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Interviewee: **Andrea Benzacar**

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ACT UP Oral History Project
Interview of Andrea Benzacar
January 5, 2013

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

ANDREA BENZACAR: Okay. Now I feel like I'm taking a test. My name is Andrea Benzacar. It's January 5th, 2013. We're in New York in the offices of retiring state senator, New York State Senator Tom Duane. And what else did you want to know?

SS: Your age.

AB: My age. Fifty. I just turned fifty this year.

SS: Congratulations.

AB: Yes. Beats the alternative.

SS: What nationality is Benzacar? Beautiful name.

AB: It's a Sephardic name. My mother's family — it's my mother's name, I use my mother's name. Her family came out of Spain in the expulsions in the fifteenth century, and they had traveled from North Africa and came up through Spain into France, into Bordeaux, where there was a large Jewish population, and the family was there for many, many years until just the period before the Second World War in — I think it was 1930, my grandfather moved to Brazil. He was an engineer, and he came to bring escalators and elevators to South America, and he met my grandmother, who was Chilean, in South America.

SS: So he left just in time to not be deported.

AB: Yes. His family was wiped out.

SS: And that's your mother's father?

AB: That's my mother's father, yes.

SS: So she grew up in Brazil.

AB: She grew up in Brazil until her mother died. Her mother got cancer of the biliary tree, which quickly metastasized, and, of course, there was rotten treatments for that, nothing to do at that point. But she was an unusual person for her time. She had trained at Oberlin to be a concert pianist, she spoke six languages, and knew Morse code.

SS: This is her Chilean mother?

AB: Yes. I'm very sorry I never knew her. She sounded like an extraordinary person. But her dying wish was for my grandfather to get the children out of Rio and to take them to Canada, which he did. She wanted them to continue to speak French. They'd grown up speaking three languages, none of which was English. And they moved to Canada.

Then my mother met my father when she — when her father abandoned her for a year, her and her sister, in New Jersey, and my father lived right down the street, so they've known each other since they were thirteen, fourteen years old. And so that's their story.

SS: So you were born in New Jersey?

AB: No, I was born in New York City.

SS: Oh, they met in New Jersey.

AB: Yes, when they were kids, and then my father moved to New York. He was a surgeon. We were very itinerant in those days, and we moved eleven times in three years.

SS: Wow.

AB: Yes. Well, he was drafted into the Medical Corps in Vietnam, and so we spent two years. The family joke is that we got to Canada and he didn't. So we were with our grandfather and my aunt and uncle and my cousins in Montreal for a year while my father was in Qui Nhon. And then the year and a half before that we'd been in a series of army bases in the South all over the place. It was horrendous. But we were little then. It wasn't quite —

SS: So are you a French speaker?

AB: I'd say that's a stretch at this point, but, yes, I used to speak much better French and Spanish. All my childhood words were either in Portuguese or Spanish or French, "Hold my hand," and, "Look at this," and, "Don't touch that."

SS: And then you grew up in New York?

AB: And then I grew up in New York, yes. I was born here, and my parents were living — I can't remember if they were in the East Village or if they'd already moved to Peter Cooper, but when I was a kid we were in Peter Cooper.

SS: So what high school did you go to?

00:05:00 AB: I went to a series of high schools. I ended up graduating from actually a private school, against my will. They were all against my will, so what are you going to do?

SS: Which one was that?

AB: The Brearly School for Girls.

SS: Oh, wow. You survived that.

AB: Yes, I did.

SS: Congratulations.

AB: Well, it was only three years. We refer to it as “The”. My friend Abby Belknap [phonetic] and I ran for president and vice president of the school on an anarchist platform. Perhaps needless to say, we didn’t win. We waited till Parents Day, and we used to serve Gaines-Burgers on a silver platter. Abby wore white gloves, since we were a white-glove school. But, anyway.

SS: So when you come from that kind of eclectic background and there’s all these different kinds of sophistications, and then you’re growing up in New York in a very politicized period —

AB: Which I never would have known growing up.

SS: Really? That’s what I was going to ask you.

AB: I wouldn’t have known from religion or politics or anything growing up. We didn’t even know anything about my mother’s patrimony until years, years later. My father is a big fascist, but my own politics were not reactive. I really had no sense of his politics growing up, and we were never politicized as children. I think my parents — I think when I was ten, they went to some antiwar rally, but it happened to be in the neighborhood.

My father's politics, I think, were very changed by Vietnam in a paradoxical way, and he hated Nixon. But that was his own — I think that was an anomaly. It's actually one of my few pleasant memories of childhood with my father, which was horrendous, is watching the Watergate hearings, which was one thing we could do, we could sit in the same room and do, and I watched them compulsively.

SS: And were you queer in high school?

AB: No. No, I wasn't, although I was very popular with the lesbians. So I probably should have sensed where my future lay. Yes, I was not a particularly successful heterosexual. But, no, I was a boy/girl then, so that wasn't part of my political structure either.

SS: So when did you start to become politicized? Was it in college or

—

AB: No, it wasn't. It was actually in high school. And it's funny, I've tried to make sense of it a million times, and I really don't understand where it came from. I guess it must have been from me or from — I really don't understand it. I almost have to understand it as something organic.

But I got involved with Leftist politics when I was in high school. I hitchhiked to my first — it was actually an antinuclear rally. Joni Mitchell sang and Dick Gregory threatened to starve himself to death — it was really old-school — when I was thirteen. I went by myself. I think parenting then was always some weird combination of micromanagement and absence, so I guess during one of the periods of absence I was able to do that. But I did a lot of that, and I started getting involved in feminist politics

and reproductive freedom stuff, and, that's been the through line for me politically through all the years.

So when I came to ACT UP, I was pre-politicized, I think, like a lot of the women there, and I always found that one of the fascinating things about ACT UP and one of the difficult things to make sense of after the fact, was how — it was the different backgrounds that everybody came from and how the women tended to be politicized, the women tended to be on the left, and to comprehend the AIDS crisis in a much more significant and larger context. And women and men as queers were so separated at that point, and the affinities weren't natural, I think, in a lot of the ways they should have been, and I think the AIDS crisis created the space for those affinities to really become strong.

SS: So did you do feminist stuff in college?

00:10:00 AB: No. During college, I was focused completely on what I intended my life to be after college, which was in theater. I had been acting since I was — it saved my life when I was young. I had a teacher who took an interest in me when I was in fourth grade or something, and it became the focus of my life, and theater specifically. I had tried all through high school to get ejected from high school so I could go. I researched the New York State laws. God knows how I got the information, but I found out that high school was not legally mandated past the age of sixteen. So I was like "RADA now, RADA now, RADA now," and, predictably, that didn't happen.

But I stayed with theater when I was college and then — it's not relevant to this story, really, but after periods of real violence and illness, everything got

sidetracked, and so my college career was also interrupted, and by the time I got out of college, it was 1986, and I was working in publishing at that point.

I had moved to Chelsea. I had moved away from my parents early, and I was in Chelsea in my own apartment in 1980, '81. Chelsea was Chelsea then and starting to be — it was already gay, but it was nothing like it is now. It was very heavily Hispanic at that point, too, and quite affordable, and I'd lived in this dump on 20th Street. It's actually funny, I went by there the other day, and it's the only shit-ball building on the entire block. Everything else is refaced and beautiful, and this still looks like a crack house, which it sort of was. Our vestibule was constantly full of people nodding out, and there were crack vials everywhere. It was not a nice place.

