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Interviewee: **Eugene Fedorko**

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Interviewer: **Sarah Schulman**

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SARAH SCHULMAN: So the way we start is you tell us your name, your age, today's date, and where we are.

GENE FEDORKO: Okay. My name is Gene Fedorko, I'm sixty-nine years old. This is being filmed in my loft at 17th Street in Chelsea in New York, and today is August the 25th, 2012.

SS: And this is a fabulous loft —

GF: Thank you.

SS: — filled with incredible artwork from the very era that we're going to be discussing. How long have you been living here?

GF: Moved here — my partner, John, moved here in '78 from Provincetown, and I moved in here around '80 or '81. I'm vague about the exact time, but there were a lot of people here from Provincetown that used to live in this loft and then — you guys, I don't know if you know a Yolo Carew?

SS: Sure, Yolo, absolutely.

GF: Okay. He used to live in this loft, and, in fact, there is a piece of glass on that table that has a poem that Yolo wrote on it in crayon. And we used to always joke that — and especially when AIDS came around, we had black humor, and we used to always joke that whoever lives the longest is going to get it all. Well, I got it all, and I've lived the longest, and I have no idea how. I did everything that the other kids were doing. I came out alive, HIV-negative. I mean, it just baffles me sometimes.

SS: What do you think is the reason, honestly?

GF: I don't know. I try to put a construct on it. I was always pretty much of the top. I never too much liked to get fucked, but I have been a bottom. So it's just a mystery to me, a total mystery. I have no idea. Do I have something in my body that repels the virus? I don't know. It's very bizarre. I'm one of the few people that came out of Provincetown. I go up there still. I'm one of the few people my age. I think there are four of us that have made it through living through Provincetown in the seventies and the eighties and it's a go-figure situation. I was just in Provincetown two weeks ago, and Jack Pierson rented this beautiful house right on the water at 29 Commercial, and it was a fabulous mansion. And every morning I would get up at six-thirty, the tide was out, and I would walk up and down the tidal flats and just weep and weep and weep. There are so many of my friends, their ashes we've committed to that bay, off porches, off little dinghies, off the big schooner, the *Hindu*, and it just brings up this whole three decades of my life walking across those tidal flats. And, again, it was very, very cathartic. I cried every day for really three or four hours every morning. I'd go to my AA meeting in the evening, and I'd start crying there. It was a safe place to do that. It's a lot. While I feel incredibly fortunate to have survived and to be healthy and just to be alive these days —

SS: So these other three guys that you're talking about, do the four of you get together?

GF: Yeah. Oh, of course, of course.

SS: And are you helpful to each other?

GF: What?

SS: Is it helpful? Are you helpful to each other?

00:05:00 GF: Yes, yes, yes, to an extent, but a lot of my friends, even those three, get very uncomfortable when you start talking about how horrible the nightmare was that we all came through. And they would rather talk about something lighter or gossip. You said something to me, Sarah, which was that, “We’ll give you all the time that you need to tell your story,” and that was such a luxury to hear that. Most gay friends, even activist friends, they don’t want to talk too long about death and dying and hospital bed situations and just the ugliness of the holocaust that we’ve been through.

SS: What do you think is the price of not talking about it?

GF: It’s hard to say. Okay. My own self, my own trajectory is that this loft was a deathbed situation. John lay on the sofa against that wall, my John Crates, and I’d come home for work every day, and it was awful. I’d try to bring some cheer in, crack a few little witticisms, and it was just not; he wasn’t having any humor. He was very, very sick, and he died here. After that, my mother died in my arms, seven weeks later, and by that time I had already lost about six or seven hundred people. I keep a list, ever since I moved to New York, of everybody who had died. There are now 1,200 people on that list.

SS: Who’s the most recent person?

GF: There was a guy at the practice that died, at Paul Bellman’s office, one of the patients there. And after John and after my mother died — this was in ’93, ’94 — I crashed. I just withdrew. It was too much grief for me to bear. I couldn’t deal with it. I thought a couple of times of — I was in therapy. I quit therapy in ’97, and I thought of going back, but I was basically shut down. And I think there are a lot of people that are just shut down about it. It’s too much to bring up. And what is the price? I think the

price could be severe. I think it could be depression, withdrawal, gaining weight, all kinds of neurosis. I think it could be a very expensive dynamic to just shut down about these issues. I know one of the things that I did was that I went out and I had unsafe sex, and I had two very risky encounters. And after the second one, I said, “You know, Gene, what are you doing?” I knew what I was doing. I was flirting with HIV and death. And I think those are the kind of prices that we pay for shutting down and not dealing with. But on the other hand, having — I wasn’t ready to deal with this. I’m just — okay, Sarah, I want to back up a little bit. Just this last winter, a lot of this stuff started coming up to the surface for me. Part of it was Occupy Wall Street. Part of it was the book that I read that you wrote, *Gentrification of the Mind*, and I read that book and I just wept and wept and wept because I remembered so much. Part of it was anger for me, about the gentrification, and what I really got out of your book, and it resonated very deeply with me, was that when 9/11 happened, it cannibalized the arena of grief. And if I was talking about grief at that point, which I was to some extent, now all of a sudden it seemed like the death of a white stockbroker in 9/11 was more legitimate than the death of my friend Max, who died poor on a mattress on Avenue B in 1991, I think — yeah. And that pissed me off. And what else pissed me off over the decade — over the decade — was that there’s all — every time I would read the paper or listen to the news, there’s all this stuff about the 9/11 Memorial and some of the survivors want this and they didn’t want this and they didn’t like that design. And I’m like, where’s our fucking memorial, you know? And we’re finally getting one down here across from St. Vincent’s. I’m not sure what the final result is, how much, how many — it seemed to me this memorial at St. Vincent’s at

00:10:00 that little park is going to be a few crumbs off the table of the Rubin Corporation, that they're going to allow us to —

SS: Because we lost the hospital.

GF: Yeah, yeah, yeah, yeah.

SS: So we get the park.

