You don't think so?**

EK: Well, I don't know. I mean, I think — do you know what year it is?

**SS: What year was it?**

**Jim Hubbard: What year?**

EK: The CDC.

**SS: The four-year campaign.**

**JH: It starts in March of '89, and they changed the definition in January of '93.**

EK: Ninety-three. Okay.

**JH: So, the occupation of the office in Atlanta is what you're [Sarah Schulman] talking about —**

EK: Yes, right.

**JH: — in December of 1990.**

EK: Ninety.

**JH: The occupation of the office you [Esther Kaplan] were talking about —**

EK: In New York.

**JH: — is May of '91 or '92.**

EK: Oh, it's after? After?

**SS: Yes.**

EK: Oh, see, interesting.

**SS: So, you didn't feel that ACT UP as a whole —**

EK: No. That was one good thing about ACT UP, is ACT UP as a whole never had to back any action. As long as there was a critical mass, things would go forward. I think that was super important, and I don't think people got that ruffled about that.

No, the CDC action in Atlanta, as I recall it, was dramatically more female than other actions. That's partly because more women came, but I also think it's probably because fewer men came. But I don't mean that there was hostility toward it in any way. There were probably people who weren't as riled up by it as there were at the big FDA or NIH actions. But there were a lot of men who showed up for it, certainly.

**SS: When you see our film [*United in Anger: A History of ACT UP*] and the CDC campaign is one of the centerpieces of the film, there are a lot of men at these demonstrations.**

EK: Yes.

**SS: But the thing I want to get to is, like, ACT UP had a lot of sexism, an enormous amount of sexism.**

EK: Yes.

**SS: And yet it successfully was able to do actions and campaigns that made things better for women.**

EK: Yes.

**SS: What's really interesting is that these two things can coexist, because in most cases, the personal sexism of men becomes so obstructive that the organization can't move forward. And yet here they didn't seem to affect each other, and I'm wondering if you had any insight into that.**

EK: Well, ACT UP was big enough — it's like Yale. ACT UP was big enough to have subcultures. First of all, there were so many structures. There were all the different committee structures, and then there are affinity group structures, which were unrelated to committees, right? Affinity groups were just the people that you — when there was a civil disobedience action, it was the people that you took risks with, the people you felt safe with and felt intimate with, or had been through CD training with or whatever.

But there were all kinds of — there was a social world in there. There was this group that people used to call the Swim Team. It wasn't even a group. It was this certain cadre of these, incredibly Ralph Lauren kind of handsome, tanned, carefully put together, handsome, gym-bodied — before everyone had gym bodies — white boys. And, there were lesbians with their own social dramas going on, and there was the Latino Caucus, and there was just so much, so much going on in there.

I don't think there was a presumption that it was supposed to be like a common culture that everyone shared or that everyone was part of the same social group. It was called a coalition, which sort of seemed silly because it was an organization. But, the dynamics of it internally were a little bit coalition-like in that everyone was just vested and everyone kind of accepted that there was all these different elements in the

room coexisting. And some people could go be fighting on the needle exchange front, and you just sort of cheered them on. It didn't mean that you were doing that. And the same with the treatment group.

Some of those conflicts really came to a head at a certain point, but that's the sort of like one year, I would say, in the history ACT UP when that stuff was an open conflict. I would say overall in the arc of ACT UP, that stuff just coexisted. And I think that there's a way in which I think ACT UP was sexist. There's a way in which, people like Ann Northrop and Maxine, Amy, were kind of venerable leaders in there, really commanded the respect of the room. So, it was a little — it would have never quite worked to just think of ACT UP as sexist. I think all the women who were in there were pretty strong feminists. Not necessarily part of the Feminist Movement, but pretty self-possessed people. So, I don't think anyone felt like they could be shouldered aside.

**SS: Well, one of my thoughts is that the women took up a strategy that was applied, so there were not debates about people's sexism. The only thing I remember is when they came in with that poster for Stop the Church, that was all these women in chador. Do you remember that?**

EK: Oh, my god, no.

**SS: And it got knocked down. But the women were very strategic. It was about using the resources of the organization to better things for women with AIDS.**

EK: But not entirely, I think also a lot of women were in the room because their gay male friends were dying. You know what I mean? I think women were — a lot of women really cared about what was happening to women in the epidemic, and a lot of

women really, really cared about what was happening to men and were spending a lot of hours in the hospital with their dear male friends who were dying and who were — .I don't think it's like the women in the room were a rump force looking out for women. I think, yes, that's part of the story, but that's not the whole story.

