

A C T U P
ORAL HISTORY
P R O J E C T

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Interviewee: **Eric Sawyer**

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Interviewer: **Sarah Schulman**

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ACT UP ORAL HISTORY PROJECT

Interview of Eric Sawyer

March 10, 2004

SARAH SCHULMAN: If you could say your name, your age, where we are and today's date?

ERIC SAWYER: My name is Eric Sawyer. I'm 50 years old, and we are in Harlem, in New York City.

SS: And today's date?

ES: Today's date is March 10th – 2004, my God.

SS: Where were you born, Eric?

ES: I was born in Binghamton, New York – grew up in a little hamlet called Quinneville – went to Green Central High School, and went to a state university in upstate New York, and graduate school in Boulder, Colorado.

SS: Which SUNY did you go to?

ES: Oneonta.

SS: Okay, the party school. So, you were growing up – a kid from a small town – did your parents have any kind of social awareness of any kind of political activity?

ES: Not really. My father was a truck driver – long distance, home mainly every other weekend. My mother was a housewife, took in laundry and welfare children to make ends meet – five kids, two older brothers, two younger sisters. I'm the middle.

SS: So you had all the foster kids going through the house?

ES: Yeah, yeah.

SS: So, when things would happen in the outside world – when you were growing up was like the civil rights movement, Vietnam – did your family comment on it?

ES: Not terribly. I guess the first awareness I have of anything political was the assassination of John Kennedy. I remember a teacher coming into my third grade classroom, informing my teacher that he had been killed. And then, breaking into tears and running from the room. And I remember we were let out from school that day, actually – the day of the funeral. And I remember my mother making us sit in front of the TV to watch the funeral. And, it was very moving. She said, “Out of respect for the president, you have watch this, and you have to be quiet.” I don’t know why that brings me to tears.

SS: So, when you went to Oneonta – that was your first time out of your town? Living on your own?

ES: Pretty much. Just to fill in the gap on political stuff – my family was a very rural, kind of poor family, but had a lot of pride. Doing well in school was drummed into us at a very young age. And we were all involved in all kinds of sports, and both of my older brothers and myself were class presidents, and both my older brother and I were student body presidents, when we were seniors. So, kind of civic responsibility or participation was something that was kind of drilled into us.

SS: It sounds like ambition and achievement, as well.

ES: Yeah, my mother was very conscious of how difficult it was for my parents to raise all of us children and very much pushed us to try and go to college and be able to get a good job so we could support ourselves. I actually went to a community college for a couple of years first, for the cost factor – that it was less expensive, and also, following a bunch of my high school athletic buddies to schools where we were kind of recruited, ironically, for athletic endeavors to a community college, of all things.

SS: So, you were a jock in high school?

ES: I was a jock.

SS: What sports did you play?

ES: I was all-county, all-league football defensive end – captain of the football team. I was a wrestler, ran track.

SS: So, you were kind of a winner from early on, actually – looking back.

ES: Well, ironically, when I was really young I was really skinny and kind of uncoordinated, and a sissy. I cried really easily – as is evident – and was somebody who everybody picked on. I had a major growth spurt in the ninth grade. I literally grew eight inches and gained forty pounds, and kind of became one of the biggest kids in my high school, and always had jobs growing up – paper routes, mowing the lawn, tending the local cemetery, working for a veterinarian. And I had actually bought a car, while I was fifteen – wanted some freedom. So, having a car – I got a license within a month of turning 16 – and having wheels, and being good in sports, kind of made me go from being an unpopular, picked on, zitty-faced, glasses-wearing geek in like, up through ninth grade to into tenth grade to getting elected class president, and kind of with the wheels being suddenly in.

SS: Was your brother drafted?

ES: One of my brothers got out of the draft because he had epilepsy. My oldest brother actually, because he had a low draft number, enlisted in the Air Force and ended up in Germany – to his good luck, I guess, and didn't have to serve in Vietnam.

SS: So, if he enlisted, was there a feeling that that was an obligation? Or was it more for his own personal –

ES: I think he did it out of fear of going – being drafted, and things like the Air Force and the Navy had a lower definite probability of being forced into an infantry type of position in Vietnam. And, I think part of his thinking about enlisting was that it might keep him out of Vietnam, and it did. But, we were very aware of the anti-war movement and the anti-nukes movement. And actually, I and some of my Student Council buddies organized some anti-war protests at our high school, when we were seniors. And you know, being in the National Honor Society and a teacher's pet and Student Council President – the way I kind of chose to do it was going in and demanding a meeting with the high school principal and telling him that we were going to organize a demonstration in protest with a group of my peers – all of whom were leaders in the school. And the principal pretty much said, "Sounds like a great idea. Why don't you have a march around town, and then we'll have an assembly in the auditorium?"

SS: Did you know you were gay when all this was – when you were Mr. Perfect?

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ES: Ironically – I mentioned, being a kind of a sissy – literally, from kindergarten on, there were some older kids in the neighborhood that used to kind of force me and bribe me with candy bars and whatever to perform sexual favors for them. And, I guess a classic definition would be child abuse, but I was giving head at age five to a number of the neighborhood pubescent bullies, and it continued until my oldest brother were bigger than the people that were making me service them. And he kicked one of their asses and told me that boys weren't supposed to do that to other boys, and if I didn't stop doing it, he was going to kick my ass.

SS: So, did you experience that as abuse at the time?

ES: I didn't, because it was about the only time any of these bullies were nice to me, and they were bribing me with gum and candy bars and sodas to not tell, and it was stuff that, you know, being from a dirt-poor family, I didn't have access to. And it was something that I didn't mind doing. It didn't seem foreign to me. I didn't even question that it was wrong until my brother told me, and then there was all this guilt. So when I started masturbating and fantasizing about that, I kept trying to put that out of my mind, and started stealing my brother's *Playboys*, because I was supposed to be interested in girls and trying to look at titty magazines to be straight. I had girlfriends in high school and didn't actually have sex as an adult until my freshman year in college, when I had sex with both a guy and a woman in the same week.

SS: When you got to college, was there any kind of openly gay activity? Or was it still underground?

ES: There was, and it was very underground until the community college that I went to. I transferred, after I graduated from a community college, to Oneonta, and I was on the wrestling team at Oneonta, and there was a guy on the wrestling team who also – when we were drunk enough – would have sex with me. And, I kind of found out through him that there was a guy on the swimming team, as well. And so, you know, if there was enough alcohol involved – started exploring my gayness. But I also – because I kind of knew I was different, I chose to be a Psych major, I think pretty much to figure out why I was gay. And, I took courses in Abnormal Psychology, Deviant Sexual Behavior, Abnormal Sociology – a bunch of courses like that. And luckily, one of the Psych professors, who also was involved in the drama club, had somebody from the Gay Liberation Alliance here in New York City come to give a lecture at our Abnormal Psych

course, and the same people came back, actually, during – there was something like the Psychology of Deviant Behavior course. And, both of those visits were during the homosexuality, bisexuality portions of the course. And, they were really normal people, and they were really attractive, and they weren't like the guys I was having sex with, who had to be really inebriated and then would be really mad if you brought it up when they weren't drunk. Or would say, "I'm never going to do that again!" And these people were portraying that, hey, it's an alternative, acceptable lifestyle, and it made me start thinking – well, maybe I'm bisexual and maybe it's okay to be this way. I had a girlfriend at the time, also – so, I kind of wasn't accepting that I was gay.