GF: At first we were supposed to get the whole park, and now we're getting a triangular corner of it. It's just another way that I feel that we've been marginalized and the whole AIDS epidemic has been marginalized. But to get back to Occupy Wall Street, some of ACT UP's involvement with Occupy Wall Street, your book, *United in Anger*, the documentary. I'm reading now David Wojnarowicz bio, a wonderful bio by Cindy Carr. That brings up the whole East Village zeitgeist in the early eighties and throughout the eighties. It reminds me of when I first came to New York in 1981, ran into Jim Fouratt, and a lot of our friends were getting sick. We didn't know why, but guys were already telling me in 1981, "Be careful. Don't get involved with bodily fluids if you have sex." So, okay, all right. And we had several friends — John Bernd was one of them — who were ill, and there was nothing. There were no answers. We didn't even know it was HIV in those years. Friends in Provincetown were already dying. In Provincetown, with the black humor that everybody had, we were calling it swamp fever or jungle fever. We'd be like, "Oh, she died of swamp fever. Better get her the blender, she needs to do some beet juice, I think she has swamp fever." We didn't know what else to call it. In reading Cindy Carr's book, I realized in context how little we knew in 1981, '82, '83, '84. There were no answers whatsoever for this thing that was killing us. I'd go to my AA meetings here, and Richard, for example, got sick and he went to the hospital, and I

went to visit him in the hospital. And he said, “Gene, I’m going to beat this. I’m going to beat this. I guarantee you I’m going to beat this.” Three days later, he was dead. And no one was beating it then, and it was really, really scary. So Jimmy and I started this group called Wipe Out AIDS, and it was —

SS: Who’s Jimmy?

GF: Fouratt.

SS: Okay. What year did you start that?

GF: It was ’81 or ’82. And it was just a very informal group of — we’d meet once a week at the Community Center, which had just become the Community Center. We met in that one bathroom where the toilets were broken off the floor and the plaster was peeling, but it was a meeting space and we were glad to have it. We just talked about — whoever would come — it was open. Whoever would come would talk about our fears, what’s going around. And there were no answers, but people were desperate, and people were trying everything from macrobiotics to vegetarianism to homeopathy because there was nothing on it. If you went to your doctor, there was nothing, you know. I think Joe Sonnabend and Mike Callen started to come up with a few observations and answers around ’83, certainly about prophylax for PCP, the pneumonia, but around ’81, ’82, ’83, those were really the Dark Ages. So we started that group called Wipe Out AIDS, and then it became HEAL, H-E-A-L, and we focused on alternative diets, holistic practices, massage, Reiki, just things like that, that I didn’t think they were working, but it was comfortable to at least have the illusion or perhaps the hope that we were trying something that would help. You know, maybe for a few months or maybe stave off the specter of death, AIDS, the horrible denouement of what was

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happening to so many of our friends. And we stayed. I think Jim came around HEAL at some point, Jim Lindsey and we did that all through the eighties. And actually a lot of it was so gratifying to all of us in our community. One of the loveliest evenings was we would have these macrobiotic soup kitchens, dinners on Sundays and on Saturday evenings at the French Church here in the park on 16th Street between Second and Third Avenues. It was a lovely setting, just so lovely, and everybody volunteered and chipped in for the food. And there were just lovely social events where people who were in crisis, in horrible medical emotional crisis, could get together and share some community, share a little bit of love. We would have Reiki practitioners come and give Reiki for free, or Shiatsu massage. I remember people putting a towel on the ground in that courtyard, and this woman, she was, like, walking on people's backs with Shiatsu massage. And people were like, "Oh, this is so wonderful. This is so great." And it was just great to be able to provide and participate in and absorb energy from the community to provide something for people to focus on other than sit home and just darkly be in the mood that their demise was around the corner.

SS: Now, what were you doing professionally at the time? What were you doing? How were you earning a living?

GF: I was a graphic arts designer at the time, and that's what I did. Then around — as AIDS even got nastier and nastier — oh, here's the other thing that happened. There was AZT, I forget when that came on the scene. And that was the nastiest medication, and people would come to our meetings with black fingernails, vomiting, and diarrhea. It had no effect on T-cells increasing whatsoever. The studies that I looked at and I interpreted with the help of Dr. Paul Bellman, who became my medical kind of

advisor about all the technical stuff, in the years of '85, '86, '87, '88 with HEAL, that wasn't doing any good whatsoever, the AZT, I thought. I thought it was better if one didn't take it.

SS: Now, did John or Yolo take AZT?

GF: I don't know what happened to Yolo. He didn't die here. I don't know if he was taking it or not. John did not take it, no. John had pulmonary problems. He was very susceptible to PCP, but the problem was that he was allergic to Bactrim and Dapsone. So we would try to titer him on tiny doses of Bactrim and increase them, and by the third titer, it'd be all red, and he'd go, "Gene, I can't take this anymore. I just can't do this. I can't." So that was very difficult to watch. So all these years, it was just so frustrating, because there were no medical solutions to what this disaster was that was happening.

SS: Now, when HEAL started, there were a few organizations that already existed, right? There was GMHC.

GF: There was GMHC.

SS: So what made you feel that you needed something different than GMHC?

GF: Well, hmm. Good question, GMHC seemed like for the white boys, for the bourgeois white boys. It seemed like that's the road it was going. And as a person who represented HEAL at times, I went over to meet the director there and —

SS: Who was that at that —

GF: Richard — I forgot his last name.

SS: Dunn.

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GF: Richard Dunn, yeah. And I could tell immediately that he was hostile to the idea of macrobiotics, but, I said, “Richard, it’s not going to poison people the way AZT does.” And he saw it in a different way, and he just, to me, was a representative of the homocracy and white AIDS establishment and political pandering, and it was just I didn’t feel right there, we didn’t click. That’s not why we started HEAL, though. We just started HEAL informally, and it grew into something that just continued. But I sensed, though, that we had very little to do with the perspective of GMHC. I volunteered at GMHC a couple of times and just didn’t find it gratifying or to my liking. In HEAL there were a lot of artists, a lot of freethinkers, a lot of people who I thought were very clever in putting together a regimen and a belief system to at least get them through the near future in a healthy way that was — yeah, anti-AZ — that was not only anti-AZT, but people just didn’t want to have contact with AZT. It was very visible. You could see people’s fingernails when they’d come to meetings; they were black. People looked horrible. They looked gaunt. And those, of course, were the days when people had those horrible Kaposi lesions all over their face. It reminds me of — I knew about the Klipdestras in concentration camps. Do you know what those are?