**SS: One quick question. Who was on the Swim Team?**

EK: I think if you asked any number of gay men that question, they would be able to answer it quite quickly for you, but they weren't really objects of sexual obsession for me, so I kind of remember them standing in the back of the room, but I really couldn't tell you.

**SS: Let's get to the NIH. One of the big questions that we've had that we haven't been able to answer is what was won at the NIH demo. Do you have any sense of that?**

EK: Yes, I'm not your person. There was a brief period in ACT UP I was — it's actually kind of an important period for ACT UP, but where I was — I became copy chief at the *Village Voice*, and we closed on Monday nights and ACT UP meetings were on Monday nights, and I was suddenly not able to come to meetings. It was a big chunk of that time when the meetings were at Cooper Union and were really massive and where actually a lot of the conflicts hit their peak too. I was present for some of it, but not all of it. But the NIH action is actually an action that I wasn't even at.

**SS: So, let's go through your list. So Invisible Women.**

EK: Well, so, YELL [Youth Education Life Line], which was the youth committee.

**SS: How did that get formed?**



EK: YELL was a funny little collection of people who worked in the public schools, and I was doing some arts education in the public schools at the time, so it was like schoolteachers and high schoolers. There were a lot of teenagers in ACT UP. I don't know if you've talked to any of them. But I remember one person who was on that committee, who's still a dear friend now, joined ACT UP and joined YELL when he was thirteen. He wasn't even through puberty. Jonathan Berger.

**SS: Oh, right.**

EK: Really amazing. I remember walking — I remember vividly the first time he walked into a meeting, and it was like, there's a child here.

YELL was a super fun committee, and it was almost all focused on the board of education, which was then at 110 Livingston in Brooklyn, and at high schools and junior high schools across the city. And we were really fighting for HIV education in the schools and we were fighting for condom access in the schools. And there were all kinds of battles back and forth on that stuff.

This was at a time when the Christian Coalition had decided its strategy was to take over school boards. So even in New York City there were a lot of local school boards that had been taken over by evangelicals and who were trying to block this stuff and try to — at one point they were trying to make — maybe did succeed for a brief period, of making HIV education opt-in. Like, only kids whose parents signed a piece of paper could access HIV education.

So, we did a lot of actions at the Board of Ed and got arrested all the time, which is hilarious because all the teenagers had to sit in jail till their parents could show up and sign them out. And then we also just would show up early morning. At one

point, we got condom distribution into the high schools, but not the junior highs. So, we would just show up with condoms at junior high schools in forty minutes as people were coming to school and just hand out safe-sex information and condoms outside the entrance.

**SS: How did you get condoms into the high schools? That's a policy change. How did that happen?**

EK: It was ultimately — there was a — the fog of years. So, there was the Board of Education, which actually no longer exists now, but we have mayoral control. Then there was this body, and I now forget what it was called, but it was sort of like the community ethics advisory board, and the cardinal sat on that. This is one of the main reasons. Like, when people went after the Stop the Church action, I would always defend it, but Cardinal O'Connor had absolutely made the archdiocese of New York a political target by interfering with policies in the public schools. It was the cardinal who was blocking HIV education and condom access on that body for a very long time.

I don't remember how it was that we finally overturned that. I'm sure it was under Dinkins. But it did at one point get overturned, and it was obviously after Stop the Church, because he was still being an obstructionist at that time. That was one of the reasons for that action.

But, again, even once it got in, then there were battles after that because it was on the books but no one was implementing it, no one was actually providing it, so there was battles around that. There was the evangelicals, Christian Right folks trying to get it to be opt-in only. So just getting the policy in was sort of the beginning of it really.

**SS: But there's a larger principal there that has to do with the changing self-perception of what homosexuality is over those years, because I think when ACT UP first started, and you're talking about this kind of more closeted period and this disgust period, there was still this thing that gay people were trying to prove that it was okay for us to be near children.**

EK: Yes.

**SS: And there was this idea that you're not queer until you're an adult and that there was no such thing as queer children.**

EK: Right.

**SS: And once you get to YELL, that's a real paradigm shift in how queer people understand themselves. It wouldn't have been possible, I think, in the early eighties.**

EK: No, but now that you say that a lot of the people on YELL who were teachers were gay schoolteachers who had been dealing with this issue in the classrooms for years, right, of trying to not be viewed as predators and the whole question of—

**SS: Do you remember who those people were?**

EK: Oh, god. One of them was a Church Lady.