But primarily, because of seeing a bunch of articles in papers, and also in *Time* magazine, about the growing gay liberation movement, and learning about Boulder, Colorado having one of the first non-discrimination ordinances in the country, in the U.S. and a big gay student campus organization. I decided to go to graduate school in Boulder, and immediately sought out the Gay Liberation Office and started going to coffee houses – they had a coffee house in the church on campus – and met some people who took me to my first gay bar in Denver, Colorado, of all places. And within six months I'd broken up with my girlfriend, had a boyfriend, was going to gay bars and doing lectures to undergraduates through the Gay Student Organization on acceptable, alternative lifestyles of being gay. At the time, that was when [Allen] Ginsberg was at the Naropa Institute in Boulder, and because of Ginsberg – people like David Kopay, who was one of the first – he was a professional football player and wrote a book about being gay. And a professional athlete came and spent a week there. And there were a bunch of lectures. And, I met him and Leonard Matlovitch, who came out as a – I think

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he was a Lieutenant in the Air Force. They were some of the first out people writing books about being out. And there was a big buzz about – related to the gay liberation movement there. And so I got kind of involved in gay politics fairly early, and you know, organized – there’s a friend of mine named Greg Hinton – he’s a writer and a screenplay writer. He produced *It’s My Party*. It’s a movie that Eric Roberts was in about a guy with AIDS committing suicide. But, he has a book out now called *The Way Things Ought to Be*, and I’m one of the characters in it, and there’s a lot about some of the things that we did at the time. We started taking over dances at the Student Union Center and making out on the dance floor and taking over some of the local bars, and doing varying things like that, in Boulder, at the time. And pretty much, it was totally, a non-issue or a non-event. It was like, “Oh, the fags are here, making out. Wow.” But, it kind of got me into a gay political mindset, primarily I think because the fact that these gay liberation lectures during my college life helped me accept – by seeing a positive gay role model – my own gayness, and made me want to return the favor to young, struggling little fags and dykes. And, I moved to New York after breaking up with a guy that I’d been with during graduate school – after realizing that anyone I was interested in in the Denver, Boulder area I’d slept with, and they were either not the right – made for me – or they were involved in a relationship with somebody else, and not about to break up with them. So, I decided to move to New York, because I was having to come here for long weekends or vacations, or fly to San Francisco in order to get laid.

SS: I have a couple of questions – so, this was around ’75?

ES: ’76 is when I moved to Boulder. And I was there through ’80.

SS: Can you characterize a little bit what the ideology of the gay liberation movement was at that time that you were participating in?

ES: It was a little in your face, but Boulder was a fairly polite place – a fairly conservative town, but a very liberal town, also. And, because of the Naropa Institute and Ginsberg and the fact that the City Council had approved a Non-Discrimination Ordinance – and actually, the book talks about – the city – and this is a part of history that a lot of people aren't aware of – the City Clerk actually issued marriage licenses and married a number of people in Boulder, while we were there, and that, I think, was perhaps a little different than it was in a lot of other areas.

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SS: I guess what I'm asking is, how did gay liberation differ from the gay rights movement that was to come?

ES: I think a lot of it, initially, was just about de-stigmatization and lack of discrimination or outright persecution. The gay non-discrimination ordinance aside – a lot of it was just about being able to have public displays of affection without having your teeth bashed in, or being able to dance with someone without having a police raid, or not getting dragged out by campus security or the local cops, and not having car windows smashed in the parking lot of the local gay bar. And, some of those issues were the things that we had demonstrations about – people getting beaten up, because of public displays of affection. My windshield was smashed in the parking lot of a gay bar, and we had a demonstration about that in Denver – and, a bunch of things like that. Being fairly hot tempered and aggressive, I did get in, literally, a number of fistfights over people calling me faggot or attempting to stop me from holding my boyfriend's hand, and things like that. It was little volatile. It wasn't quite the same – I guess we weren't

sophisticated enough to know how to demand our rights or to know how to – or, at least, the college organizations that I was involved with in Boulder, wasn't sophisticated enough to know how to work the political channels to get things. But there were some people, like Ginsberg, that were. And he and people at the Naropa Institute were instrumental in the gay marriages and anti-discrimination ordinance.

SS: Did you come out to your family at this time?

ES: I did, actually.

SS: How did that go?

ES: Ironically, well. I chose to write my parents a letter and let them know, primarily because I was tired of hiding who I was, and I had always had girlfriends, and my father – who was a truck-driver, didn't finish high school – a bit of the stereotypical truck-driver – would ask me on the phone, “Hey, you getting any ass?” I wanted to laugh and say, “Oh dad, you wouldn't believe the ass I'm getting!”

SS: Do you think he ever had sex with men when he was out on the road?

ES: I don't think he did. He claims that he didn't. But ironically, when I came out to them, their reaction was pretty ideal. It was kind of like, they weren't surprised. They were upset. They knew it was a really hard lifestyle. They hoped that I could be happy. They wanted grandchildren, and they knew how important children were, and they hoped that I realized that I would be giving up having children, but that it didn't matter, that they were proud of me, and that they loved me. And my parents had never told me they loved me, in my entire life. So, that meant a lot. But then when I came home, we talked about it a little. And, my father actually told me that one of the truck drivers that he hauled chemicals with – a mulatto guy, from a town where my parents

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grew up – who my father trained when he was coming to work for this chemical company – so, they double-teamed – my father and he went cross-country together, while this guy was training – was gay. And, I didn't know that. He was actually a really handsome guy. And that my father had actually gone to a couple of gay bars with him. He was like, "I couldn't believe it. Guys were like, kissing and holding hands and stuff." It was kind of interesting to hear that from my father – Yancy's okay. And he said at the time, "It's nothing I'd want to do, but I don't care."

SS: So, then you moved to New York. What year was that?

ES: I moved to New York in '80, and I kind of decided that – it's kind of ironic in retrospect – that I wanted to come to New York. I had renovated a two-family house – a Victorian – with my ex-lover in Denver, while I was in graduate school and sold it, and made some money. And, I was reading a lot of books on how to make money in real estate and whatever. And I was like, I'm going to work really hard while I'm young. I'm going to renovate a lot of buildings, and make enough money so that some day I can just live off of my rental income and go into gay politics, because it's really unfortunate that we don't have the same rights, and that it's so hard for little dykes and fags to grow up in America. And, I remember actually kind of, at the beginning of the whole AIDS crisis, remembering that game plan, because I was living in Harlem, renovating my second townhouse, had rental income coming in, and eventually, that happened. But my political involvement ended up being AIDS activism. But, we didn't know about AIDS in the '70s, or '80 when I moved to New York.

SS: Well, you said off-camera before that you thought your first AIDS symptoms were in '80.

