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Interviewee: **Scott Wald**

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Interviewer: **Sarah Schulman**

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ACT UP Oral History Project
Interview of Scott Wald
June 1, 2012

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

SCOTT WALD: Okay. My name is Scott Wald. And today is June 1st; first day of June, 2012. We're in Chelsea, in Manhattan, on 21st between Ninth and 10th. I'm living here, and I'm 53.

SS: Same as me.

SW: Are you really?

SS: Yes, yes.

SW: I don't know how that happened. It did, it did. Life seems like a dream.

SS: So you didn't expect to hit 53, or because it passed so fast?

SW: Both. When I was, I explicitly remember, when I was 29 — 28 or 29 — my only hope was to live till 30. 'Cause I thought, for some reason — it doesn't sound to my parents or anybody, it doesn't sound so young, like he died in his twenties. I thought that was a big achievement, to live till 30. And I barely did.

SS: You got really sick at 29?

SW: No, actually it was shortly after that. It was 32, I think. Exactly 20 years ago, this summer — it's the 20th anniversary of when I was — I did almost die. I don't know if you're interested in that.

SS: I'm interested. Tell me.

SW: Okay.

SS: Yeah.

SW: Well, just to give you a little background: as far as Act Up, I basically was not participating in Act Up anymore. And a lot of different things. Maybe we can discuss that later, at some point. I had pneumocystis. And it was a lot worse than they thought. Lots of complications occurred, because they gave me sulfa drugs – it's an antibiotic which I'm allergic to. And at that point, I almost died.

So I was in Cabrini Hospital, the now-defunct Cabrini Hospital, on 18th Street.

{JIM: I believe it was on 19th.}

SW: And all the nuns were running [UI] around. And it was the summer, and I remember just – I was so sick that I could barely see, I was on oxygen. And all I could think about was that this wasn't supposed to happen: I thought I'd escaped this.

It didn't seem like it was happening to me; it felt like it was happening to somebody else.

I was in the hospital for almost a month. When I did get out, I was very weak, but I got better.

SS: You came back to this apartment?

SW: No, I hadn't moved here. I was living in the East Village. I remember going to a bodega when I got out, and I remember Whitney Houston being on the radio. What was her big hit from Bodyguard?

SS: {SINGING!} I will always love you.

SW: Right. I remember buying something. I think it was one of [UI] my first days out. And I remember – I'm a real sentimental person; I always remember things that, music that – and that song was on the radio in this bodega on First Avenue and like Fourth Street. And I thought it was so beautiful. And I just remember that. I thought it was gonna be okay. I think that's just how I left that bodega that day.

And it did; it was okay.

And then the cocktail came around.

SS: What's the consequence on you of having had an experience like that?

SW: Well – it sort of was a conclusion to a larger experience. It was part of a continuum. The promise that I thought I had of life, the hope I had, the dreams I had; the excitement of life, was largely squashed much earlier than that, you know. The epidemic started.

And you can tell me if this – if you're not interested in this.

SS: I'm interested.

SW: Okay.

SS: Yeah.

SW: You will let me know. I grew up in Chicago. I went to college; I came back; lived in the city; came out. And I just, the world was my oyster. I mean, I just thought it was absolutely beautiful. I was surrounded by a lot of positive people. I had two cousins, my two first cousins, Chuck and Howard — one on the East Coast, one on the West Coast — and they are both gay. And they were much older than I was. And when I came out, they said, you're part of our — we sort of had an idea; it's no shock — they saw me as like a little nine-year-old gay boy. So they just had to wait. And they were both amazing. They were both very — my cousin Chuck, in San Francisco, was a big part of the gay community there. And he lived in a commune. They lived in a commune in San Francisco, where him and his lover — they used the word 'lover' {MUMBLE} — and they lived with other, like, gay women and straight couples with children, and they all took care of the children, and they all shared all the responsibilities. And they were part of — they were safe in their community, and they also were connected. So I saw a lot of promise in that.

My cousin Howard taught English to Spanish-speaking immigrants. He lived in the Village.

So they were both big influences on me. And that was very exciting.

Early on, before I moved to New York — I moved to New York in 1985 — and before that, I had that relationship with my cousins. And I also had a

boyfriend in Chicago, who was 12 years older than I was. Who was just the greatest guy in the world. He was just – he treated me like royalty. {GIGGLE}

I mean, we met in a leather bar. {LAUGHS} And it was just great.

We had –

SS: The Gold Coast?

SW: Touché.

SS: Oh, okay.

SW: I can tell you stories about Touché. Chicago is very, very, like, out there, as far as sexuality. Way more out there than New York, actually, in the bars. His name was Pat, and he was a vice president of a bank, but yet very cool. We rented cars; he didn't have a car, and he would rent a car and take me places, and make cookies for me after having great sex. He was just a great guy, all around. And he taught me how to have a gay relationship – that it wasn't just backrooms or bookstores. Not that he was averse to some of those experiences; but that wasn't his entire being, which I totally aspired to.

I was in the hotel business at the time. Don't even ask me how I got there. I was a journalism major in college. But I got a job with Marriott Hotels believe it or not [UI] – 1984, and they like slipped a piece of paper into our paste-ons before the elections – the Marriott family would greatly appreciate you voting for Reagan-Bush.

SS: Wow.

SW: Yeah. That was interesting. But anyway, so I moved here. And I left Pat. We just decided we weren't gonna hold on to each other. We loved each other, but I was gonna be here, he was there. But we were still very close.