SS: So you moved there in '81, and that's the beginning of the AIDS crisis. How did you first become aware of AIDS?

AB: I first became aware of AIDS in a general way, living in my building, because it was all studio apartments, and with the exception of two other people, everybody else in the building was a gay man, and people started disappearing. And I had a neighbor, this beautiful gay man, probably mid-twenties. I think back on that period, and it's hard for me to reconstruct how old people were, because I'm fifty now and everybody looks like they're a kid. But he was probably mid to late twenties, he was beautiful, Angel, and I saw him on the street in front of the A&P on the corner of 20th Street and Eighth Avenue, and he was homeless and he was sick, and he didn't know me. And that was the first time it came into — at a personal level and an environmental level,

that's the first encounter. It's the first thing that made it personal and brought me into a place where all of a sudden it was everywhere for me.

And I had a friend, my friend Robert Love, who was one of four fabulous black gay brothers. They were all queer, and I think three of them ended up dying of AIDS, maybe all of them at this point. His brother was a choreographer for John Waters, and he was a musician, he was an organist, and another beautiful, fabulous gay man. He had TB three times.

And when I was in Seattle, at one point I'd moved away for about three months, and I came, and it wasn't like now; you didn't have cell phones and Internet connect. You went away and you were away. And I moved someplace for a few months. I didn't get a phone. I really wanted to be by myself and work a few things out. And I came back, and he was dead. And we all knew he had AIDS. We all knew he was positive. He never talked about it. It was during that period where that happened, where
00:15:00 you knew, your friends knew, they knew what they had. It wasn't true with everybody, but it was true with a lot of people, and you didn't talk about it because they were going to lose their job and they were going to lose their health insurance. So it was this open secret all the time.

I will never forget the last time I saw him, and you just didn't know when it was going to be the last time. And he was wearing these bright yellow bicycle shorts and carrying this enormous banana plant. He lived right near where the [ACT UP] Workspace was in Upper Chelsea, and I remember watching him walk away with the banana plant shaking from side to side, and that's the last time I saw him.

What was the question?

SS: I want to ask you something. So we're talking about the early eighties now and when AIDS starts to come into focus personally, and you're working in publishing.

AB: Yes, and then I went back to college. I was in college — I started at Brown. I was off for a year and a half, two years. I was at Oxford briefly, and then I came back and I went to Columbia, and I went through G.S. I went through the School of General Studies because at that point, Columbia, if you'll recall, was the last domino to fall in the Ivy Leagues where women were concerned. So if you were over a certain age or you were a woman, the only way you could get admitted to Columbia was to go in through the School of General Studies, which was fabulous, because you could get access everywhere. You could take graduate classes. It turned out to be the best thing possible. And I needed something to immerse myself in for psychological and emotional reasons, and I did, and I completely immersed myself in school. And I think it's one of the reasons why I wasn't more aware of anything else, because I was so deep inside the university, and that's all I did. I took extra classes. I graduated first in my class. It was the only thing I did, that and work, because I didn't have money and —

SS: Were you still in publishing?

AB: I did publishing on the side, yes. I did a lot of —

SS: Because this is what I wanted to ask you.

AB: I did a lot of copyediting just for different houses and worked with different editors on the side. So I was constantly, constantly, constantly working. And,

again, it's not like today where you are relentlessly bombarded with information everywhere you go, and shackled to your cell phone. The only thing I did, I had a TV, which I never turned on, and so I listened to Public Radio, listened to [W]FUV and [W]BGO and Pacifica.

SS: You're a jazz fan.

AB: Yes.

SS: I want to ask you a question about publishing. Okay. So here's AIDS going on in your front door, and you're going to work in publishing. Was there any ever conversations in publishing about covering AIDS or books about AIDS?

AB: It wasn't that kind of publishing. I wasn't doing magazine work. I was working with book publishers. I was working with the New Press and with Oxford, and my relationship with these houses was usually through an editor over there, and they would farm out work to me. So it wasn't the sort of thing where I was attached to a community in publishing either. So, no, there really wasn't any. I was reading a lot of queer theory and I was editing bell hooks, so I was making my way into it that way, but there was no discussion. I don't remember that being on the table at all. But I had continued to stay in — where I found the time, I have no idea — but I was working in antiapartheid stuff there and reproductive freedom stuff.

SS: What groups were you working with?

AB: I worked with Planned Parenthood. I worked ad hoc with whoever was organizing demonstrations, and there were plenty of them during those days. And it

was actually the first time I got arrested with ACT UP was at the Holland Tunnel, which was —

SS: Okay, we'll get there.

AB: That was the *Casey* decision, but, yes, that was later. But, I was in WHAM! (Women's Health Action and Mobilization) and WAC (Women's Action Coalition) and the usual suspects.

SS: So you got out of school in '86.

AB: Yes.

SS: And then how did you first start to get repoliticized or where did you first put your energies?

AB: Well, it was in reproductive freedom.

SS: So would you say WAC or WHAM! was the first one?

00:20:00

AB: Yes, WHAM! more than WAC.

SS: How did you get to WHAM!?

AB: I have no clue. There was probably a poster. I didn't have anybody bring me into the organization anymore than I did into ACT UP. I didn't know anybody when I walked into ACT UP.

SS: So who was in WHAM! when you got involved?

AB: Oh, god. This is twenty years past the fact, so I can't remember who was where. It was the usual lesbian suspects.

SS: Oh, them.

AB: Oh, them.

SS: The ULS.

AB: Yes, exactly.

SS: Were you involved in any of their actions or anything you remember working on with them?

AB: I wish I'd done this ten years ago. Maybe it would have been a little bit clearer, but I don't remember anymore who — a lot of these actions were co-sponsored too. I worked with them on clinic defense, and there were ad hoc protests. But a lot of this happened — when I got out of school, I had to go to work, and I ended up working a lobster shift for a lot of years in publishing, and then I went back to school during the day. I got a massage license. I went to the Swedish Institute and actually — and this is why it's hard for me to reconstruct some of this, because part of the reason that I did that was to work with people with AIDS.

So I was in school all day and then I was working all night, and that was the thing that kept me from going to the meetings. So I would go every once in a while, but there really wasn't any point, because I never got to go to any of the committee meetings.

SS: All right. Then let's go to the Holland Tunnel then. So do you want to explain what the *Casey* decision was?

AB: Yes. The *Casey* decision was *Planned Parenthood v. Casey*, who was the then-governor of Pennsylvania, and it was one in a series of reproductive rights cases that were challenging various aspects of *Roe v. Wade* or that were being challenged based on the freedoms granted through *Roe v. Wade*. And there were various restrictions,

including, if I remember, there was a twenty-four-hour waiting period, and there were four or five different things, elements, that were being challenged in the decision. Again, this is a long time ago.

But the action had been planned, and that was another collaboration action that was TAG. TAG. That was ACT UP and WHAM! or WAC. I can't even remember at this point, but that was co-organized, and the action was planned around the time when the decision was expected and nobody knew what it was going to be, so it was plans with whatever outcome was going to happen.

But that was really amazing, and it happened on an incredibly hot day. And I'd never been arrested before, oddly, and I wasn't thinking straight, so I wore shorts, and I got so badly — because, of course, we were all sitting down on the blacktop in this incredible heat, and I got so badly burned. And so that never happened again and after that I —

SS: Did you do civil disobedience training?

AB: Yes, I did. I did after that. I had done some of it.

SS: But you didn't do it before?