ES: Yeah, before I moved to New York, actually – I mentioned that in the late ‘70s I was coming to New York and going to San Francisco to get laid. And, it was a time when there was a lot of drug experimentation – MDA and acid and white crosses – were kind of the drugs of choice with the people I was involved in. It was like – 9 West, 12th Floor, Flamingo, in New York, were kind of the gay dance palaces. Everybody talks about ecstasy and that kind of stuff, but you know, the pre-cursors of those drugs and the dance scene was already thriving in the mid-’70s. In San Francisco it was the Trocadero and the Eagle and varying places. But anyhow, I’m quite sure I know when I was infected. I think I was infected on New Year’s Eve – ’79 turning into ’80 – after going home with two guys from Flamingo and having a three-way, after doing acid. And, I returned to Denver – to Boulder – and, immediately had a horrible flu and flu-like symptoms – swollen lymph nodes. I was sick for weeks, and they thought I had mononucleosis. I didn’t have mononucleosis. They thought I might have Hodgkin’s Disease, because I had so many swollen lymph nodes. They did a biopsy, it wasn’t Hodgkin’s Disease. Eventually, it kind of passed. And then, I moved to New York, in the summer of ’80, and in ’81 developed shingles. So, in retrospect, my doctors think that that was probably my conversion.

SS: When did you realize it was, whatever – GRID, AIDS?

ES: You know, I had had similar kinds of symptoms throughout the early ‘80s. I have a skin problem where I have really dark pigmentation on my legs, and when those spots started coming up, immediately, they thought I might have KS. So, they did a biopsy for KS, when KS was first being talked about on the news. It was probably ’82. And then a boyfriend of mine, early in 1984, came down with KS. So, by then I was

pretty sure that I was also infected. As soon as there was a test, my doctor tested me, actually, under my boyfriend's name, and I was positive. And my boyfriend, actually, was in a lot of early Seramin and Interferon trials at the NIH. He was a Wall Street lawyer, and a couple of years younger than me. And, he used to take off a couple of days – two or three days – he would go on the train down to NIH and be in the hospital, hooked up to intravenous Interferon for one trial, and another drug called Seramin, for another trial, both of which didn't end up being approved or effective.

SS: So, when the two of you realized that you both had AIDS or HIV – I don't know how you conceptualized it, at the time – did you try to hook up with other people? How did you deal with it, as a couple?

ES: Actually I had met Larry Kramer when I very first moved to New York. We both went to the same gym and we were both runners, and we used to run a lot together. I met him at the West Side Y, actually, by Central Park, and we used to run around the Park together. And he had a little group. They called it the Network, at first, when HIV first came – it wasn't even called – they hadn't discovered the HIV virus then – they started calling it GRID, but it was actually even before GRID. He and Larry Massey [Dr. Lawrence Mass] and other people were writing articles about the gay pneumonias, the gay cancers, the gay plague, and sounding the alarm about it. I met Larry, actually, because I was reading *Faggots*, and somebody in the locker room, when *Faggots* fell out of my bag on the gym floor, said, "That's the guy who wrote it." And, I went over and introduced myself. And he was like, "Oh, who are you? Do you want to go to dinner?" I, ironically, met him early and starting going to the meetings that he and

Massey and other people were having to keep the community informed about what was going on.

SS: So, who was in the Network?

ES: It was people like Larry Massey, a psychiatrist named Goodwin, Larry – I don't even remember a lot of the people. I went to four or five of the meetings. They were Tuesday and Thursday mornings at 7:30, and they were in people's apartments. And then, one of the guys' – I think a psychiatrist's office. But, I was renovating a brownstone at the time, and I didn't stay involved in that group, but was doing a lot of reading about it, and got, fairly soon thereafter, quite involved in caring for my boyfriend, who had pneumonia a bunch of times and eventually died in '86. And after he died, I actually became aware of a lot of homeless people with AIDS. Partially because a homeless drug user in this area came down with AIDS and had nowhere to stay, and some of us were collecting money to rent him a room in a rooming house. And after he died, I called Larry, who I had been in touch with up through the time when my boyfriend started getting sick or whatever, and then I was so consumed with work – renovating my townhouse, at the time – and caring for my boyfriend, that I wasn't doing hardly anything else. And, I called him and let him know that Scott had died, and that I was aware of homelessness and AIDS and that I wanted to try to – ironically, Larry and I had tried to buy a couple of buildings together, with a couple of other people – a woman I worked with – and then the deal actually kind of fell through. Larry's brother, Arthur Levin [Arthur Kramer], was a senior partner in a big law firm, and some of the lawyers didn't like the fact that the buildings we were trying to buy were SROs [Single Room Occupancy], and a bunch of other things. And so, Larry backed out of the deal. But,

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Larry was aware that I was renovating townhouses and what have you. And, I called him up and said I want to use my housing development skills or whatever to try to develop some housing for people with AIDS, and could he put me in touch with people, because by then the Network had evolved into GMHC and Larry was one of the prophets of the epidemic.

And he said, “Sure – there’s the AIDS Resources Center. There’s a guy named Doug Dornan. I’ll set up a meeting, but I’m going to do this speech at the Community Center next week, and the NIH has got a hundred million dollars to test drugs, and there’s a hiring freeze, and they’re not hiring new researchers, so only one drug – AZT – is being tested. I want to start a protest group, like the anti-war movement, to try to sound the alarm and get the hiring freeze lifted, so that some of these drugs that are promising can get into trials. Do you want to come to the meeting?” And I’m like, “Sure, yeah – I’d be happy to.” And he said, “Cool – why don’t you be in the audience, but ask for volunteers. Stand up, be a rabble-rouser. Try and get other people to help organize the demonstration, and help me do the first demonstration” or do a demonstration. We weren’t even talking about there being multiple ones at that time. Then he said, “Then I’ll hook you up with Doug.” And I was like, all right, cool. At that time my lover Scott had been dead about nine months, and I already had a new boyfriend, and his name was Frank Jump, and Frank and I went to the meeting. Frank’s mother was in P-FLAG. So, Frank was pretty politicized. So, we went, and we were some of the first volunteers. We planned the first demonstration in Larry’s apartment – used my truck, actually. I had a pick-up truck to take some of the props down to City Hall. Joseph Papp had the Theater

Department at the Public do a big puppet of [David] Kessler – the head of the FDA at that time – so that we could hang him in effigy from a light post. The rest is history.

SS: I just want to talk about the context of housing for people with AIDS at this moment when ACT UP is being founded, because there already was Bailey House, right?

ES: Well, yeah.

SS: Was there anything else?

ES: Bailey House was pretty much the only thing. And, ARC was renting a few apartments, you know, from raising money for people because there were far more people than could fit in Bailey House. It was partially because of the fact that there was a lot of political scuttle-bug – or whatever the proper term is – there was a lot of press about the group trying to get this old hotel on Christopher Street turned over to them, to do AIDS housing. And the fact that I knew a couple of people in the neighborhood who were homeless, who didn't have housing, was what sensitized me to the issue. And, I just started reading a lot about it. And, because of the connection with drug use, you know, started learning that there's this whole other AIDS plague, tied to drug use, that is very prevalent in homeless communities, and it's a whole area where there are no services.

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There was no group like the Gay Men's Health Crisis advocating for homeless people, other than the AIDS Resources Center, and I think Bailey House had 16 or 20 rooms, something like that, and there were thousands of people already with AIDS and hundreds of homeless people. And, there were lots of stories about people being beaten in the shelters or driven out of squats or out from some of the areas, like under the bridges or in

the subway tunnels, where a lot of the homeless people were living. And, you know, people being beaten and what have you, because of having AIDS.