I should say that the year before I came to New York, my first cousin, Howard, died. And that was a time — just to backtrack a little bit — I was in Florida, in Key West, on vacation. And still very, very green, very idealistic. I was just so excited about life. And AIDS was something we weren't hearing in the early '80s. In Chicago you didn't hear about it very much. Howard Brown Clinic, which is the health clinic there, was always packed. It was a party there, when I was coming out of the closet. Everyone's had STDs. I think — there's been a lot of revisionist history of what that was like. Sure, we all had those things; but we all, like, came together — [and there were] people helping us. We sort of wore it like a loose garment. I don't think we saw it as anything else.

My parents were down there for the winter, and they picked me up in Fort Lauderdale, and they told me that Howard had died. I didn't even know he was sick.

SS: He had never told you.

SW: Never. He kept it secret.

SS: And they said he died of AIDS, or they just said he died.

SW: No, they said he died of AIDS.

SS: Okay. All right.

SW: And I grew up in a very – supposedly liberal family, Jewish family. But my mother was just – this was very difficult for her. Very difficult. I think it still is; my father has passed away now.

But when I came to New York, Pat died. And I think I saw, at that point – that was before Act Up.

12:10 I didn't see any hope at all. It was 1985. And then several months later, my cousin Chuck got sick, in San Francisco. And he died in '86.

So within two years, those two died.

And then my roommate died a year later.

SS: Here.

SW: Yeah. My first roommate in New York.

SS: Who was that?

SW: His name was Ron [Kwall]. That was my first apartment – just three blocks, exactly three blocks from here.

SS: So he died while you were living together?

SW: No, I had actually moved out of that apartment –

SS: Um hm.

SW: –when he started getting sick. But he was old-school, like gay New York. He was older than I was, and he was into leather, and he was into opera and all that. He was a character, a real character. We actually had those in New York, right? {MUMBLE}

SS: There's three or four left.

SW: There's three or four left? So that was a very difficult time. I felt very powerless. I started drinking heavily at that time, which I never did before.

SS: Did you think it was inevitable that you would get infected? Or did you already know that you were infected?

SW: Well – I started to – yes, I didn't know if it was inevitable, but I just assumed I was. And then I did know that when Pat got sick, obviously, that I was probably sick. But I was – I [never] felt sick at the time. I think that was an appropriate word, 'cause there was no – there was no hope at that time — at least I didn't have any — and I didn't think there was any way to act on it.

And then I dated. It was difficult, in those days. I didn't really like it. I went out with guys that didn't want to kiss me. Forget about having other kinds of sex.

SS: Didn't want to kiss you 'cause you were HIV-positive?

SW: Yeah.

SS: Okay.

SW: There was a lot of fear, yeah. I felt like I was a pariah. And other people that were – at that time, there wasn't really an HIV community. I mean, there was – GMHC had started, but most people were sick and dying, or they didn't know if they had the virus or not. That's how I saw it, anyways.

That's what it was like in Chelsea, was, you know, people you had seen, and a month later, hear that they were dead. That's what life was like.

Yeah.

But I went on, you know. I tried to – but it just became harder and harder. It wasn't until Act Up that I felt like I – I think I went to the March on Washington, which was in '87, and I knew about Act Up. I knew a couple people in it. I just didn't know if I – I don't remember what clicked, but I realized at that point that I had to be one of the people doing – you know, on the right side of this.

SS: Now, had you ever been politically active before?

SW: {LAUGHS} Well, in junior high school, I was recruiting people to vote for McGovern. And I was working on his campaign, even though everybody was [not] voting age. But I would try to get their parents to, in a largely Republican suburb. But that was, yeah – I had worked on campaigns all through the years. In '88, I worked for Dukakis.

I have to say, though, that I wasn't – it was here and there, at that point. I think coming out – I did think it was political. I marched in the parade in Chicago. In my own little ways, I was political. And Pat – [I just cry] to talk about him. He's one of my heroes. Because he had a lot to lose. He was an executive with a big bank in downtown Chicago. When I was working for Marriott, he came down to visit me. We actually made a couple trips. I was working in St. Louis at the time, and we took a trip to the Ozarks. They had a Marriott hotel in the Ozarks; Lake Osage. Maybe the most conservative place on

the face of the earth. The only thing you could buy in the souvenir shops was little Jesus figurines. Which I thought was actually sort of cute. When they asked us to – we did this in St. Louis as well, after that. But they asked us what kind of room we wanted, and [do you want] separate rooms. We said, no. And he said, no, we don't want two beds, we want one. 'Cause I was afraid to say it. And he was, that's the kind of person he was. 'Cause I was afraid.

SS: Sure.

SW: Who I was working for. I thought I was gonna lose my job. I thought that was a big possibility. And that might have actually been the reason I left there. I wasn't getting along with people above me, and I wasn't sure what happened. But I found that – I'll always remember that – one of those situations that I realized I could be bigger than I think I can be. Which is hard.

SS: Yeah.

SW: Today, it doesn't seem like much, but it was a big deal then.

SS: Believe me, I totally understand.

SW: You do, right?

SS: I'm exactly the same age. I remember the whole double-bed crisis.

SW: Yeah, we're talking, yeah.

SS: Yeah, exactly.

SW: We're talking like 1983, '84.

SS: Right.

So you said you had a couple friends who were in Act Up. Why were they?

SW: {SIGH} God, I don't even remember. I don't think they were actually that involved. You know what I mean? They went to an action or something, and told me about it. I don't remember even who I went to the first meeting with anymore.

SS: When did you come to Act Up?

SW: I think it was at the end of '87, early '88.

SS: What was going on when you first got involved? Do you remember?