**JH: Steve Quester.**

EK: Steve Quester was one of the main schoolteachers, stalwarts on that committee. I can't remember now who the other schoolteachers were.

**SS: Do you remember for yourself a sense of changing how you understood your own sexuality over the time of being in ACT UP?**

EK: Yes, but in a funny way. Not in a typical way, I think. There was this period where a lot of the lesbians in ACT UP — and I'm bisexual but was more kind of living a life as a lesbian at that time — we were so much in a gay male culture that we were sort of like, I think, trying to become gay males in a certain way. So, it wasn't — it wasn't so much the broader cultural shift of gays moving to acceptance. I think I was part of this sort of funny little thing where lesbian clubs would start trying to have back rooms and promote anonymous sex and trying to embrace this sexual libertinism along a gay male model that didn't quite translate.

**SS: That's very significant, Esther, that you bring that up, because the outside lesbian culture was dissipating, and it was this new lesbian culture within this gay male context that was going to be the future.**

EK: Right.

**SS: And that eventually became queer.**

EK: Right. That's true. Well, and it was a flowering, actually. I have a lot of nostalgia for this of — at least a decent handful of not nightclubs like every night, but like weekly parties that were male and female queer culture united in spaces, and that was really fun and great, I think, and it didn't last very long. There was probably only a few years where that, where there were a lot of spaces like that around.

**SS: Here's a weird question. Okay. What you're bringing up is really making me think. There's a way that those of us who were women who were in ACT UP won a kind of legitimacy with men that queer women who were not in ACT UP did not win.**

EK: That's probably true.

**SS: And it's helped us all our lives to gain access to things and to be seen.**

EK: That's interesting.

**SS: In a way, it's like heterosexual privilege in some sense, because —**

EK: Because we were attached to certain men.

**SS: Yes, and because they noticed us because we were doing things for them, and that has carried on for twenty — I know in my life it's had an impact for decades now.**

EK: Yes, that's a slightly cynical way that you're putting it, but it's definitely true. I got the job at *POZ* after I was involved in a spectacular failure of a kind of collective attempt to open up an alternative public school and was in debt and demoralized, and it was an old ACT UP comrade who just kind of offered me a job there as an editor. I remember really thinking like, wow, who knew that ACT UP could function as like a social safety net for me.

**SS: But that's what I mean when I say sexism, because there's a way that they saw women who helped them but didn't see women who didn't help them. Do you know what I mean? We were elevated in a certain way.**

EK: Yes. I don't know, because, of course, the men I was closest to in that world were men, were not super homosocial men. They were men who had a lot of intimacies with women in their lives.

**SS: And they were younger.**

EK: Yes. So, I think what you're saying — I was remembering that aspect of it watching the David France's film, that there was a kind of very homosocial male

elite. Well, Larry Kramer has never had much interest in women, and his imprint was on that organization. But, yes, I don't know that those were the people who became really important to me there.

**SS: So, let's keep going. So, YELL.**

EK: So, one thing I feel like I should talk about at least a little, because I can't imagine you'll have anyone else talking about it, was the big campaign that we did around Guantanamo.

**SS: Oh, yes, please. We definitely want to hear.**

EK: Which was '92, '93. I think it ended up being almost two years, and that started when an old friend of mine, who I'd done anti-nuke activism with at Yale, who was then at Yale Law School in Harold Koh's human rights clinic there, had gotten these cases of these HIV-positive Haitian political refugees. They'd already been cleared as political refugees who were being quarantined at Guantanamo, and they were trying to get them out. He called up and he was like, "Do you think you could get ACT UP involved? We're trying to pursue a legal strategy, but we're really struggling." And I brought up to the ACT UP floor and got a little committee together.

**SS: Who was on that committee?**

EK: I don't —

**SS: Betty Williams, was she part of that?**

EK: Betty Williams was. [William] "Bro" Broberg was. Bro and I were the main folks from ACT UP, but we probably had half a dozen people that were involved in the planning. And then we got Black AIDS Mobilization, which at that point

had gone from being an ACT UP committee to being an independent organization. We got them involved.

**SS: Wait, hold on. I have so many questions already. Okay. First of all, how long had Haitians been kept at Guantanamo?**

EK: When we started, it was new. It might have been a matter of months.

**SS: That's so interesting, because AIDS was associated with Haiti so early.**

EK: Yes.

