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Interviewee: **Emily Gordon**

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Interviewer: **Sarah Schulman**

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ACT UP Oral History Project
Emily Gordon
November 5, 2010

SARAH SCHULMAN: So we start if you could just tell us your name, your age, today's date, and where we are.

EMILY GORDON: It's like a psych test. {LAUGHS} My name is Emily Gordon. I'm seventy-four, soon to be seventy-five in December, on the seventeenth. We're in Carrboro, North Carolina.

SS: Right. And it's November—

EG: She had to prompt me. It's November 5, and I knew that.

SS: 2010. And I believe you're the oldest person we've interviewed.

Is that true?

JIM HUBBARD: Probably, yes.

EG: Quite likely, because I didn't advertise the age. It was enough to be a straight woman in ACT UP. I definitely didn't advertise the age.

SS: So where did you grow up?

EG: I was born in New York. I grew up pretty much in Detroit, Michigan, Ann Arbor, Michigan, around there.

SS: Were your parents born in the U.S.?

EG: My father was born in Greece. He came here illegally, and he left before I was born. My mother was born here.

SS: Your mother was born here?

EG: Yes.

SS: So Gordon is not the Greek name?

EG: She was a little angry with him about having split before I was born. Consequently, the name apparently was supposed to be Jokaris, but when she went to put it on the birth certificate, she put it on as Gordon. I didn't figure that one out until I was sixteen when I halfway reunited with him.

SS: So you're half Greek, half—

EG: Unfortunately, yes, because I worked a lot of Greek restaurants, and I can't say as I have a really positive thing about the Greek culture. When I was sixteen, he wanted to send me to Greece. He didn't have funds to go with both of us. He wanted to send me to Greece so I could meet my grandmother, but I wasn't into international travel, so I passed on that one.

SS: So you were growing up in Detroit and Michigan, and I assume it was a union town at that time.

EG: Actually, I didn't know too much about that. We grew up incredibly poor, on welfare. I was at the end of the Depression. I remember the soldiers coming home and all that fun stuff. I didn't have a real strong concept of war, but Mother was trying really hard to keep a roof over my head. She took a series of live-in jobs as a housekeeper. She also had some serious psych problems, and they didn't last too long, so probably the most productive part of her life was when she made it to a factory job at the tail end of the war.

SS: So is that when your sense of justice started to develop?

EG: Not really. It was too much on a survival basis, and when you turn into a teenager, you always have those parental conflicts anyway. Mine was sort of

exaggerated by the fact that she was hospitalized permanently when I was fifteen, and I had to look for some other type of roof over my head, and I moved in with a really nice Jewish family in Ann Arbor, Michigan, and I cared for their two kids. They were quite political and quite liberal, and I was free enough to sort of look at the bigger world and get a sense as to what's going on. Probably never would have made it to college if Mrs. Gomberg hadn't said, "If you plan to live in my home and I'm a professor and my husband, Henry, is a professor, you will not ever give to our children any possibility of the fact that there's any world besides college, and that means you're going to go."

I said, "Hadn't really thought about that," at that point. I had a few goals: to get laid, to move out, maybe work at Kresge's. "But if you think I can go to college, and you just found me a job at good old University of Michigan Hospital, I guess I'll go to college, because I kind of like it here and I certainly like the security of having somewhere permanent to live," because we hadn't been that permanent.

SS: So what year did you start college?

EG: Boy, that's a good question. Fifty-two, I think. I have to think way back there. {LAUGHS}

SS: So this was in Ann Arbor?

EG: University of Michigan. I had moved into co-op, and once I moved into co-op, I got much more politically involved because I was freer. I used to come home every day after school in high school and take care of Richard and Bobby, and then work every weekend at the hospital and then work summers at the hospital, so I didn't have too much chance of going around and understanding what was going on. But I

started volunteering at a community center, and I joined the American Friends Service Committee and I did some projects with them.

SS: Were you aware of McCarthyism, the Rosenbergs, and all of these events?

EG: Not as much as I would like to claim. I think it was a little bit more intellectual than it was. My first thing at the university with the Friends Service Committee was working in a hospital for epileptics in Indiana, and there was a huge disparity. Believe it or not, they had just raised the minimum wage to a dollar an hour, and there was a huge disparity between the college kids that they got to come in for the summer and the regular staff there. We had some concerns about that.

The second, in my sophomore year, I was much more involved, and I joined a summer project where I went to Philadelphia and we were supposed to be learning about labor unions. We even went to Daddy Grace, which I don't know if any of you remember.

SS: The black evangelic?

EG: Yes. Daddy Grace plied you with food, and our project got to go and eat some delicious food. People stood around behind the tables and sang to us. The problem with Daddy Grace is that he didn't believe in any sex, and we were all trying to figure out how you could have a religious movement without having procreation.

We visited some factories. I worked in two factories. I found out that I hated it with a purple hatred. I was really bad at it. We were responsible for getting our own jobs. I sold cemetery plots for a while. I worked in Campbell's Soup factory, and I

was on the streets of Philadelphia at the early morning shift, which is probably the worst time as a woman to be on the streets. Cars would drive up right over the curb and sort of pin me against phone booths, and everybody was totally drunk, and all my woman stuff came out. I would just hit the phone booth and pretend I was calling the police. But I ended up quitting that job because I could work the late shift, but the people at four and five in the morning were not the sanest people on the streets. So I was happy to go back to school at that point, but I was living in a co-op, and I really wish there were more now.

SS: Were you religious?

EG: Not at all. The only times I went to church was wherever we ended up living. My mother thought that it was important that I do that, so whatever church was close that she could shoo me into, I would go to. I ended up in an evangelical church, which had a great youth group, and I was totally into it, and then they made the youth group end up going to the main service. Here was this woman, and she said, “Who are you?”

I said, “Emily Gordon.”

She said, “You’re wearing lipstick.”

I said, “Yeah. Isn’t it pretty?”

She said, “It’s against our church policy.”

I said, “Really? Everybody in my group wears it.” {LAUGHS} So I decided I wasn’t going to be oriented that way.

It’s kind of funny. I have a friend who’s a nun and she worked with me with Just Kids Foundation, that I founded, and she also came to a few of the ACT UP

meetings. She was at college in New York. Sister Linda and I took some trips together, and she said that I was very spiritual, but I didn't see it, because basically I'm pretty anti-religious. I did the university. I did the Friends Service Committee when I was in Ann Arbor and throughout different places in the country. If anything, I'm a little more Unitarian, but both of those organizations are really different, depending on where you physically live.

SS: What did you do when you left Ann Arbor?

EG: I left Ann Arbor, going into my senior year, to get married. Fatal mistake, bad plan. I was of the generation where you don't get asked to get married that often, and you were sort of conditioned, you're supposed to be married and procreate. So the first guy that asked me to marry him, I was still a virgin, and I said, "Bernie, your family is Orthodox. I know a little bit about Jewish culture. This is not going to work."

He said, "Oh, but it will, because we'll have a baby and then my mother will be so happy that she has a grandchild that she'll accept our marriage."

I said, "I'm not going that route. I really want to finish college."

So the second guy was pretty much my second lover. When Jerry graduated a year ahead of me, and he was in a co-op and he wasn't wild and crazy, but he was okay. At that point in my life, he was quite okay for me. But he graduated, and he moved down to El Paso, Texas, to work for Douglas, Douglas Aircraft. I came down one summer, and he's like, "I really miss you."

I'm like, "Well, to be honest, I think I miss you, but I'm not so sure I want to quit college and get married, because I still want to graduate."

So in the height of passion, he screamed, "I want you!"

And like a well-behaved young lady, I said, "How?"