SS: No.

GF: The sadistic German guards would hit a couple of people on the head and they would have bruises that would show up three days later, or even the next day, and those bruises would mark them for selection and death. And I would always think of the KS lesions as Klipdestraesque, that these poor guys — again, ’84, ’85, a lot of them did die very, very soon after they developed KS or PCP. In the Cindy Carr book, there’s also a reference to Cookie Mueller —

SS: Whose picture is right there.

GF: — whose picture is right there by — David Armstrong took a fabulous va-va-voom picture of Cookie with her sharks-tooth necklace and her monkey-claw necklace. Cookie kicked ass. She was great. She had this column called “Ask Doctor Mueller” for the *East Village Eye*, and she dispensed advice on romance, etc., but people started to ask her about AIDS and HIV. And we were all so naïve at this time — I think it was 1985 — and I’m not excoriating Cookie for this at all, but her response was, “Well, honey — .” The guy wrote in the letter was, like, “My boyfriend has probably, you know, AIDS,” or whatever we were calling it at the time, or HIV or GRID. “And I’m worried now that I’m going to get it, even though we have safe sex.” And Cookie’s response was, “No, don’t worry, honey. We’ve all been exposed to it by now. You’ll either have it by now or you don’t.” It was a very naïve answer, but it was an authentic answer because that’s how little we knew at that time. And Cookie also dispensed advice about diet and cleaning up one’s — if you were going to use needles, to wipe them off. Don’t use anybody else’s dildo. She had all of these ideas about urban good manners and cleanliness. But at one point, she stopped giving advice about AIDS, and her response was — maybe this was around ’86 — that, “This is becoming so dire, this epidemic, and it’s such a bigger phenomenon than I had imagined, that I really am going to refrain from advising people about what to do, other than safe sex, a healthy diet.” And she started taking it very, very seriously the more we knew about AIDS.

SS: When she died, she had an open casket, I remember that.

GF: I went. Did you go?

SS: Yes.

GF: Oh, that was spooky.

SS: And Sharon [Niesp] standing guard over the body.

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GF: I love Sharon. I saw Sharon a few weeks ago. Sharon and I are the same age, and we used to play poker in Provincetown together. If you lost, sometimes we'd pay each other with marijuana, sometimes with artwork. And they were the girlfriends back then, very, very good girlfriends. They were gorgeous, they were beautiful, absolutely legendary, the way they would strut down the street in these fabulous outfits and in love with each other. They were just great. But, yes, when Cookie died, she had that open casket. Now, her husband, Vittorio [Scarpati], Count, he was a count, he was an Italian count, and I met him in Positano, because in the late eighties we would go to Positano every summer, and Cookie would be there with her new husband, Vittorio. And the guy that lived here, Jimmy Wellins, he was the guy that finished the floor of this loft in 1978 or so, he designed Cookie's wedding dress for that marriage to Vittorio. Everybody was stoned out of their mind, of course. But Cookie used to come to Positano every summer, and she would stay with Vittorio and his parents, and I met the parents a couple times, and they were just the most gracious people in the world. And Vittorio had scandalized them because he was the first — perhaps it was '85 or '86. He gave an interview to one of the Neapolitan press journals, newspapers, and it was all over the front pages that he had HIV. It was the first case of known HIV on the Amalfi coast in Naples, and his family was scandalized by that. But Cookie and Vittorio, I think they got off on scandalizing, like a lot of things. It was a great deal of fun that way. But her casket was open and at that —

SS: Which was very unusual for people who died of AIDS.

GF: It was.

SS: Very unusual.

GF: It was. Willie Smith had an open casket too. He had one of those caskets at Frank Campbell Funeral Home that the bottom is closed but the top is open. And he had shrunk down to such a small size by the time he was in that casket, you had to peek over, and it looked like an Egyptian mummy, almost, because he was so small and shrunken, the poor guy.

SS: Yes, and Frank Maya, also, I remember. He looked like an old man.

But, I mean, that was a statement.

GF: That was a huge statement. And if you want to talk about statements, let's fast-forward to Jon Greenberg's funeral where we carry his casket down — I forget what avenues, his open casket, and had a ceremony in Tompkin Square Park for him, and that spooked a lot of people out. Then I'm reminded of all the trips that people took to Washington, D.C. to scatter ashes on the White House lawn or to, I think in one case, successfully dump a body over the fence there.

SS: Did that ever really happen? I don't think so.

GF: That didn't happen, okay? So that's apocryphal. But ashes, yea.

SS: But ashes, I mean, James shot that, and we have the footage.

GF: Yeah.

SS: So —

GF: Go ahead.

SS: I want to find out when you came to ACT UP, actually.

GF: When what?

SS: When did you first come to ACT UP?

GF: ACT UP, okay. When did it start?

SS: February 1987, when Larry gave that big speech.

GF: Okay, right. There was so much energy about ACT UP that the tom-tom drums beat immediately. And I found out, I heard about the first meeting, and I was mortified that I had missed it. I wanted to be there. And I probably went to the second meeting and the third, and there was just so much energy involved. And by this time I had seen so much death and frustration, and nothing was happening. And I grew up a white boy myself, thinking that, well, if there's a medical problem, the doctor will fix it. Well, here all my friends were dying. I didn't even know if I was HIV-positive or not. I was terrified to get tested. And why can't the doctors fix it? Aren't we living in modern scientific times? What is going on here? And with ACT UP I came to realize that a lot of the constipation involved with doctors not having an answer and being able to fix this stuff or AZT was the politics in Washington, D.C. So I was immediately attracted — it was like a magnet — to ACT UP to see what was going on there. And the creativity and the zany energy of some of the demonstrations and how successful they were, were just so invigorating, and you just couldn't resist. There would be no question of leaving a body of energy like that, that was just so effective and exciting and creative and artistic and dynamic and was really shaking America by its shoulders and saying, "Look, look, look, look, look, look." And we got America to look for a while, we really did.