AB: No. I had it around South Africa, but I don't remember if it wasn't as good or — it didn't get into details like that, like make sure to wear proper pants or don't drink too much coffee before you get popped. {LAUGHS} I don't remember it being specific that way. I remember it being more about what you needed to tell the police and how to stick together in lines and what to do about horses and things of that nature.

SS: So what did you actually do in this action?

AB: We met at a loft. I think it was a penthouse loft. I want to say it belonged to Laurie Anderson, but I'm probably wrong about that. It turned out to belong to somebody —

00:25:00

SS: Like that.

AB: Yes, somebody like her. And it was over on — I guess it was on Hudson Street, and there were several different places where people were secreted. And, of course, the action had been very widely advertised, so, it's incredible to me, in retrospect, that it came off, because the cops knew all about it. And on cue, everybody came streaming out of these various locations and closed the tunnel. We sat down, and it was amazing. It was a really transformative experience for me, seeing the way it was organized, seeing the intelligence with which everything had been produced, all the documents that went with the action, the commitment of the people there, how tightly everybody worked together and how flawlessly it all came off. It was absolutely, totally exhilarating.

The ACT UP actions that I had been to in the past, I'd been to Stop the Church, one of my favorite days of my entire life. I think it was the second Wall Street, I think that was the first ACT UP action that I actually was present at. And that one, I think that was the first time that I went. I know it was the first time I went. I went with a man who was my best friend at the time. He's a well-known writer, so I'm not going to name him, but he was going out with somebody who had discovered David Wojnarowicz's diaries and was working with him on this. I remember seeing the

physical diaries and thinking, “How the hell is anybody going to make something readable out of this?”

SS: Was David still alive?

AB: Yes, he was still alive, and I met him.

SS: So your friend was collaborating with David on his diaries?

AB: Yes, she edited *Close to the Knives*, and I think that was her first big thing in publishing. And she had been married to a gay man who was positive. Of course, there were a lot of stories like that. I’m pretty sure I went with them to the first action.

SS: So when did you start going to ACT UP meetings?

AB: I started going to ACT UP meetings as soon as I was off the lobster shift. It’s pure coincidence that that’s — that was just the timing, so that ’92 — because that was the summer of ’92, I think, the Holland Tunnel, and that was the first. So I went as soon as I was free, and then it became my life, and I got involved with Campaign ’92 and became completely immersed in that.

I knew enough about activism and organizing and writing at that point, that I could make myself useful. I think, apart from everything else, it was the first time that I had felt empowered by an intelligent, passionate community outside of theater. I felt passionately about the politics. I felt passionately about the other people in the organization. And, of course, the deeper you get into it, you made more and more connections with people. Obviously, people who had HIV and people who were caring for them, and you became a caretaker. It’s really all I did. I think I was one of those

people, and there were so many of us, whose lives it absolutely, totally consumed. All we did was go to committee meetings and raise money and steal stationery supplies — whatever it was — and go to funerals, and go to the hospital and get medicines.

It's hard to think back on it — and I was talking about this the other day, that Kaufman's was the only place where you could get medicine at night. There was one pharmacy in all of New York where you could get medication. Everything was so different.

00:30:00 I didn't prepare for this the way I should have, because most of my documents are not in New York anymore, but I remember thinking before I came here, "Remember what it was like. Remember how different everything was, how differently you had to organize things." And I continue to believe that despite Facebook — and I don't want to sound like a fuddy-duddy, because it has enormous utility, and, god knows, we could have used it — but the kinds of connections that needed to be made for people to really work together are all face-to-face connections. And we lived with each other. We were just with each other absolutely all the time.

SS: Right.

AB: And we worked together as if our lives depended on it, because they did. In some respects, of course, I hope none of us have to live through that particular period, that particular kind of crisis ever again. But it was a singular transformative experience, and continues to be. My life is radically altered because of it.

SS: Before we get into the specifics of your long and complex activism, I just want to follow up on what you're talking about now. What happened to your

other relationships when you were living in ACT UP? What happened to the other people in your life?

AB: They were completely destroyed. {LAUGHS} Anybody who didn't understand what I was doing got left at the roadside so fucking fast. I don't want to be too banal, but as fifty rolled around, I started — I'd been thinking, actually, for a long time about different people that I really lost during that period. There was just no room for anything else, and either they got on board or they didn't. Everything was radically simplified by the crisis.

SS: So let's start with Campaign '92. So who was your person that you were following? Were you assigned to — you were on one of the teams?

AB: It was all ad hoc, although I got to do plenty of Quayle, which was actually the last time I ever had a dress on my body was in 1992 where I — the absurdity of this will never cease to amaze me. If you'd ever seen a picture of George Catravas, who said one time he was asked if he'd ever gone in drag, and he said, "No, because they'd never get it off me." He was too afraid of it. He was a big beautiful queen, and he and I used to take walking tours of the Village, and we never got very far because he would stop and tell me who he had fucked in whatever building we happened to be in front of. He's the only person I know who had sex in a public — it's not a public landmark building, of course, but it's the Mariners House on Fourth Street.

SS: Oh, yes. That building was closed.

AB: He somehow managed to have sex in there. Anyway, so he was my “husband.” He was my date for the afternoon, and he and I and Drew Kramer and — Suzanne Bender?

SS: The doctor Suzanne?

AB: No. No, no, no, no, no. Bender or Benzer, Bender? She was very beautiful, very butch, young, and then I think ended up dating John Kelly, of course. That’s a long story too. But, anyway, so we were the two couples who went into this Republican fundraiser. It was down by the Trade Center. I think maybe it was in the Marriott. God knows how we got in, but we were all dressed Republican, or our best approximation of that, and I think Drew’s the only one who pulled it off, as usual. But we got in there and made a scene and got dragged out really violently.

SS: What did you do? Tell us. We want to know.

AB: It was a Republican fundraiser. We went in there and screamed, “What about AIDS?” and, “You’re a bunch of criminals.” Then we had factsheets, which we threw in the air. We were taken out of there really fast, and George got beat up. It was pretty hairy. It was very scary because, of course, they had Secret Service there. But, yes, we didn’t get very far with that, but they were so angry, the other people in the room. We were all hit by other people, not by Secret Service, not by the police, but by
00:35:00 the other people attending the event. Nice.

SS: Any other Campaign '92 stories?

AB: I should have spent more time thinking about this before.

SS: What did Campaign '92 achieve, in your view?

AB: I think Campaign '92 was one of the most important working groups of ACT UP. I think when we think back to the period of Bush and Reagan, and how the word "AIDS" never passed Reagan's lips, there was a plague in the country and people were dying. The government was doing absolutely nothing, and there had never been such an obvious constellation of homophobia and sexism and racism. We forced all the candidates to talk about AIDS, and we were everywhere. They couldn't go anywhere without AIDS being somewhere on the table. I think that changed everything. I think it was enormously important.

SS: It's really interesting, because you could not find an LGBT organization today that would not endorse candidates or would simply go after everybody. That has disappeared as a point of view. And yet you're saying it was very effective.

AB: Oh, enormously.

SS: So I'm asking you to give big-picture here, but why do you think we lost that as a tactic?

