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P R O J E C T**

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Interviewee: **Jean Carlomusto**

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Interviewer: **Sarah Schulman**

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**ACT UP Oral History Project  
Interview of Jean Carlomusto  
December 19, 2002**

00:00:58           **SARAH SCHULMAN: Please say your name, the address of where we are, today's date, and how old you are.**

JEAN CARLOMUSTO: My name is Jean Carlomusto. We are at 84 Horatio Street in the West Village. And it's 2002. I was born in 1959, so you do the math.

**SS: So, Jean, do you remember the first time you heard the word "AIDS"?**

JC: You know, it's a vague transition between GRID to AIDS for me. I can more likely go back to the first time I heard of GRID. Then AIDS started slipping into more common usage.

**SS: What was it? What was the first time you heard "GRID"?**

JC: It was in the early 1980s, and I was a student at NYU. I heard it on the news. I heard it as part of these broadcasts, these little snippets that you would hear on the news with that graphic. You could just see it. GRID, in a box, over the guy's shoulder, with the graph line or something next to them.

**SS: So, what did you feel when you heard that?**

JC: Well, the method of delivering that message was totally to desensitize you to what GRID was: "It's not your issue, baby. That's why we're reporting on it." GRID didn't have meaning to me until people in my life, people in the community around me, were sick. Then I understood more what was going on. The media certainly didn't educate me on it.

**SS: Did you identify as gay at that time?**

JC: Yeah, I was out at that time.

**SS: So, when you saw “gay-related immune deficiency,” did you think that you could get that?**

JC: Wow, that’s a tough one. I thought I could get the stigma and everything that came along with it. But at that time, even then, the images you saw, or the image that was being delivered, was really specific to gay men. I still can see it, a shot from the back of two gay men walking down the Haight, holding hands. That was the shot. So, I don’t know that I came to this through feeling that I would be infected. What I came to it with was this horror of seeing homophobia manifested when people were sick and dying. That’s what really galvanized me to the issue.

**SS: Who was the first person in your life who had AIDS?**

JC: Joey Lianti is like a really important person in my life. When I was teaching at NYU, we were doing a course in educational media. Part of the assignment was we would have people from different groups come in. They all needed video assistance, so they would come in and present to our students what they needed help with. And our students would then have to pick one of these community groups to go work with. Joey came in, and he was from Gay Men’s Health Crisis. His message for me was the strongest. And I was so appalled that none of my students picked to go work with him  
00:05:00 that I picked to go and volunteer at Gay Men’s Health Crisis in 1986. So, Joey was really the person who said, “Girl, we can use you.”

**SS: So, when you walked into GMHC for the first time, what was it like?**

JC: At the time, the educational department where Joey was, and where I would end up working, was in a building on 26<sup>th</sup> Street with halls that were being urinated in

regularly. It was a different kind of GMHC than later evolved. And it was a really exciting place to be working at in 1986. *Chance of a Lifetime* had just been made, and that was really one of the first safer-sex intervention videos that I remember seeing.

**SS: Who made that?**

JC: That was made by Lewis, right?

**JIM HUBBARD: John Lewis.**

JC: Yeah, and it was produced by Raymond Jacobs. So, one of my jobs was, as a volunteer, to project this gay male porn flick every Saturday in the High School for the Humanities. It was part of these really innovative workshops that GMHC was doing at that time — safer-sex workshops. You came for the weekend. You got to see *Chance of a Lifetime*. They gave you lunch. The men who came would sit around in groups and process: “What is safer-sex? What are your sex practices? How can you make them safer?”

**SS: Was this a different kind of a relationship for you with men?**

JC: You know, it seemed very natural because a lot of my friends were gay male people. So no, it seemed very natural. It was fun. In fact, the thing I missed early on at GMHC was how mixed these events might be. I remember one safer-sex forum that was mixed. It was really great to be sitting around in a group of men and women talking about sex practices. I learned a lot. I never had heard of, what is shrimping? I didn't know what shrimping was. Or I didn't know the name for it. So, it all seemed very natural. It was the kind of job — when do you have a full-time job when it was so queer? It was just so queer. It wasn't necessarily lesbian — and that was one of the first things that, when I got there, I was just hungry to meet other lesbians who were doing this. And

there were very few at the time. And actually, my good friend Jane Rosett was one of those people who I met back in 1986. She was working over at PWAC, the PWA Coalition. It was just so exciting to meet another out lesbian who was there for similar reasons.

**SS: So how did you make the transition from volunteer to employee at GMHC?**

JC: GMHC needed someone to coordinate audio-visual aspects of their expanding mission. So, I took the job. It was kind of hard for me at the time, because it meant leaving a full-time job at NYU. And it meant losing — I was in the middle of trying to get a Master's degree, so I was going to lose the free tuition and everything. And I was kind of uncomfortable with working full-time. What's an A/V specialist? I wasn't going to go around and set up projectors and wear tape on my glasses for this group. But the best jobs aren't necessarily ones that you apply for; they are ones that you make. So, I went for it because I thought that we needed to shape a new message. And my being at GMHC would become, for me, a way to do interventions around representation. So, as I was working at GMHC, the first thing I did was say, "Hey look, we need to get a camcorder." And I was really glad we had that, because that's what enabled us to do the cable show *Living With AIDS*, to produce our own material, not to be beholden to a local gay cable impresario who we would have to go pay to use the same set that every other gay group was using. We wanted — I wanted — to fashion something a little bit different.

00:10:00

**SS: What was the old message, and why did you feel that you needed a new message?**

JC: Well, the old message — well, the message that we were receiving from the mainstream at the time was, first of all, AIDS is not your concern because you're straight. The message was AIDS is very stigmatizing, so much so that we cannot show you this person. We are going to show them in silhouette, because if they show their face they are going to be subject to extreme discrimination. Plus, they are just so humiliated at their situation, why would they want to be on? That was true for a lot of people, but it was also not true for everybody. And working at GMHC, I was working with a lot of people with AIDS who were really out about who they were and who were really strong advocates. So, on early *Living with AIDS* shows, we might have someone like David Summers, who was such a strong advocate, who was really out there so early. Who were some of the other people? Scott Jordan, a younger fellow. Or Kevin Mahoney. All these people were out about their status, and we all wanted to get across a message that we're all living with AIDS. We need to get information out there. We need to really get people connected with services. And that's what the early messages were about.