And he choked and said, "For my wife."

When I announced that to the waitress the next day, he looked utterly miserable, and that should have been a clue, but what happened was we did get married. My father came down, believe it or not. He didn't been very visible in my life. And we got married. I discovered that I hated El Paso with a purple hatred. It was a military town. I was very uncomfortable. I kind of hated marriage too, but at that point I didn't articulate it quite so well. So I got him to move to Los Angeles, and he took a pay cut.

Then I finally got residency, so I could go back to school, because I tried to go to school in Texas. I asked this guy, I said, "Where's the sociology department?"

"Sociology, girl? I reckon it's down the road a piece."

I was like, "Oh, my god. I think I'm in the wrong place," because I didn't want to lose those three years of college credits.

So what happened was I ended up getting residency and I went to UCLA. Took forever to graduate. Jerry got more and more right-wing without knowing that he was right-wing, because he hadn't been very political, and I, of course, got a little more left-wing.

There is an organization called SANE, safe nuclear policy program, and what I was doing was I was participating in that group and they said, "Everybody get in the car, we're going to go demonstrate against nuclear weapons."

I said, "Great! Wonderful!" Got in the car, we pulled up to Douglas Aircraft, and I went, "Oh, shit, I have fucked up royally this time. I'm only a year and a half into this marriage." And we demonstrated, and I went back and then I ran home and prepared a little dinner, and I said, "Honey, how was your day at work?"

And he said, "Oh, it was really strange. They brought everybody from Douglas into this big auditorium, and they said something about the communists were coming, and they showed us these movies about what the communists do, and they had this thing in San Francisco where they were dragging people down these marble steps, and it was all very confusing."

I went, "Oh, my god, those are my people." {LAUGHS} Those are the people that they hosed the steps down and had a lot of blood following them as they pulled them down the steps. I did not tell him I had been in front of his place, because he had a security clearance and that would have totally screwed him.

However, he decided that he wanted to be a company man. I finally graduated and I got a job. I got several jobs. I thought I wanted to be a social worker until I worked for the Welfare Department, discovered I really didn't want to be one because they were too ridiculously punitive.

We were supposed to be going to Europe, so we had this big map on the wall, and a little boat was going across. He forgot to mention that he had a \$10,000 student loan, so one day I opened up the mail, and I said, "What the hell is this?"

He said, "Oh, that's mine."

I said, "We're freakin' married. It's ours. Don't you get it?"

He said, “Well, I’ll pay it off. My salary’s good. My job’s secure.”

They had a weird thing with Douglas Aircraft where they would give the engineers assignments. When the assignment ended, they never fired them, so they basically sat around and sharpened pencils and ogled the secretaries, and it was really weird. He eventually married one of those secretaries, remarried.

What happened was he came home one day and said, “I have a friend and he owns some property in El Segundo,” which was probably the ugliest part of L.A. at this point with these oil wells that just continually went up and down. “And we could buy some property and we could build a house.”

I said, “We don’t have that kind of money. We’re going to Europe. You’re going to take a six months’ leave of absence. We planned this.”

He said, “Well, it would be such fun to draw the plans up on a house.”

I said, “What do we need a house for?”

He said, “For the children.”

I said, “What happened to the conversation that went—and I quote—‘I want to graduate and travel before the family’?”

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“Oh, I didn’t think you really meant that.” So much for male-female conversations.

At that point, I was beyond conflicted and I told him flat out, “There’s no way in hell that I’m going to do the build-a-house-in-El-Segundo route.” And he told me that everybody else would be lapping at that chance.

At that point, we'd started having some parties, and I had my friends from UCLA coming and he had his engineer friends, and he thought my friends were like pieces of meat, and my friends thought his friends were probably the ugliest, stupidest people they'd ever had the unfortunate thing to be at a party, and the married people came in in clumps, with the women holding onto the men in a death grip. At one point Jerry said, "Why don't you guys come outside. I want to show you a car I've been working on." The women marched out, and then there were these two camps of people sort of glaring at each other, and I realized that I was in the wrong place.

But at that point I ended up taking a lover and being a little conflicted about that. We weren't even having sex that much, but he wanted to have sex at that point, and I still had the diaphragm in. I couldn't figure out how to take the diaphragm out from Bob so I could wash it and put it back in for Jerry, so I figured it was time to tell him. "Guess what? I have another lover." {LAUGHS}

He freaked out, and I started crying and feeling guilty, and he decided to leave. I, at that point, of course, was in therapy, for what good that did. He took me to a psych unit and dropped me off, and I fell asleep.

I woke up the next day and I said, "Oh, shit. I thought I was in a psych unit. This lady's got a cast. Where am I?"

They said, "Well, Dr. Colley said to put you here because there are no beds, and he's going to come see you."

I said, "Oh, no, he isn't. I've got a test. I have to leave," and I fought to get out. It was kind of weird, because I was really seriously wanting to do social work, and I felt like I was walking a fine line, but I didn't.

Colley set that up. He set it up with, "If you're in conflict with your marriage, you can always come to the hospital." I wasn't taking any medicine or anything. So having done the "come to the hospital" thing, I said, "Fuck this," and I just left, with the hospital screaming after me, "We've called Dr. Colley. You have to come back. You're on the wrong unit. It's a medical unit. Come back. They have a bed upstairs for you."

I was like, "Never mind." {LAUGHS} So I missed a final, but I survived quite well.

Jerry stayed out of the little apartment we had, and I decided it was definitely time to get a divorce, which was really hard because at that time they didn't have agreeable divorces. You had to come up with something. So I happened to have a black female friend who was married, and what happened with Angie is she said that she would go and say that Jerry had made a pass at her, and we thought for sure that was going to work. So we got to the divorce proceedings, and her son had thrown her wedding ring down the toilet, and she couldn't make it, so we had to do it again. And we did it again, and that worked. The judge got very unhappy, and Jerry knew she was lying. I knew she was lying. It was just that there was no way this was going to continue into a viable marriage at that point. So finally got divorced, which was very upsetting and at that point made me feel like shit.

At that point, I continued politically with a series of strange lovers and a lot of emotional up-and-downs until finally I decided the best thing to do was go back to graduate school. So I went to graduate school, University of Michigan, loved it, and kind of felt like I was on a path. Graduate school at University of Michigan at that point was a tiered master's program, and they wanted you very much to really, really focus on the intellectual part of it. At that point, civil rights was just beginning, and I joined an organization on campus, so I ended up picketing some of my professors' houses because—

SS: What was the organization?

EG: To be honest, I can't remember.

SS: What years was this?

EG: This was '64, because I was already planning to go to Mississippi, so it was probably – it wasn't SNCC, it was more likely CORE or something like that.

So what happened was I remember picketing. "Oh, we're going to go picket a house that discriminates." And one of my teachers was hanging out the window, going, "Miss Gordon!"

I was like, "Oh, shit. I'll never graduate."

I was seeing this black guy who was divorced, and we had already decided we were going to go to Mississippi, so that meant that we had to sort of drive around and collect money, \$500. Everybody had to go to Mississippi with \$500, which at that point was significant money for a student. So we went upstate Michigan. He was a folksinger,

and we got harassed and we got followed and we didn't think we were going to make it to Mississippi.

Then what happened was we went to Detroit and we were raising funds in some of the black churches, and we kept asking, "Do you guys have any family in Mississippi?"

"Oh, no, no, we ain't got no family in Mississippi." Please. They all went down there for the summer, but they weren't admitting it.

SS: Why weren't they admitting it?