AB: Well, I think that's a very complicated question. I think AIDS is not what it was then, and there are very few things, with the possible exceptions of capitalism and sexism, that are so enormous and so egregious that they don't get addressed in some fashion by everybody, and AIDS was just nowhere. Nobody was talking about it seriously. Nobody had a plan. Even the people who were on our side, the candidates who were allegedly going to produce results and set up a substructure for dealing with all of this and take it seriously and appoint the correct people and engage the community,

there was no guarantee that any of this was going to happen. There was nothing that was settled. There were no real allies, probably outside of Ted Kennedy's office and — oh, my god, he was my hero, our own congressperson — Ted Weiss, of course. But there weren't very many people like that. It's difficult to — I think that's why *United in Anger* and *How to Survive a Plague* are such important movies.

SS: But they're making opposite arguments from each other, aren't they?

AB: I think the function of the movies is very different, and they're both bringing information that's absolutely imperative for people to have to the public. And I'm constantly shocked and horrified by how young people, especially young gay people, have no conception of how treatment activism arose, how different everything is now and why. They don't know their own history.

SS: Then let's find out how you see that history. So after Campaign '92, where did you put your energies?

AB: Oh, god, the Lesbian Caucus.

SS: What was the Lesbian Caucus?

AB: That was kind of a mess, but that was formed — Maxine [Wolfe] was one of the principal advocates of that being formed as a separate committee from the Women's Caucus or Committee. And we were dealing with how the AIDS crisis affects lesbians, and how lesbians aren't included in trials and modes of transmission and the definition of AIDS. And it was a lot of stuff that was carried over from Women's, but it

was much smaller, and things were even beginning to come apart at that point. We had one, I think, very successful demonstration in Washington where we got a meeting with Donna Shalala [Secretary of Health and Human Services under Bill Clinton], but things
00:40:00 were beginning to — things were not as coherent at that point.

SS: With hindsight, is there such a thing as lesbian transmission?

AB: Yes.

SS: Lesbians sexually transmit HIV?

AB: Well, I think, if you have bleeding gums. There has to be blood involved.

SS: But do you know of any cases?

AB: No, I don't. I will say, however, that I am not involved in arenas that would make me deeply aware of those facts.

SS: Because I think that that was a really interesting moment, and I never believed in lesbian transmission, but I think that there was a moment —

AB: Well, I think it's still unclear, but I'm not going to pretend to be an expert on that. I really am not.

SS: But just in terms of the psychology of ACT UP and also the subsequent divisions —

AB: Well, that's what I mean by things were starting to come a little unglued.

SS: But there was a lot of anxiety about something for which there was no evidence, and I've always tried to understand exactly where that came from.

AB: Well, I think, part of the anger came from there being no attempt to collect evidence, and there being, especially in any kind of structured way. It was as much as anything else a call for real scientific investigation of that.

SS: It's funny, because there would never be anything called a Lesbian Caucus anymore, right? That's something from the past.

AB: Who knows?

SS: Right. But what was the lesbian experience in ACT UP? What was the lesbian psychology at that moment? Because this is already late in ACT UP.

AB: It is. Yes, that was late in ACT UP. I'm not sure I could really say that there was a singular lesbian psychology. There were lots of different lesbians, and that was not a united front any more than gay men were a united front, or people of color were a united front. And I think there were very distinct factions within the lesbians within ACT UP.

SS: What were they?

AB: Oh, lord. I think there were people who were very attached to treatment and getting drugs now, getting testing now, in a way that was centered on gay men. It's the weak paradigm, although it's a useful paradigm that always comes up when you have discussions about ACT UP, which is there are the treatment people and there are the social issues people. I think there were groups of lesbians, as there were groups of everybody else, who disaggregated and went to these different camps — if that's what they were, because there's a Venn diagram that includes plenty of both at different times. So I don't know. I'm not sure that's even a useful thing to talk about. Certainly there were

groups of lesbians who were very angry at the men. I hate talking in tropes like this. I think they're —

SS: I know, but it is historical, it's a long time ago, and we're trying to understand it.

AB: It is historical but those are probably issues that are better addressed by the individuals who had axes to grind.

SS: Well, let me ask you this way. What was the difference between people who were focused on treatment issues for women with AIDS and people who were focused on treatment issues for gay men? Would you see those as two separate —

AB: No, and I think there's a lot of reductive thinking, especially in hindsight. And when you speak to people individually or you remember individual conversations or conversations that took place within working groups, everything's a lot more complicated. The things that came out of ACT UP were results of long periods of bargaining, and discussion, and concession, and it was a sausage-making factory not dissimilar from federal or state legislators. You came out with things that not everybody was happy about, not everything was included. So I think people tend to remember, or to think back — and also you think back on particular pivotal moments, especially those that were captured by film. People have much more distinct memories of that. Spencer [Cox], and Mark [Harrington], and Gregg [Gonsalves] at the front of the room, "dictating" to everybody about what was supposed to happen with treatment and how we had to have more testing before we had drugs — and the other Suzanne disagreeing.

SS: Suzanne Phillips.

AB: Yes, Suzanne Phillips. So it's very difficult, I think, especially at this distance of time, to disentangle real memory — whatever that is — or real memory of general events and distinct groups of people from what happened, individually. I think it's too complicated a question. It's too broad a question.

SS: Okay. Then let's go back to your particular experience. So where did you put yourself?

AB: Well, I came out of left-wing social activism, and I didn't think then, I still don't think that these discussions are separable. I think they're all intertwined. They always have been intertwined. I think it's hard to get away from Vito Russo talking about how we all need to be around to kick the shit out of the system after we're finished with AIDS. The system's still broken, and the system still doesn't work. The big co-infections and co-morbidities of AIDS at this point all have to do with poverty and drug use and racism. I don't think it's very complicated. I don't think that piece of it is very complicated for anybody who thinks in a full and intelligent way about the issues. I think those things have always been intertwined.

But that was a period of incredible emergency. People were dying and there was nothing we could do about it. So when you had these conversations about drugs into bodies and waiting some period of time, well, if you had a friend with KS or you had a friend with CMV and there were drugs that were there, that were being tested, you wanted the fucking drugs. And you didn't want to wait around, and they couldn't wait around. So when people talk about there being these opposing forces, I think it

creates this really false impression that there were people there who were standing with their arms crossed saying, “we don’t want our friends to live,” or it’s one versus the other. I think it was an impossible position for people to be in.

SS: But that’s why I’m trying to understand exactly what you were doing. What projects were you working on?

AB: I worked on — there was actually a Cure Project at that point.

SS: You worked on the AIDS Cure Project?

AB: Yes, McClintock, with Avram [Finkelstein] and Maxine and Scott Sawyer. And I think Brownie Johnson was in that, wasn’t he? I can’t remember. All the committees run together after a certain point.

SS: Can you just summarize for history what exactly that was?

AB: The Barbara McClintock Project was named after the co-discoverer of the structure of DNA, who is rarely cited. The project was aimed at creating a structure within the national health system to explore a cure for AIDS. So part of it was not — it was not lobbying, but it was a legislative committee, effectively. I think Avram and Maxine were principally responsible for drafting that.

Most of the work that we did in committee was strategic work, and, unfortunately, that didn’t get very far either. I came into ACT UP, and the committees, and the working groups, and the affinity groups in ’92. I very rapidly started getting involved with treatment issues, and I have been involved with TAG since the very early days. I worked for TAG. So, part of the reason that I get animated or angry when I’m talking about this false bifurcation between treatment and social issues is that — it’s just

00:50:00 very deeply — the marriage of those two things is very deeply integrated into my own politics and my own life. So, I don't know, I guess it's troubling for me to look back.

Those were painful, painful times in those meetings. We couldn't afford to destroy each other, and we did.