**SS: And it took till '92?**

EK: Well, I think it was — okay. When was Aristide? I think it had to do with the fact that there was suddenly a swarm of political refugees coming out of Haiti, so, yes, there was already an association with it, but suddenly there were people who the U.S. State Department was deeming political refugees and yet holding back. There'd always been Haitian immigrants here that were demonized, but these were people coming out of Haiti who had been screened as legitimately in fear of political persecution or having experienced political persecution.

**SS: Now, I have never heard that Black AIDS Mobilization started as a committee of ACT UP.**

EK: I'm pretty sure.

**SS: Who were the people?**

EK: Oh, my god.

**SS: Or what was the name of the committee?**

EK: Oh, what was it? You mean was it called something besides Black AIDS Mobilization?

**SS: Is this like Michelle Adams?**

EK: Michelle Adams.

**SS: And Cathy Cohen?**

EK: For sure. I don't remember.

**SS: So, when you made a coalition at that point on this issue, who were the people from Black AIDS Mobilization that were working with you?**

EK: I think Michelle was. God, I'm sorry, I can't remember who was there from Black AIDS Mobilization. But it was ACT UP, WHAM, and then people from the Haitian pro-Aristide movement here, Ray Laforest and some of those folks affiliated with *Liberation* — not *Liberation, Haiti Progrès*.

**SS: What's it called?**

EK: *Haiti Progrès*, a little lefty publication. And then there were the lawyers and ultimately Center for Constitutional Rights got involved, so Michael Ratner there, which is just interesting because CCR was the first to start challenging Guantanamo and its subsequent usage for terror suspects, and that's because Michael had already been there multiple times on this other campaign, so he knew Guantanamo inside and out at the time that it got designated to hold terrorist suspects, and that's part of why CCR swung into action so quickly around that.

**SS: That's really important.**

EK: So basically, it was this campaign. I think we thought it was going to be a few months and it dragged on. It was like a year and a half, two years, and it had so



many prongs. I was working with Coalition with the Homeless, just because there was a wonderful attorney there who decided to get involved, Lisa Daugaard, and we organized

—

**SS: Who was that?**

EK: Lisa Daugaard. We organized these volunteer attorneys to try to handle people's asylum cases, and then there was CCR and the Yale Human Rights Clinic leading the legal challenge through the federal courts, and then we were just busy doing little demos all the time. We never had huge ones, but every time Clinton was in town, we were hounding him. And every time there was any development in the court cases, we would pack the court. There was actually a black judge on the case, and I remember he was clearly pretty impressed that there was a constituency for this case, and I think it made him pay a lot more attention to it.

And eventually it kept dragging on and on. We had one person die while still held there. It was just getting more and more dire. The numbers were rising up north of a hundred people there. I think there might have been north of two hundred at one point. Then at one point, we won and they all got released.

**SS: You won in a court decision?**

EK: Oh, goddamn it. I think it was a combination. I think what happened is the State Department started compassionate releasing the sickest people, and we started getting people out in dribbles that way. That was just due to the political pressure.

**SS: Do you remember the name of the case?**

EK: I don't. This is the kind of stuff I should have —

**SS: Well, what's interesting is that the ban on HIV-positive people coming to this country persisted until Obama.**

EK: Yes.

**SS: So basically, you were asking for an exception.**

EK: No, we were asking obviously for the policy to be overturned.

**SS: Right. But they created — whatever decision this was or whether the government changed their position, they created an exception without lifting the ban.**

EK: Yes. So, it must not have been won in court. Was it won in court or was it — I can't believe that I'm now forgetting it after all that years of struggle.

**SS: What are saying, James?**

**James Wentzy: It was won in Supreme Court in Brooklyn.**

EK: It was won there?

**SS: But how come it only applied to people in Guantanamo and it didn't apply to lifting the ban?**

EK: It might have just applied to political refugees. That might have been the difference. They weren't average immigrants.

**SS: So, did you go down there?**

EK: They were political asylees. No, I never went down.

**SS: Did you meet people when they came here —**

EK: Yes, tons of them.

**SS: — when they were released? And what was that like? What was waiting for them?**

EK: Well, I ended up being the one that was trying to coordinate the pro bono attorneys for people, which was kind of a mess. We were training law students, and some people were getting really good representation and some really weren't. They basically got in, but they still had to each individually win their asylum case. And we were trying to find community housing. Betty ended up taking in a juvenile, young kid, and more or less parenting him.