SS: So the focus of this interview is your experience inside ACT UP, right, because that's what we're documenting. So if you could tell me, like, what kind of projects you worked on, who you worked with.

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GF: We were involved — I was involved particularly with the Alternative and Holistic Committee.

SS: And who founded that, do you know?

GF: I think it was Bob Lederer, but Jim Fouratt was involved, too, I think. We were all involved in ACT UP, and I think —

SS: So its people who had started HEAL came into ACT UP?

GF: Bob Lederer was not involved with HEAL, but Jimmy was, and there were a few others, foot soldiers in ACT UP who were involved in HEAL. We all kind of congealed around alternative and holistic treatments because, again, at that time all we had was AZT and then later ddI, which was equally disastrous and toxic. It was horrible.

SS: So how was that viewed in ACT UP when you guys formed that committee?

GF: We were marginalized. We were intellectually marginalized. There was a lot of hostility against us. A lot of people didn't even take us seriously, wouldn't even talk to us at all.

SS: Why is that?

GF: I think because they put their hopes and all their eggs in the basket of medicine and didn't think that — and I would be the first to agree that I really don't think that macrobotics is going to cure HIV or PCP or that a vegetarian diet does. But I still thought it was important for people to have a safe place to meet where they had a holistic philosophy, while we kept an eye on what was going on with the medicines and the toxicity of the medicines and the politics of the medicines. I really still thought that at some point they were going to make a breakthrough medically and come up with some

medicines, which they did, which were not as toxic, but, of course, that didn't come around until 1996. But until that point, that was basically the structure of our mutual support for each other in HEAL, and then in Holistic Committee of ACT UP was that, okay, we're going to stay with our clean diets and safe sex and homeopathy or Reiki or whatever we were trying. As well as keep an eye on the medical field, which didn't look too good again until 1996. It was awful. It was awful.

SS: Did you ever see people in your committee not take medication that could have helped them because they were ideological?

GF: Yes. I mean, what could have helped them? AZT and ddI.

SS: Well, later on some people, for PCP, for CMV there were some things that were developed.

GF: Oh, okay. I see what you're saying. Okay. One of the greatest contributions, I think, of Joe Sonnabend and Michael Callen, who were marginalized by AIDS Inc. — Joe Sonnabend is still hated to this day by mainstream AIDS physicians. One of their huge contributions was prophylaxis of PCP with either Bactrim or — what's the other one? It starts with a D. I just mentioned it earlier.

SS: Dapsone.

GF: Dapsone, yeah. It's another sulfa drug. And Tony —

SS: Fauci.

GF: — Fauci in Washington, D.C., he did not see the effectiveness of that for a year or two. I don't know how many people died because he didn't take that seriously. Now, I don't know why Joe was so marginalized, Joe Sonnabend.

SS: What do you think? What's your guess?

GF: He was, like Paul Bellman, outside the box, and he criticized a lot of the mainstream. He criticized the mediocrity and the cautious approach of a lot of doctors who were involved with GMHC at the time, who are now dead, like Barry — what was his name? Barry — I forgot. And then around this time, also — what?

SS: Barry Gingell.

GF: Gingell, yeah, yeah. Around this time, also, a lot of doctors were being bought off by Pharma, and we had a couple zaps at HEAL and maybe even with the holistic community of ACT UP where I remember Barbara Starrett was having this with the Grossmans, Ron — and what was his brother?

SS: Howard.

GF: — Howard Grossman. They were having a top in some penthouse hotel out — we went there and we zapped it because they were really being bought off by Burroughs Wellcome, and we went into that to zap it. There was this tableful of the most delicious canapés and salmon and shrimp and cuts of meat and beef and these little lamb chops that had those little paper crowns on the end of them. And it was a really nice spread, but what was the information there? It was just — pardon me.

GF: — that, hey, come on, on board Margaret Fischl's little train, and let's start giving AZT to people. And at that time, around that time, I was already friends with Paul Bellman, and he and I would go over the studies, Margaret Fischl studies, and the big cohort studies.

SS: And who was she, just for the record?

GF: Oh, Margaret Fischl was with the University of Miami and she did some of the first studies on the effectiveness on AZT with HIV people, and the results were really

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muddy and marginal statistically. I just couldn't see the point in all of that, but here was Big Pharma, though, whipping up all these doctors to prescribe AZT and giving them these lovely soirées with these fancy canapés and —

SS: So what did you guys do?

GF: Somebody read a statement denouncing Margaret Fischl's — I think it was AZT 40 or something, her trial, as just being that, as marginal and not effective, and we needed better answers and we deplored the cahoots between AIDS, Inc. doctors in Manhattan and Big Pharma, and we thought it was a disgusting relationship that they didn't even care to hide. That here was this forum, this cocktail party being given like right out in the open, and we thought it was obscene and vulgar. And, of course, we weren't received that well at this, and Barbara Starrett hated me to this day. In an ironic twist, she came to work at Dr. Bellman's office at one point for about a year and a half, and we had shouted at each other across so many rooms at that point, and now all of a sudden I'm working with her. We both put on a professional face and got through that year and a half without belligerence.

SS: But how did ACT UP respond to the fact that you did that?

GF: I'm not sure. I really don't know. I think we —

SS: Because I remember Peter Staley standing up in a meeting saying that his friend Griffin Gold had died because he didn't take AZT.

GF: Mm-hmm, mm-hmm.

SS: So there was some staunch pro-AZT people.