SS: But I want to just focus on you and what projects you worked on and what campaigns you personally were involved in. I think that's probably the best way to just tell the story.

AB: I don't know. I'm not sure my story is particularly interesting.

SS: Well, you're the 152nd person that we've interviewed, and our strategy to date has been to tell each person's story, because the story of ACT UP is a cumulative story.

AB: It is a cumulative story. It's a collective story.

SS: So you're not responsible for telling the whole history of ACT UP.

AB: No, I'm not.

SS: So all we want to know is what you did.

AB: Is what I did? You're having trouble keeping me on track? Welcome to my brain.

SS: I asked you what you did next, and you said the McClintock Project.

AB: I worked on that.

SS: And why did that not go anywhere?

AB: I don't know. There weren't enough people working on it. We were operating in a vacuum. You can't put forward a —

SS: Weren't you trying to work with Jerry Nadler?

AB: Yes, and we did. But that's not coalition-building, and that's what you have to do. That's what sustains organizing, working with other communities, working to educate people at the grassroots. I believe in grassroots organizing, I believe in community organizing, and things do not happen because ten smart people sit in a room and create a fantastic blueprint for work on a Cure Project. It doesn't happen that way.

Nothing that Gregg wrote, nothing that Mark wrote would have made any difference at all if ACT UP hadn't been there behind them. And I've heard this at conferences, and from scientists within the NIH who were actually in the building when the NIH was stormed, who said that that changed everything. It changed everything for them.

SS: What did we win at the NIH when we did that demonstration?

AB: Well, I think what we won, what we won at the NIH, is what we've won in subsequent years, because it wasn't just something that was won on that day. That was a door that was opened, and I think the conversation changed, and I think it increased awareness within the NIH that this was a group of people who couldn't be ignored. And I think the biggest accomplishment of that and other related work — because, of course, there was a tremendous amount of work going on behind the scenes. People think back on ACT UP, and, in a general way maybe they remember Storm the NIH, or

Kennebunkport, Target Bush, or St. Patrick's, but most of the work that went on went on in committees, went on in working groups, and went on in conversations behind the scenes.

The actions were great, and the actions were imperative. They had utility that nothing else would have been able to — they forced things in a way that nothing else could. But they were one piece of a much bigger strategy. So I think the action in combination with work that T&D [Treatment and Data] were doing started a process wherein people who had a disease, people who were affected by a disease, had to be involved in every level of planning and decision making about how that disease was managed by the government — was approached by the government. At all stages — who gets included, how much money is allocated, what the research priorities are.

I think we got a lot of what we were asking for, and I think we've changed how research is done in this country. I don't think there's any question about that. I don't think any organization has had that kind of dramatic impact on the lives of people of every economic group, gender, race. Everybody gets sick, everybody relies on drugs, and we changed completely how all of that happens, all that research happens.

SS: So you think that that action was an important part, but part of a larger strategy to get people with AIDS involved in all every level of decision making at the NIH?

AB: Well, and more broadly, that was one action. I think it's very hard to separate the effect of one action from the effect of other actions and from conversations that were going on in the background. The strategy was always to get more information,

make ourselves responsible for being engaged with and directing the course of how trials are constituted, how drugs are tested, in what order, how they get funded. And I think it's impossible to refute that that's been accomplished in a very substantial way.

SS: Okay.

AB: Is that something you disagree with? I'd be fascinated to know.

SS: It's not that. It's that I've asked about seventy people what did we win at the NIH, and you're the first person who has an answer.

AB: You're joking.

SS: No. It's a very murky thing in people's minds. We have footage of Bob Rafsky and Maria [Maggenti] at the ACT UP evaluation meeting after that saying, "Why were we there?" And a lot of people don't understand what was won there.

AB: Wow.

SS: So, anyway, it's just really interesting. You can see all the transcripts online, but I've asked a lot of people. So, good. That's an interesting answer.

AB: Well, I don't know. I think about it a lot. Maybe it's because I've been involved with TAG for so many years. It's interesting, my mother, who is a little clueless, was talking for the first time the other day. It's taken her twenty years to understand this, but she was talking about ACT UP and the impact they've had on

medical research, and access to drugs, and how trials are conducted, and it was something that — for her the penny had finally dropped. And she's a tough case.

But I think there's a broad, broad array of people who are aware of that, and I want them to be aware of that from a historical perspective, on a practical level. I don't care. I just want things to function. If I'm sick, I want to be engaged in my own treatment. I want to be able to effect decisions that are going to have an impact on me as a person. I want my friends to be well. I want us all to have the power that we need and deserve and have worked for to effect the course of our own lives. And it's still very moving to me, that that's something we were able to do.

SS: Let me just ask you one more thing about the McClintock Project.

What didn't happen because that was unable to be implemented?

AB: Well, we didn't have any kind of federally investigated search for a cure. Work on a cure, serious work on a vaccine, I think, was made a very, very low priority, and I think basic science suffered enormously.

I'm sorry. You were asking what have we not accomplished as a result of that?

SS: Yes.

AB: Yes, well, we don't have a cure and we don't have a serious search for a cure.

SS: Now, we just interviewed Kevin Frost recently, and he said 1.2 million people have HIV in the United States, only 30 percent are undetectable.

Now, I am not as up to date as you are, and I was surprised by that, that it was so low. And I think most people would be surprised.

AB: He's including in that figure people who don't know they're positive, because that's an enormous number.

JIM HUBBARD: Yes.

AB: Well, that brings it down quite a bit.

SS: Do you think it's 70 percent who don't know that that they're positive?

AB: No, no, no, no, no. But of that remaining group —

SS: Because the general perception is that all this medication is available here. So, can you analyze that for me and help us understand that?

01:00:00

AB: I am not enough of an expert to parse the reasons for that, which are obviously very complicated. I don't know if his numbers are correct, so I would be reluctant to answer that question, because I don't like answering questions out of nowhere. I don't have what I feel is a responsible answer.

SS: Okay. Let me move on to another thing that he brought up that we've also been grappling with. In ACT UP there was a profound effort, and it's in the earlier days, it was before '92, to say that everybody was implicated by the AIDS crisis, that it could happen to anyone. But according to amfAR, the number-one group of people being infected today are white gay men. The second group are black women, who have dropped 21 percent in their infection rate. The third is black men who have sex with men. And the fourth is Latino gay men.

AB: That sounds right.

SS: Now, when you look at that, AIDS is a gay disease, yet Gay Inc. has pretty much kicked AIDS out of the discourse. The official national gay agenda of what the major organizations are fighting for, even things like film festivals, AIDS is very marginal. Yet when you look at those statistics, it's gay people who are getting infected.

AB: Yes. I have very strong feelings about this — about the way gay people are being heterosexualized. I like things to be separate, but that's a personal issue. But I think as the big gay organizations get bigger, fundraise bigger, become more mainstream, this is not only happening with AIDS. It's happened very dramatically with issues regarding transgender people, or people who are non-gender-conforming. They get very, very super marginalized. Look at what the big organizations are focused on: getting us into the military and getting us married. I think there's a strong argument to be made that these are not the issues of most — certainly working-class gay people — or most women.

SS: So who's getting infected? It's not that they're not gay.

AB: No.

SS: It's their class. It's gay people of a certain class who are —

AB: Again, I don't know what information you're working from, so I'm not —

SS: I'm asking you.