Tape II
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SS: Since the era that you're describing is 18 years ago, can you describe a little bit what the real estate situation was like in New York?

ES: In the '80s, real estate was pretty expensive. It was kind of the beginning of a real estate boom. The whole Upper West Side, which had been pretty abandoned and dilapidated, which had a lot of rooming houses, SRO hotels, inexpensive housing – was being snapped up by gentrifiers, who were throwing all of the poor people, the homeless people, the mentally ill, the underemployed people out and making them homeless. So much so that they started enacting legislation to make it harder for these landlords to buy these cheap apartment buildings and SROs and evict all of the tenants. There had been a big de-funding of mental health services, and drug treatment services, when the financial problems of the '70s and the '80s occurred. So, there were a lot of marginal people – people who had limited social skills, not very advanced job skills or life skills – living, often on welfare, often on whatever they could panhandle, in a lot of these welfare hotels, or SRO hotels. And, a lot of them had severe mental illness and when they were de-institutionalized, thrown onto the streets, weren't given any job training or any socialization, to help them cope with even activities of daily living. So, there were a lot of vulnerable people around. The economy – the Reagan years – the economy was booming, Wall Street was booming, banking was booming and a lot of buildings were being converted into high-priced co-ops.

SS: I have to ask you this – do you feel that there was a relationship between the kind of renovation you were doing, and the creation of so many homeless people?

ES: I think the fact that I was renovating housing in Harlem – in one of the areas that was still affordable – wasn't lost on me. And, while there are a lot of people who were evicting people, I was buying abandoned buildings that weren't being occupied and was converting them into usable housing. And so, I didn't feel bad about doing that and I mentioned that I'd renovated a Victorian in what was a slum, in Denver, and so I knew that you could make money renovating great old housing stock into nice housing. And, Harlem was the only place in Manhattan that I could afford to buy something and do the same thing here. But because of that, and I guess my own principles – not to want to evict people, not to contribute to those problems – I always bought empty buildings, and decided to use the skills that I had in developing housing to try to develop housing for people with AIDS. And we ended up starting Housing Works, after having first started the Housing Committee of ACT UP, to advocate for housing for homeless people with AIDS.

Tape II
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SS: Let's start with the Housing Committee. I remember going to a meeting with you, and I think it was at – what's his name? The guy that wrote *Gay American History*? Jonathan Katz's house. You started it in ACT UP. What year did you start the Housing Committee?

ES: God, it probably would have been '88 or '89.

SS: And how did ACT UP respond when you brought it to the floor?

ES: Not particularly well. And, ironically, even though Larry had introduced me to Doug Dornan and some of the other people, Larry wasn't particularly happy that we were introducing things like a Housing Committee to ACT UP. Or that we were bringing up issues like needle exchange, or that we were doing a lot of work advocating for Medicaid cards and for income maintenance and expedited social services. A lot of Treatment and Data folks felt that – and Larry – also felt that we were diluting the energy and the resources of ACT UP, taking up too much time on social justice issues, and deviating from the intended purpose of getting drugs into bodies.

SS: How was that expressed? Was it expressed openly on the floor or privately to you?

ES: Both. On the floor, less openly, sometimes there would be outbreaks by people complaining about the fact that we were spending too much time on those issues, and there were life-saving therapy issues that we needed to be discussed. And there were things done like – there was an amendment passed, a vote taken to block the first 10 or 15 minutes of the agenda of ACT UP meetings for life-saving information – to share information about the latest clinical trials, or latest drugs coming onto market, or what have you. And so, some of us kind of die-hards, like myself and Charles King, decided that we could play that game, too. And, we asked for a vote for life-saving information about housing and access to social services and Medicaid cards as well, because if poor people didn't have a place to live, or didn't have a Medicaid card, and didn't have health insurance, they couldn't afford the drugs. And so, when there were issues about getting on Medicaid or laws or rulings being passed that would, in some way, either increase people's ability to access social services and Medicaid, or prohibit,

prevent, make it worse, we needed to be able to share that information on a priority position in the agenda, as well.

SS: But, what about ACT UPpers who were on Medicaid? Did they speak up?

ES: Yeah. They would. And there were, ironically – the Housing Committee – it was kind of like the social justice squad of ACT UP. It was people dealing with housing. It was the Women’s Committee, dealing with issues of women and children. And, it was the needle exchange group, and Minority then Majority Action Committee, that was dealing with issues of access of social justice. And so, we kind of had our little cabal, and alliances, that we would work to – and it was a really interesting time – incredibly educational. It was an incredible time of learning for myself – just in terms of how to work networks and groups. Having gone to graduate school for public administration, I’d taken a lot of courses in organizational development and group behavior and whatever, but it was a microcosm of society. There were power brokers, amongst varying populations or sub-groups within ACT UP, or varying committees. And, we were working the phones during the week, or having meetings or dinners or coffee with varying groups to get them to support our agenda, so we could get a demonstration or get money to go to Washington about a housing issue or whatever – horse-trading. It would be like, “Well, we want a demonstration about a needle exchange,” and, “We’ll do that. We’ll help you do it. I know this person. I can get you into the Department of Social Services, help us do this.” There was a lot of that going on.

SS: How were the foundational people on the Housing Committee?

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ES: Initially, it was myself and Rich Jackman and – Rich Jackman was an architect. It tended to be people more like people who worked for architectural firms or were on their on co-op boards, initially. Then Charles King – and ironically, my lover, who died in '86, worked for a Wall Street law firm and a partner whom he worked for got fed up with Wall Street, did a couple of years in Florida on death row doing free legal work, or subsidized legal work for people on death row, about the death penalty. Then, she moved to New York and joined the Coalition for the Homeless.

SS: And who was that?

ES: Virginia Schubert. And, she recruited Charles King out of Yale Law School to work on homelessness and AIDS. Ginny called me up and said, “I’ve seen you doing a lot of stuff about housing, why don’t you come in and meet with us? This guy, Charles King is just finishing law school. He’s going to intern for me, for a while. I’m trying to raise money to recruit him. But, I think you guys would have a lot in common, and why don’t we start working together on some of these issues?” And then, Charles joined ACT UP, and not too long after that Keith Cylar, who was working for the Minority AIDS Task Force, and Charles started dating. So, they started coming to the Housing Committee. And, eventually we realized that while we were making a lot of headway in terms of helping to push policies and getting additional funding approved from the city and the state, there wasn’t really anyone stepping up to do the kind of housing that we would want to live in if we ourselves needed to be a client in one of the housing programs. And, everything was being developed in a very judgmental, clean and sober way, or being done in a very institutional – I mean, the city and the state – their bright ideas were doing segregated wings in the shelter system, or nursing homes for

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people with AIDS that would either – in terms of the shelters – just ensure that everyone with the most compromised immune systems and the most likely to have bacterial infections or pneumonia or tuberculosis were all being warehoused together in stigmatized areas that would make them further targeted to violence and discrimination. And, that if anyone was going to develop humane, non-institutional housing, it would have to be us. So we decided to incorporate, to start raising money to develop our own housing, because we felt we had the skills.

SS: How long was it between the time you founded the Housing Committee and you incorporated?