That was given to me by one of the guys in Guantanamo who got out. They were pretty shattered. It was pretty awful. They hadn't generally known they were HIV-positive when they were in Haiti. They suddenly get a needle stuck in them by the U.S. government and then told they have HIV. So, tons of them were convinced the U.S. government had given them AIDS — these were all left-wing people protesting the Duvalier regime. So, it's like they didn't exactly trust the U.S. government. They'd been behind barbed wire for a year, year and a half, two years.

**SS: So how did you find housing for them?**

EK: The typical stuff, through Catholic Charities and through a lot of the standard relief organizations, mainly. A lot of people lived in church basements for a while.

**SS: Is there anyone who's still alive from that group?**

EK: I'm not in touch with people, but I'm sure that there are. Not every, there were some people who were quite ill, but a lot of people weren't super ill at all.

**SS: And how did ACT UP respond to this campaign? Had we had other campaigns that had to do with immigration or —**

EK: Yes, there had been a longstanding campaign and position against the immigration ban, and there were always politics around that every time there was a national AIDS conference around. There was that year that it was in San Francisco, right, and people couldn't come in to speak at the conference because of the U.S. immigration ban.

So, it was obviously an ACT UP issue. I don't think there was any controversy about it. The question was just like how many people were going to show up and be involved, and it was never a huge number. But every once in a while, after one of the first people died there, and Clinton came to town and we brought a casket to protest, so there were certain actions where more people would turn out.

**SS: Did Clinton end up taking a position on this?**

EK: Well, that was the whole thing. Previous to this, we'd had this whole campaign where we, during the Democratic primaries for president, we dogged all the Democratic candidates, and I was on the Target Clinton group. There was target everybody, and we were all trying to get them, among other things, to take a position on lifting the ban, and he did.

But it was one of those things where he did it — he tried to do it right when he came into office, and he just completely politically bungled it, and the Republican Congress ending up responding by actually making it — it had only been a policy, and the Republican Congress had made it a law in response to his efforts to rescind it. So, it was just like a complete disaster, and once he saw the backlash coming from the Republicans, he dropped his resistance. It was just a colossal disappointment.

After that he never would really — I don't know. Maybe he gave lip service, because that was technically his position, but he never again put any political capital behind it.

**SS: So, what was the experience of targeting Clinton? Did you see a lot of Clinton when you were doing that?**

EK: We did see a lot of Clinton. It was during that campaign that, like, there's that footage that we've all seen of Bob Rafsky at that one dinner just screaming at him. But, yes, it was just like showing up at all — he was an underdog for a while, so there were a lot of events that were small enough that it was pretty easy to —

**SS: Did you have a perception of him then that's different than how we see him or how you see him now?**

EK: Well, he's a very different guy now. I have a lot of bitterness and anger about the way he's devoted a lot of his post-presidency to AIDS, after completely punting on it as president. I think that that's clearly in some private way he knows that he fucked up. But it's sort of thin comfort to have him waltzing around the globe now when he had eight years as President of the United States to do stuff, and now he's busy wining and dining pharmaceutical companies to get them to offer drugs at a discount as a supplicant when he was the president.

**SS: But there's also this perception that when Clinton was elected, a lot of AIDS activism demobilized because there was this wish or misperception that he was going to help us and that now we were in the White House, and you see a lot of our leadership going into these bureaucracies.**

EK: Right, because they thought they'd have access.

**SS: It had a huge impact, yes.**

EK: Well, I think it's so many factors. I think he was elected in '92, and that was also, like, people were dying right and left in '92, '93. So, we lost a lot of leaders because they died and also for people who were still living, they were just surrounded by caregiving and death and were exhausted emotionally and had been pushing — the people that were around in the beginning had been pushing hard for five years. So, I think the Clinton thing was part of it for sure, but I think a lot of stuff conspired to make '92 a year when there was a lot of attrition from ACT UP. I think ACT UP definitely was starting to enter a second phase then where new leaders had to emerge.

**SS: I'd like to talk to you now a little bit about The Split. I don't know how much time you've spent in the last twenty years thinking about it, but —**

EK: Not too much.

**SS: How do you understand what happened?**

EK: That's also around when The Split happened, right? So, a lot of people left in the wake of that. For all those people you talk to who left around then, it just means something different than for people like me who stuck it out for several more years and kept working really hard in ACT UP. I think it's less of a showstopper in my memory because I just kept plugging away. In fact, I became more active after that because so many experienced people had left. But I was obviously on the side of the social issues people, the access people, and not just the treatment wonk people, but I also — I think there was a little bit of wrongheaded thinking on both sides.