SW: I knew you were going to ask. I was telling Ken that my memory isn't as good as it used to be. Well, everything was going on. We were coalescing around a lot of different things. There were a million zaps going on. Which I thought were amazing. I can't underestimate, I think it's, Sarah, it's been said in the documentaries – but for me, my personal experience was – just the most beautiful experience I ever had, when I went to Act Up. It was a spiritual experience. Yeah. 'Cause I thought I lost that – like I never – wouldn't – I would never see that. When I was younger, I was sort of involved with the synagogue youth groups. I was very involved, and I was very – I would plan retreats, and put on productions of Hair. It was very hippy-dippy. We sang Simon and Garfunkel at our services. That's really a throwback; that was when I was in high school. Everybody kissed, and everybody was like really warm to each other. But when

that was over, I never found my place – I never thought I could be Jewish like that anymore, for instance. And that was – at the time, I thought that was a powerful statement, not to be involved in my religion. But I think I was fooling myself that I didn't need something like that.

SS: Right. So were you a zap queen? Did you like to do zaps?

SW: I was total zap queen! Which is amazing! I mean – gosh – I mean – I think I just destroyed your system here.

SS: No, you're fine.

X: Not yet.

SW: Okay. Let me get untangled. Yeah. I was. I remember a lot of the big demonstrations. I was at the Mall; City Hall; FDA, CDC.

SS: Let's start with the zaps.

SW: Okay.

SS: Did you plan them, or did you go – were there any where you were involved in the planning?

SW: I think I – yeah, I mean I think – somebody came up with the idea, and then we all planned on what to do. And I think it was, it was very collaborative.

SS: Is there one in particular that you loved?

SW: I remember [going] to Stephen Joseph's house.

SS: So you were one of those people who went to his house.

SW: Yeah.

SS: Where did he live?

SW: On the Upper East Side.

SS: And can you explain who Stephen Joseph was?

SW: Stephen Joseph was the commissioner of health under Ed Koch.

SS: And why did you –

SW: He was public enemy number two, back then. And that's –

SS: And number one was?

SW: Huh? Well – well, between him and Reagan, I think it was close. But definitely it was Ed Koch, the mayor. Which was interesting for me personally, because it was the first time – I mean, I saw him before I came to New York, I sort of saw him as a folk hero.

SS: Stephen Joseph?

SW: No, Ed Koch.

SS: Oh. Why was he a folk hero?

SW: Well, just because – like during the – was it '83, or – when he – there was a strike, a transit strike, and he was telling everybody to walk across the bridge. He just seemed like, someone like Harry Truman. Of the people. A Jewish urban version of that.

But – I later found out that, very soon, I started to educate myself.

SS: And what was the complaint against Stephen Joseph?

SW: What was the complaint. Well, there were budgetary concerns. We just didn't think he was bringing to the mayor the urgency of the epidemic. I'm sure there were a lot of other things he didn't do. But we saw him as someone that was sitting on his ass while people were dying.

SS: So did you have –

SW: The mayor, he was the mayor, so he had his own issues. But he was the person supposedly in charge of this epidemic in New York.

SS: Well right. But going to someone's house is fairly dramatic. Did you have any questions about doing something like that?

SW: No. I never did.

SS: So who did you go with?

SW: I was always willing – I think from the start, I was willing to put my body on the line.

SS: So who did you go with, to Stephen Joseph's house?

SW: Don't remember, Sarah. I'm sure it was my friends.

SS: And what did you guys do –

SW: I mean, I went to a lot – hm?

SS: What did you do when you got there?

SW: We probably banged on drums, or we yelled and screamed. We made our presence known. That's how I remember a lot of these things. We're here; you can't ignore us. And what you're doing is wrong. We did that so many times. Like at the FDA. Later on, a lot of us went – that was in the

documentary. I was there. And we went, we broke into a hearing on the approval process of some drugs. We broke into that meeting, a lot of us. And that was, of course, a little more – we had become very important by then, by 1990. At the beginning, I think all of us were just finding our way.

SS: Did you ever get arrested?

SW: Um hm.

SS: What was the first time you got arrested?

SW: {SIGH} I want to say City Hall. I was arrested at the FDA, the CDC; Trump Tower – which I will never forget. His goons – really beat the crap out of me.

SS: Really?

SW: Yeah. Yeah.

SS: So what happened in all of these arrests? So they would just take you – so what happened at Trump Tower? It was Trump's guys who beat you –

SW: We were doing a zap. That was one of those instances where we were doing a zap. And that was just – it wasn't directed at Trump as much as it was directed at awakening the top one percent, so to speak. We didn't have that language then, but the people that –

SS: Actually – I think I was there with you.

SW: You were?

SS: I think it was about homelessness.

SW: Was it?

SS: And we all laid down on the ground –

SW: Probably.

SS: – and then threw these –

SW: Well –

SS: – leaflets from the fifth floor?

SW: That's what it was, Sarah. But I went up to the, on the escalator.

SS: Oh, okay.

SW: And that's where they grabbed me. 'Cause I think I separated from the group. And they – yeah, they brought me downstairs, they banged me on my head, like they punched me in the head before I got in the van, in the back of the van. I can [almost] see this guy's face right now.

I just thought that was shocking. Immediately I thought, like, this is a person that's the most, you know, admired people in New York, and [it's just what's], what's going on.

SS: And so when something like that happened, did you press charges, or did you just have to eat it?

SW: I ate it. I never did press charges. Maybe I should have. As bad as that was, I thought I was taking one for the team.

SS: Right. So can you tell us what it was like to be arrested with Act Up? What would happen?

SW: We knew what to do. We had civil disobedience training.

We became sort of experts at that. And usually — that Trump incident withstanding — we usually knew that we were — where we were going would lead us to an arrest. We were sitting in the street, and they told us, You are gonna get arrested. We knew that was gonna happen.

It was fairly orderly. I don't think we, at the time — I'll be honest with you — I don't think we appreciated the dangers or the risks completely. That's coming from a 53-year-old guy.

SS: So did you ever stay overnight in jail?