ES: Actually – kind of thinking about it in retrospect – I think we started the Housing Committee in ‘88, and we incorporated Housing Works in late ‘89, ‘90.

SS: Let’s talk about the interim period first. What were some of the actions that you did as the Housing Committee?

ES: We had a lot of really quite fun actions, in the creative, street theater tradition of ACT UP. On tax day, we were really furious that the city was giving Donald Trump a whole bunch of real estate tax abatements and incentives to develop Trump Tower, when we couldn’t get money for homeless people with AIDS. And so, we had a big march from the Plaza Hotel to Trump Tower and took over the lobby of Trump Tower, and you know, threw “blood money” around and targeted the tax incentives that Trump was getting for building luxury condos at the expense of housing money for poor people or for homeless people with AIDS.

When the DAS was first started – the Division of AIDS Services – when there was a lack of funding to recruit new case workers for the Division of AIDS Services,

which was the one-stop shopping area where homeless people or poor people with AIDS could go see one case worker, to get a Medicaid card, welfare payments, get a housing subsidy for rental assistance – all of which were programs that we helped fight for – expedited access to welfare, income maintenance, expedited access to housing allowances, and the creation of housing subsidies for people with AIDS. And then, we helped advocate for the Division of AIDS Services, but yet there was a hiring freeze, and there were space limitations that were literally making case workers have hundreds of clients and having to operate in the halls of city office buildings without desks, without phones. Having to coordinate services on pay phones in the lobbies and basements of buildings, carrying, literally, file boxes full of client folders around with them, because they didn't have desks. We decided to organize new offices for DAS workers in the middle of the street in front of the DAS offices, and literally went around with my pick-up truck, collecting desks that people had discarded on bulk pick-up days, or getting them from thrift stores, and literally collecting old phones, and what have you, and setting up a Division of AIDS Services office in the middle of Church Street. When we couldn't get capital funds approved to develop housing for homeless people with AIDS, we did the same thing. We collected sofas and discarded televisions and chairs and stoves – anything that people were throwing out on bulk pick-up nights, and stored them in the basement of the couple of buildings that I had here on Manhattan Avenue, and then planned a demonstration where we went down and set up – in front of HPD offices – housing for homeless people with AIDS, and threw all the furniture in the middle of the street and chained ourselves to the furniture. And not only forced the city to arrest us, but by chaining ourselves to all of this furniture it basically ensured that it would take the five

and six o'clock news hours for them to get us free from all the furniture that we had collected, to get garbage trucks down there to get all the furniture out of the street and have to tow my pick-up truck and the van that we had rented out of the street. And, it was on the news for both the five and the six o'clock news.

SS: Did you deliberately time actions for live feed for television?

ES: Sure, yeah.

SS: I'm going to ask you a really broad question. Was gentrification a deliberate social policy?

ES: I don't know that gentrification was a deliberate social policy. I think it was more – it developed because of the economics. When there was a housing boom, and a desire to – an economic boom – a desire to, again, return to the city – cities like New York – from the suburbs, and there was a lack of – because, cities like New York – every square inch of build-able space in good areas is built upon. The creation of new housing opportunities for rich people – luxury housing – has to come from existing housing stock, or existing real estate. There's not a whole bunch of empty lots in New York City. And the most affordable places were welfare hotels, or apartment buildings, where a lot of poor people lived. And because of racism and discrimination, buildings – sometimes on the same plot – were very much, there's the poor house, there's the rich house.

SS: Yeah, but in the Trump case, you're talking about governmental policy supplementing the construction of luxury housing – not building low-income housing. So, isn't that a policy decision?

ES: It's very much a policy decision. And, there were a number of those kind of social incentives, or public incentives, made by city and state and even federal politicians to both reward wealthy real estate developers who were contributing money to political election campaigns, but also to encourage big capital investments in the creation of new housing. And, what better way to get people to take the risk and tie up capital, when for a long time the movement was fleeing central cities to suburbs. And if you want to reclaim the cities for rich people – and where there is a lack of affordable building sites, and you have to give some kind of incentives to make it profitable for people to invest the kind of capital needed to develop new luxury housing – the bright idea of giving tax abatements and giving low interest rate, or no-interest loans, or subsidized loans, developed as a way to encourage gentrification or reclaiming of cities.

SS: What was your relationship with homeless organizations that were not focused on people with AIDS? Did they feel competitive with you?

ES: We worked, actually, quite collaboratively with a lot of – like, the Coalition for the Homeless. There were three or four different organizations that were helping low income housing or homeless individuals – groups that visited the shelters to ensure that people living in the shelter system had access to Medicaid cards or mental health services, or psychotropic drugs if they were schizophrenic, or mental health services. There were groups like the West Side Housing Federation, or groups that were servicing primarily seniors, but some of them gay seniors, who also had AIDS. And, the fact that most of those organizations had no expertise or connections to the AIDS community, made them kind of welcome – our involvement and our assistance, and the fact that we were not afraid to get arrested, and that we knew how to work the media and

we knew how to put pressure on politicians, kind of made us welcome to the fold, in terms of vocal, effective advocates.

SS: At what point did the ACT UP Housing Committee start getting involved in actually creating, literally creating housing?

ES: Well, we actually from the very beginning had that thought. Literally, people like Rich Jackman, who was an architect, and myself, and a couple of other people who worked for either architectural firms or – there were even people in HPD who came to ACT UP – were literally pouring over Division of Real Property and New York City tax records to find empty buildings that were owned by the City of New York. And, we were asking for meetings with people in the mayor’s office, or people with HPD to try to get them to turn over some city-owned buildings to us to rehab for housing.

SS: Which mayor was that?

ES: That was back in Koch’s administration.

SS: And how did he respond?

ES: We never actually got a meeting with Koch. We got a meeting with several of his officials, both in the mayor’s office and in HPD. Initially, they were kind of like, yeah, yeah, yeah – didn’t take us seriously. They had the polite meet and greet. “Oh yeah, we’ll take your considerations under – we’ll take your recommendations and your requests under considerations,” or, “You’ve got to understand, it’s very political, we can’t just be turning buildings over to groups. If every group who wanted a building turned over to develop low-income housing came to us and we handed them a building, imagine the mess we’d be in” – blah, blah, blah. And, it wasn’t until we started blocking the street and getting coverage on the five and six o’clock news on a regular basis, and

really embarrassing the mayor at fund-raisers for Richie Rich members of the gay community that we started, actually, making some headway in getting housing allowances. Actually, after the big demonstration we had in front of HPD, where we blocked the streets creating AIDS housing in front of HPD – it wasn't long after that that Koch actually announced a \$25 million capital fund, to create housing for homeless people with AIDS, that was soon matched by New York State.

So, you know, we pretty much made enough noise both in Albany and in New York. One of the demonstrations we did in New York was – we couldn't get Cuomo to give any money for AIDS housing, and so we had this demonstration where we ran all around the Capitol building. The Empire State Plaza in Albany has all these office towers that are connected by a concourse underground, and they were announcing the state budget and what have you, and we decided that we were going to have a Mario Cuomo, Let Them Eat Cake demo, where we would all dress up in Marie Antoinette drag. We actually went to thrift stores and got prom gowns and put pillows for big bustles in the back, and got these big, white powdered wigs in kind of the Marie Antoinette costume ball theme. We blew up pictures from the newspaper of Mario Cuomo's face that we cut out and mounted to tag board and literally glued them to tongue depressors. And so, we had these Mario Cuomo faces with these Marie Antoinette prom gowns and wigs on, and we were running all over the concourse area, going into – we tried to go into the State of the Union Address, into some of the meetings, some of the legislators' offices with crumb cakes – throwing crumb cakes all over these offices. Eventually, about 15 of us got arrested by the Capitol police. The capitol police actually loved the demonstration. They thought it was really hysterical, and it was all over the

papers and the news in Albany. But shortly thereafter, Mario matched the Koch \$25 million capital fund.