Even things about treatment — there wasn't a heck of a lot going on with treatment at that time. But an early show might have brought you to the PWA Coalition living room for a make-up session, because Kaposi's Sarcoma was such an awful disfigurement at that time — not just for the lesions. The fact that you had these lesions meant that it was going to be hard for you to get a cab. It was going to be hard for you to go into a grocery store. So, having a make-up specialist, who was just like any make-up specialist or any good hairdresser — they just put you at ease. And that's what Deborah did. And actually, in one show the person she was working with was Joey Lianti, who hired me. At the time, I know how broken up he was about the KS. But he went on

camera willingly. He offered to do this, not just because he wanted to be an out person with AIDS, but because he really wanted the information to get out there.

**SS: So how often did the show run?**

JC: We tried to get it out once a week. But with one person on staff, and not a heck of a lot of resources, sometimes we made it and sometimes we didn't.

**SS: On what channel?**

JC: Oh God. Was it 53? I would have to go back. The reason it's a little vague for me now is because public access cable was changing. Now it's Manhattan Neighborhood Network. At that time, we had a different system. We had Paragon Cable. And it also alternated between different channels, because every so often they would kick you off when you had been on one channel and one slot.

**SS: What time?**

JC: Generally, it was at 10:00 p.m.

**SS: Do you know how many people watched it?**

JC: It's very hard to tell. But people were watching it, because I would get people writing things in to me saying, "Thank you." And also, people calling up GMHC, wanting to know how they could get a dub or how they could get more information about a particular segment. They would be calling up the hotline.

**SS: And ultimately, how many segments did you film?**

JC: Of *Living With AIDS*? Many. I couldn't give you an exact number. Jim could probably come up with a better number than I could, because he's been archiving them. But we did any number of them. And there is also a separation. I was there between, what, 1986 and maybe 1994. And after that, *Living with AIDS* still went on.

Gregg [Bordowitz] was producing for *Living With AIDS*, and then Juanita Mohammed, and Charles Brack. So up until a couple of years ago, it was still in production. So, I couldn't quantify.

**SS: About 400?**

JC: Okay, about 400.<sup>1</sup>

**SS: How did you come with the idea, and then how did you proceed?**

00:15:00

JC: I came up with the idea because I had been —

**SS: Of a particular episode or segment.**

JC: Of the KS makeover?

**SS: Any one. How would you decide what you were going to do that week?**

JC: Like any reporter, like anyone who comes up with an idea, you just have to be immersed in a particular culture and see what issues are prevalent. Sometimes I made them up and sometimes I might have seen a piece in the PWAC newswire: "Come by on Fridays. Debbie Provenzano is doing KS makeovers." And I thought, "Wow, we should do a segment on this." Or I might have overheard something at a GMHC staff meeting. What I am talking about right now, I am talking in the context of — I haven't even gotten to ACT UP yet. Everything I am saying right now is before March 1987. This is, for me, what was going on right before that.

**SS: What were some of the other subjects of segments that you did?**

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<sup>1</sup> In 2000, GMHC donated 55 boxes of videotapes to the Division of Manuscripts and Archives of the New York Public Library. These boxes contained copies of 15 *Living with AIDS* shows. These were remastered and became part of the AIDS Activist Video Collection. Since one of the programs is designated #31, there is evidence that these represented only a small number of the shows actually produced. However, it is unlikely that 400 were made. In his interview with the ACT UP Oral History Project, Gregg Bordowitz says he believes it was 25 -30 tapes. (See Interview #004, pages 66-67) – Jim Hubbard



JC: March on Washington. There was one about treatment. There were portraits — this is hard to remember everything. There was one man, David Sanford, who had lost his sight. And the segment, particularly about him, was learning how to deal with loss of sight. Treatments — we were doing segments on whatever treatments were available at that time: aerosolized pentamidine. We were trying to promote that, promote people get treated for that. Also, I believe in 1986/1987, testing had started to come into the picture. So, we were doing shows examining why or why not to test.

**SS: So, for example, if you were going to advocate for a particular treatment, how would you make the decision that that was something worth promoting?**

JC: We always worked on an informed choice model, especially then because information was very vague. So, the idea was to get as much information out there to the potential person who was dealing with the treatments, enough for them to make the right choice based on their given circumstance. And testing was, at that time, a case in point. There were no treatments, so really why are you going to test? Who is going to have access to this information? It was more a matter of bringing up all of the subtext to the forefront so that people could analyze the situation for themselves.

**SS: So, from the beginning, before you even came to ACT UP, you were surrounded by people who were sick and dying, from the moment you walked into GMHC.**

JC: Mm-hmm.

**SS: How do you think that affected you, initially?**

JC: How did it affect me? Initially, I think I was just kind of naïve, because I hadn't lived through that kind of situation before. I had a number of my supervisors who were telling me they had just tested positive, and then it seemed like a year later I was cleaning out their desk. So, as I unpack it, the cumulative effect of this grief did take its toll on me. I think it made me much more clear about my intentions when I decided to become caretaker for someone, more so now because I understand that that is really a commitment and what that commitment means. Hey, you know, I've been a practicing Buddhist for twelve years now. And I think becoming Buddhist, to be honest, that kind of trauma — I don't want to use the word "trauma." I'll keep that out of the air for now. But that kind of experience, let's say, was something that led me to look for a deeper meaning in everything around me.

00:20:00

**SS: So, you were running *Living with AIDS* and you were also in care groups at the same time?**

JC: I was running *Living with AIDS* and providing media support for any of the events that we did, one of them being the safer-sex weekend interventions. Another one, I remember, was called "Epidemic Center Stage." Colleen Dewhurst, and Joseph Papp, and all of these people — who else? Chesley?

**SS: Robert Chesley?**

JC: Yeah, he was there. Basically, everybody was giving readings and advocating for more public awareness and support around the AIDS crisis.

**SS: Were you in personal care groups? Because you had said "making a decision to be a caregiver."**

JC: I wasn't talking about being in care groups. I was talking about taking care of people who were sick. So, while I wasn't necessarily an official GMHC volunteer, I was serving in this function for individuals around me.