SW: No. I don't think I did. Actually, in Columbia, South Carolina, I think we were there for awhile. That was my favorite arrest.

SS: You were arrested — okay — that, you have to tell us that story, 'cause we don't know about that.

SW: You don't?

SS: No.

SW: Oh, that was the best action that we did.

SS: Okay. Start from the beginning.

SW: I mean — I'm surprised that — well, no, we — the gay community — the gay and lesbian community in South Carolina — they were fighting for their lives against this legislation that was being passed — anti-gay legislation. Pretty severe at the time. And I think the very, very — HIV laws that were unparalleled in the country. And these people were — I mean — along with

my boyfriend, Pat, these were some of the greatest people I met. They asked us to come down. I don't know how that happened, but the four activists down there and their friends, who worked in the beauty salons, and the hairdressers and people in the shadows. I know that sounds sort of – very 1965, but in this country, at the end of the '80s and beginning of the '90s, that's what gay life was like in the South, for sure. These people were very brave.

We got a bus down. I can't remember if it was one or two. I think it was one. And we drove down there, to help them, do a demonstration with them, on the steps of City Hall – excuse me, at the state capitol, you know, with the Confederate flag proudly flying.

And we got arrested there. That was scary. We were in Columbia, South Carolina. But so were these other people. I felt like they were putting themselves out there, they were demonstrating on the street with us. We went to meetings – sort of planning meetings with them. They wanted to throw us a big party – like that's, you know, Southern hospitality. It was [something of the quality of] like a dance hall – we all sort of were snobs – we're all like East Village–elitist. But we all had a really good time. And they were amazing. They were so appreciative of us coming down there. I'm surprised you haven't heard about that.

SS: No.

SW: Yeah. That was one of Act Up's big things that we did. I thought.

SS: So how did you end up getting arrested?

SW: Well, probably during the demonstration, I think it was, yeah.

SS: That must have been really scary, those police there are frightening.

SW: Yeah. Again, it was scary. I don't think that we – I think we sort of knew that it was pretty dangerous. But again, we were – we drove down there on a bus, saving people's lives. That was the least of our concerns, at the time. I do feel like that was so important, because – we were getting [beyond] the science, to people's survival. Not only from HIV, but just as – people like me, who was prancing all over the place, in New York. These people couldn't do that. So that, for me personally; that affected me quite a bit.

SS: Did you have an affinity group?

SW: Yeah.

SS: Which one were you in?

SW: Wave 3.

SS: Okay, so who else was in Wave 3?

SW: Oh, god. Jim Eigo, Melissa Pritcher; Mark Harrington; [Pam Ealing]. I know I'm gonna leave other people out. Mark Fisher. And there were others.

And I apologize for this, for those [who hear this] history without me mentioning their names. But when I've seen other oral histories, they've forgotten my name.

SS: Okay.

SW: Tit for tat.

SS: So how did Wave 3 get started?

SW: I don't know. That's very interesting. I think that someone just asked – I know someone asked me to work with them. I was very close with Mark – oh yeah, Spencer Cox was there, Ken was involved, to some degree. Even though Ken was sort of a [UI], but –

33:41

And I think Mark probably got me involved, Mark Harrington. Mark and I were very close. Very close.

SS: So how often did Wave 3 meet?

SW: A lot. Act Up was part of our, a year of absolute immersion in this. I'm sure it's [UI].

34:08

But there was something every night, including once a week, we met at somebody's apartment to discuss actions. And it would go on for hours and hours. And then it sort of morphed into somewhat of a treatment and data group. Which I particularly loved, because, you know, I don't have a science background. And I was able to have a conversation – I felt like, okay; it felt good to me. I was always a bad math student. I [didn't know] if I could have a discussion about math, but this is something that, I was always interested in

science and this kinda thing, but I never really did anything with it. I wasn't really involved.

SS: Did you make your own treatment decisions based on what you learned in Act Up?

SW: Uh – well, there weren't that many decisions to be made, at the time. I think I was – on AZT, at one point – during that time.

SS: And there was a lot of discussion in Act Up about AZT. That was hugely controversial, right? So did you – some people refused to take it.

SW: Yeah. You have to understand, back then, it was very toxic, because people were taking so much of it.

SS: Right.

SW: To seemingly no efficacy, because it was –

SS: Do you remember the dosage that you were on?

SW: {SIGH} I don't.

SS: And why did you stop?

SW: If you ask me right now all the different medications. You probably will [UI].

35:49

I can tell you what I'm on now.

SS: What are you taking now?

SW: Huh? Isentress and Truvada. I just changed from Atripla.

SS: Why did you change?

SW: I think – I have liver issues. So there were – I'm also Hep C– positive. Which I don't usually talk about. But we can talk about that. I'm open to talking about that. And a lot of other people are – that's another issue altogether.

But anyways, that was one of the reasons. And also, I knew there were more drugs that had been [UI] approved since I started Atripla.

36:37

SS: Right.

SW: I was very curious about them. And I was doing well; but not great. And I was undetectable, but my T-cells have always been very low. And they have been since the beginning. And they haven't gotten much better. So I was willing to try something else. And I heard this was easier on the body altogether, this combination.

SS: Okay, good.

SW: So that's why I switched.

SS: Good.

SW: The Atripla was very easy, it was one pill a day.

SS: So if you were in T&D, and –

SW: Yeah.

SS: – I mean, Mark Fisher died; Mark Harrington lived. Were people talking about what medical routes to take?

SW: No.

SS: That's so weird. Why was that?

SW: No, they were – {SIGH} – you know, that's interesting. We didn't think there was mu-, you know. Especially, we're talking about 1988, '89.

SS: Okay.