SS: But now didn't some of that money go the Catholic Church, actually?

ES: Some of it did.

SS: What was the issue there?

ES: And actually, I was pretty good friends with Nick Rango and Jeff Carples. Nick Rango was the director of the New York State AIDS Institute, and had worked at the Village Nursing Home. And, Jeff Carples was the Deputy Commissioner of Social Services, and they used to leak information to me about budget problems or issues where they were having problems of getting either the Cuomo administration or their bosses to – although, David Axelrod [Commissioner, New York State Department of Health] was pretty much on our side – but, getting policies passed that were favorable to people with AIDS. This was the time when Cardinal O'Connor was trying to block condom distributions and safe sex education in the New York City high schools and was doing a power grab for this huge amount – and eventually, there was over \$100 million between city, state, and federal money to create housing and nursing homes for homeless people with AIDS. And, the Catholic Church – the Cardinal Cooke healthcare subsidiary that the Catholic Church had was trying to get all of the nursing home money. And, they were refusing to allow condom distribution. They didn't want gynecological services, abortion services. They didn't want drug treatment. They wanted only clean and sober establishments. They basically were trying to get all of the money set aside for AIDS housing to create nursing homes, and they also wanted to only have 10-year limitations on the use of those facilities for, specifically, for AIDS patients. So, okay we'll take all

of your money. We'll create these nursing homes. We'll treat the nice, polite faggots who don't use drugs, but they can't be pregnant women, they can't be drug users, and we won't talk about sex. Or let them have sex, or whatever. They can come here and die, and then after 10 years we want to turn them into nursing homes for elderly Catholics. And so we organized a pretty aggressive campaign to ensure that, you know, O'Connor and the Catholic Church didn't get all that money.

SS: How did you get it away from them?

ES: By really aggressive demonstrations against the Catholic Church. The first time that Cuomo and Koch and O'Connor were going to have an announcement ground-breaking of one of the nursing homes, we disrupted it. And, we did position papers on how the lack of gynecological services or drug treatment and condom distributions and safe-sex education was going to increase the spread of AIDS and got basically into the general public enough negative publicity that it was a power grab by the Archdiocese to try to get all the state money to provide medically inappropriate housing for people with AIDS for a short period of time, so that the Church could basically get capital facilities paid for by state funds, taking advantage of the AIDS crisis to build a larger empire of housing for the elderly. And we got ourselves positioned on the committees that were reviewing all of the draft documents for the operating procedures for running these facilities and ensured that condom distribution, drug treatment, access to gynecological service, access to counseling about and paid abortion if someone was pregnant and blah, blah, blah – that we made it no longer attractive, and insisted on at least 20, if not 40-year codified special use deed restrictions on any facilities developed with that money, so that they couldn't just take a nursing house after 10 years and turn it

into elderly housing for Catholics. And, by making all of those things happen – affecting the actual legislation, by which bond issues would be given and the operating requirements for the facilities, and making enough negative publicity directed at the Archdiocese, we made it no longer attractive for them to pursue that funding.

SS: So, they withdrew?

ES: They pretty much withdrew.

SS: Now, this is a few years before Stop the Church.

ES: Yeah, it actually was kind of coinciding with Stop the Church, because that whole cycle – I mean, we started the Housing Committee in '88, but the whole creation of nursing homes and special needs healthcare facilities or whatever, went up pretty much through the advent of protease inhibitors. And so there was continual development of AIDS housing residences right up through even current day. Housing Works is developing some AIDS facilities right now in Harlem, for transgender sex workers.

SS: What was the first building that you guys got, and when was it?

ES: The first building that we got, actually – the first building that we developed was East 9th Street. And, I came up with actually a model that I suggested to Nick Rango, where we co-located an Adult Day Treatment Program and clinical facilities and a Cobra case management system with a residential tower. We wanted to create independent housing – not communal, institutional housing, not dormitories or nursing homes. But, we wanted to create independent apartments, and have services provided off-site. And in discussions with Rango about that he was like, “Well, you’ll never get enough money. Maybe we can do AIDS housing, but how would we build it? And, how

would we pay for it? If you have to build a separate clinical facility, you have to have two different housing sites,” etc. And I’m like, “Well, there’s office towers all over New York where there’s housing above commercial space, and sometimes it’s residential, sometimes it’s doctors offices. Why can’t we” – and Rango had developed an Adult Day Treatment Program for people with AIDS at the Village Nursing Home. And I said, “Why can’t we do an Adult Day Treatment Program to provide the services in the commercial space on the first couple of floors of a residential tower?” And he said, “That’s a brilliant idea, but how are we going to fund it?” And I was like, how did you fund the Village Nursing Home? “Well, you know, we got a healthcare bond issue and a Medicaid license.” Well, why can’t we get those? “Well, I suppose you could if you got some healthcare providers on your board and hired a doctor.” And I’m like, well that sounds pretty easy. And then he goes, “Well, I don’t know how we’d finance the residential towers.” And I said, “How do they finance housing for the elderly? Or dormitories for universities?” And it’s like, bond issues. Yeah exactly, bond issues by the New York State Dormitory Authority, right? It’s like, yeah, yeah. “Why can’t we do bond issues for AIDS housing? And we’re getting contracts through scattered-site programs to pay for apartment rents, why can’t we get contracts to pay for these residential towers from the city and the state? You probably could.” So, we kind of sat down and hammered out the model. George McNeely and I started looking for sites, and ended up actually going to a city auction where they were auctioning a couple of sites on the Lower East Side. And this was actually kind of the third site we’d attempted to get. And we had bought an option for two lots next door to the two lots that were being sold at a city auction, and we knew that on 9th and Avenue D, right by housing towers, there

probably wasn't going to be too many people bidding on those lots, and got a pretty good deal on a couple of vacant lots next door in terms of an option to buy them for \$10,000 from the guy that was trying to sell them, and bought the buildings for the asking price. Bought the lots, rather.

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SS: Now what year was this 9th Street site?

ES: When did we buy that? Might have been '93, '94?

SS: Okay, so this is after you incorporated. So, when you were in ACT UP, you actually never could get any buildings?

ES: Well, I'm actually still going to ACT UP –

SS: I mean, the Housing Committee.