**SS: With people who you were close to.**

JC: Yes.

**SS: So how did you get to ACT UP?**

JC: On the morning of the first demonstration, I picked up my camera and I went down to Wall Street just to see what was going on. It was kind of amazing that day, because I surprised myself. There were a lot of police around. And at this event, everybody was very skittish, more so than in subsequent actions, when people really knew what the drill was around ACT UP actions. But in this one, especially when I look at the footage now, you can see a lot of people were clearly nervous about what they were doing. When they were sitting in the street — the people who were protesting in front of the Trinity Church ended up in the street — you could just sort of see that there was an element of the unknown. I'm saying I surprised myself, because I just found myself at one point just using the camera as a weapon and pushing people out of the way to get to — and at this point, it was mostly cops because their legs were in the way — to get to the people in the street and to shoot this. It was just like such an amazing thing. I had gone through so many different events where people — it was just the same modality: performer/audience. And here, all of the boundaries were erased. It was sidewalk/street. The people inhabiting either of these places were moving around. And it was exciting. It was incredibly exciting — and powerful.

**SS: Had you ever been involved in any kind of direct action, in any kind of lesbian, or feminist, or anti-war activity?**

JC: I had gone to Cherry Hill and shot footage out there. I was around for some of the organizing around reproductive freedom. So that was kind of my model. But what I had seen just didn't have the same edge to it.

**SS: So how did you follow-up with ACT UP after that?**

JC: I got involved. Actually, that day, at the action, I met Gregg. And I met David.

**SS: David who?**

JC: Meieran.

**SS: And Gregg Bordowitz.**

JC: And Gregg Bordowitz. And we developed a relationship based on necessity, because the footage in my camera came out and the footage in their camera didn't come out. They were starting to work on a piece that would be done called *Testing the Limits*. So, the idea of networking and sharing footage was brewing, and it was one that I really supported. So, we started, because there were all these actions that were now being generated and all these shoot opportunities. We needed to coordinate our efforts so that we could all be there to cover it and make sure people were there. And by the way, at the time, it wasn't just us being there to cover these events for visibility. We also had a purpose in being there in terms of police surveillance. In other words, we were there to make sure that no one got roughed up, and also just to make sure that the police were following procedures.

00:25:00

**SS: Who decided that you were going to do that?**

JC: Well, initially we decided it. But because we were also involved with ACT UP, our organizing as a group was done within the context of ACT UP. So shortly after *Testing the Limits, Part I* was completed, then we started looking at affinity groups within ACT UP that might be able to really coordinate our efforts. And that's when DIVA TV was formed by this group of folks who were interested in doing media coverage within — video activism, not media coverage, video activism.

**SS: Now was there a problem with police violence that led to this decision to do police surveillance? Or was it preemptive?**

JC: No, there were situations. I'm not going to be able to give you always specific incidents. I'll give you one that's documented in the *Cosmo* tape where Maxine Wolfe is talking about every time this officer came up to her, she would take his badge number down. And finally, the officer just got so fed up with her and said, "You have taken my badge number five times." You can see that he starts pushing her down the block very hard. Now, first of all, it's important to see how she is being handled. But it was also very important for us to see that footage at the time because that's an education. I never knew that. I never knew in an action to get the officer's badge number down. Nowadays, that's part of your 101 civil disobedience training. But at the time, we were just learning these techniques that would really serve us well if we were going to take to the street and deal with police force.

**SS: Some of these *Testing the Limits* people came out of the Whitney Program and they had a particular kind of training, and you had a different background. How was that communication between the two cultures within that?**

JC: My footage tended to come out. You know, the split didn't necessarily become apparent to me until later on that there was any kind of real split. At the time, I just remember being so energized by what was going on, by the thought that together we could be such a more potent force than one person. Because I had had that one person — the one-man band thing at GMHC — and I knew how grueling that could be. But working with a group of people was truly amazing, and we could really cover these events. And also, in the case of *Testing the Limits* collective, we could use our abilities to edit and then disseminate this tape. Later on, this became different because, as a video activist, I don't think any of us really — or I didn't think about the major art issues of copyright and everything like that. I thought we were a collective and operating under collective rules. Later on, over time, when people started going their own way, all of a sudden there was an issue over who actually had ownership of this. And that discussion didn't happen with me around. So, it is still a painful subject for me. I've got that list over on my desk over there. I still haven't brought myself to go through and decide which tapes I'm going to argue about.

**SS: I don't know anything about this. You mean, whether or not your name appears on it as a maker?**

JC: Whether or not I have access to use it.

**SS: Stuff that you shot?**

JC: Yes.

**SS: Okay, you need to explain this, because I don't know about this.**

JC: Can we just stop the camera for a second?

00:30:00 **SS: Okay, now we had our little off-camera discussion. So, you were part of *Testing the Limits* and you all never signed any agreements with each other at the time.**

JC: No, the agreement was that we would be there and we would document these actions. And we were going to try and provide a video message to the ACT UP mission.

**SS: I think what's really interesting is, in that moment back then, what did you think the future was going to look like? Because that's what your actions reflected — a certain vision.**

JC: I guess to really go back and capture the true level of my own naiveté; it would be like the anti-war organizing. By that, I mean the war would end. We would bring the boys home. That part, over time, was the hard part to deal with — that there was not going to be a distinct end to the AIDS crisis. In fact, it was going to continue to mutate and exhaust resources.

**SS: So, you were really in the urgency of the moment, and you were using all of your talents.**

JC: Yeah, for the first time I really felt immersed in what I wanted to do. I've always wanted to make films and videos. And being able to use this ability as part of a community that I felt really ensconced in was a truly wonderful experience.

**SS: How much of your week did you spend in ACT UP, in ACT UP-related activities?**

JC: Well, wait a second. You have to realize I was working full-time at GMHC and, especially in the beginning, spending all my other time at ACT UP. So, I would have to say that, especially between 1987 and 1989, it could be close to seventy or eighty

hours a week, including the weekends. That's what was happening then. A movement was growing.