**SS: What was the wrongheaded thinking on your side?**

EK: Well, there was that moment of a proposal to have a ninety-day moratorium on cooperating with the government or going to meetings with NIH or I forget the exact restrictions that were proposed. Like I said, this happened to be this year where I wasn't at the big meetings a lot, but I was at some, and there was — I think I, happily, don't remember who, but some HIV-negative women who stood up and said, "You know, come on, ninety days, it's not the end of the world," or something like that, and it was just like one of those things where, it was kind of like a big "Fuck you" to the people who were really ill in the room, to act like ninety days was nothing.

I think that there were always these tensions there, I think. Yes, there were political differences, that in gross terms you could say that there were these fairly privileged men who had access to decent healthcare and all that and they just needed the fucking drugs and that was their focus. And they did not, by the way, run around showing up for the needle exchange actions and the women's access actions and the condoms in the public-school actions in the way that everyone else showed up for the treatment actions.

I got arrested at drug companies a lot. That wasn't my focus at ACT UP, but I would show up and stick my hands in a tube in front of — So, yes, they were admittedly not very preoccupied with people who had less access to stuff or to the prevention side of things in a way that was not very generous, but they were also HIV positive, and part of the incredibly vital force that we were talking about earlier who were keeping ACT UP relentlessly focused on solutions and not to devolve like so many leftwing groups into taking moral positions for the sake of taking moral positions bullshit. I think that their kind of relentlessness and the ambition that they had to

really find an effective treatment, nothing short of that, and the urgency, the sense of time clock behind that was essential to the DNA of ACT UP. I think without the presence of that strain within ACT UP, ACT UP could have broken off in a million pieces.

**SS: But aside from the personal experience of seeing footage, when you saw David's film and you saw these people being put front and center as *the* thing that — and all these other communities that we've been discussing being ignored, what was your reaction?**

EK: Well, that's his narrative. That's not necessarily the narrative as people in the Treatment Action Group would have told it. Let's start there. But, I think one of the things that I felt like he really, really missed, which we were talking about earlier, is the fact that ACT UP really was this ecosystem that those truly sharp minds and fanatically focused people in TAG had power because of the rest of us. It's inseparable. You can't take the research work and sort of agenda-setting work that they were doing and separate it out from the larger body of people who were willing to just show up and lie down in front of the doors of a building.

Yes, I think the film really, really, badly missed that. But, like I said, I think the reverse is true too. I never was in that camp. I sat next to Mark Harrington at the screening of that film, and he couldn't remember who I was. That's just absolutely classic. But I respect the hell out of them, warts and all, and I feel like it was that presence in ACT UP that helped make it what it needed to be and made it so incredible.

And those folks spent a lot of time educating the room. There was not an elite knowledge hoarding at all. To the extent that they learned stuff, there would be these whatever, ten-, fifteen- minute, in the middle of a political meeting, there would be



these teach-ins on any, any important new lifesaving information, it was part of the agenda. But beyond lifesaving information and about drug developments, it was just helping the collective understand how drug development worked in the public sector and in the private sector. I think they understood themselves to be part of a broader community, understood that they needed to be in conversation with that community. It did reach a pivotal moment and there was a split, but I don't think of that split as characteristic of how the dynamic was in ACT UP's most effective years.

**SS: So then in the next four years where you stay in ACT UP till '96, right, what were the key things that you felt were accomplished in that time?**

EK: Boy —

**SS: Or just one thing.**

EK: Well, the Haiti thing happened.

**SS: Right.**

EK: The public-school battles continued and reached a much better resolution.

**SS: Let me ask it differently. This is what I'm thinking about. We interviewed —**

EK: I need to look at, some Bob Lederer or timeline or something like.

**SS: We just interviewed Kevin Frost from amfAR, and one of the things he told us is that right now there's 1.2 million people with HIV in this country and only 30 percent are undetectable. So, 70 percent of people in America are not getting access to treatments that exist.**

EK: Well, or have poorly managed bullshit.

**SS: Or have never been diagnosed or live in states where it's not available or all kinds of things. But that's not the general perception. The general perception is that AIDS in America is fine and the problem is in Africa. Where did that come from? Where has that, in your mind, that distortion come from?**

EK: Everywhere. *The New York Times*. I think it's still a massive qualitative difference. It used to be no matter how knowledgeable you were, no matter how much health insurance you had, you could not walk in to see a doctor and have a solution. It was like, "try to eat healthfully, and there's these, like, egg lipids from Mexico or France or something that you might want to try", and that's not the reality anymore.