ES: Yeah, the Housing Committee never got any buildings or even any money actually, to do any housing work. It wasn't until we incorporated Housing Works in '89, '90, that we started actually getting money. We kind of began in an interesting way. Charles decided that he was going to quit working at the Coalition for the Homeless and try to open the Housing Works office. We had been approached by a guy named Joe Allen – not the guy who was the theater restaurateur – but who was one of the owners of the Bear Mountain Paper Company and *Interview Magazine*, *Art in America*, *Arts and Antiques*. He and a guy named Peter Bryant were also real estate developers. They developed something called Conyers Farms, which was Betty Williams, an ACT UP Housing Committee member's family's huge estate in Connecticut, into polo grounds and luxury housing development in Connecticut. And when they were developing this – in launching the polo grounds and whatever, they did things like had Prince Charles and Prince Andrew and Fergie over for a polo match, and a bunch of things like this and

wrote off a lot of that kind of stuff as costs for the development of this hugely expensive development and got nailed for tax evasion. And as an alternative for going to jail, Joe Allen had to do community service. And he was doing some of it at the Coalition for the Homeless, but liked us, and we were talking to him a lot about what was going on with AIDS and stuff. And, his wife was a sculptor who had offices in the same building that the Latino Commission on AIDS is in. And, they offered us her loft – her artist studio – offices and use of her secretary to launch Housing Works. And, they also agreed to give us \$100,000 to launch the organization, with agreement that because we were a non-profit or whatever, Joe could switch his community service assignment to working with us, doing fund-raising and visiting clients with AIDS in hospitals instead of having to do stuff in the shelters and what have you, which is what he was having to do for the Coalition for the Homeless. So we said, sure.

SS: Why did you need to have a separate organization outside of ACT UP?

ES: Because ACT UP didn't want to do AIDS housing. They didn't want paid staff. They wanted to do activism. They didn't want to do housing or provide services. We would come to the floor and tell people about our search for buildings or whatever, and there was a huge outcry of, "You can't have paid staff, you can't get governmental contracts. That's going to limit what we say. It's going to compromise our voice." And we were like, hell – that's bullshit. We'll not only bite the hand that feed us, we'll chew it off, if it's trying to slap us. And we kind of like, took that motto with us to Housing Works. But one of the first things we did actually, was we got Nick Rango, through the AIDS Institute, to give us a development grant to build this AIDS housing model, and we

got him and Jeff Carples and some of the other people that worked for the city after Dinkins was elected, to help us get scattered-site housing contracts so that we could start providing services. Scattered-site housing is where you rent apartments in regular apartment buildings, and then you provide drug treatment and health education and coordinate social services, get people on Medicaid cards, on welfare, etc., in a separate office. And there were contracts that we had helped advocate for. The first one, actually – the model was developed by the AIDS Resources Center, the people who ran Bailey House. And the need was so huge that Bailey House couldn't meet all the need, and they were starting to peddle those contracts on request for proposal, competitive bids, and some the groups, like the Jewish Board for Children and Family Services, who we were doing a lot of advocacy work with, trying to get them to enter the battle for nursing homes, because they didn't have all the condom, birth control hang-ups that the Catholic church had. We talked a bunch of those types of groups into applying for some of those contracts, and applied ourselves and got first a 30-unit scattered-site contract, which let us rent our first offices and start recruiting staff members and gave us a base and a government contract to have paid staff that we could pursue the building of buildings and obtaining Medicaid licenses and opening clinics.

SS: Who technically owns these buildings?

ES: Housing Works owns them.

SS: Okay, so let's say AIDS ends tomorrow and there's no more need for this? What would happen to these buildings?

ES: I don't think AIDS is going to end tomorrow –

SS: I understand –

ES: If there's a cure that would be terrific, but the contracts for the building of all these facilities – most of the capital funding either came from grants, and we got grants from New York City, New York State, the Homeless Housing Assistance Program from HUD. We floated bonds on Wall Street that were low income housing or healthcare facility-related bonds that were coupled with nursing homes or homes for the elderly, or homes for nurses – subsidized housing for nurses. And, all of the deeds for those properties have deed restrictions that say they have to be for public use and social justice type services, and, if the AIDS crisis ends, then they need to be converted into low income housing or housing for the elderly or housing for the mentally ill or the mentally disabled.

SS: So how much real estate, right now, is Housing Works administering?

ES: Housing Works at one time had a whole bunch of contracts to do scattered-site housing, and those contracts were yanked by the Giuliani administration. We had hundreds of units of housing for housing homeless people with AIDS, homeless people with drug problems, with tuberculosis – some paid by the state, some paid by the city, some combinations. We lost all those contracts. In terms of buildings and capital real estate, Housing Works runs three Adult Day Treatment Programs. We have a couple of diagnostic treatment clinics. We have two residential towers that have Day Treatment programs in them – one in Brooklyn and one on the Lower East Side. We've got a couple of small buildings in Brooklyn. We've got four buildings in development in Harlem for transitional housing, and housing for transgendered sex workers.

SS: So, how many people are you housing right now?

ES: There are somewhere between two and three thousand people getting housing and services through Housing Works, on a yearly basis.

SS: And, how many homeless people with AIDS are there in New York who don't have housing?

ES: You know, I don't even know what the statistic is these days. I think there are somewhere around 40,000 people living with AIDS in New York, right now. And, I would guess somewhere around 60% of those or more are somehow in government-assisted housing and getting government-assisted services. How many people are not being served? I think Housing Works and the Coalition for the Homeless probably have numbers that they use. The last time I knew, they were in the area of 10,000 people. But I don't know, actually, what they're using today.

SS: Do you think that ACT UP made a mistake? That ACT UP was wrong, looking back, in hindsight?

ES: Well, I guess it depends on what ACT UP wanted to do. If it was trying to stay true to its activist roots and not be encumbered by provisions of services – I mean, that was a lot of the fear – was that, GMHC actually was initially started to do advocacy, as well as provide social support to people with AIDS, and governmental contracts and the provision of services compromised the voice of the organization to a degree where they weren't doing really very aggressive advocacy, which was why Larry and others decided to launch ACT UP. And so, kind of keeping that spirit, ACT UP has tended to agree not to have any paid staff. But looking back, had ACT UP done some of the things that Housing Works did, like – the other thing that this guy Joe Allen helped do was, he and his wife suggested to us that we do a thrift store, because they had given a lot of

money to the Sloan-Kettering Cancer Thrift store, and it literally made millions of dollars a year. And they were like, “There’s a lot of gay designers in stores that you could probably get free donations of stuff that’s on displays in department stores, or stuff that designers don’t sell out, or whatever, and you can get volunteers that work in retail to help run the stores. You get free merchandise that you can sell. It’s a great way to make money.” And so, Joe helped us raise the money to do our first thrift store, which was hugely successful, and now Housing Works has four thrift stores and a used bookstore/café, as well as a catering business, that they’re all for-profit, entrepreneurial subsidiaries that literally generate somewhere between eight to ten million dollars a year, which then gets plowed back into apartment rents and paid staff positions and services for clients.

SS: Eric, all this work is so impressive and you’ve made such a contribution. I want to ask you some questions about yourself as a person with AIDS inside ACT UP, outside of this other work. Did you go to ACT UP for treatment information, for yourself?