EG: It was that difficult. It's a good question. I found this out after I got to Mississippi, which wasn't the easiest thing, by the way, because we were in the first session of trainees from SNCC, and we went down and then Goodman, Schwerner, and Cheney sort of disappeared, and they weren't even sure whether they should send the second group down.

So what happened was I ended up on the phones. I was in Holly Springs, this little bitty city up north, and they were terrified. They said, "We've got to get all the white people out of here immediately and send them down to Jackson," the so-called liberal place, and I was on the phones down there. We had a list of everybody. We were trying to monitor where everybody was. So we had a list of people. This guy called and he said, "My name is Clarence Wiggins, and I'm in jail in Itta Bena."

I'm like, "Clarence Williams. Clarence Williams. Clarence, you're not on our list."

He said, “Oh, well, I came down to visit my mother, and I’m really not part of your organization, but I’m in jail and you’ve got to get me out!”

I was like, “Oh, god.” Sure, a lot of people were going down there back and forth. It was a little circular thing.

Joe and I looked at each other and we said there must have been a million people we talked to, because we wanted to learn about Mississippi before we went.

But I went from Jackson, got arrested three times in demonstrations. I got bombed in Vicksburg.

SS: How was that?

EG: It was kind of serious. We had a three-story house that was the Freedom School part. I was doing voter registration. People were doing Freedom School things. The house was owned by the Methodists, and we had this woman, Mrs. Brown, who had eight kids that was living sort of in the basement, and the rest of the house was on us, and it was on a hill. It was very interesting racially because there were black people that were from Mississippi that were in charge, but there were also a lot of white male volunteers.

When we first got there, we kept getting invited to go to the clubs, and that was the social thing, the church and the clubs, church and clubs, take your pick. As long as I got a ride, I didn’t care where I went. But what happened was the first time we got invited, none of the white guys wanted to go to the clubs, and the black guys were pissed as hell. There were like twenty of us, staying in people’s houses and things. “If you don’t do that, the deal is what are you going to do?”

“Oh, we’re going to stay here and protect us.”

I said, “We’re nonviolent. What the fuck are you going to protect people with? Your attitude? I don’t think so. You got a stick somewhere?”

So they wouldn’t go, and what it was is they were incredibly uncomfortable in a black club. They were uncomfortable around younger black males. They learned that the younger black guys were hitting on the white women, and a lot of the white women were cooperating. I know I was. And they hated that.

There was huge differences in the group that came down, and we figured that out because there were people from Vicksburg, which was sort of a liberal-ish town, not like Natchez, which I always wanted to go back to Mississippi and see the real Natchez, because I saw it laying on the floorboards just looking at the poles that went by. But what happened was people would come from their colleges up north, and they would come to our place and they would say, “Hi, y’all, just wanted to see what y’all doing.”

So the first time I encountered one of those people I said, “Oh, I’m so glad you’re here. We’re trying to find out about the segregation in the hospitals. Could you please go to the hospital and tell us about the black units and the white units and maybe take some pictures or something?”

“Oh, no, my mammy would be real unhappy were I to do that.”

I said, “Didn’t you say you were in college in Illinois? Why would you argue this point?”

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We had a steady stream of people coming up to visit us, and I knew in my heart that that was a disaster, but there wasn’t shit I could do about it, because there was a

conflict within the group. So what happened is one night we had come back from a church in the country, and it was really a wild thing because we were nonviolent. The community wasn't nonviolent. So we went to a meeting at the church in the country, and there were outhouses out back, and my friend Jeanie and I decided to go to the outhouse, and this guy sort of grew up out of the ground with a twelve-gauge, and we said, "Hello?" It was a black guy. We said, "Hello?"

He said, "What y'all doing out here? Don't you know we got this perimeter?"

We were like, "We kind of wanted to go to the outhouse."

He said, "All right, but make it fast, because we got warnings about what's gonna happen. We ain't going to be firebombed. We're protecting. We're veterans. We're protecting you."

So okay. So we went back.

I had a friend named Brian, and there was this great big room which was almost the size of this apartment, and I asked him, I said, "What are you doing?"

He was sitting way over there, and he said, "I'm writing a letter to my girlfriend."

I said, "What are you going to say about tonight?"

Johnny, this kid that was sort of attached to us, he was like this seventeen-year-old kid, was sleeping here. My friend Eileen was screwing this other guy, and we couldn't get a ride home until she finished screwing. So I was just sort of floating and on

the phones. We'd get all these horrible phone calls, "What you doin' with those N-words? Is it big? What color is it? Does it look good?"

So there's this guy, Len Chandler, that's in the unit at the time, and he was a folksinger and he sounded very white but he was very black, and he used to answer the phone. He'd say, "Oh, hello, so nice to talk to you, ma'am. And, by the way, I got me a twelve-inch," and freak out the phone people. I didn't particularly like to play that game. But what happened was, in Len's case, he was doing the right thing, although I think it took a little emotional toll on him to play that game.

But I was talking to Brian, and Brian had come over to show me the letter, and all of a sudden—boom—the ceiling started to fall down. I looked, and the entire back end of the house had been pushed out. I was on the third floor. People were laying in their beds with nothing to hold up the beds, and all the nasty clothes that people had sent to us had been sort of scattered all over. I have to say we were not unhappy about that, because they were sending us rags, dirty underwear and stuff. We were not that poor. But the books were gone.

So I grabbed Brian and Brian grabbed me, and for the life of me I couldn't remember what you're supposed to do in case of a bombing. So finally I said, "Oh, hell, let me just call out names. Eileen!"

And she's like, "I can't find my pants, Emily."

I said, "Fuck the pants. Are you safe? Are you alive?"

I looked out the window, and the police and the FBI were marching up the hill, so they knew who it was, and they knew that what happened was—you have to

register if you have explosives training, so they knew what was going to happen. They had it all planned out. I went, "Oh, shit."

So what happened is Eileen and I went down to see Mrs. Brown, and she had like a seven-month-old baby, and the baby had had something fall on her forehead, so we were getting her and the baby in our car to go take her to the hospital. Up comes the FBI, "Hi! I'm the FBI! I'd like to interview you."

I said, "Excuse me, we have no time for you. We're going to the hospital."

"Oh, no, we're the FBI. We have to interview you."

I said, "Forget that."

So we drove off, and the baby was fine. We got back, and they had condemned the building, and that was the plan, really, just to wipe out the whole program, because, golly, gosh, nobody else wanted to rent to us after that. That's when we had the Freedom Summer and the Fannie Lou Hamer and all that stuff.

Then I went back and stayed about six more months, because a lot of people had to go to college and I'd already graduated. One guy and his girlfriend were supposed to be doing the Peace Corps thing, and this was their big trip. They were going to Africa, they were going to bond the relationship. They were doing Peace Corps. The girl made it on the plane. The FBI was waiting for him and turned him away and wouldn't allow him to go.

Another girl, nicely and politely, was hospitalized psychiatrically, and we were living in fear of that. I was especially living in fear of it, as your friendly social-

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work person, because once they hospitalize you psychiatrically in Mississippi, you don't get out. I mean, you are just there, and they shove meds down you like it's going out of style. They got a rule toward the end where they said no more than three people can sit together, so we'd be five in a car, and two people would go in this little crappy store, and then three people would go in this little crappy store, and we'd order Cokes and pig-foot sandwiches, and just pray that nobody would come in and get us because we really thought we were going to be arrested in a bad, bad way. Survived it.

Lyndon Johnson's thing then came in. A lot of SNCC people took the money. A hundred and fifty dollars a week looked like five.

SS: What do you mean, Lyndon Johnson's thing?

EG: Well, he did the, "Let's help the poor people" thing.

SS: You mean VISTA?