I think what's happened in the last decade or so is America's become a much more radically economically divided country. It's much more a country of haves and have-nots than — when ACT UP began, it was still the Reagan years. The full legacy of Reagan hadn't penetrated. So, HIV is not the only — you could say that about diabetes and you could say that about cancer and you could say that about heart disease, that there are communities in which people get state-of-the-art treatment, and it's sort of a blip. And there are communities where people die in their fifties of diabetes.

So, it becomes one of these endemic questions of radical social and economic inequality of this country, but we don't have a political party that's willing to acknowledge or address. We have the beginnings of a social movement that's willing to address it, but —

**SS: So, the thing that ACT UP couldn't overcome was the class system, ultimately.**

EK: I think for all that people who think of ACT UP more through the lens of the Treatment Action Group, think of it as having been an elite activist movement, I think ACT UP actually accomplished a ton. People went out and did needle exchange when it was illegal and forced it to be legal. That was about people who were using heroin on the street. That was not elites whose lives were being saved.

The prevention work in the public schools, the Housing Committee that became Housing Works, which now provides more housing to homeless people than any organization in the country, I think, pushing through programs like ADAPT that provide HIV meds to uninsured people, obviously, like everything else, a victim of budget austerity now. But ACT UP accomplished a hell of a lot of stuff for marginalized people, for a group that's widely seen as elite.

**SS: Why is it seen as elite?**

EK: Because it was mostly white, I guess, mostly white and male. It was — that's not unusual for an activist movement in the United States that's not right-wing. It really is.

**SS: Well, Alexandra Juhasz says it's one of the only times in history that privilege and principle existed in the same room. I only have one more question. Is there something we haven't covered?**

EK: Oh, I'm sure, but —

**JH: Do you want to talk about the Holland Tunnel?**

**SS: Oh, yes.**

EK: Oh, yes, we should talk about that. That didn't accomplish a lot, but it was a pretty cool thing.

**SS: What was the purpose of it?**

EK: So, it's funny. All these mayors that paraded through and presidents during the course of ACT UP, all these different villains, but as bad as Koch was, Giuliani was really a monster and came into office just going after the weak. His campaign against squeegee men that he started his mayoralty with was just outrageous. Like, really, that's who you, the mayor of the city of New York, is going to go after, some guys on the corner trying to clean some windshields for pocket change. Wow.

So, there were massive budget cuts. There was harsh rhetoric emanating from the mayor's office, but what was happening is he was — it was such a, like, you know, the victims were everywhere. So, every mobilized constituency in the city was, every day on the steps of City Hall. One day it was the soup kitchens, and the next day it was the CUNY students, and the next day it was ACT UP. And everyone was trying to fight back the damage in these brutal budget cuts and these quality-of-life crackdowns and so on, and it just started feeling ridiculous. If one person won, one group — like if ACT UP won its budget line, someone else was going to lose theirs, and it felt really awful, actually, for a while.

So at the time, I was getting involved in police brutality work more broadly, and this woman at Coalition for the Homeless who'd been involved in the legal challenge around Haiti, Lisa Dugaard and I approached Richie Perez, who was the head of the Committee Against Police Brutality at the time. We basically said, "Why don't we try — let's try to do a massive civil disobedience. Let's get as many of these constituencies as possible together and see if we can take on Giuliani in a united front way."

It's funny, I think of it as very similar to a lot of the anti-globalization protests and stuff that happened afterward, but at the time it felt pretty unusual. ACT UP was the only group really doing civil disobedience at that time. It was kind of exotic for other organizations, so we actually — ACT UP ended up doing the CD training for all the other groups, because we were the only ones that had the recent experience of doing it. We had secret meetings for months, trying to keep the NYPD from finding out, and got a bunch of different constituents and organizations involved and finally brought it to the ACT UP floor and got approval for it.

But it was — in the end, it wasn't as big as we'd hoped, but we shut down on a single day four bridges and tunnels coming in and out of Manhattan, and it was CUNY students who were protesting these really draconian cuts and tuition hikes at CUNY. It was police brutality, activists protesting police violence. It was homeless activists protesting the crackdown on homeless people, and it was AIDS activists protesting these drastic cuts to AIDS programs in public hospitals. And I think it was the Holland Tunnel and the Queens Midtown Tunnel and the Manhattan and Brooklyn Bridges during rush hour one morning.