ES: I went to ACT UP actually primarily, I think, as an outlet for my anger and my rage. My boyfriend died of AIDS, and I was really, really upset that I couldn’t do anything to help save his life. I was really angry that there wasn’t a cure. And, at the time he died, I was working for a management consulting firm that – while his company treated him fairly well, kept him on full salary, let him take time off from work to go to NIH for these clinical trials and stuff – the company I worked for wouldn’t give me time off from work to take care of him, or wouldn’t let me work from home when he was in end stage AIDS. And even though the woman that I directly reported to was working

from home because she was pregnant and had had a couple of miscarriages, and was in danger of miscarrying her third pregnancy and to ensure her health and the safety of her child, she could work from home and I was shuttling her work back and forth to the office, but my lover was dying of AIDS, didn't matter. And literally, my boyfriend on a United flight on the way to visit his family with his secretary, because the day I was supposed to leave to go with him to visit his family for the last time, my boss decides a report I'm working on wasn't good enough to turn over to a client, and the night before tells me I can't go, and literally, at eleven o'clock at night, I'm dialing for somebody to accompany Scott – who's in a wheelchair, at that point – on an airplane to visit his mother, because literally, we knew it was weeks. And he died on that flight. I was so furious that I was so dependent on my job for mortgage payments and health insurance and whatever, that I allowed myself – or was in a position where I couldn't quit and I couldn't take care of him, and where I had to be treated that way – that I saw this as a vehicle to help fight the kind of discrimination and stigmatization and inappropriate, unfair treatment that I received. And, given that I knew I had AIDS and needed health insurance, and wanted – if I needed to go on long-term disability – to have a job, where I knew I have a long-term disability insurance policy, felt that I had to hold on to that job. And, it was a way for me to help fight for the kind of the protections that weren't in place when my lover was dying and, hopefully, I could help put in place, should I need them.

SS: When you were making your own treatment decisions, did you get information from ACT UP?

ES: I did. And one of the good things, I think, about ACT UP, we attempted to, through our fact sheets, not only educate the general public and the press about our

issues, but keep ourselves informed so that we could not only manage our own health, but be able to talk to the press or to the general public about what our issues were, what research issues were, what appropriate prevention methods and treatment and methods of care and support for people with AIDS were, and it was a way to keep ourselves educated. But, because I was more concerned about social justice and because I – even though I’ve had an AIDS diagnosis since ‘87 – I’ve never had really life-threatening OIs – opportunistic infections. Because my health has been relatively good, I never totally immersed myself in the treatment agenda. And so, whenever anyone was approaching me for an interview or to do a talk or something about treatment stuff, I always passed that off to the Treatment and Data or the medical geeks – the medical experts – because they were better able to talk to those issues than me.

SS: One thing that we’re doing with everyone that we’re interviewing who has AIDS, we’re asking if you don’t mind if you could tell us what meds you’re taking now?

ES: I’m taking – as far as my cocktail – Sustiva, Emtriva, Abacavir – it’s also known as Ziagen – and Viread. I take a bunch of other things like, Acyclovir/Zovirax for re-occurring shingles, and I get a lot of herpes-related ulcers in my throat and mouth and a number of different things for nausea, diarrhea – now, arthritis, because my depressed immune system has triggered an early onset of arthritis. I probably take about 13 or 14 different drugs a day to combat HIV or related opportunistic infections. I’ve got a lot of neuropathy – things like that.

SS: Okay, I only have one more question for you, unless there’s something that you think we really missed that you want to talk about.

ES: I think I started to talk about unsung heroes. There were a lot of people – like Nick Rango is one of them – who worked within government, who did incredible things to ensure that people with AIDS got proper medical care and treatment and support. And, a lot of them, at risk of losing their job, if it was known that they were literally calling people like me up and inviting me to come over for lunch or taking me to dinner, so they could leak information about what the government was or wasn't doing right, and about what issues really needed to be brought to the public's attention to ensure the rights and safety of people with AIDS. A lot of those people died without anybody really knowing what they did. And that's too bad.

SS: Well, that's part of the reason we're doing this is to try to remember the work that people have done to the extent that we can. So Eric, just looking back, you're still in ACT UP, and you're doing all this amazing work, and you're just one of those people that's just kept up your responsibility to other human beings all these years. What is the achievement of ACT UP of which you're the proudest?

ES: I guess it's actually something that we haven't really even talked about and that's helping to bring the world's attention to the global AIDS crisis. Ironically – I'm very proud of what we did through Housing Works, and what we did to try to ensure that people with AIDS have access to entitlements and social services. And, I think Housing Works has done some incredible things. But, when I was forced onto long-term disability, and started being able to do things like go to international AIDS conferences, and learn about the plight of people with AIDS in the developing world, my social justice spirit was taken to a totally different level. Realizing that there were wonderfully heroic – often women – in Africa and other places in the developing world who, literally – you

know, their children were being beaten in schools, their houses were being fire-bombed, bullets were being shot into their houses. They were having to sell their farms and their pigs and whatever to try to get things like Diflucan, an anti-fungal disease to treat cryptococcal meningitis, to keep their children's or their husband's heads from swelling from fungal infections of the brain lining and turning to toothpaste. Knowing that we were able to obtain – even though there were horrendous situations here – some safeguards to help people with AIDS survive here, and to see these wonderfully heroic people, without any help, or without any safeguards in their countries, die, needlessly, very rapid, very painful, messy deaths, and leaving whole countries full of orphans, to the extent that it's destabilizing whole continents, like the continent of Africa.

Tape III
00:25:00

And in '96, when David Ho was selected the symbolic Man of the Year for the advent of the protease inhibitor, and jerks like Andrew Sullivan were proclaiming the end of AIDS, some of us knew that it was only the beginning. And, I had lobbied to position myself on the NGO Liaison Committee of the Vancouver Conference, to help make access to treatment a major focus of the Vancouver Conference. And actually, through that work, and through work I was doing with a global network of people with AIDS, was asked to speak at the opening ceremony of the Vancouver Conference. And, I stood up and said "I'm here to sound the alarm and to do a reality check. I mean, everyone is running around – the cure is here, the cure is here. The cure is not here. This isn't the end of AIDS, just the beginning. And, for ninety-nine percent of people with AIDS, nothing's changed. They don't even have access to aspirin. What the world needs to be saying – and not that 'The cure is here' – what the world needs to be saying is that people with AIDS need access to treatment, that people with AIDS need discount prices in the

developing world so that they can afford access to treatment, and that we need a global war chest of at least \$10 billion a year to fight AIDS in the developing world – for prevention and access to treatment.”

And that speech got a fair amount of press, and kind of jump-started the whole access to treatment for the developing world campaign. And not without huge negative reaction from the treatment activist community. It was kind of funny – anybody that worked on development issues, or from the developing world, was running around the conference, congratulating me, thanking me, and I was doing a lot of interviews about the issue. And it was again, one of those situations of – you know, I’m friends with Peter Piot, the head of UN AIDS, and literally we were sharing drafts of our speeches, and he was echoing the things I was saying. And we were outlining this whole action plan of priorities that needed to be brought to the world view. And finally, some of that stuff was getting some media play. And the treatment activist people were furious. They wouldn’t even talk to me. Some of them were, “How fucking dare you. How dare you get up there and say that. Who do you think you are?” It was like, who the fuck do you think *you* are? Maybe you’ve got access to treatment, but what about the three million people that are going to die this year in the developing world, because they don’t? I’m glad I was able to use my big mouth to bring voice to some of those issues.

SS: Great. Thank you so much Eric. Really appreciate it.

ES: My pleasure.

SS: You’ve done so much.

[END OF INTERVIEW]