SW: You're talking about seven, eight years before – '96 was when most people went on the cocktail – '97. So this was quite a bit before that. And at the time, we were not – most of us had tried AZT, and gone off of it. 'Cause it was all about quality of life. If we were on AZT, we couldn't do what we wanted to do. And people were trying all kinds of things at the time, through the '80s. [The '80s were] chock full of experimental drugs; cracking an egg on your head three times a day –

SS: Compound Q [UI] –

38:12 SW: I'm being facetious. But like –

SS: Yeah.

SW: – some of those were that silly.

SS: But you avoided that. You didn't take dextran sulfate, you didn't take Compound Q, you didn't –

SW: No.

SS: And how were you wise enough to do that?

SW: I always thought that as long as I was feeling good, I wanted to stick with that. I was sort of in tune with my body that way. I saw a lot of

people ahead of me try it, and succeed. And I didn't know my — well, that's another issue — I did not know my HIV status until 1989—

SS: Oh, okay.

SW: — '90. Yeah. I just assumed I was; I just — I didn't see a reason to get tested, at the time. But I knew I was. But there wasn't a test till '84.

SS: So why did you decide to do it?

SW: Um — I had a new doctor, and I think he just, you know, asked me if I had had one. And [after] he saw my labs, and — there was no record of that. And I said I would.

SS: So did people in Act Up — so if you didn't —

SW: I was more devastated by that, by the way, than I thought I was gonna be.

SS: Oh. That's interesting.

SW: Yeah. It hit me like a ton of bricks. The reality of it. You know — ignorance is bliss.

SS: Right. But so people in Act Up who felt that they were positive were not discussing their own treatment. And were people talking about whether — and were not talking about getting tested or not getting tested. In other words, there's a public conversation in Act Up, and then there's a private conversation.

SW: Yeah. I didn't know anybody was positive. I mean, early on, I just, I don't – I was friends with Vito Russo. Vito was – Vito was friends with my cousin Howard in New York. They went way back.

SS: What was Howard's last name?

SW: Solomon.

SS: Okay.

40:25 SW: Howard and Chuck Solomon. My aunt Betty, who was their mother, became – she was a judge [UI] [UI] – my uncle, her husband, was a judge, and very – very cultured and very sort of shut down. She ended up having two gay sons. And it wasn't until they were – especially when her first son died, she became totally dedicated to her son in San Francisco. And not only that, but somewhat of an activist. She dragged my mother to PFLAG at one [UI] time. She lived with him for awhile, slept in his bedroom. She became very close with all his friends.

And when he was diagnosed, and he realized he was gonna, he didn't have much longer to live; she decided that she was gonna throw him a memorial service while he was still alive. And it was amazing. 'Cause, like, why have it after you're gone? It was a huge celebration. He was involved with theater, and so there was a lot of just – exuberance there, and love, and yeah. And he had a great time.

And it was amazing. 'Cause I thought, like – and I did, that sunk in too, early on; that you have to appreciate life.

41:55 And it [always hasn't] been easy for me, but that was –

SS: Do you feel like your friends in Act Up, that your conversations with them were very honest?

SW: Hm. No. Not the way I see it now.

SS: Yeah.

SW: We were together all the time. It was extremely intense. A lot of the conversations that we had, we were like – we were at the bars, definitely we were drinking a lot.

42:37

After meetings, and after, like, [their] three groups, et cetera. And I don't think a lot of us talked, none of us talked about what was really going on inside. And I think that's an element of youth, and just sort of an element of [what a] crisis that was at hand. People were dying, you know. I had other friends that were dying as well, outside of Act Up. Vito was one person, and then – who was a super-cool person. I don't know if you –

SS: Yeah, we knew him.

SW: Yeah, yeah. I mean, he was just – you know – he lived up, you know, he lived on my block when I first moved here, on 24th Street.

A funny story was that he was, you know, he had a lot o' different – his life was fairly compartmentalized. You might know, he was an activist, he was a film historian; and just sort of a real New Yorker. And one day, I was at his apartment, and it was his birthday. And I don't know which birthday it was. He

was living in his walk-up, in [sort of a] crappy building on the corner of 24th and Ninth. But it was definitely like a pilgrimage, going up there, 'cause, you know.

And I was up there, and we were just talking, having, whatever we were doing. And the doorbell rang. And the person at the door said, look outside. And he said, we have something for you. There's a huge, huge limousine out front, on 24th Street. And – it was someone – now the name is escaping me — one of his socialite friends — was delivering a birthday present. It was like a huge check. It was sorta like five thousand dollars, or something just crazy. And the driver, like, came up the stairs and [got to] the door. {LAUGHING} I just thought that said a lot about him.

SS: Yeah, he crossed worlds, definitely.

SW: He crossed worlds, yeah.

SS: Yeah.

SW: He was one of my role models. It was very intense, and a lot of people – we were very serious at the time. And we didn't talk about what was going on, and how much the anger was affecting us. I have seen that through the years, in the subsequent years, like a lot of – a lot of damage that's been derived from that, I can see [that] now. We didn't know better. We could always [stay angry]. We were so enmeshed in crisis.

45:18 Brian Damage was [in there with us]. I don't know if you knew Brian.

SS: Sure.

SW: And he was someone I became very close to. I curated an art show for him. And he was very – again, it was something I never did before. {MUMBLE}. I do some work, but it's not enough. But anyways, he was someone who inspired me quite a bit. And he got sick, and it was really, it was extremely difficult. There wasn't any, there was probably not much difference between his case in St. Vincent's and a lot of other people that were there. Nurses weren't changing the bed sheets, and – going to the nurses' station with the dirt, you know, begging for new laundry – and his meds, and tension – being ignored, and –

Yeah. And we knew it was basically was a death watch.

SS: And did he know that?