EG: Yes, VISTA and everything else. He came down with money. That's how they really, on some level, bought out the movement. So a lot of the SNCC people just gave it up, and a lot of the SNCC people went national, nationalistic.

At that point I was involved with a black guy, and we ended up going back to New York. He was pretty functionally illiterate but incredibly sharp, and he had been in a movement from back in the early sixties. He had burns on his feet to prove it because he'd been in Parchman and things, and, needless to say, John couldn't get a job, nor could his brother, but I got a job. Then it was kind of awkward because I was very sensitive to the nationalistic thing and all the shit that had happened. So I ended up telling him, I said, "Not for nothing. If it's time for us to part, it's time for us to part."

And he said, “Are you crazy? I’ve been going to all those Stokely [Carmichael] meetings. That’s a bunch of shit. He’s a college-educated guy. He’s not for real. If I want to leave your ass, I’ll leave your ass, but I’m not going to leave your ass over some bullshit, just because I’m wearing a dashiki. Screw that.” So that’s how that went.

John and I ended up going down to Florida doing migrant work. That was a little on the hard side for yours truly because I wasn’t a good migrant worker, but he was great. Then we ended up going out to California, going through the little hippie thingy. I got involved in People’s Park, which was really an amazing thing. And then back, just floated around. I’ve been involved in prisoners’ movements.

So when ACT UP first came along, I’d just gotten back from New York. Well, I was in New York, but I’d just gotten back. I’d quit a couple of jobs and saved money and went to Europe, and I’d been in Europe four months. When I came back everything was AIDS, AIDS, AIDS, and I was like gay, gay, gay? Finally, I got a job at Covenant House, and I was very close with a friend of mine who was an attorney who came up positive. When Michael became positive, his roommates sort of freaked out, and they left him. So what happened is we ended up living together in Harlem. I was very concerned about him when his ex-lover was in the hospital seriously dying.

SS: What year is this now?

EG: I’m trying to remember. It was in the early nineties at that point.

So my initial response was – well, there’s two things happened. As a social-work professional, I was working at Covenant House, and at the same time

Michael was living with me and I was worried sick about him, I also had a young black mother and her daughter, and she was diagnosed through her daughter, and her boyfriend/partner had been in jail and got out and refused to take a test.

So I found ACT UP, but it was really hard to find ACT UP, because I went to the gay parade and I'm marching along, and I'm asking everybody, "Do you guys know where ACT UP is? Because I think that's what I think I want to be involved in."

And they said, "You know, Emily, it's really kind of funny because my roommate's in it but I can't find my roommate and I can't find the group," so I think this was more right after the Wall Street thing. It was right around that time.

Once at the same time I was looking for ACT UP, I went to a professional conference, and it was all these social workers and all these doctors, and they're like, "Everybody's going to die and the babies are going to die in the first two years." I'm like, "Kill me, kill me, kill me."

At the very end of that conference, Griffin Gold got up and there he was in his nice little black motorcycle jacket, and he's like, "I'm in People with AIDS Coalition, and I'm sorry, we're not planning on dying anytime soon."

So I just practically leapt on him, poor guy, and I said, as a professional person, "I'm so glad that you gave a breath of fresh air to this conference, because all the nurses and the social workers are scribbling notes, 'Going to die soon.'" That's the shit they were putting out. So I think Griffin more or less pointed me toward the regular meetings, and I started going to regular meetings.

At that point things were going to hell on the job because my co-social workers at Covenant House, of all places—you remember Covenant House with Ritter screwing all the kids and he had the staff thinking that he was just looking for kids that needed midnight help. It was really weird. What happened is I left Covenant House. I got a job with the Health Department right about that time, because I couldn't take the bullshit that was going on.

But what happened was Michael was one of these people, kind of like, "Kill me or cure me." And I've always been one of these people like, "Let's help. Let's get information." I don't know if you remember lipids. They had the egg lipids thing. They had Suzanne. Suzanne and I were in the demonstrations.

SS: Suzanne Phillips?

EG: Yes.

SS: Where is she?

EG: I have no earthly idea.

SS: How did you hook up with her?

EG: Because of the egg lipids thing and I was trying to get some for Michael, went over to the Village and stood out by St. Mark's and tried to get the product, and then I tried to hook it up for him. But it was so funny because—

SS: She was distributing there?

EG: She was helping them. Wasn't supposed to. I think it was the People With AIDS Coalition.

SS: Do you remember where this was?

EG: Over by St. Mark's Church we were doing it. There was a huge line of people going – and someone I know is nodding. {LAUGHS} There was a huge line of people that were trying to get it. I'd gotten him a doctor at that point, but he got this Dr. Fonville, who was black, and Michael happened to be black, and it was kind of weird because I thought, "Oh, this is really cool, black doctor, black client. How cool is this?" Fonville didn't even have admitting privileges to the hospitals. I don't think he was the greatest doctor, but I think he was just taking it on because he felt an obligation to take it on. But we told him about lipids. He's like, "Oh, that's not going to work." And Michael didn't want to take AZT, and that's when everybody was overdosing on AZT.

I kind of understood that on a lot of levels, but at the same time, I had AIDS 24/7. I had it at work and I had it at home, and I really think on a lot of levels ACT UP saved what little mental health I had at that time, because we got the stickers. We put them on the escalators, Silence = Death, and I got a lot of people when we were living in Harlem – we finally moved down to the Village, but when we were living in Harlem, I had a lot of people that were doing those stickers too.

I went to some amazing demonstrations. Even when I was in the Health Department, we had a demonstration that involved a lot of Haitians. It was so funny because I was officially at a demonstration, but one day when I was working I went through Washington Square Park, and there was a demonstration on housing. I forgot I was on my fucking lunch hour, and I just joined in. Like, oh, okay, housing, yes, we need housing. I was like, "Oh, my god, I've got a meeting. Get the hell away from this demonstration. You're going to lose this job."

There was a demonstration in the Health Department, and I walked in as the older covered person to try to figure out where the goddamn doctors were so we could do the thing, and I subsequently found out that my immediate supervisor, Thank Jesus, did not see me, had been barricaded in there because they were so worried about ACT UP. It was the damnedest thing. She said, "I couldn't even get my child out of school. Those people came in, and, oh, my god, we had to put things against the door. It was just awful."

I was cracking up. I was like, "Oh, yes. Wow. Fascinating." Please, Jesus, don't let her ask where I was, because I was floating all around trying to figure out where the doctors were at that point.

SS: So when you came to ACT UP, that was at the Center, right?

EG: Yes.

SS: How did you first plug in?

EG: I didn't know what to do, and I was looking for medical things, so it was all treatment and data, which was way over my head, and also I was amazingly impressed at how somebody like Jim Eigo, he was a poet, and Iris [Long] mentored him and got him into looking at things, writing leaflets and things. Iris told me, she said, "I asked him, 'What do you do?' and he said, 'I'm a poet.'" And she said, "Great, that means you're a writer. You can make some leaflets. That's so cool." So what happened was he ended up writing leaflets. I ended up going to Treatment and Data. I was very uncomfortable in Treatment and Data for a variety of reasons.

Tape I
00:40:00

SS: Why is that?

EG: I kind of felt like everybody had known everybody all their life, and there I was the old white straight lady who actually cared about women and children, and there was this whole huge thing in ACT UP, which wasn't ACT UP's fault, but it was there, the media had done the innocent victims versus the evil gay guys, they made that division, and it was very fucked up.

At the same time, the girl that had—she'd just gotten her first apartment, this was her second child, and she'd gotten away from her mother and she was finally on a path. She was just turning nineteen, she had two kids, and all of a sudden HIV hit. Then the mother had ended up taking care of her because she went down real fast.