GF: There was. There was definitely. And I felt a sense of hostility. I definitely felt a sense of hostility from Treatment and Data and then later TAG. It was not only the

HEAL and the Holistic Committee of ACT UP were about holistic approaches. We became fierce critics of the efficacy of some of these very toxic drugs and of the relationship between Pharma and these doctors. Anyway, Joe Sonnabend railed against that from the beginning, and he was marginalized by these doctors. I think that's why. Okay, and Michael also. And certainly Gay Men's Health Crisis took the side of the conservative white pro forma contingent of ACT UP, and the rest of us were, somehow marginalized on this side.

SS: Now, you're talking about a very important historic division within the gay male world that has existed since the time of Harry Hay, right?

GF: Probably since cavemen, yeah.

SS: Yeah. And here it's being expressed through AIDS, but it's expressed all the time.

GF: All of the time and —

SS: And how do you understand this?

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GF: Having lived in Provincetown through the seventies and lived with all of these freethinkers and artists and people — we lived outside the system. We would go to Berlin. We would take blotter acid, fifty on a cigarette paper, and we'd take like about fifty pieces of cigarette paper and go and live in Berlin for the winter and sell blotter acid for five bucks, or live in Rome or live in Paris. We were outside of that stuff, delightfully so. And, I'm just not like the rest of them. I don't want to be. I never will be. And I love my outsider outlaw identity. I adore it.

SS: But then I have to ask you a really tough question.

GF: Go ahead.

SS: Would there be protease inhibitors if the other type of gay man had not been doing his thing?

GF: No, no, no, no, there would not have, and to that extent, it's a conundrum, and it's not a tough question at all. I mean, I see the value of both. I see the value of critical people like those of us in HEAL and Provincetown and Dr. Bellman and Joe Sonnabend. There's a huge value in that. And I also see the effectiveness of some of the achievements that Treatment and Data did in getting these protease developed on a fast track. I'll be the first to admit that the protease saved the lives of so many of my friends when they came along. I don't see that as I either have to believe in either/or. I believe in both. My only regret was that protease didn't come along fast enough to save John's life, who died here on the sofa in 1993. So there was always that tension going on and it still exists. You know, Dr. Bellman has always been very critical of AIDS Inc. and of the filthy connection, really, between Pharma and the doctors in New York. I'm not going to mention their names, but they have these clinics whereby they get all these people from Medicaid and people that have less-income communities, and they get them into their little duchies, and they try these medications on them that are paid for by our government and by Pharma. The thrust of research these days is they will take a study of two thousand people and find out who likes to take one pill, Atripla, rather than three pills a day, which Atripla combines three pills. And the thrust of the studies, all these millions of dollars are wasted on, well, if we titer a little more reyataz into the formula with Epivir, how are these people going to do in this control group versus Control Group B. And these doctors corral and suck these patients in. We get some of them after they —

SS: When you say “we,” who do you mean?

GF: Dr. Bellman's office, as patients, we get some of them.

SS: So you're working there now?

GF: Oh, yeah. I've worked there for, god, twenty-two years.

SS: Oh, okay. I didn't realize you were employed by him.

GF: Oh, yeah. I started working for Paul in, like, 1990. So, anyway, we get some of these people from these cohort studies, and they're told that they're contributing to mankind and they're saving lives and it's very important to stay in these studies. And some of them get placebos still. That's where most of the thrust of AIDS research is going these days, which is dismal and ugly. And people like Joe Sonnabend had other ideas about research. Dr. Bellman and several other doctors that he's involved with think that it would be helpful to study the immune system at large, in depth. We know very little bit about it. They think it's time to start studying the role of inflammation, the inflammation process in people that have AIDS. People with HIV and AIDS tend to develop gastric problems quicker, coronary problems quicker. Is it secondary to the medications that people are taking, or is it secondary to the HIV infection? All these other areas, a new paradigm really needs to be established in AIDS research. Meanwhile all the money is going through Pharma into these little duchies.

SS: So if you could articulate this new paradigm that you're proposing, how would you describe it?

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GF: I think I just did, which is studying other components.

SS: But like what specifically?

GF: Okay, the immune system and inflammatory processes. Most of our patients have inflammatory processes of one sort or another or several, and the inflammatory

process is the one that's going to take you out. Whether its hepatitis or some kind of a lymphoma, and, again, it would be helpful to study what role the immune system has in keeping these inflammatory processes at bay. Nothing is known. It's a very, very naïve field, and a lot of people think we need to go there too, with the next conception of dealing with AIDS.

SS: Okay, thanks for explaining that. So what were some other actions that

—

GF: I liked in ACT UP?

SS: — that you guys did?

GF: Oh, that we did? There was — I think, Jim, you came along on this. We went to Kansas City, and there were these despicable people. What was that woman's name? Her name was Grace something, and she made a living by denouncing any form of vitamins or holistic therapy or bee pollen or — I mean, I take bee pollen now when I get energies, and trust me, kids, it's incredibly effective. But her name was Grace something, not Metalious. She was as banal as Grace Metalious. And there was this other doctor. Renner, I think his name was, that had this group that got funding from — they got government grants as well as money from Big Pharma to shut down a lot of holistic practices and companies, etc. And that was really, really, really nice.

SS: Did ACT UP pay for that?

GF: Yeah, yeah, yeah, yeah.

SS: So you were supported by the organization?

GF: Yeah.

SS: Great.

GF: They paid for us all to go out there, and my understanding was that a lot of people squawked about that spending because it cost thousands to put everybody on a plane to go out there. Of course, we were accused of draining the treasury for insignificant actions, but —

SS: What was the action actually? What did you actually do?

GF: We busted up zapped a conference that they were having out in Kansas City and —

SS: Did you get arrested?

GF: No. Some did. Some people did. Some people did.

JAMES WENTZY: Front-page headline.

GF: Front-page headline. It was good. It was good. It was good.

SS: Was there ever something, an action or a position that ACT UP took, that you profoundly disagreed with?

GF: No, no, no, no.

SS: Stop the Church?