**SS: What do you think you were expressing personally that led to such a huge commitment to AIDS at that time?**

JC: I was expressing solidarity with the movement. I have to say, in that period of time, I was growing as an individual but I had never been less aware of myself, because we were all going with a certain flow around us. I became more aware of this side of myself that would fight that would, if I needed to, get a camera between a cop's legs and push. And that was all good training for me later on, to see how to go about making videos with a community, whether it be my own or a community I'm not necessarily knowledgeable of.

**SS: Do you think there was also an avoidance, a personal avoidance on some level?**

JC: A personal avoidance? Explain to me a little bit more what you mean by that.

**SS: Well, you said that in some ways you were never more unaware of yourself. I'm just trying to understand what you mean by that.**

JC: Well, I don't know that I'd say — I was never so willing to let go of this identity as artist. Because the artist wasn't as important as being an activist. So, I began to just really see myself first as an activist and secondly as an artist.

**SS: Do you think that in the long term it hurt you professionally that you made this commitment at that time?**



00:35:00 JC: I don't know if it hurt me professionally. Did it hurt me in the long run professionally? Well, I suppose you could say that going to college hurt me professionally. If I had just wanted to be a professional working at a network or something, or in the film industry, I would have started doing production assistant work then. But I was always interested in hidden histories and in ways of representing things that were not out there. And that is still an important part of my life. So no, I can't say that, in my true professional aspiration, that anything I did around ACT UP hurt me.

**SS: So, let's get back to your activities in ACT UP. So, what were some of the other campaigns and events that you worked on, besides DIVA and *Testing the Limits*?**

JC: By campaigns and events, tell me —

**SS: Or committees, projects. Did you do organizing in a capacity other than video work?**

JC: Well, I'll go back in the case of *Cosmo*. I go back to that because that was an important demonstration on a number of levels. First of all, it was the first time the women in ACT UP really got organized. Second of all, it was the first time really that the video and the organizing were not separate. The organizing itself, from its very inception, had the component of video coverage in it.

**SS: So, let's start at the top, then. How did it get started, and how did the women in ACT UP get organized, and why this topic?**

JC: Like most of the best projects at ACT UP, I think they dropped out of these kinds of very casual social contexts. In this case, I think basically Maxine, and Rebecca, and some of the other people who were going —

**SS: Rebecca Cole?**

JC: Rebecca Cole and Maxine Wolfe were sitting in a diner, and somebody marched in with a copy of the *Cosmo* magazine that said that straight women don't have to be concerned about AIDS. Everybody was just so appalled at this. So right away, this anger was funneled into planning. And the planning was for an action that would be directed specifically against *Cosmopolitan* magazine. But beyond it just being an action against a building — which we had many actions that were basically in front of buildings, protesting in front of buildings — we wanted to do some different things. Like we wanted to try to interview Dr. Robert Gould, who wrote this particular piece. And actually, in retrospect, he was a pretty gay-friendly guy. He had done a lot of work trying to take gay sexuality off the list of psychiatric impairments. But in this case, he had put information out there that was really harming women or really harmful to women. And we wanted to know why he did this. So, we just picked up the phone, and called him, and arranged an interview. I brought the camera along.

**SS: Who went with you?**

JC: Denise Ribble, Maxine Wolfe, Maria Maggenti, Rebecca Cole. These were the people who were present at the interview. They are not the only people who organized the action. And at this interview, each one of them took on a different mode of questioning him. One person was questioning him why, in a work that supposedly was scientific, there were so few footnotes and why the research was so dated. Part of the article's assertion was that women in Africa were getting AIDS at such a higher rate because — and this is the quote from the magazine — men in Africa take their women in such a brutal way. So, I think it was Maxine who brought up the point that, in America,

00:40:00 so many women are raped. How can you say this? It's racist. Denise Ribble talked anecdotally about her experience actually treating women — straight women — with AIDS, that these women weren't lying. They did not get AIDS through anal sex, because this was what Dr. Gould was saying — that really healthy vaginal sex wasn't going to put you at risk that basically the women who were getting sick were ass-fucking and not telling the truth.

So, all of this put together would really explain what this action was about. So, *Doctors, Liars and Women AIDS Activists Say No to Cosmo* was a tape that I made with Maria Maggenti that essentially, first of all, told of a genesis of an action — how it began. But it also really tried to explain the issues by showing this interview in detail — what the doctor said and our response to it. And then it went on to actually show the action. As I mentioned before, this action itself was a way that we were getting educated about things like taking badge numbers and what to expect when you organize an action. But then, we brought this issue to the public eye, because then all of a sudden the mainstream media really picked up on it. Phil Donahue did a show on it, and *People Are Talking*. They all wanted to do shows with, essentially Dr. Robert Gould and some ill-equipped specialist to do some half-assed job refuting him. And the women who actually organized the action were not put on the panel. So, I think one of the most powerful — .

So, in terms of the organizing around *Cosmo*, for me the thing that really was mind-blowing was when we took over the set of *People Are Talking*. Essentially, this was our anger at being closed out of this particular show. All right, we had brought this issue about this article to national attention, and all of a sudden we were not allowed to

participate in the show. So, the people who did manage to sneak into the audience essentially took over the show. They marched on stage —

**SS: Who was it?**

JC: Chris Norwood and Denise Ribble marched on stage and sort of just sat down there and said, “Why don’t you have any women on this panel? You’re making us invisible. This is the message. You are killing women by making us invisible” — something to that effect. It was just so great to hear the host of the show say, “Can we get security in here?” to sort of shuffle these women out. That was the first time I really saw our activism subverting dominant media messages, taking over shows. And that would be something that ACT UP would do subsequently in a number of different interventions. But I thought it was so powerful when these shows, which are so scripted, and everything has a run-down, all of a sudden when people just say, “Uh-uh, we’re going to walk on stage and we’re going to do this.” It’s sort of similar to just walking in the center of the street without a permit, and sitting down, and being carried off.

**SS: Would you say this was the first time that ACT UP did that on a television show?**

JC: I’m sure. This was 1987. ACT UP was very young then, so I don’t think that had happened.