So I had that, and I had Michael, who was still working, but on the other hand, he wasn't very out at his job, and so as he got sicker, I was like, "Honey, you've got to call GMHC."

And he's like, "No, I don't really want to." I found out after the second hospitalization he didn't want to call them because he thought they were going to call the job and say, "We're Gay Men's Health Crisis. We'd like to speak to Michael Anderson." Not happening. I ended up on the phone with the hospital, screaming at them. I think everybody was in a meeting because everything was so chaotic.

But what happened was the biggest thing, and I have to admit this, I might as well admit it publicly, I was very comfortable with gay guys, but I was not that comfortable with lesbians, especially butchier lesbians. So what happened was Maxine Wolfe, who I adored, invited me to this thing in Brooklyn. We're having this brunch in Brooklyn. My little homophobic brain clicked over to, "Oh, my god, I'm being invited to

an orgy and I'm not even gay. What does this really mean?" {LAUGHS} I kind of said, "Michael's really sick, and I think I need to spend more time with him." It took me almost six months to figure out it really was a brunch. It was a social activity. It was not a Saturday morning orgy.

Tape II
00:00:00

EG: Where was I? Where was I?

SS: So you're in ACT UP and got in Treatment and Data to get information for Michael, and at some point—

EG: Yes, and for the girl that I was working with, too, which really didn't work. I was trying to find my niche, so we had the Majority Action Committee, and I'm very comfortable with black and Latino and different people, and I joined that. A lot of people in that said that they felt very uncomfortable with the white guys because they thought all the white guys wanted to do was fuck their brains out, and they didn't really want to involve them and be part of a real group. They were also very shy about talking to other people. So I would be the representative for the Majority Action Committee and would go around and go, "Hi, so glad you're here. Is this your first time? My name is Emily. We have this really fabulous committee you really might want to be concerned with joining." That worked for about a year and then—

SS: How many people were in Majority Action?

EG: It varied anywhere from twelve to fifteen, but it went down to five at times.

SS: What were some of the things you guys did?

EG: Tried to stay alive more than anything else, but they participated fully in all the demonstrations and everything. I made a serious contact within that when I was working at the Health Department because one of the guys that went there, his lover was positive, and Victor had some good data entry skills, which I didn't have because I was too busy visiting dying kids in their homes. So he helped me put together an AIDS Resource Manual for families, because I was working four boroughs, and a lot of families did not identify with GMHC. They did not see themselves going there for any services, and the only services that really were were within the hospitals like in Brooklyn and the Bronx. But there was also organizations that would send kids to Disney World, Make A Wish and stuff like that.

So I put together a really decent directory, thanks to ACT UP, because Victor did the whole thing, and I just happened to have a good boss who said, "Do whatever you want to do and I'll print up 10,000 copies."

SS: What was Victor's last name?

EG: Parra. Actually, his lover was one of the ones that said, "ACT UP is really turning us off. We just feel like they see us as hunks of meat, like in a club or something. They don't see us as people who are exactly the same as them with slightly different skin tones." Latino people in that group were more oriented that way.

But I joined that and I felt very good about it. At one point, I went up to this black guy in the meeting and I said, "Oh, there's this great organization, great subcommittee. Is this your first time? It's a great subcommittee."

And he said, “I know I’m black and I know you’re white, and I’m guessing you’re straight, so why the hell are you talking to me again, lady?”

I was like, “Okay.” So I went back and I told him, I said, “It’s about time you guys stepped up to the plate. If you want to recruit and get a committee going, maybe it shouldn’t be me out there all the time because that was a little awkward.”

{LAUGHS}

From that, at the same time I had quit the Covenant House job and I was working with Children with AIDS. From that I got very focused on women and children with AIDS, and that was a hard call because a lot of the mothers that I was working with initially were foster parents.

SS: This is through the Health Department?

EG: Through the Health Department, and what I did was I was able to bring some of them into ACT UP. I wanted them to have the same opportunities that people in ACT UP had, so if we were going to D.C., let’s take some parents with kids. I did that, and I think I did it very effectively because I ended up taking a group of people to a Pediatric AIDS Committee, and they would get up and speak. They were a little overwhelmed at the medicalization of it, but they would get up and speak.

Then, say, like Dr. Wiznia was from Bronx Lebanon, would come up and say, “Emily, I’m so impressed. That woman Linda, she said such great things and she’s so intelligent.”

I said, “Her daughter’s in your clinic. I’m amazed you haven’t met her yet.” So I was able to open it and get them power and get them—

SS: I have a bunch of questions.

EG: Please do.

SS: So the Pediatric AIDS Committee of ACT UP—

EG: Which really wasn't that.

SS: What was it?

Tape II
00:05:00

EG: We didn't call it that. It morphed into Just Kids Foundation. I got three parents to form a 501(c)(3), and we were the Just Kids Foundation. Our mission was to empower and educate parents and caregivers of kids with HIV. We did this through a newsletter. We did it through going to conference. We did it through telephone support, recreational support. We caught hell trying to find money. The only money we really ever got was from a friend of a guy that was in ACT UP who apparently had a trust fund or something, and each year she gave out money to small nonprofits.

He told me for two years that we were going to get some money, and I was like, "Yeah, \$100, wow." I mean, one of my parents wanted me to get hold of Magic Johnson, and we sent for the paperwork and I handed it to him, and he said, "We're suppose to give five years of tax returns from the bank. I guess that's not going to happen."

So this woman actually gave us \$10,000, and the first thing that happened is everybody started fighting, everybody in the group. The parents had not seen money in so long, and some of them had substance-abuse histories that they were in marginal recovery with, and they saw the dollar signs. Our treasurer was not a mother. She was good, but she ran screaming. We took people to San Francisco one time, and they're like,

“Well, I’ve got a caregiver for my child, but she needs \$100 a day, and how many days are we going to be gone?” So money really does corrupt on a lot of levels. It was very hard to keep it going.

I had some amazing women in there. We kept meeting. We met once a week on Sunday afternoons.

SS: Where did you meet?

EG: In the Center.

SS: They came to the Gay Center?

EG: Yes. Some of them were very uncomfortable meeting there too. Especially Sunday. I didn’t know. Really, I was so stupid. {LAUGHS} I was living in the Village at that time, but I honest to god didn’t notice what a huge AA presence there was on Sunday mornings. So hundreds of people were coming out as my parents were dragging their kids in. They finally said, “Isn’t there anywhere else we can meet?” So GMHC started letting us meet over there, and they were more comfortable with that at that point.

SS: Did they ever integrate into ACT UP?

EG: They were integrated to a degree because they didn’t start out as Just Kids; they started out as people that Emily knows. One of the mothers came. Kwan Bennett came, and her husband was positive and Kia, her daughter, was positive, and she was willing to speak to the group to get money for the parents to go to D.C. Right? We were the last people on the agenda. It was close to eleven o’clock. Her husband had

already called her five times saying, “Kia needs her medicine, and I don’t understand her medicine, so where the hell are you?” The marriage was failing.

She was exhausted, and we didn’t get to speak until like five minutes to eleven, because the priority was not women and children. We pulled it off. We made it to international conferences. We had a presence. I was a hell of a cultural trip because my Spanish-speaking mothers, when we went to Italy, said, “Oh, Emily, no problem. You don’t speak Spanish, who cares? Italian and Spanish are the same.” They’re not.

{LAUGHS}

SS: So you brought them to the International AIDS Conference?

EG: I brought them to two.

SS: And ACT UP paid for that?

EG: Yes.

SS: What year was that?

EG: I can’t remember when that was.

JAMES WENTZY: Ninety-one.