GF: Oh, I was there. Oh, I thought that was vital. I loved that. Jimmy Fouratt and I went to that, right? And we got all dressed up in, like, little ties and everything. So the ushers would think that we were like little white boys going to church. And that was so brilliant. That action was so great. I despise the Catholic Church. My people are Catholic, okay, and I love my people, and I make a big distinction between my people who are spiritual and religious in Ambridge, Pennsylvania, and this male hierarchy of the Catholic Church, which I think is killing us all. I have no problem with my relatives and people in my hometown community who need to have faith and believe in their particular

god. They're very, very kind, lovely, lovely people with great small-town values. That's one thing. The priests, the bishops, the Vatican hierarchy is another insidious form of just evil. And I'm so glad we did that demonstration. It was electric and —

SS: Let me ask you a question about it. So as you saw in *United in Anger*, ACT UP had decided to go into the church and do a silent die-in. But when they got in, that's not what happened. Why do you think that changed?

00:50:00 GF: I think rage and anger at the church. I've been furious at the church for — you know, when I first moved to New York — I go back to history of why I'm furious at the church. When I first moved to New York in 1982, the bishop — what was his name at the time? He died. Over here at St. Francis Xavier Church on 16th Street, run by the Jesuits, on Saturday night there would always be a Mass for gay people and lesbians, and they were lovely Masses. Jimmy Fouratt used to go. And people would come out. One time I was walking by and people were coming out and guys with AIDS on canes and a guy in a wheelchair. And it was such a comfort to them, because they needed that, to have a Mass that they could go to with other people who had AIDS and people who were kind to people that had AIDS. And the cardinal at the time made them stop having that Mass, and he closed that down. I thought that was so despicable and just [slaps hands] slam, slam, slam of hatred from the hierarchy of the church over the decades for me. I hate the church. I'm very angry. So I didn't realize that there was a pre-agreement before the Stop the Church action that people were not going to become vocal, but when they did become vocal, I was there like, "Yeah, yeah, yeah." I was shouting myself, and it was absolute pandemonium, and the bishop, the cardinal, he was —

SS: O'Connor.

GF: O'Connor. That was his name. He was just awful. And it was — what year was that?

JIM HUBBARD: 1989.

GF: That was '89 or so, yeah. Was Reagan still president? I think so, yes. Yes, Reagan was still president. Oh, that whole disaster.

JH: No, no, Bush was president.

GF: No, '89.

SS: Well, Reagan was elected. He was sworn in in '81.

GF: So then Bush. It would have been Bush at that time, yeah, yeah. But somehow I always connect Reagan and Cardinal O'Connor together as two of the biggest ogres, not to mention Mayor Koch, that closeted pig who — did you see what he recently did? He excoriated Pussy Riot and said that they're in jail where they belong. I mean, what a miserable cultural relic of a closet case he is. He must be so full of self-hatred to — so all that stuff makes me very riled up and crazy, and I was glad ACT UP got angry that day.

SS: So I want to ask you about your personal experiences inside ACT UP. How did ACT UP affect your personal life, your friendships, how you spent your time?

GF: I don't understand. What do you mean?

SS: Like, did you spend a lot of time in ACT UP?

GF: Yeah, as much as I could.

SS: Did it become your world?

GF: Yeah, as much as I could. It was exciting. It was dynamic. I loved the people I was involved with. I loved the people on the committee. I was fascinated by the overall politics of it all, including all the conflicts and the women's issues. I feel — it really pissed me off the way women were marginalized, and there had to be a lot of table-pounding to get people to consider women's issues and women's testing.

SS: What do you think that was all about?

GF: I think ACT UP was a microcosm of the general sickness of the larger society, and that we took our own prejudices that we were brought up with and installed with, growing up in the United States. We just took all of that stuff very unconsciously into the ACT UP arena. That's what it was about.

SS: So when people inside your committee got sick, did the committee become a kind of care group, or did you end up being involved in care groups for people? Was it its own little community in that sense?

GF: Yes and no. It depends. The committee was so vast at some point, so big, that it wasn't the Daughters of the Sodality would go and say a Catholic rosary if one of their members died or something; all of the Sodality members would go. A few people would go that were close to that person. They would go to the hospital to visit that person or help that person. People jumped in. There's no question, people jumped in. I want to get back to a question you brought up earlier, was that were there any people in HEAL or within ACT UP Holistic Committee who didn't take drugs. And I really have to answer, there were several. There was my friend Allen Burns, who I adored. He had bronchial problems, pneumonia problems, and he was such a firm believer in his own holistic path that he chose for himself, that he would not even touch any of the Bactrim or

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whatever came down the medical highway to treat pneumonia. So he ended up taking no medications and died of PCP. And there were several people like that. Vince Satmary was another person who — I don't know if — I don't think AZT was a question for Vince. That would not have saved him. But there were other medications. I'm trying to remember if he had pneumonia or not, or if he had bronchial issues, but he could have extended his life if he had tried.

SS: And how do you understand those choices?

GF: I think, you know Sarah, I've seen so much destruction and death and tragedy, and I stopped long ago questioning people about what decisions they make personally to live out the quality of their life, whatever they're trying to get out of the rest of their life. These decisions, to me, I've watched so many people make them or not make them, and they're just something that's very, very personal, and it's a process I really don't feel that I have the right to even interfere with. Some people take themselves out. Some people commit passive suicide by all manner of methods, and not taking a medication could be one of them. And I've come to respect people that want to commit suicide, whether it's oblique or demonstrative.

SS: You know, so many iconoclastic people were in ACT UP.

GF: So many what?

SS: Iconoclasts.

GF: Yeah, yeah.

SS: And people who were not group people, people who had never worked. What was it about the structure of ACT UP that allowed individuals to participate and still be part of the group?

GF: Just the energy of it, just the fact that finally here we were. I mean, I was around for Gay Liberation in '69, '70, '71, those really heavy years. John and I marched in the first Gay Pride March up Sixth Avenue in 1970, I guess it was. We were three abreast, and maybe there were only 100 people. We marched from Sheridan Square up to maybe Bryant Park. There were police scooters on our right separating us from the traffic. So I go way back to those marches. And for me, I also go — one of the favorite zaps I ever took place in in the world was — I think it was in 1970. John and I went to Washington, D.C., where the American Psychiatric Association was meeting. They were having their plenary session. And Franklin Kameny, do you know who that is?