**SS: Did you constitute a committee?**

JC: Can I just add one thing? It’s not the first time, though, that people subverted the dominant media. I remember David Summers, when he was on the Donahue show, speaking out because a technician wouldn’t pin a mike on him, and just really vocalizing that we had an incident here, before, where this guy wouldn’t pin a mike on me because I

have AIDS. I'm just trying to counter this thing where so many characterize activism as really beginning with ACT UP. I do think that activism was really organized and energized by ACT UP, but I don't want to make the people before invisible — because too many aren't around.

**SS: Now did you guys constitute a committee around *Cosmo*, or was it just an independent action?**

00:45:00

JC: Well, at first it was an independent action, but very early on it became a caucus — the Women's Caucus. And the Women's Caucus would go on to do other actions. But the *Cosmo* action was really what melded us into a group.

**SS: And how did the floor receive this?**

JC: The idea for *Cosmo*? They went. They went for it. The guys were really there in support, and that was powerful, too.

**SS: So, there were no men in the Women's Caucus?**

JC: Not at that time, no.

**SS: So, what were some of your other actions? Well, let me just ask you. In the Women's Caucus, were there straight women in it also?**

JC: Yes, there were. There were straight women, there were lesbians, and there were also people who were migrating back and forth across those lines. That's also the thing that I hope you will pursue in this, just who was fucking who because it's just so fascinating.

**SS: Well, let's go there.**

JC: I'll never forget. Gregg Bordowitz and I have a long history together. We're very dear friends. But there was one time I remember being on a subway platform with

him when I really wanted to throw him on the tracks because I found out that he had basically slept with all the women I was attracted to.

**SS: What do you think was his appeal?**

JC: He's still around. I think his appeal is that he's very articulate, and he's got this kind of Leo "I'm very comfortable in my skin" thing going on. And he's charming. He's charming. I have to say, in terms of — I've had a lot of experience working with different people, and some of them were really, really difficult. But I can look back over the time with Gregg, working at GMHC — and sometimes we'd just be working late into the night — I can look back at those times as being some of the most productive collaborative moments of my life. When you can work with someone that deeply, that the idea, when it is not formed yet, is bouncing back and forth between the two of you — I still just enjoy hanging out.

**SS: How did you feel when the lesbians and gay men or men in ACT UP would have sexual relationships?**

JC: I felt better about it if I knew about it, than when I found out afterwards. How did I feel about it? There was a period of time in ACT UP when we really all used to socialize together. We used to go out to Escuelita, which was a popular club, and listen to the drag queens and just dance together. I really enjoyed that. I enjoyed it for the same reason I enjoyed that phenomena when it was happening at GMHC. I really enjoyed gay men and lesbians working together. I wasn't so crazy about negotiating around straight women and their issues with gay men. That was a little bit harder. But the thing is, within ACT UP — I'll put it straightforwardly — the straight women really had to sort of behave, because you couldn't get away with the same things that you could

at, let's say, GMHC. Because ACT UP, the lesbians within ACT UP, were very strong and vocal about not wanting to be made invisible once again.

**SS: When you say, "they had to behave," what do you mean explicitly?**

JC: The idea about making lesbians feel second class. That just wasn't going to wash. If you were going to work with the Women's Caucus, you had to be very comfortable around lesbians — very comfortable around them.

**SS: Do you think that there were straight women who left ACT UP because there were so many lesbians?**

JC: I'm sure that people might have gotten turned off. Maybe you've spoken to some of them. I don't know. But the women who stayed, whether they were straight, or lesbian, or bisexual — I think everybody there was essentially aware that they were just going to have to sort of negotiate the terrain. It was this activist environment. You were questioning everything. So, if you were having trouble with something within the group, you questioned it. It was something that was usually spoken about and addressed, in very many ways. I'll give you an example. I remember when Michelangelo [Signorile] and Gregg had just broken up, and Michelangelo just carried on for a long time after that. I think at that time Gregg was sleeping with Zoe Leonard. Michel just began one of his articles with this diatribe about bisexual people who don't put all their cards on the table. We were negotiating with these issues of sexual attraction between the group all the time, and it crossed boundaries — all kinds of boundaries. I know some people did not have good experiences with it.

**SS: Did you have sex with women in ACT UP?**

JC: Yeah, I did. Not enough, really not enough. But I did. It was a great part about being involved with ACT UP. The men were having sex with men, the women were having sex with women, men and women were having sex with each other. It boiled down to the Emma Goldman saying: “If I can’t dance, I don’t want your revolution.” If we can’t fuck, what are we doing here?

**SS: So, what were some of the other campaigns that the Women’s Caucus got involved with?**

JC: Well, another really successful action was around making a really distinctly male space into a medium for a message. And that’s what the Mets game was all about — how to go to Shea Stadium and really get the message out that men needed to use condoms, and that you could score with safer sex. “No glove, no love” was another saying.

**SS: How did this idea to go to Shea Stadium come up?**

JC: I have to say I do think it was — and I could be wrong here — but I think it was really pushed along by Rebecca Cole and Maxine Wolfe. I know at first that, being from Queens myself, and being a long-time baseball fan, I think I was intimidated at first. At the very beginning, I was like, “Eh, I don’t know.” It just seemed too big to go into a stadium of 60,000 people. It was really audacious. And it was a really wonderful action. Shortly into the organizing, though, I was on board, too. I just thought it was a fantastic idea.

**SS: So, it was organized by the Women’s Caucus.**

JC: Yes.

**SS: Okay, so tell me about what the action was.**



JC: Essentially, we bought a slew of tickets and arranged them throughout the stadium. And there would be different groups holding up different signs, or different pieces of signs, just like anyone who has a message to give, whether it's an insurance company, or "happy birthday, Dottie." You go there with your sign, and at the right moment when the cameras are rolling you get the sign visible. So, the women organized this, organized getting the seats, organized making the posters, and making sure that the action received support on the floor of ACT UP. A ton of people showed up. Everybody was facing all of the internalized homophobia that they had grown up with, specially around professional athletics. It was just a great day for everybody involved, and a real success — a real success for the Women's Caucus.

**SS: But why was the Women's Caucus interested in telling men at Shea Stadium to wear condoms? What does that have to do with women?**

JC: Well, so much of the early information around safer sex — the onus of it was always on women. Many of us realized that that was just half the picture. The other half of the picture was that straight men needed to be encouraged too to use condoms, that this was their responsibility. And I think truly it was something that people came along with from their feminist background. In fact, a lot of the strategies of ACT UP were things that were borrowed from the women's self-help movement — things around the handbook. That was definitely something that was influenced from the women's movement.