EG: Yes. Florence and also we did Amsterdam. We did two conferences. We did about five or six ACTG, Pediatric ACTGs in D.C.

SS: What were you able to do?

EG: I did some posters for the one in—it wasn’t Florence. I think it was Amsterdam. Trying to really put a child’s face on this epidemic. The parents loved going against the drug companies at that point. They participated fully in the demonstrations. They participated in San Francisco not so much, but they participated

because they loved the activism. My goal was really to get that myth that all the kids are going to die in two years. Carol DiPaolo was very good with helping me with that until she splintered off.

SS: Who's she?

EG: She started a Joey DiPaolo Foundation for camp, and it was really funny because apparently they follow him on one of the talk shows. Now he's graduated college and he's going bald. But this was the seven-year-old hemophiliac that was supposed to die real fast.

Tape II
00:10:00

A lot of my kids made it to college, which I really feel like sounds like Jerry's Kids or some shit, but they made it to college. We went through all the bar mitvahs and all the things that kids normally go through. I felt really good as a social-work professional who never had enough money to not work, to do this full-time. I was working either with Health Department or eventually with Housing. But I felt really good about empowering the organization ACT UP to notice women and children, especially women that were not gay, because that was another stumbling block. Literally, unnamed people a couple of times came up to me and said, "Do you think she's gay?"

I was like, "I really don't know, and I don't think that's the issue, because she's trying to keep her family alive." So backburner for that one.

Jeanie helped me get over my homophobia.

SS: Who's Jeanie?

EG: She was an ACT UP member who eventually got married, and she was living with her lover in New Orleans. She was the youngest lesbian, and she was at

one point a virgin and she was going to all the ACT UP guys saying, “How do you not be a virgin?”

And they’re like, “We don’t know how it works for women. It’s a different process for guys.”

But we went to Atlanta and we shared a room, and she got me over some of my little “Why am I in this club raising money for women and children and it’s a dyke club and they really don’t seem like they care? Come to think of it, I haven’t been in an all-dyke club ever, so what exactly am I doing here again?” She pulled me through some of my homophobia, which was still there. I mean, scrape it and it’s still there. You get the layers down.

She finally met a much older woman, and they fell in love and they got married. Her girlfriend would call her, and some of the more out ACT UP women were partying around, and they’d drag somebody in the room at four in the morning. We’d say, “But you really can’t have sex in that bed because it’s really late in the night.”

They’re like, “Oh, no problem. We’ll go in the bathroom.”

I was like, “All right, in the tub, sure.” Boy, do I have a headache from this one.

SS: I have a bunch of questions if we can backtrack.

EG: Please do.

SS: So, Just Kids, what were some of the concrete demands that you had and the things you were trying to win at the time?

EG: We wanted parents to be on the investigational drug panels. We wanted more funding for not just recreational purposes, but more funding for anyone who was caring for an HIV-positive child, like if you have a developmentally disabled child, you got extra money from the foster care system. You finally got it from the foster care, from the Child Protective Services, but it was hard to get that money.

We wanted emergency funds. Life goes on whether you're positive or negative, and somebody's mother dies in Florida, and Naomi needs to go to Florida to see her mother on her deathbed. Forget the fact that she's got a positive son and she's positive; she still wants to go to Florida. There were no discretionary funds for life. She wants to go to school. Michelle Lopez is probably one of the best networkers ever, and she made her way.

My friend Phyllis Sharpe, who I totally over-identified with, Phyllis lost her recovery a couple of times, which hurt the hell out of me. But in the beginning, she was so pro-ACT UP and we were going to all the demonstrations, and she's like, "I'm going to wear fatigues and bring Siouxsie and we're going to do this." Then it was one of those things like, "Oh, shit, I'm still alive, and the demons that were getting me with my substance abuse are sort of creeping up now that I'm stabilized, I have a Co-op City apartment, and nobody's dying yet." She lost her recovery and got it back, and she lost it, and I was with her through a lot of that.

SS: When did she finally pass away?

EG: I don't remember the year. I really don't.

SS: How did she come into ACT UP?

EG: Through me, strangely enough. I had to think on that.

SS: How did you meet her?

EG: Hospital. See, I visited all the hospital social workers. What would happen is if you had a child that was HIV-positive, the Health Department had this school review panel. So my job was to go out there and do home visit and say, “Rosa, tell me about your grandson.” This all started back with Joey Di Paolo and the whole hemophilia drama and stuff like that. I would meet people in all the boroughs except Staten Island, strangely enough. I had all these contacts, so in the process of talking to them, I would say, “Oh, my god, I just heard about what they were saying.” Stupid stuff like in Bronx Lebanon, if you had a pediatric HIV clinic, you had to walk through all the substance-abuse people, and that just set off all sorts of triggers in parents’ minds like, “How am I going to explain this to a seven-year-old why that guy is there and why he’s hitting on me?”

Tape II
00:15:00

Just like one of my mothers told me, she said, “I went to a VD clinic, and the fuckers were hitting on me in the VD clinics. We’re all there for the same thing. Jesus Christ.”

SS: You met Phyllis because her child had HIV?

EG: Yes. I met a lot of the—Renelle. We had a white woman, Sharon. We had a Latino woman, Marlina, and Michelle to a degree. So we had Hispanic, we had white, we had black. We made a board of directors, and it just so played out that we had everybody on the board of directors, so they had contacts. We brought in people, and finally right about that time GMHC discovered that there really was a need for women

and children, and they started having parties, and we started plugging in a little bit more in their services.

But our thing was not a traditional social service thing. A traditional social service thing is usually like me the worker; me gets money. You the client. I listen, I help you out occasionally. Our thing was like, “Let’s share the knowledge that we have.” I used to constantly tell my parents, “I happen not to have a child. If I had a child that was positive and it was the middle of the night, I wouldn’t call me. I would call another mother and say, ‘Do you think it’s time to go to the frickin’ hospital?’” That’s the way I would play it. You can ask me anything, but as far as day-to-day raising of a sick child—.”

I had a foster mother that had three kids, two of them died the first year that they got diagnosed, and I went to those funerals and it was very hard. The other one made it through with severe developmental disabilities, and the fourth one ended up in jail. I can’t believe she took a fourth child, because she was trying to replace the two that had died, Ra Ra and Nay Nay.

But I wanted to empower people to educate their community, because people were so spread out, and it worked. We had some amazing, amazing parents, and fathers occasionally, and we did wonderful things. If we had had funding and if I had not realized how incredibly hard it is to start a nonprofit startup, and if I’d had economics so I could have not worked, I probably could have really got it off the ground. I left it. I left it with Brian McGovern, who was a social service professional that I knew, and it held together a little bit, but it pretty much fell apart.

SS: I want to ask you a couple of things.

EG: Sure.

SS: Pediatric double-blind studies. Was that still operative when you were working?

EG: It was initially, and nobody wanted to believe it. We fought with the doctors. It was kind of like one of those “aha” moments when parents went, “You have to be kidding. You mean I went a whole year taking my child into the hospital for what?” Informed consent was a joke. With a lot of people, you have to go over each line, but they don’t do that. That’s why we wanted parents on the investigational drug things that were making it up, and that was really hard to get them. The hospitals didn’t want that; they wanted professionals.

SS: How did that finally come to an end?

EG: Not through us, but it did come to an end. What’s interesting to me, when I went to Canada, I think that was the first international conference I went to, which was a kicker, and that one didn’t have any parents that I was aware of. PWAC got a lot of people involved too. When I went to that and people took over the stage, and I was like running around the stage saying, “Do you need some water for your medicine?”

There were so many concerned professionals that said, “Fuck the conference. This is more important. This is lifesaving. We’re not listening to the people that presumably we’re earning our living off of.”