AB: Yes. No, I mean, I don't know. I don't have a demographics sheet in front of me. I assume amfAR has good information. I don't know how they are classifying "class," by income —

SS: No, I'm just looking at that at who — if it's gay people who are getting infected primarily —

AB: Gay men.

SS: — or people having gay sex, men who have sex with men are the ones getting infected, and 70 percent of that group are not undetectable, that's about access to healthcare, so that implies a certain kind of class position.

AB: Well, or testing and awareness. If there's a large group of those people who don't know they're infected to begin with, there may be another group who knows that they're infected and isn't seeking treatment for whatever reason. Again, without seeing the data, I would find it difficult to comment on that. I think in a general way, the staggering amount of gay men — or men who have sex with men who are becoming infected — is a failure on the part of gay organizations in — it's a disgrace. It's a disgraceful failure.

SS: What do you think they should be doing?

AB: I think they should be doing AIDS work. I think it should be front and center in their mission statements. I think they should be doing real work around it, and I think people with AIDS are left by the roadside again. It's a very, very depressing

state of affairs, after everything we've been through, to see this what feels like a recapitulation.

SS: People who we've interviewed who work in prevention now are seeing this enormous crisis in prevention, that no matter what the strategy is, there's a certain percentage of people get infected no matter what.

AB: Well, yes. I think that's probably never going to change. People are human. People are human, and there's a certain percentage of that that you are never — it's like telling somebody who needs to eat not to eat. That's not a perfect analogy, but people are going to have sex. They're going to have sex unsafely. There's a certain percentage of that that's always going to happen. It doesn't mean you don't address the health issues, or that you stop doing prevention work.

SS: So we have functional treatments. We have certain sectors who are involved in efforts about prevention, and yet we're seeing significantly that there are groups of people, even gay people, who this is not reaching. So developing the treatments ultimately did not address the problem.

AB: Well, we still don't have a functioning healthcare system in this country. We have drugs that are staggeringly expensive. If you don't have insurance, it's the same thing we were talking about twenty, twenty-five years ago. That, that piece of the problem hasn't changed.

SS: So looking back at ACT UP, there was a moment when ACT UP was trying to create a healthcare movement, and you're —

AB: That was the unsexiest group you could possibly sit in, and I sat with Karin Timour. I went to those meetings. And I love Karin Timour. I think she is one of the great unheralded heroes of ACT UP. I worshipped her. I thought she was fabulous, and she still is.

But the information in Treatment and Data was nothing compared to the insurance stuff. That was so much harder to understand at that point, and, oh, my god, was it boring. So not only were you studying something where you couldn't see a saving of life immediately — I shouldn't joke about it, but it was really difficult to understand, and nobody wanted to sit through those meetings, and it was vitally, vitally, vitally important.

And we still don't have a functioning healthcare movement in this country. The politics of this country are so degenerate, and backward, and focused on the wrong things. And the fact that we've made an enemy, not just of socialism but of any kind of communal concern, leaves us in a position where there are so many issues that become hopeless or near hopeless. Until you can evolve that kind of mentality in a nation, you're nowhere. Grassroots organizing is nowhere.

The things that we worked on within ACT UP that were really successful long-term were successful because they were coalitions, and some of the most satisfying work that I did over the years came in offshoots of ACT UP. I was one of the founding members of a group called City AIDS Actions, which we did with Joy Episalla, Barbara Hughes, Jim Baggett, a lot of the Marys.

SS: I want to get into that in a second. Can we just hold on that, because that's my next subject.

AB: Sure.

SS: But I just want to kind of wrap up this other conversation. I think from all the things that we're raising and all the way we're engaging it, at the time it was impossible to know what the future was going to bring. Now we have the benefit of hindsight, and now we can see that no matter how effective the production of treatment was, without this other context, it ceases to reach huge numbers of people.

AB: And that's only in *this* country.

SS: Right.

AB: The situation elsewhere is much more desperate.

SS: So the success of the treatment activist agenda is always going to be limited if it's decontextualized from other —

AB: But that's true of any treatment movement. It doesn't matter what the disease is. You can't segregate it. And while all the different miseries have their own organizing groups around them, you can't disaggregate these problems. They're all part of one problem. All the different interest groups have to work together for a solution. It's straight out of the manual. It's not very complicated.

SS: But so let me just ask you, as somebody who's been in TAG all these years, do you think that at the beginning of the formation of TAG they really understood this, or are we only —

AB: No. The constituency of TAG is completely different. The organization is completely different. It was like ACT UP. It was a volunteer

organization, nobody was paid, there was no board, there were no rules of incorporation, no bylaws, no staff, no nothing. So I think it's impossible to make comparisons between what the organization is between now and then. I just don't think there — obviously the through lines are very strong, but organizationally it's very different. Most of the people who work for TAG now are women.

SS: But I'm not asking that. What I'm asking is at the time, I think a lot of people thought, "Oh, we're going to separate from ACT UP and we're going to have a treatment agenda and we're going to produce these treatments, and that's going to address the AIDS crisis."

AB: I don't think anybody in TAG ever thought anything of the kind. No.

SS: Oh, okay. So what was their agenda?

AB: I think it's actually interesting, because when I was thinking about where people came from, and the loose dichotomy between men and women and their political backgrounds, or their political experience before coming into ACT UP, I was thinking about the men who came into ACT UP already politicized, or who already came from progressive organizing, or with strong political awareness. Mark Harrington was one of them, and I'm not sure that people have ever given him credit for that. Were there people within TAG who were misogynous, or who didn't give a shit about fixing the healthcare system, or weren't worried overly much about socioeconomic disparity? Sure.

SS: I'm not saying that, though.

AB: Okay.

SS: I'm saying that perhaps at the time, given the situation, people thought that they could solve certain problems by having a treatment agenda.

AB: No, no. But, no, I don't think that's true at all. But you can't do everything. Not everybody can do everything. Not everybody needs to be doing everything. Not everybody should be doing everything. You can only do something effective. Nobody else was doing what T&D was doing. Nobody else was doing what TAG was doing, and what TAG has done has been absolutely indispensable. Does that mean that it's the only thing that needs to be done, or that people within TAG thought it was the only thing that needed to be done? No. And it never did. It never did.

So I think TAG continues to take flak — although less so now — for things, for faults that were perceived — sometimes correctly in its early days. But I don't think TAG, as an organization, ever thought that the AIDS crisis had nothing to do with poverty, or had nothing to do with racism. I think the people who were working within TAG were working on the things they knew about, were working to save their lives, were working to save the lives of the other people. I think it's a terrible insult to the people who organized TAG — especially the women — to continue to put that forward as historical fact, because it's not.

SS: Put what forward?

AB: That TAG, as an organization, didn't think that treatment issues, or that a cure for AIDS, or treatments for AIDS, had anything to do with the medical system, or poverty, or anything else.

SS: I don't think I really said that.

AB: Well, something like that. Why don't you tell me. Why don't you tell me what you said.

SS: Okay. Then we can move on.

AB: Okay.

SS: What I'm trying to say is that the existence of medications that are functional for people with healthcare have not had the broad benefits that many people hoped for.

AB: Of course not.

SS: And that early in ACT UP in the drugs-into-bodies politics, that was what people were hoping for.

AB: Well, I think that paradigm fell apart pretty fast, even with ACT UP. TAG was advocating fairly early on for more testing, more structured testing, rather than just drugs into bodies. I don't think anybody accepted that as a working paradigm for very long.

SS: So have we survived a plague?