And there were — with each civil disobedience action there was also a public protest in conjunction with a non-civil disobedience action with each one. We worked really hard. Each group got to have their own flyer, but on the reverse, we had a joint statement that was really trying to put forward this kind of politics of solidarity, and it was really a pretty beautiful thing, I have to say.

**SS: Which tunnel were you at?**

EK: I was at Midtown Tunnel, because it was right — there's a hospital right there. What's the hospital that's right there at Queens Midtown? But we had the protest, and 1199, which is the hospital workers, was involved, so they got a lot of the protestors out. The public protest was in front of the hospital, and then we had — the rest of us went down and blocked the access to the tunnel.

But, yes, it was a really exciting and great action, and it was sort of my exit from ACT UP, because I think at that point it just made less sense to me to be focusing only on AIDS in the context of the broader politics as they were playing out. So, I got involved in other work that was more — that was broader.

But it was a fun thing, and it was nice to feel in a way that ACT UP was this resource for these other organizations and that sort of germ of militancy or something was being spread into these other groups.

**SS: I only have one more question. So, my final question is, given all the many years you've had to change as a person and all of that, looking back, what would you say was ACT UP's greatest achievement and what do you think was its biggest disappointment?**

EK: Oh, god. I really think ACT UP achieved so many things, really remarkable things, that that is genuinely a hard question to answer. I don't think I have an obvious answer for that. I think ACT UP changed the culture. I don't think that massive advances in gay civil rights that we've experienced would have been remotely possible without ACT UP. I just think ACT UP's putting gay people out into the public life not as people in the shadows, but people in a proud, righteous people, I just think it was huge.

The advances in HIV treatment, it's hard to imagine where we'd be with HIV treatment if ACT UP hadn't been on the scene. It's almost actually — it could be really awful. You know what I mean? Even as many people in the developing world that just don't have access to drugs, like, a lot of people do. It's really hard to imagine how bad it would be if the treatment activism hadn't radically pushed forward research on a disease that everyone with any power was happy to neglect.

I think for me as an activist, certainly a lot of it, just the willingness to be absolutely clear-eyed and just go at every public and private institutional target. That's why the changes were just — these were institutions that had never been taken on by social movements before, and that NIH made changes, the CDC made changes, the State Department made changes, that City Hall made changes. It's just — drug companies made changes. *The New York Times* made changes. For a very, very small little army of people — the impact was really vast.

I guess, for me, it's hard to figure out how you would narrow down the impact, because again, it relates to my feeling about The Split as being a little bit of a false issue. It was the combination of all of those campaigns with all of those different targets and goals.

I mean, prevention. Before there was any publicly funded prevention telling people how to use a condom, it wasn't just ACT UP. It was other grassroots gay efforts. But people were handing out information everywhere, at schools, on the streets, showing people how to inject safely, showing people how to use a condom safely. How many lives were saved by that grassroots prevention work, and just the fact that it forced institutional prevention work? It's all just massive — a lot of it, in my mind.

**SS: So, what's ACT UP's greatest disappointment?**

EK: Oh, I think a cure. I think it's a real compromise that where we got was having to stay on drugs — a combination of expensive toxic drugs for life. The failure to get universal access, the broader failure to help play a role in universal healthcare, and the failure to really transform the movement into a global movement. One of my other frustrations with that film is that there are a handful of people who took their treatment activism onto the global stage, like Gregg Gonsalves, who are total fucking heroes.

**SS: And Mark Gevisser.**

EK: Well he's more of a journalist, but, yes. But I'm talking about the treatment works, even within that framework, the TAG guys. Why wasn't Gregg Gonsalves the main character in that film? He's been playing a massive role in recent years in southern Africa, bringing that battle there, working with local activists.

But a lot of the ACT UP Philly people, like Asia Russell, really made that leap. There are some incredible people that completely took all of that experience and all of that information and strategic know-how and became global AIDS activists in a really important way. But the organization as a whole didn't manage to do that.

**SS: Okay. Thank you.**

EK: You're welcome.

**SS: How long was that? Two hours.**

EK: Oh, I'm so — I feel so sad about my memory.

**SS: You did really well.**

EK: So pitiful.



**SS: Well, you don't where some people are at and you told us a lot of things that we really didn't have. I really appreciate that.**

EK: Thanks for doing this you guys.

**SS: Thanks**