SW: Yeah.

SS: Did you guys talk about that?

SW: {SIGH} Uh – no. No. End-around, we talked about it. He would say things like – he would want something from the store, like the grocery store, like a candy bar or something. He said, there's money in the drawer. And there'd be like a twenty-dollar bill or something. And I said, well, I said, I'll bring you the change, or whatever he wanted. And he said, oh, don't bother, I'm not gonna need it. Like that kinda thing.

So he knew. That was really hard, on Mark as well. On a lot of us, though. There were a lot of people there that we weren't friends with that were suffering as well.

SS: Was there any particular campaign that you felt very, very proud of, particularly? I know you were involved in almost everything.

SW: Yeah, I was.

SS: Yeah.

SW: The only big action that I didn't go to was Stop the Church. I think probably the FDA action.

SS: What did Wave 3 do at the FDA action?

SW: Well, we wore our white lab coats, of course. I think we – we took over – I say we corrupted one of their, like, office, like research rooms, or something like that.

SS: Oh, you went into the building?

SW: Yeah, not the main building; it was [over] on the side, we got into. And I think we waited there for awhile. And we of course did everything with the group, but I think [when] no one paid attention to us, we left.

48:20 [UI] to be arrested there, but nothing happened.

That was – we had treatment-issue information we were passing out. And we had put a lot of work into that. By that point, we were all about the solution. That's what we were interested in, by that point.

SS: Did Act Up ever do anything that you really disagreed with?

SW: Hm. That's a good question. No. You know what? I really don't.

SS: What did you feel about Larry Kramer?

SW: I have wildly divergent feelings about Larry. He was someone I got to know. He was – I thought he was a performer. I never – his whole shtick – he did a lot of – I think he was all about his shtick, which really offended me. ‘Cause if you got to know Larry, [UI] –

49:40

– you know – he was like, sweet and gentle, actually. If you went to his apartment – we talked about his Oscar nomination, for Women in Love. {LAUGHS} Which is one of my favorite movies, ‘cause Alan Bates is delicious, and he's naked in it.

Yeah. The usual. I mean, his sort of ownership of the creation of Act Up.

SS: Where did mourning take place during that time?

SW: In the Act Up meetings.

SS: In the meetings.

SW: Yeah. We didn't take a lot o' time for that, at all. I don't remember going to – you know what? It's interesting; I remember going to – we had some memorial services. But at the time – there were many people that passed away that we either weren't allowed or we weren't encouraged to participate in – families – we had some arguments – a lot of the families came in, and they took the body, and everything was back in Cincinnati or something.

SS: Do you have any examples of that?

SW: I think, yeah, Brian was one of those people.

SS: His family took his body?

SW: Yeah, I guess so. I mean, they just, you know, there wasn't a service, and they took everything, and –

SS: What was his real name?

SW: I remember getting into – I have a couple things of his, but they basically took everything in his apartment. I mean, we were his family. And so – it was very difficult for us – to think that these strangers were coming. But they were his family. We didn't know them.

SS: What was his real name?

SW: I don't know. I used to know that. I think you could safely say his name was Damage. I think he'd appreciate that. 'Cause that was – that was his name that he took with his community. And that's what was important [to him]. That's where the love was. Family is love, right?

SS: That's the idea.

SW: Well –

SS: That's what it's supposed to be, yeah.

SW: Yeah, well, wherever you find it, you know. It doesn't have to come from your blood relatives.

SS: So how did you feel in Act Up? Did you feel respected, or did you feel –

SW: Interesting question. I probably – I mean, I felt I was respected; but not to the extent as – I think there were a few people that always had, took all the respect. But I have to take responsibility for that. I think a lot of it was fear of really competing. I felt like I was competing with certain people. And I didn't feel like I needed to, as well. I mean, I was – working – I felt the respect of people like Mark and – Jim. That was enough for me. These people were very – they were very into all the science. And the fact that they appreciated my opinion, and I was able to communicate in their language, was enough for me.

And I think by putting myself out there, and getting arrested, and being at those meetings every week. That was a bigger part than most people probably give people credit for. I think that just going there and seeing a roomful of people; that people were staying committed; that was very important to everybody. Some of the most important people were the people that just gave the best hugs in Act Up. 'Cause that's what we needed, too.

SS: Yeah.

SW: {SIGH} You know, Sarah, I can't – it was the most important thing in my life, to this day. And then it was over. And – I got sick, I got – life happened. And we splintered.

SS: Why did you leave –

SW: Some of us were so – why did I leave?

SS: You say you left in '92, right, before you got sick?

SW: Probably. Well – I think – the group was – our group [was splinter]. I mean, I think that the identity politics was – we thought was ruining Act Up.

SS: What does that mean, by the way?

SW: Huh?

SS: What does that mean?

SW: Well – we thought it was – I mean, we thought it was invasive that, like, Hispanics were [UI] [a voice] at the table. {LAUGHS} You know. You know what I mean? We didn't say so, but I think we did, 'cause we thought it was taking away – a lot of the issues came up. I think that there – I can't underestimate the male – you know – white male power structure was very much intact there. You know? I thought so. And other people were allowed to, you know, to sit in the audience, but we were on the field. And – it just makes [UI] [UI] [UI].

55:35

SS: That's okay.

SW: In the stands, I should say. {LAUGHS} You could appreciate that, Sarah. {LAUGHS} And when people started standing up for these issues, at first –

SS: So wait, for which issues?

SW: Well, like women's health, for instance. And all the, quote [unspeak] –

56:00 – now we consider them majority issues, but – vis a vis HIV, but they were minority at the time. At least those were very silent voices. We didn't really – you know – this may sound harsh, but I do, I felt like we – for a lot of us – and I'll even include myself in that – we had the singleness of purpose, and it became getting drugs into bodies.