SS: Sure.

GF: — and Barbara Gittings, they had arranged to take the stage, and somebody let us in the back door of the Shoreham, Omni Shoreham Hotel. And there were all of these shrinks and their wives in evening clothes, black — not black tie, but dark suits and ties, and the women had on gowns. And Franklin and Barbara and the rest of us took the stage and read a document saying that, “Okay, kids, it’s over. We are no longer going to accept your definition of homosexuality as pathology. We’re just not buying it anymore, so stop it. Okay?” And I remember people in the audience, the shrinks and their wives or their husbands, they were just vitriolic. They were like, “You bums! You scum! You — .” And they were just such ugly faces. They giving us these Picasso faces like, “Get out, get out, get out!” And I thought that was such a brilliant zap. And the next year already there was a consideration to drop homosexuality as pathology as a definition. A year after that it was adopted, and I thought that was so wonderful. And I’ve also been to civil rights marches, and ACT UP was finally the kind of energy that I remember that

was so effective from the early AIDS — I'm sorry, the early lesbian and gay civil rights zaps and movement. That energy was back on the streets again. It was kind of an anarchy. And you're right, we were a lot of iconoclasts and a lot of us fit in with each other even though I can't imagine myself more diametrically opposed to anybody than Peter Staley, perhaps, or some other white person that was on TAG, but what brought us together quite easily was that zeal for the effective communal action that I thought was so —

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SS: Do you think that fact that you and Marc Rubin and Marty Rosen — what's his last name? Robinson.

GF: Marty Robinson.

SS: That guys who had actually been in the early zap element of the Gay Liberation Movement were now in ACT UP. Do you think that that brought some continuity to the tactics?

GF: Oh, there's no question. There's continuity now with Occupy Wall Street, which I'm afraid has fizzled and died. I'm just waiting. That energy is still there. I just hope something else comes along to capture all that energy and take us out into the streets again, because that's where it's done, is out in the streets. As Edmund White said — and I adore Edmund White — as Edmund White said, it was not the white boys who started the lesbian and gay revolution; it was the A-trainers. It was the people of color who came down from the Bronx and northern Manhattan and Bed-Stuy on the A-train, black people, Puerto Rican kids. They were the ones that started the Lesbian/Gay Liberation Movement, Civil Rights Movement. And the white boys were in the Hamptons or Fire Island or something, you know. So, yeah, I look for that energy, I love that energy, and I

think that's what was so attractive about ACT UP for me was that finally it had coalesced, that energy coalesced, as it does every decade or two, into an effective movement.

SS: So now I want to move into the difficult subject of ACT UP's demise.

How do you understand what happened there?

GF: Okay. Some people tell me I oversimplify, but I really see it as a separation between the white boys and the rest. And it reminds me of Jimmy Fouratt when right after Stonewall these groups formed up spontaneously, including Gay Activist Alliance. And Gay Activist Alliance were a bunch of white boys, very GMHC-like, and they did not want to get involved with drag queens or even effeminate homosexuals or butch lesbians or any of that, or even women of any kind, and they didn't want to rock the boat. Then this other group started called Gay Liberation Front that was a big umbrella for all of these other groups that were marginalized by the white boys. And I see the same thing that happened in ACT UP. It was, I think — again, I think it's a microcosm of the society that we grew up in, that we live in, that has been instilled in us. It replicates itself as we go down the decades. So I think when TAG decided to go off on its own, get a seat at the table, that was the beginning of the dissolution of ACT UP.

SS: And when did you leave?

GF: When did I leave?

SS: Yeah.

GF: I left around — around then. I started to become —

SS: After John died, is that when?

GF: No, because John died in December of '93. I was still involved. But at a certain point I became disillusioned even before John died. I saw what was going on in ACT UP. I saw it was becoming divisive and toxic and ineffective. And at that time, I really had my hands full here with his deathbed situation every night. But it was more than this. It was more that I perceived that ACT UP was just over, just like I perceive now Occupy is over.

SS: Did you get support from ACT UP people when John was dying?

GF: Support from them? Yes, I got a lot of support from people on my committee, even from people that knew John in ACT UP. And he wasn't necessarily on the Holistic Committee. He had friends within ACT UP on different committees, and he became too sick to participate in any of the actions of the past few years, but, yeah. ACT UP was a very important community dynamic, and the emphasis is on the word "community." It was wonderful.

SS: So I only have two more questions. Is there anything that we haven't covered that you think is important?

GF: What are your questions?

SS: My first question is about your art collection.

GF: Okay.

SS: So let's go there.

GF: All right.

SS: You have a stupendous art collection. It's incredible. And so much of it is East Village and from that era and —

GF: I know. It's eighties. It's very, very eighties.

SS: Yeah. Did you collect it consciously?

GF: No, Sarah. A lot of my friends are artists, and it's that old Provincetown dynamic that I've been imbued with, which is that I've just always hung around artists. They've always been my friends. I'm very — okay, let's put it this way. I've always been very comfortable in a community that's very creative, full of geniuses and self-destructive people. I'm very self-destructive. I'm a drug addict and an alcoholic. I've been clean for thirty-five years, but, oh, boy, do I love that, the bad boyism of it all and the outlawism of it all and the outside-the-systemism of it all. A lot of my friends are artists, and I just love art. I think the art gives this place an energy that is just unbelievable. I wake up every morning and I go, "Oh, my god, Gene Fedorko, you're the luckiest fuckin' person in the world." The art also is a symbol, a metaphor of free thinking, of living outside the system, of being critical of the system, of having a system that's like on the outside looking in, a perspective of being on the outside looking in, and I love all of that too. And, artists are, like, very, very interesting people. I like smart people. Artists are, for the most part, smart.

SS: Have you ever done a public show of this collection?