People started to wake up, and it wasn’t one thing. I like to think, and I know I’m correct in this, that just the simple fact of bringing parents to conferences to

attend as many—the first conference we went to, it was hell. They all came out of the meeting saying, “What the hell is it with that slide, and why does it go so fast? I have no idea what the fuck they’re talking about. Why am I even here? Where’s my per diem, Emily? Now can I go to bed? I know it’s five o’clock, but I don’t want dinner. I just want to collapse.”

I tried to get some of my mothers to meet me in the lobby of the hotels, and I said, “Look, now that you’ve had one day of the joy of professional conferences, why don’t we meet together to plan what we’re going to do tomorrow, so all the bases are covered. Rosa can go to some. Renelle can go to some. Michelle can go to some.”

The mother that I’d probably been with the longest, who was a foster mother, Renelle, looked at me, and she said, “Emily, have you lost your mind? I am in a hotel room, with a remote. Nobody has my fucking phone number. You want me to get dressed and go downstairs? Hell, no. I don’t get vacations.” That was serious.

There were trips for the kids, but that just put extra strain on the parents. Just going to Disney World was a drama. So big deal, you got a trip to Disney World, and I’ve got three other kids that are negative and I’m taking all of them, and oh, my god. And why is their brother in the wheelchair? And why are we going to the front of the line? It’s just so many layers and layers of issues.

We went to Italy. One of the mothers was horrified because when we were leaving to go to Italy, and we almost didn’t get there. I mean, the hotel was fucked up. There were so many things, so many layers of insanity, and people missed the trains because they were popping medicine and stuff. Everybody was exhausted and unhappy.

But they got up the next day to go to the conference, and what did they see? “Oh, my god, I see my social worker from the Bronx, and she’s going the other direction. Why is that?”

So I’m, “Hi, Mrs. So-and-so. Can I ask you a question?”

“Oh, isn’t this is such a beautiful city. We’re just going on a little tour. That’s what we do when we get here. There’s nothing that you need to go to today in the conference, Emily. It will all be published. Don’t worry about it.” And they were hurt because this is their life, and the people that they half-ass trusted didn’t give a fuck because they were just earning money off of them.

SS: Did ACT UP ever object to paying for this?

EG: No. The biggest problem I had with ACT UP was even getting on the agenda. It was silly for me to go there and talk about women and kids, especially if you put me on at eleven at night when everybody’s kind of exhausted. But once we finally kicked it off, then it was okay. They didn’t understand why parents and kids wouldn’t come to ACT UP at night. They didn’t understand it was a school night. It was the wrong part of town. They didn’t understand parental obligations.

SS: Do you feel that their presence at these international conferences had a substantive impact?

EG: Very much so.

SS: In what way?

EG: Probably more long run with T&D, but short run it made a lot of professionals think. I’ve always loved being a social worker, but I’ve not been happy

with social work per se, because a lot of social workers, they end up in master's programs because they haven't gotten married. They just got to kill some damn time.

I have to backtrack. When I was at Covenant House and I got my first client by accident, and probably was some kind of weird serendipity, because at least I knew the topic, there were three social workers that said, "Oh, my god, is she coming? We're going to be out of the office. We keep washing our hands, but we're afraid we're going to get it in the air." This was a small group that was working with serious substance-abuse people and everything else, and I'm trying to say, "You probably have a lot of clients that just don't happen to know that they're positive, so you need to educate your asses." But they didn't care, they didn't want to care, and the director of the department didn't fucking care either.

I have lost a lot of faith in social workers that are just putting in their time, but to move it to the level where they're sitting at a nice little dinner table and there's speeches and it's international conference, and the women are getting up and doing their thing and there's publicity, and all of a sudden they go, "Oh, my god, I think I know that one. Come on, Myrtle. Oh, she does go to our clinic. Oh, shit." Then they look at people differently and they finally get some attention.

SS: Now I want to move into the grand topic of 076.

EG: Yes.

SS: So, what was your involvement with that trial?

EG: Wait a second.

SS: 076 was the fetal transmission one.

EG: Yes. We had Dr. Ed Handelsman, who was from Bronx Lebanon, who was openly gay, attend our meetings, and he and I went to the mat. The parents were sort of caught in the middle, because they loved him. First of all, they couldn't believe they had a doctor attending the meetings. We had nurses attend occasionally. But I totally questioned it at all times and he totally bought it at all times. I didn't feel hurt that theoretically I lost or whatever, but he was not one for questioning, and he flat out came to me and said, "If these meetings continue like this, then I'm just dropping out, because I have a professional obligation to do this, and you're just stupid because you're a social worker, and you don't understand the medicine behind it," and blah, blah, blah.

SS: He wanted to recruit for 076.

EG: Oh, he completely believed in it, and he was doing it at his hospital anyway, but the deal was he didn't want any guff from the activist parents. He wanted them to go out and spread the word. That was a problem. He dropped.

SS: In a sense, that's what ACT UP, 076.

EG: It split Pediatric Committee, too, because they would have appreciated some guidance from us, and we were split. I cannot look an HIV-positive mother in the face and say, "You can't do this because it's wrong." There's no way I'm ever going to do that, and I was hoping that when everything went overseas, that some of the people from overseas would say, "Why us?"

SS: But looking back, recreating what your position was at that time, now that essentially there is no more fetal transmission in the U.S., how do you

understand why that was so contentious? Or do you see it differently now than you did then?

EG: Of course I see it differently now.

SS: I'd like to hear what you're thinking.

EG: I see it differently now. I think I overreacted, and I didn't really understand the science, because there were so many other issues that were hitting us at that time. I don't feel bad about being against it. When it happened, it happened, and I waited and I went, "Okay, fine. Let's move on." And no one came back and said, "Oh, thank god." The biggest concern we had on the committee was fathers wanting to have babies and sperm washing and things like that. It wasn't 076, because that just happened. We did have guys coming to the committee and saying, "What do you know about sperm washing? I really want to have a baby."

SS: Why do you think 076 was so huge in ACT UP, was such a huge conflict?

EG: I don't know. To be very honest, my version of ACT UP at that time is that people were fighting for their lives. You may remember, and I know everybody here does, that there were people coming to ACT UP that were sort of guilt-tripping ACT UP about their own death. Peter Staley comes to mind immediately. If I were to stand at the door of ACT UP when we finished a meeting and say, "What about 076? What about 076?" I don't think that many people would have said, "Oh, this is an issue with me." They'd say, "T&D is an issue with me. It's a closed group. I'm down to two T-cells and I've named both of them, and I hope one doesn't leave." I think people were more

concerned about their lives and their situation than they were about 076 in flaming letters. That's the way I remember it.

SS: At the beginning, when you're first starting to do this work, ACT UP is, you're saying, putting the issue on at eleven o'clock at night in all of this.

EG: Yes. That bothered me greatly.

SS: Of course. It's very significant. But then shortly after, ACT UP began a four-year campaign to change the CDC definition of AIDS, which, of course, changed the situation for women with AIDS.

EG: Yes.

SS: How did we get from A to B? How did that consciousness expand to that extent?

EG: I don't know. I would like to put it on international conferences and media being more open.

I got interviewed by the media in Florida. I was at that point still employed by the Health Department, and that wouldn't have played. But there was a greater media focus. There was just greater attention being paid. Let's face it. I came into ACT UP when I was hearing about Koch and, what the hell, they were going to murder him because he wasn't responding to anything, and, golly, gosh, it's amazing he didn't die, and all the Larry Kramer stuff and all the things that were happening then. How it went the other way, I cannot specifically say. I wish I could. I wish I was more insightful.