AB: No, of course not. No. We still have a plague, especially globally. And this crisis is not going to be over until there's a cure for AIDS, and it's broadly available, broadly accessible, affordable, and all of that. No, we haven't begun to see an end of the AIDS crisis.

SS: So let's go to City AIDS Action. How did that get founded?

01:15:00

AB: Well, there were a bunch of us who'd been working together in ad hoc affinity groups, and some within the Marys for a long period of time, and we were

fed up with the way things were working within ACT UP. Nobody was happy there anymore, and we wanted to continue to do work around AIDS as our own organization, and we wanted to focus on something manageable. And we decided to work around AIDS in New York City, and with the new mayor, Giuliani, there was plenty of work to do. He was horrendous. He was horrendous. He tried to do away with the Division of AIDS Services, and there was the — was it WIP, the Workers Improvement — there was always some horrendous euphemistic acronym for putting people — people who had no business working — into the workforce, in order to receive the benefits that they were entitled to as citizens. So there was plenty to do. I don't know — I feel like we spent most of the mid-nineties up at Gracie Mansion getting arrested. We were focusing on local issues, on things that affected people with AIDS in New York.

SS: So how did it go?

AB: It worked really well for a while, and then it didn't. People got tired. People started needing to live their own lives. I think it's a common narrative — and I think there's a lot of truth to it — that after HAART the whole movement changed. Because, all of sudden, people were not dropping like flies. People were getting better. People were rising from their hospital beds. And I think it made it very difficult — and probably not even a good idea — for us to maintain a crisis mentality. People couldn't live this way for long periods of time. I often think about psychology studies of people living in environments where there's constant war, or constant disease, or constant poverty. At some point vigilance collapses, because you literally physically cannot sustain it. In some ways, that happened to us as a community. People started to get

better, there were real treatment options, and I think people were wrung out. And I think we're still wrung out.

And I think a lot of us have been thinking about that very deeply since Spencer Cox died recently. I think it's wrong to take him as an example, because he's a particular person, but I think he has made a lot of us reflect on various aspects of post-traumatic stress disorder that many of us suffer from. And the way, for a lot of us, our lives have been completely derailed — careers that we had, and ambitions that we had, and friends that we had. It doesn't mean that we don't have lives now that we don't value, that we don't love, but some of us don't. And sometimes that's hard to reconcile. Sometimes that's *really* hard to reconcile.

SS: Let's talk about the public conversation about Spencer.

Obviously, a lot of people in ACT UP have had crystal meth problems and —

AB: Yes. And a lot of them have been public about it, and have done great stuff around it.

SS: Yes, and some people have died.

AB: Yes.

SS: But in every community there are people who have addictions, and there are people who don't comply with treatments in every community as well. But there's a tendency in the public conversation around Spencer to say that this is AIDS-specific because of the ongoing weariness and depression.

AB: I'm not sure that — what do you mean, that this is AIDS-specific?

SS: That this particular combination of addiction and of deciding not to take meds and giving up and depression is related to this trauma that our generation has experienced, that we've never coped with, that especially people who
01:20:00 **have had AIDS or HIV for a long time have had an experience that no one understands outside of our community, and yet you can find this in every community. So is it really specific to AIDS, or is this —**

AB: No. I think there are plenty of other communities within which post-traumatic stress disorder is probably incredibly prevalent. I didn't mean it to sound that way. And, again, I think in a lot of these public conversations that have been occurring — particularly on Facebook — about Spencer, people have their own opinions. But a lot of these people didn't even know Spencer, and I don't think his particular case can be generalized. I think his death has made a lot of us think about those issues.

SS: Right, because there were tragic ironies that a person who makes treatments available then chooses not to take them. Okay, that's a tragic irony. Or also that other people in ACT UP who fought so hard to not get infected, then end up getting screwed up with crystal meth and end up dying. We have a few examples of that. There's tragic human flaws and incredible irony in those narratives.

But we are a particular community who are in a particular kind of conversation, and probably if other communities were talking to each other with as much frankness as we do, they would probably have the same examples. So what about this is specific to AIDS?

AB: What about Spencer's death is particular to AIDS?

SS: This larger self-destruction experience that we've seen with people who we know.

AB: Well, as I said, I don't think it is particular to AIDS. It is part of our community. It's particular to our community. I don't think post-traumatic stress disorder and its influence on other things, including addiction, is particular to the AIDS community, if we even have an AIDS community anymore.

I think the terms of that conversation are already problematic. I think especially when people are saying, "We should have done this for Spencer, we should have done that." Well, I don't know who "we" is anymore. I think it's part of the problem, and it's also part of the reason that organizations that are supposed to represent our interests like HRC, or the Victory Fund, or whatever, have AIDS nowhere at the top of their mission statement or agenda.

SS: Do you think that their putting forward gay marriage is a kind of antidote to AIDS, like gay marriage is clean?

AB: No, I don't think that's a fair statement. I think AIDS is a troubling issue in the same way that it was always troubling to people who are conservative. I don't see them as oppositional. Except in the way that — well, the gay marriage conversation is a hornet's nest, so I'm not going to walk into it.

SS: But the people who run those national gay organizations that are not talking about AIDS, many of them are HIV-positive themselves, right?

AB: Mm-hmm. I believe that's a paradox we've seen before.

SS: Right. That's true. That's true.

AB: Yes. I don't find that very surprising. I find it enraging, but I don't find it surprising.

SS: So as someone who's really, really involved right now, what do you think are the things that need to be done right now, realistically?

AB: I think we need single-payer healthcare now. I've always believed that's at the heart of an enormous number of problems. I think we need to fix the way income is distributed. I see a lot of the problems as having to do with the basic fundamental building blocks of the culture. I think we are a culture that is poisoned by religion, and capitalism, and sexism, and racism. I think those are all poisonous influences on individual and cultural and communal health.

Those are long-term problems though, and I think as with most long-term problems, they need long-term solutions — which doesn't mean we give up on them —

01:25:00 but it's long, slow, unrewarding work, I think, on a daily basis. And people who do it are incredibly courageous. I think it's one of the reasons why I've always had such incredible regard for Karin. She did really seriously unglamorous work. Relentlessly, and with high intelligence and commitment. I find that really heroic.

SS: When did you leave ACT UP?

AB: I left ACT UP, I'm going to say '95, sometime in '95. And it was a trickling away, too. I think I stuck around longer than some of my colleagues. But at that point we were already doing — most of the people that I was working with — were working in City AIDS Actions with me. We did a lot of great stuff, and we did a lot of great organizing. We worked with South Brooklyn Legal, and UJC [Urban Justice

Center], and Harlem United, and we did a lot of educational forums that I think were incredibly productive. And I think it was very satisfying, because we were getting back to work — especially the women amongst us — that was more familiar, and where we could see — the rewards were smaller, but they were *real*. After leaving ACT UP, that was enormously meaningful for us; to work with people who were committed to changing things that were small but tangible, quantifiable, that had real immediate impact on people's lives.

SS: What are you working on now?

AB: Now I'm working effectively as the senior editor at TAG — in charge of all the publications, and making sure we're one organization instead of being atomized, which we have a tendency to be.

SS: What's your most recent publication?

AB: The most recent big publication was the annual pipeline report, and that was in June of last year. That's produced once every year, but we do *Tagline*, which is produced, more or less, quarterly. And we have a website that's updated regularly, and conference reports, and things of that nature. So there's always stuff coming up.