GF: No, but one time the Leslie homo [Lohman] Gallery, they had a benefit, and it was like \$500 a head or something, and they came here and they toured this place, and they want me to leave them a lot of my work. And I will, I'll leave them some of it. But I really have a lot of it is going to institutions in Provincetown and here — and here because some of this stuff is significant. Some of it's worth a lot of money. I don't care about the money. I would never part with it. I'm not selling anything before I die. I won't. It's not about money for me. And then the other odd things is that people come

here, I've had dinner parties and stuff, and people bring me these books on lofts in New York City, and there are these — I can't relate to them. All the surfaces are stainless steel and white and Formica and white floors, and I'm like, what does this have to do with my place? I've always joked that minimalists hate me because — and there's this new — the new trend now in decorating is mid-century modern, right? Those people hate me too. But even, you know, I have a lot of friends who are decorators and who are antique dealers or who are dealers in mid-century modern, and they come here and they love it. People relate, and they feel very, very comfortable to the art and to Edgar Oliver. Do you know Edgar?

SS: Sure, of course. This is like a high school yearbook. I mean, it's like all these people are related to each other.

GF: Yeah, exactly, and they are. Yes, Edgar, I ran into him on Houston Street, right, a couple weeks ago, and he went, "Ah, my dear." You know how he talks, right?

SS: Yeah.

GF: "I was trying to cross Houston Street last week, and I was almost run over by a taxicab." You know, everything has fifteen extra syllables. And god bless him, and he's on heroin. So are most of my friends in Provincetown. I was up there, again, a couple weeks ago, and my friend Jack told me, "Well, you know, Carolyn just fell out window." I said, "What do you mean, she fell out the window?" I'm like, how the fuck do you fall out of the window, a second-story window? And she was shooting up and you just go into the dip and dive, and she dove off the second floor. She's on crutches now. I still collect art. I still look for it. I'm lucky enough — I mean, David Armstrong — look what David gave me. Let me get up.

SS: Be careful. You're plugged in. You're plugged in. Jim will get it.

GF: You can get it. It's right over there.

JH: What am I getting?

GF: The thing in the black frame right there on the —

JH: Is this it?

GF: Yeah, yeah. David just gave me this yesterday. Am I still plugged in?

SS: Yes.

GF: Okay. And this is fabulous, and this is my — okay. John and I were

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boyfriends, of course, like Lucy and Desi for twenty-four years, but we had a — after the first five years, our relationship was so open you could drive a couple of Hummers through it. He'd have his boyfriends and girlfriends in his room, I'd have my boyfriends, and it didn't matter. At the end of the day, we loved each other. We were like an old married couple. So this was my boyfriend Max diCorcia in 1988, '89, and he died of AIDS in '89 on Avenue B in the East Village, and he was in HEAL. This is his brother, P.L. diCorcia, who is a very, straight guy, very, very successful fine artist and photographer. They were all friends with Nan Goldin and Cookie. And, you're right, you connect all the dots in this loft. And then Cindy Carr's book. But my point is, is that I just got this yesterday from David, and I'm so excited by it. And he's giving me another print of a lesbian friend of ours in Provincetown.

SS: Who's that?

GF: Who?

SS: Who's the woman?

GF: In Provincetown?

SS: Yeah.

GF: By the name of Eve Archer, and she runs a garden shop in Provincetown, and she's just a dear, lovely, lovely woman who, thank god —

SS: You know, it's like family photos, really.

GF: Family photos. You know, I'll go back to Provincetown and it's like coming home from the war. All the men are dead, but the women are still there, thank god. I had dinner with my friends Helen and Hilda. Hilda's an artist. And they said something that made me start crying. They said, "Gene, if anything — if anything happens to you." We're all seventy now. Okay. "If anything happens to you and if you get sick or you get infirm or something, you come live with us. We'll take care of you in Provincetown." And that meant so much to me, because I do have fears about getting —

SS: Of course.

GF: We all do. But, I'm getting to an age where I have less days in front of me than I have behind me, and, you know, I seven stents and these things occur to you. And, I mean, it was just so beautiful. And I think the larger point I want to make is that the art connects these communities for me, connects them, and then they're just lovely, divine communities. I'm so fortunate to be able to participate in them.

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

GF: I think its greatest achievement was putting AIDS on the table for the American psyche to like or not like. That was one of the big achievements, and it was right in your face there. And I really — we used to joke, but I'm not sure how much of a

joke it is — I think ACT UP and AIDS contributed to — John used to say that our contribution to the last century as gay men has been disco and anal sex. And now all my straight friends, like my co-workers, they're all having anal sex with their girlfriends, and their girlfriends are sticking their finger up their ass and they're playing around, and you never did that before, AIDS was put on the table by ACT UP and the gay community in general. I really do commend ACT UP. One of the biggest achievements that it did was to thrust forward the medical issues that did develop these nontoxic, relatively nontoxic medications, the protease that saved so many of our patients' lives. We still have patients at the practice that have had AIDS since 1981, 1983, and Dr. Bellman, Paul has brought them along. His philosophy is that, it's like jumping across a creek. You jump to one stone, you get your balance, hopefully you'll see another stone and ad infinitum until you get across the creek. I think that's a huge achievement that we've been able to do that. I think otherwise they'd be still dicking around with these AZT medications, because they don't care. It's all in the interest of Pharma not Washington, D.C. They're so bought off by Pharma that it stinks. One of the biggest disappointments of ACT UP? Of course, the obvious one, that I really wish that we could all have come together and continued to be effective in focusing on a lot of the individual needs of some of the communities within communities within ACT UP. The women's stuff, the marginalized groups, the poor people, the medical insurance, a lot of those social issues, I wish that we had been able to resolve those more effectively. But all in all, really, my reflection on ACT UP is a very positive and vital one, and I think we accomplished a lot, and for me, just to, again, be aware that there's that body of energy out there, that when the right time comes along, like the black Civil Rights Movement, the Lesbian/Gay Civil Rights Movement, ACT

UP, Occupy Wall Street, when the times comes along that we're able to gather that energy and be effective. It's very important.

SS: Great, thank you.