Like Queer Nation, for instance, which I was part of, around the edges. We appreciated all these things, but we felt like they were gonna, they were breaking us up. We were so focused that anything that was divergent from our original purpose at the beginning of Act Up, we thought was gonna destroy us. And I think it did.

SS: You're saying that when women with AIDS or Latinos with AIDS wanted to make their issues – wanted Act Up to do things that would be more central, or that would address their needs –

SW: Um hm.

SS: – that the guys in Treatment and Data felt angry about that?

SW: I don't want to just single them out.

SS: Okay; some guys in Act Up felt angry about that?

SW: I think the original people in Act Up – you know, the people that were there at the beginning.

SS: Right.

SW: And that included some of the women. I think I – specifically with Treatment and Data, that putting drugs into bodies was their focus, was our – it wasn't my focus. My focus was, that was part of my focus. [Mine], personally was empowering other people to know that there was hope, and change could happen, and to be a power of example. That was my major focus. And I realized it was saving my life, selfishly. Not medically, but just my spirit. And it was, it did save my life, I think –

SS: Yeah.

58:05 SW: [UI]. And there was community.

SS: You know, Scott, you're the third guy in three days –

SW: What?

SS: – to bring this up. It's really interesting.

SW: What is that exactly?

SS: In the last three days, the three people, all very nice people, that we've interviewed –

58:28 SW: [UI] included –

SS: – have said that when women with AIDS, or people of color with AIDS have different needs in order for their AIDS issues to be addressed, there was a problem. And really honestly, if you can give me insight into why. And I'm not gonna argue with you; I just really want to know.

SW: No, I mean – I mean, I think it's – it's on its face, what it is. Prejudice. In the traditional sense. We all have it. And when those issues came up, we needed to deal with it. The downtown New York gay scene was very insular. And those were the people that, you know, a lot of people came from the – you know – either jobs on Wall Street, or the drag clubs in the East Village, or they came from Bennington, or wherever they came from. Those were all largely very, in their own ways, very insular communities that didn't have a lot – and I came from a family like that. We weren't allowed to say pejorative things about blacks, Negroes at the time – or anybody else, at the dinner table. We were definitely not allowed to say the N word. We were taught that that was wrong, we should never say that. There were Humphrey Democrats, civil rights was very important. But when it came to their neighborhood or it came to my dad's [UI] in his business; those issues came up –

60:38

– and it's there. People's security is threatened, emotionally and physically, by change. And that's –

SS: So Act Up was like the neighborhood, and it was like, not in my neighborhood.

SW: Exactly.

SS: Amazing.

SW: Huh?

SS: That's really interesting.

SW: Yeah. And that destroyed Act Up. I mean, it destroyed, in its original state, anyways. Once we moved to Cooper Union, as well, that – heh – that was horrible, too. ‘Cause the big part – I mean – I hope that's been discussed by other people –

SS: No, go ahead.

SW: When we were at the Center, we were like, I mean – we couldn't breathe.

61:25 And [UI] [UI] the Center, you know, the Keith Haring – you know, like the big art fest, when they put all that murals –

SS: He did the bathroom, right?

SW: He did the bathroom, and the stairwells, and – which we were having sex in, by the way, during Act Up meetings. Um – {LAUGHS}. I don't know if anyone's told you that.

SS: No.

SW: No?

SS: No one.

SW: {LAUGHS}

SS: You are the hundred-and-thirtieth person I've talked to, and you're the first person who said you had sex during Act Up meetings.

SW: I hope it doesn't surprise you.

SS: It doesn't surprise me, I'm just amazed that no one else has mentioned it.

SW: Well, and then, you know, you were like, it was this – it was just like, great. I mean, this is our space, you know. And we did with it what we thought we wanted to.

SS: No, [good].

SW: It wasn't nearly as institutional as – we weren't the LGBT Center, obviously, or – you know, gay and lesbian. But [UI], I, um – I thought that when we moved to Cooper Union — back to that — people were sitting all over the place, like 10 rows in back of other people. And people were allowed there to more align with the people that they knew; and not with the people that were just coming in. Whereas before, we were all together, and we could talk to each other. And get to know each other, and get to know each other across – socioeconomic lines, for instance.

And I think most of us were doing that, at first. 'Cause we weren't feeling that threatened, first of all, but – I think when we went to Cooper Union, that gave us sort of the freedom to sit at the lunch table with who we wanted to sit with.

SS: So any kind of little bit of privilege makes people get screwed up, basically. It's only when everyone's absolutely on an equal plane.

SW: Well, I don't know if anybody [always is].

SS: Wait; you left in '92. What was –

SW: I did. I was going through my own personal crises.

63:44 [UI] before, I got – like around '91, [UI].

And if you want me to discuss it –

SS: No, but I mean, you gave up –

SW: Yeah.

SS: – doing Act Up every single day –

SW: Yeah.

SS: – to not doing it. That's huge. That's enormous change.

SW: I had to leave.

SS: Yeah.

SW: Couldn't take it any more. We were destroying me from
inside out.

SS: Because of the –

SW: –

SS: – of the dying, or because of the splitting?

SW: I couldn't maintain the – no, not splitting, I mean, not [at all].

SS: It was the [UI].

SW: I mean, I saw it going on, but I – I mean, I'm not saying I
wasn't, I didn't feel that. But I didn't think – my personal – I was destroying
myself. And I saw the people doing it that I was really close to, as well.