SS: Were you involved with the CDC definition campaign?

EG: Pretty much, yes. My problem with this whole thing was that I was involved but there were so many other things hitting me. I was a point person for a group of people that were pretty much going to soon die, and if they didn't die, they were soon going to have children to die. So I would get four-o'clock-in-the-morning phone calls. I got laryngitis at one point, and I had to get someone to come over and answer the phone. Roberto came over and answered the phone for me and said, "It's not that she doesn't care, it's not that she doesn't want to go to the hospital and sit with the baby, but she plain can't even speak right now."

I was still trying to keep a job. Michael had just died, and I was looking for a support group of some sort, and all the groups were on hold for three or four years out of St. Vincent's. There was just too much happening. If I had been independently wealthy, I think I would have been a much stronger presence and hopefully hastened things, but, unfortunately, I had to go from a shit job to an ACT UP meeting, to a four-o'clock-in-the-morning phone call because Lydia can't go because she's got herpes, and somebody has to be in the hospital with the baby, and the two teenage brothers hate hospitals. You were negotiating everything.

Initially when I joined ACT UP, I was, as I sort of kind of figured out, the only straight old lady, only straight person. I wouldn't even consider myself old. The only straight woman, and I tried to get—

SS: Oh, that's not true, Emily.

EG: I don't know, honey. Suzanne and I were the two that we identified. We would walk—

SS: Iris [Long], Deb Levine.

EG: Well, Iris was a whole special case. Iris was amazing. I adored Iris.

SS: Let's turn that question around. There's still some more like Karen Ramspacher or all those video people, but why were there so few straight people in ACT UP?

EG: Women. I don't know about guys.

SS: There were hardly any.

EG: Because there's a lot of homophobia out there. Like at Covenant House, I told people, I said, "You guys, this shit is just beginning, and you need to educate yourself, and there's practically no education out there, so come with me to an ACT UP meeting."

[gasps] "Well, I don't think my boyfriend would like that."

"What the fuck is going to happen to you? Nobody wants your tired body." It was that kind of thing. There was the gay thing, and that's the way people looked at things.

SS: When did you leave ACT UP?

EG: When I came down here in 2001.

SS: Because you stayed really late.

EG: I was in it over fifteen years, yes.

SS: What made you keep up when some of the other people left?

EG: I really cared, and I always wanted to be there for the people that I'd started out with, even though they had this bad habit of dying. It bothered me greatly

within the group that—remember Aldyn [McKean]? I said, “What is with some of these people?”

He said, “You need to see.” There was a split in ACT UP with me, with, “I’m positive and you’re not, so you can’t say shit to me.” That was where there was a lot of split.

I was glad that my foster mothers didn’t get caught up in that. I really was. They’re like, “Fuck, I’m raising three kids. What the hell are you doing? Being positive, big deal.” They would have been very upset about that.

Alden told me, he said, “Whoever people were when they started out in life is who they’re going to stay.”

I was always left-wing. I was always inclusive of people. I had a certain political thing. Let’s look at what Peter was doing before ACT UP. Are you surprised that he’s coming back and trying to guilt-trip us now, because he’s really sick? Why are you surprised?

But there was a thing going on with there was lines right down the middle, toward the end especially. “I’m positive. You’re not. Shut the fuck up.” It was that kind of thing.

“But I was out there from day one.”

“So? What do you want, a medal?” It was that kind of thing.

JH: Maybe you can give us a sense of what it was like really towards the end of ’98, ’99, 2000.

EG: I was getting burned out, and when you get burned out, you don't even know you're burned out. It happens on a job. It happens politically. I wanted to go and continue going, but it wasn't fun anymore. Everybody gets something from something, and it just wasn't fun. It was work to go. It was work to deal with. I didn't have a problem dealing with memorials and deaths and things like that. I had a problem with people decomposing in front of my eyes and drawing lines. I had a problem with not totally understanding the gay culture, and then people who had known each other for years, so if somebody's going to break up, "Well, honey, you don't even know the history on that drag queen." They would do things like that. I was, like, "Actually, I don't know the history. I didn't even know he used to go in drag. Wow! Where have I been? I should know these things."

It became harder. And the money thing. Once we moved into the other location, after Texas and after the money got ripped off, Majority Action Committee would go to the so-called board of ACT UP, and they would say, "Hey, guess what? People steal. People have addiction. They relapse. Money is being ripped off, and we don't want to be part of that."

The people that were on the board sort of said, "Yeah, yeah, yeah. Interesting. Next?" They blew people off, and there was a split that way that was very upsetting.

SS: So you're saying that Majority Action wanted this? They wanted to expose Dan?

EG: Oh, yes.

SS: Can you tell us about that?

EG: We saw what was happening, and we knew that he was playing, "I'm a gay guy and I'm black and you should kiss my butt, and money is nothing."

Ron and I went and we said, "Look, this is wrong."

SS: Ron Medley?

EG: Yes. "This is wrong. This shouldn't happen. You shouldn't fuck off your money. We're already losing the 19th Street place."

I think after we moved, after we moved the office, the little storage place I was very uncomfortable with because I felt like I was going to get raped every time I was there. The people that were on security would just watch and say, "Ooh, that's interesting. She's old." I was very uncomfortable with that location.

After we moved from the Center, it just seemed like a lot of things went down in a very negative way. We got lost over at Cooper Union, we really did, and the spirit of the group sort of died, and even when we went back, it just wasn't the same.

I was learning a lot about medicine. I was learning a lot about technology. I was out there to the best of my ability. I couldn't hang banners. Even back then, I couldn't hang banners, but I sure as hell could guard demonstrations and be out there for needle exchange, which is something that was very hard for me to do because I was scared shitless. And Dan couldn't even get arrested. We were down there on the Lower East Side doing needle exchanges. It's the first time in my whole fucking life that a black guy is down here with needles in his hand and the cops don't care. It was kind of weird. I don't know what else to say on that one.

SS: I just have one last question. So, looking back on ACT UP, what would you say was its greatest achievement? What would you say was its biggest disappointment?

EG: I think they saved a lot of lives, not just for people that went, but for everybody, and they changed a lot of medical people's visions. Less really is more. I mean, that's what I take now, because when I came down here, I started working with the Hospice AIDS thing, and I was sort of doing the less is more.

When I did civil rights, we had paid informers that came in and did everything they could to tear apart SNCC and CORE and everybody else. ACT UP didn't need that. We sort of cannibalized ourselves in a lot of ways, and that was really upsetting to me.

SS: Why was that?

EG: I don't know. I really don't know. This whole thing about money and who took the money and what happened to the office and all that, I'm guessing that a lot of people just didn't want to say. When Ron and I went to the whatever they called it then, that Executive Committee [Coordinating Committee] or whatever the hell they were calling it, and we said, "We're unhappy about this. We know it's wrong. We know drugs. We know it's wrong, and we want you to pay attention. This money shouldn't just keep evaporating." Because a lot of money evaporated, by the way I remember it.

Tape II
00:40:00

They said, "Eh, so what?" I took that as, "Well, it's a gay community and it happens, and stop fucking with us, old lady." I don't know how he took it, but I know he was very upset.

I don't know. I think people just plain got worn out. It's a hard one, because, see, like with Phyllis, when Phyllis first relapsed, and I was very close with her, I took some ADAPT trainings, and they said, "There really isn't shit you can do for her at this point. Just be there for her. Big deal. It's happening all over. People are realizing they're going to live, and they just go back to drugs." It's like people are realizing they're going to live and maybe they should get married. Maybe they should move in a different direction and let that whole AIDS thing go. I don't know. That was, to me, a good question, by the way.