**SS: What handbook?**

JC: The *Women and AIDS* handbook. I wasn't a member of that group, at that time, so it's not something —

**SS: I just had a transmission question for you, back to the *Cosmo* thing.**

**Okay, so he was saying that heterosexual women are unlikely to get infected through vaginal intercourse. And you were saying that he was wrong. But statistically, hasn't that turned out to be true?**

JC: How many people have a healthy vagina? What we were saying is that, maybe in a perfect environment, this might prove true. But how many women have had chronic yeast?

**SS: But has AIDS ever become a heterosexual epidemic through sexual transmission?**

JC: Sure. Look what's happening in Africa.

**SS: I mean here.**

JC: Sure. The numbers — the fastest growing number right now are heterosexual women of color. It's definitely an issue here.

**SS: So how do you understand, just in terms of epidemiology or whatever, in the early years when we were in ACT UP, that the rates of heterosexual transmission — male to female — were so low, compared to how high they were male to male in those years?**

JC: How do I account for it? Well, let me just first say that I am not an epidemiologist, so this is just from someone who is a video maker. So that's where it's coming from. I think that in many cases it had to do with the number of sexual partners. I think it had to do with a lot of different co-factors that were going on, a lot of STDs that were chronic. That's why the numbers initially were so high in the gay male community, and a lot higher than for women.

**SS: So, you're saying that co-factors which may still not be known —**

JC: Well, some of them were. Cytomegalovirus — that was just so rampant. Hepatitis. People's immune systems were getting bombarded over time when they were sexually active. If you want to know why I think the number was initially so much higher, I would look to that.

**SS: So, what were some of the other campaigns that you were part of?**

JC: *Seize Control of the FDA* was a tape that Gregg and I made that was around the FDA action. This wasn't specifically a Women's Caucus action. I felt at this point I had sort of moved out of being specifically only with the Women's Caucus and was doing more general work, and also more work with DIVA TV, the Damned Interfering Video Activists. So, at the FDA, every single affinity group there had some contact with the camera crew. At least one camera person was assigned to cover each affinity group, so that everyone would not only have some kind of surveillance, make sure they were on the map, but also that the actions that they chose to do were documented and part of the bigger picture. I look back at that tape and the final the images were burning an effigy of Ronald Reagan, and just chanting: "Seize control, seize control, seize control." We had just done so much work. At this point, the media was listening to us. We were sculpting media events put out there, and also then shaping our own messages from these events that would be used to document our own histories. *Seize Control of the FDA* is a tape that documents this action. But it was like a clarion call for us at the time, those of us who were so — maybe we spent half the day in jail, we could come back and we could watch the tape and see the action as a whole.

**SS: What was the point of the FDA action?**

01:00:00 JC: To really move things along with access to drugs. At that point, the FDA approval process was so arcane and so — oh God, it was like cooking with glue on the floor. You just couldn't get things moving along quick enough. And also, it is still — different companies like Lyphomed were just charging amazing amounts of money for the drugs. So, it was to both get access to more drugs, and also to do that by speeding up the approval process, but also to shed light on how expensive these medicines were for people with AIDS.

**SS: Now what was the difference between DIVA and *Testing the Limits*?**

JC: It was a question of roster — who was doing what. And at times, some of these groups co-mingled. I know for Gregg and myself, we were in both. *Testing the Limits* was a collective that was formed earlier than DIVA. Originally, it included Gregg Bordowitz, Hilery Kipnis, David Meieran, Sandra Elgear, and Robyn Hutt, and myself. I was in on the first tape. And then it grew. More people came into that. DIVA TV, which was an affinity group of activists who wanted to specifically work with video within ACT UP — the early people I remember there were Ray Navarro, who was an early person involved with DIVA, as was Ellen Spiro, Catherine Saalfield, Gregg Bordowitz, Costa Pappas. Jim, when did you come into DIVA? Were you in the original group?

**James Wentzy: 1990.**

**SS: Where did the idea for the FDA action come from?**

JC: I think it grew out of this general concern that we all had from the very beginning of access to treatment, access to drugs. That's what it grew out of it.

**SS: And where did the slogan “seize control of the FDA” come from?**

JC: It came out of one of the chants that grew. There were a lot of chants that ended up becoming slogans for us: “seize control, seize control.” People were chanting this as they were marching towards the building. What they were doing is this kind of lock arms things where they would squat whenever the police approached them and chant this. Then, when the police might back off a bit, they would get up and they would move forward more. But that’s where I remember it coming from.

**SS: What other campaigns? Were you involved in the CDC definition campaign?**

JC: The first one. I went to CDC the first time to change the definition.

**SS: Do you remember how that got started, that campaign?**

JC: Well, a lot of it, as I recall, got started around Terry McGovern’s work with women who were routinely being denied benefits — were not getting benefits because their conditions didn’t satisfy these criteria that were set up with the gay male model. So, things that were killing women weren’t on the list that would qualify them for benefits. By the time they get the benefits, they would be dead — or practically dead. So, this is what necessitated that specific action to get the women benefits.

**SS: What about women with AIDS inside ACT UP? What was their relationship to you guys, to the rest of the Women’s Caucus?**

JC: Specifically around this action, I know a lot of the plaintiffs in Terry’s case were a part of the action and spoke out in front of the Health and Human Services building. I remember that was one of the times that I remember just crying and doing camera work. Because at one point during the action in front of HHS, whenever a woman was going to speak about her case we sounded these horns and everybody sat

down and shut up. And it was really notable, because before that we were all chanting, we were marching and chanting. “How many more have to die before you say they qualify,” was one of the chants I remember. But when that horn went off, everybody shut up. And I remember specifically when Iris De La Cruz took the megaphone and spoke about not being able to get health care. She said her physician didn’t take food stamps. Clearly women — their needs weren’t being met.

**SS: But inside the organization, like on the floor of ACT UP, women with AIDS, where were they in the organization, or who were they?**

JC: The women with AIDS — I’m trying to go back here.