**SS: So do you think Act Up was traumatizing? It was
traumatizing to be in Act Up?**

SW: Yeah. I mean, I – {SIGH} – extremely traumatizing. I've seen a lot of – it's been very interesting, over the years. A lot of came – there were many, many years [where we] couldn't talk to each other. We couldn't communicate with each other. Just couldn't go back there. It was just too hard, it was just too intense. And there's so much love, and so much commitment, that – I think a lot of us were, and [in] different directions – we felt a little like we've lost something bigger than ourselves, and we didn't want to admit that to each other.

SS: So why is it now, why are we healing that now?

SW: It's interesting. I can't speak for everybody. When there was the exhibit at White Columns; I hadn't seen a lot of people for this whole time. I mean I really haven't. I went there, I was scared to death. Scared to death. That maybe people didn't like me as much as I thought they did 20 years ago. Or maybe they didn't respect me as much, or maybe they didn't think I was cuter. I had all these, like, what-ifs, you know; and none of them were coming on my side, they were all – it was all about fear, about – 'cause if anything destroyed, in my mind, what that was; I was gonna be very hurt. And as long as I could just, you know – it was in the past, in a scrapbook, no one was gonna take those pic-, no one was gonna change that scrapbook, except me. So I had a lot of fear about that.

SS: How did it go?

SW: Well, it went – I went to the, I watched the videos. I went before, [I went] before that. And it was not – a lot of it, some of it was good. I

didn't remember a lot of people's names that I talked to every day, which is very embarrassing. There were a couple people that I was really afraid – I was like I saw that they weren't there yet, or they weren't there, and I was really afraid [they weren't coming]. A couple women.

I always thought that — I don't know why I thought this — I always try to get respect from women; and I've always found it difficult – including my mother. It was a mommy thing. Yeah, that was always something that I, I had to [UI] that fear.

67:35

And a couple – maybe a couple people I didn't get such a warm reaction from. But I did okay, I did okay. But that was crossing a big threshold for me; [UI] those recollections

67:52

And then, when we were at – [UI] getting acquainted, like I said, with a few people from those days. I have a couple fri-, well, Jon Nalley's a friend of mine. And I recently got reacquainted with Ken. And probably – I don't know if I – if he'll hear this or not, but I hadn't seen Mark, who I was really close to – extremely clo-, I thought. And he just – I left Act Up, and I left him, and we both left each other. The last time I saw Mark was at Mark Fisher's funeral. And then we just didn't see each other, or talk to each other again. I think that was symbolic of a lot of people. That really stood out for me. And I saw him across the room, in the lobby, at MoMA. And I said, oh my god, I don't know if I can

deal with this. And we both saw each other, and we gave each other a huge hug. And I remember that hug. That was like – it was just like, you know – muscle memory, or something.

SS: Hm.

SW: And it was okay. We still loved each other. And we'll see what happens, as far as that relationship. But that was important, that that happened for me.

You're probably asking, why does there need to be healing from the Act Up experience, but there does. It was – I think – and I appreciated the documentary a lot, Jim. And I – there was anger; but there was a lot of – love and loss, and there was a lot of things that we all felt. And it was the most intense experience of our lives.

SS: Yeah.

SW: All of us. [We lived it] every day. It was absolutely, it was like a tsunami of feeling every day, for us. It was amazing.

And that was gay pride, for us. That was our Stonewall, in a way. We were on the streets, we were saying we are who we are; and you're not gonna push us around anymore. So we had that, continually, day after day –

SS: Yeah.

SW: – and Stonewall lasted, like, three nights. That's how I saw it, for that generation.

SS: Right.

SW: But I was a little older than a lot of, some of the other people, so I had seen some things. Some people were like, a lot of them were just out of college. And I was already like 30, I was about 30. I felt a lot younger, though. Even at 30, I felt like I was just growing up; that I hadn't been allowed to really grow up yet. So I find myself –

But I look back on that time, when I found out my boyfriend was sick; and I realized that I was gonna die. And in that moment, I just remember that – leaving work, and going home, and opening a bottle of wine, and standing in the kitchen, drinking the whole thing down, and crying. And thinking – all hope is erased. For someone 25, that's very traumatic, thinking like you don't have a future. And I really think I felt that. And that's been, I have carried that throughout my life.

SS: But now you also know you saved your own life.

SW: I do. That involvement – I do; I believe that. I believe some of the things I did –

SS: It's true.

SW: Yeah.

SS: It's a fact.

SW: Yeah.

SS: So I only have one more question.

SW: Oh my god.

SS: Do you have anything else that we need to talk about?

SW: No, I think – I hope you get to talk to people that – a lot of people – there's a lot o' stories to be told.

SS: We're trying to get to everybody. It's just taking us a long time.

SW: It is. When did you start this project?

SS: Ten years ago. But you're number 130.

SW: I remember that day at Columbia. We hadn't worked [on it] yet, but I've always loved seeing you, Sarah. I miss you.

SS: Thanks. Oh. So you ready for your last question?

SW: Yeah. I thought that was my last question.

SS: No, I saved it.

SW: Oh.

SS: So looking back, what would say is Act Up's greatest achievement, and what's its biggest disappointment?

SW: Hm. Well – our greatest achievement was ending the AIDS crisis as we knew it. As we knew it. People are living today because of what we did. And I firmly believe that. And, if I can add one [UI]

73:46

– on the side of the ledger was that we show what a community in love was about amidst hardship – they were stronger than – than the outside world thinks we are.

And then, on the downside, I think that it was – well, I don't know if this is Act Up's fault, but I think people's experience in Act Up – that a lot of our lives were fractured from Act Up. How could we top that? And I think that's the experience I had, and I think a lot of people I've talked to; we can never top that experience we had at a very young age. So – it's like we went to the moon, we came back, and now what? You know?

SS: Right.

SW: So that's what I have to say about that.

SS: Thank you, Scott.

SW: Thank you.

SS: Wow. Hooray. I feel like clapping.

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