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

AB: The work of YELL [Youth Education Life Line]. That was some of the most rewarding work that I did within ACT UP. I loved working with YELL.

SS: Who did you work with there?

AB: Kate [Barnhart] and Denny Lee, and Drew [Kramer] and BC [Craig]. I think we were all very attracted to that, and I think it touched all of our outraged nerves. I think it was also another one of those cases where we felt like there was something where we could have an immediate effect. Here was a situation where we could intervene, especially with condom distribution, and make sure that children who didn't have access were going to have the opportunity to be protected — both with condoms, and with information, and appropriate support. And they were just really *fun* actions. They were great. And Kate was fabulous. She's another activist that I admire enormously.

SS: Was there any particular school that you worked on or —

AB: No, no. A lot of the stuff was done on Jay Street at the headquarters, and I certainly testified at a lot of meetings, and did support. I think there was a school on Gold — no, no, no, that was the precinct where I functioned *in loco parentis* to a lot of the kids who got arrested, and that was always a nice experience. But I thought that was a working group that did tremendous work within ACT UP, whose praises were probably sung insufficiently.

01:30:00 I'm not sure what else I would really — I don't know. I think there's a lot of work that went on in ACT UP that doesn't get documented because it wasn't part of a more sustained affinity group like the Marys, or Action Tours, or something like that, because we were constantly forming ad hoc groups and pulling groups out of working groups and out of former working groups. People were doing things all the time. All the time. And some stuff got brought to the floor, some stuff didn't get brought to the floor,

but people were working constantly. And there was such good work, and such intelligent work that went on, and those relationships were so astonishing. I never have the feeling of love well up in me so quickly as when I see somebody that — I see Amy Bauer on the street, and I fall apart.

These were just — in the midst of this hellish, horrendous, incomprehensible time — Jesus Christ, the support was just unbelievable. And emotionally, as you go through the rest of your life — most of my close friends came out of ACT UP, are still part of — you know. That's the circle of my life now, for the most part. But that incredible intimacy and sense of support, that *real community*, is something that I don't expect to experience again. In some ways, I guess that's okay because of the context of it. And the work goes on, but it's this paradox that everybody talks about with ACT UP. It was the worst of times. It was the best of times.

SS: Before I ask you the last question, I just want to ask you something else. Is there anything you want to know from us? Do you have any questions for us? We've interviewed 152 people over twelve years from ACT UP. Is there anything that you're interested in about —

AB: Well, I've been interested over the years in why this hasn't happened. I didn't feel like there was enough sense of urgency about it. We've lost people, or people have drifted away, and I feel badly because — as you can tell from the interview — there are a lot of details that are already gone for me. If I had really prepared, and

gone over the timelines, and looked at my old documents, I probably could have made more details available to you.

But from organic memory, which gets worse all the time, I can produce less at this point that is historically useful. And that makes me sad, and it makes me unhappy for people who come after us, because I think it's so difficult to communicate. And I think this is the beauty of this project, and the importance of this project, is that you — it's not triangulate, but from all the different stories, a story emerges.

SS: One thing is that we will give you an opportunity to review the transcript and you can amend. So if you have other stuff that comes to you later and you want to add it to the record, you're certainly welcome to do that.

AB: Obviously the project has to be carefully curated, and these interviews are in some ways impossible without you. But I wonder if there isn't some way for people to produce their own testimonials through —

SS: Oh, sure. People can add whatever they want. It's just a file.

AB: No, I mean people who aren't interviewed by you, people who are elsewhere, or people who are — to provide their own —

SS: We don't refuse anybody. Anybody who said they wanted to be interviewed gets interviewed. It's just that we have a really long list.

AB: Oh, no, no, no. I meant as an adjunct to the project or as some other piece of it that isn't necessarily produced through interviews in New York City, because we lose information all the time.

SS: We have gone to other cities to interview people. We've traveled far and wide. I mean, anyone who says that they were in ACT UP New York, that's enough for us. If they want to be interviewed, we do interview them. I don't think there's anyone who's wanted to be interviewed that hasn't been. It's just that it takes a long time.

01:35:00 AB: No, but it's a question of people knowing about the project and coming to you and being proactive that way, rather than making some kind of solicitation for information and testimonials through Facebook or something like that. To remind people, or to tell them for the first time if they don't know about it — because people leave ACT UP, and not everybody was as intimately involved as the people in this room.

SS: Are there people you think that we should be contacting?

AB: Well, I don't know who's been left off the list. If you haven't talked to Drew Kramer, he'd be a great interview, just because he's a great person and talks beautifully.

SS: K-R-A-

AB: K-R-A-M-E-R. You should speak to Beth Stroud if you haven't already, because I know she has a complicated life.

SS: You know she's sick right now.

AB: Yes, I know.

SS: But we went to Princeton and she hosted us and we haven't done an interview.

AB: That's great. I would love to convince Barbara [Hughes] to come, because I think her testimony would be very significant.

SS: Yes, I think so too.

AB: I assume you've gotten all the missing Marys by now, besides her.

SS: Well, Joy gave a very extensive interview.

AB: Yes, yes, I know about that.

SS: Carrie [Yamaoka] has refused to be interviewed.

AB: Well, I can try to prod her too. I'm not sure how much success I'm going to have.

SS: I think we've asked her six times. She's even scheduled it and cancelled. So did Barbara. So we're trying.

AB: However uncomfortable it may be, and however bad we may be at it, that it's an obligation.

SS: Thank you. Because we did great interviews with Mark [Harrington], Gregg [Gonsalves], Peter [Staley], David [Barr]. All of those are very extensive. But, okay, great. Drew Kramer. Thank you.

So my last question is, looking back in hindsight, what would you say was ACT UP's greatest achievement, and what do you think was its biggest disappointment?

AB: Well, in a grand way, I'm sorry we didn't end the AIDS crisis. I'm not sure that was accomplishable but, of course, that was the big — I don't think it gets much sadder than that.

I think its greatest accomplishment was the way it changed research in this country; the way it changed the perception of AIDS; the way it changed the perception of gay people; the way it empowered the gay community; the way it brought the gay community together, men and women, in a way that hadn't existed before — although it ruined a lot of dyke bars. I think we're still calculating the impact, and I think it continues to branch out in greater and greater ways. I think it was the massive boulder that falls into the water, and we still feel the ripples, even now.

And the work of ACT UP hasn't stopped. The organization continues in a different form, and with different ambitions, I'm sure. But it's produced Housing Works — Charles King is still there, for god's sakes. And they still do tremendous work, and I will always love them for being the standout in the storm against Rudolph Giuliani. TAG persists doing tremendous work. Changes in needle exchange legislation, the way we deal with drug abuse — I think we can take significant credit for the way people think about that.

SS: You mean harm reduction.

AB: I think we changed the country. I think we changed people's perceptions about their own engagement with their lives and their health — what they can do. I think we've empowered other people to think in more expansive and passionate ways about the things that they can do collaboratively to change their lives, change the health, change the world.

I think ACT UP has provided an incredible ongoing example and lessons for organizing. I look at the Occupy Movement, and movements, as they branch out, and

there are people within that organization, within that movement, who are aware of ACT UP as an influence and there are some people who aren't. And the influence is still there, and I think we should all be very proud of that.

I don't know. At a personal level, I think ACT UP accomplished great things in terms of the way it made us feel as activists — and as people — about each other. I think it was a great gift to all of us. Maybe a gift we gave ourselves but, to me, that's an accomplishment.

SS: Okay, thanks.