**SS: Like Katrina Haslip.**

JC: Katrina Haslip didn’t like ACT UP or wasn’t particularly fond. I don’t remember seeing a heck of a lot of Katrina. I know she hated, I think, GMHC. I don’t know that many of these women really felt a strong affinity for being within ACT UP. There were some. I know that Iris loved ACT UP, because she was an activist at heart. I think some women might have felt left out of ACT UP — some of the very same women who were up there with the megaphones. I don’t know. I don’t remember seeing somebody like Phyllis Sharpe, who was somebody who was there that day. Do you remember seeing a lot of Katrina at meetings?

**SS: Yes.**

JC: Really?

**SS: Yeah. There was a period of time when she used to come a lot — I think up until she got sick.**

JC: And what period are we talking about?

**SS: I don't know what year. It's kind of like when Tracy Morgan first joined. I remember them and Maxine hanging out with Katrina — also Marina Alvarez.**

JC: That was later. Marina is more in the early 1990s. So, in answer to your question, then, when women were present on the floor they would be with the women from the Women's Caucus, because that was their connection to the group.

**SS: So, what was the structure of ACT UP? How did decisions get made?**

JC: I still use ACT UP when trying to organize my students, because I think that the basic organizing strategy is a really sound one. Each meeting would be moderated and the moderator for the meeting would be a rotating moderator. It wouldn't be one person all the time. The purpose of these meetings was to inform and to organize. So, when you walked into a meeting, you'd walk through a table of different literature about events and about issues that you needed to know about. You would get educated at the meeting or you would find out more. People would propose actions, find out if there was support for the action on the floor, find out maybe if some part of the action needed to be modified so that more people would get on board. And it would go forward. Some very interesting discussions would happen. I remember very early on that there was a discussion about an action where we were going to carry coffins through the streets. And Griff Gold, who at that time was head of PWAC, sort of came out of the sidelines and said, "Uh-uh. Can't you folks think of any other way to represent people with AIDS other than carrying coffins?" As time went on, ACT UP did indeed carry coffins at the City Hall action, but that was in a different context.

**SS: What was different?**

01:10:00 JC: What was different was that so many people in ACT UP had died that there was no denying that people were not only living with AIDS, they were also dying of it in massive numbers. And that wasn't a crime. People died of AIDS and that had to be recognized. Whereas at this point in time, people with AIDS, people at PWAC, were fighting so hard to stay on board of this movement that was about them. So I think part of Griff's frustration, and part of a lot of the frustration of people who were still alive now, who were active at PWAC, was that ACT UP came along and basically got a lot of credit and coverage for things that people at PWAC — like smuggling drugs and doing that kind of thing. People at PWAC had been doing that back in the early 1980s, but that wasn't so well known. Or the idea that somebody could make AL721 in their bathtub. I mean, that wasn't as celebrated as marching on the FDA. Or the idea that I'm a person living with AIDS and I don't want you to look at me as a dying victim. That in itself was such a statement of empowerment, and one that Griff really wanted to get across to many people in that room who at that time may have been sero-positive and just didn't know it or were making assumptions about their own health. So maybe the idea of carrying a coffin wasn't so threatening.

**SS: So how was illness and death dealt with inside ACT UP, culturally, in the culture of the organization?**

JC: You know, I think one of the most important documentations of how the issue of illness and death was dealt with in ACT UP is Douglas Crimp's essay, "On Mourning and Militancy." And this is one of the few times when I think that an academic really helped us to understand what was going on. Because too often in ACT UP, I think, academics — people look at the academics and think how much they



influenced ACT UP. That is just not true. If anything, ACT UP influenced a hell of a lot of academics and really invigorated their work. And at a moment when I'm most generous, I am just going to say you cannot deny that there was cross-pollination going both ways. But in "On Mourning and Militancy," Douglas lays out how at first we were really reluctant to give into our own grief — the kind of Joe Hill message: "Don't mourn, organize." That was really a strong part of our make-up. But over time, we had to stop and give ourselves time to really open up to the fact that, whoa, we weren't going to end this immediately. And even if it did, our own community, or our communities, had been so devastated that that had to be acknowledged. And it was going to be acknowledged — I don't know that Douglas said this, but I'll say it. It certainly wasn't going to be encompassed completely by a quilt or whatnot. It's much broader.

**SS: Were the particular deaths that affected you differently than the general experience of the constant death rate there?**

JC: I will say that Ray Navarro's death had a big impact on all of us who were doing video activism at the time, because Ray was such a — he was one of these art school guys out of the Whitney Program who also, I think, had his head straight as an activist. He'd look at the flack that occurred after the St. Pat's protest, right? And in front of the group — because people in ACT UP were really questioning themselves. Many were. There were a lot of folks who felt that we never should have done that action. There were a lot of folks that felt, "Oh, maybe we went too far." But Ray got up and said, "You know, it sounds to me like we're letting our perception of this event be structured by the media and by the aftermath of the St. Pat's action." So, he was able to provide those kinds of insights.

**SS: How did you feel about “Stop the Church?”**

01:15:00 JC: About “Stop the Church?” How did I feel about it? I felt like it was time to challenge the Church. I didn’t have a problem with that. I don’t know, in the long run, how much was gained by that action. It wasn’t one of the ones that I felt more strongly about. But in the end, I’m not going to say I didn’t think we should do it. I think that it really showed the American public how serious we were about this. Let me just say, it was also really powerful because Ray, whose own illness was progressing very quickly, dressed as Jesus Christ that day outside was sort of leading chants outside of St. Pat’s. And in his own way, as someone who had grown up Catholic, too, was sort of reclaiming this Christ figure as a revolutionary — use of Christ as someone saying, “Use condoms.” As he grew closer to death, he became more and more religious. So, for him, that action was a very empowering action for getting him closer to his own spirituality. And for me, it was powerful for that reason, too, to just get in the face of the Catholic Church and go up against this monolithic behemoth that has grown beyond all proportions from its original inception.

**SS: So, I want to talk a little bit about the lesbian transmission debates inside ACT UP.**

JC: It would be good if Jane [Rosett] was here, too. Because actually, Jane and I were on — I don’t know that I would say “different sides.” I hate to think about that lesbian transmission thing as a binary opposition, as like there were people who were against it and people who were for it. There were people who wanted to talk about it and there were people who didn’t think it was relevant. And I thought it was relevant. And I still think it’s relevant.

**SS: What do you think made it bubble up? What do you think made it surface as an issue? One of the many, many controversial debates in ACT UP was about lesbian transmission — does it exist, and if it does what should we do about it? Do you recall how that debate started or why?**

JC: How the debate started — well, I remember how we started talking about safer-sex and what that might mean for lesbians. Part of it was that people like Denise Ribble, who were seeing women at the Community Health Project at the Gay and Lesbian Center were seeing some lesbians. So, what would safer-sex practice be for lesbians?

**SS: Now let me ask you, in your own sexual practice did you have any concern about HIV transmission in the day?**

JC: I wish one of these cameras was on you, because this is going to end up being a discussion. Yes, it did. First of all, dental dams is what garnered a lot of the controversy, understandably. It's a hard sell for women who have always been taught that they're dirty so all of a sudden have to put a piece of saran wrap in their lover's crotch. Now for me, safer-sex practice was never so much around dental dams, because I never felt that saliva-to-vaginal secretions was a mode of transmission. However, I am someone who does a lot of construction work. So, I can tell you it's changed my practice, in that if my hands were cut up I would not put them inside another woman without putting some kind of glove on my hand, because the possibility of blood-to-blood was there. So, for me, the practice changed. Or I might choose to do something else that night if I didn't have a glove. So that is how it changed my practice. And that is, for me, what the discussion was always about. It was about talking about lesbian sexuality and

talking about what really transmission was and figuring out if there was any risk. And if there was risk, how to make you more comfortable with that level of risk.

01:20:00           **SS: Now looking back with hindsight, which is 100 percent, do you think that that concern of yours at that time was actually justified by fact, or that it was emotionally justified?**

JC: Well, I still, if my hands are — I have to say, it helped me draw a lot of lines. I still, if my hands are bloody, or if my hands have open cuts on them, I am not going to put them inside another person's body. I just don't think that that's wise. By the same token — and I'm not saying this is any kind of risk for HIV — it just made me think more about my own sexual practice. Many of us transmit yeast infections between each other because we don't wash our hands. But what I was saying all along is not, "Hey, let's put the lid on lesbian sexuality by talking about safer-sex practice." What I wanted to talk about was lesbian sex practices and any health problems that might come up. And HIV, in my opinion, is one that people need to think about.

**SS: Do you believe that HIV can be transmitted sexually between women?**

JC: Yeah. If I'm talking about fucking with cuts on my hand, there is the potential for blood-to-blood transmission there. So, I do believe it is possible.

**SS: So, what happened when this discussion came to the floor, and how did it surface in ACT UP?**

JC: You know, it's hard for me because my memory of this discussion is not just an ACT UP memory. A lot of this for me is flavored through GMHC, because at the time Gregg and I were involved in producing a series of safer-sex shorts and one of them was for women. The one that was for women did cause a little bit of controversy, because we

had an interracial cast. So that interracial cast, because the butch woman in the video was a Black woman —

**SS: Who was the actress?**

JC: Joy. Her last name is Joy Brown.

**SS: Oh yeah, sure. She was my UPS driver.**

JC: And you know how I met Joy? Joy and I went to high school together. So, one day I ran into her on the street. And you know Joy. She is just so friendly and she's so over the top. She was asking me what I was doing, and I was telling her. And I told her about the safer-sex shorts, and she was really excited about it. She wanted to play a role in it. The other person in the video is Annie Sprinkle, who is always an amazing advocate, and who is still — she just got her doctorate in human sexuality. And she is someone who, as a former sex worker, fought to make safer sex a reality on sets of porn films. So, my whole experience of this came through making this safer-sex video and all the fall-out that happened afterward.

**SS: So, who objected? Where did the fall-out come from?**

JC: The fall-out was because I had cast a Black woman as a butch.

**SS: But who objected?**

JC: Well, the real objections that I heard came at a conference called “How Do I Look?” At the conference, the question came up. I think it might have been Isaac Julien. Isaac Julien and some of the other people there were questioning why I chose to put a Black woman in a butch role. My answer to it at that time was partially, “This is one video. You can't expect this one video to represent the whole panorama of sexuality.” In fact, we had tried to address that by having the butch woman be in both the passive and

aggressive roles within the video. But it wasn't good enough. I think a lot of it was that this tape became a lightning rod for a discussion that needed to happen within the community, and that discussion was about sexual stereotyping. And a lot of that discussion happened around the tape.

**SS: So how did it come up within ACT UP?**

01:25:00

JC: The issue of lesbian safer sex?

**SS: Yes.**

JC: I don't know. What do you remember?

**SS: Well, this is about you.**

JC: I'm trying to remember this, Sarah.

**SS: Well, how was this resolved? Do you remember anything about it, about how it was received, how it was resolved?**

JC: Well, I don't remember any kind of — I don't know if the issue was still resolved. One of the things that did happen was a lot of advocacy happened over at GMHC to start a lesbian AIDS project. And a lot of the people from ACT UP like Rebecca Cole and — well, Denise was there at the time, too — fought to get some real education and resources directed towards lesbians from GMHC. Some of the action that happened within ACT UP is that there was some safer-sex information for lesbians that was put out in the handbook. But there is an event specifically in your mind that you're trying to get me to come up with and I can't. I don't know what it is. Tell me. It might spark a memory.

**SS: No, no, I just remember like a very impassioned debate. It doesn't matter.**

JC: I don't think I saw that debate. Do you think it's totally impossible for lesbians to get HIV from having sex with each other?

**SS: You can interview me when it's my turn. Right now, we're talking to you. So, what was the relationship between ACT UP and GMHC?**

JC: I think it was unnecessarily acrimonious at times. A part of it was AIDS chic reinventing itself over and over again.

**SS: AIDS chic? What's that?**

JC: Well, GMHC in its own way invented AIDS chic. In other words, part of how GMHC became so successful is they were able to put it out to the community that being involved with GMHC was not just something you needed to do for your community, but it was *the* thing to do — going to the circus. It was *the* event of the season. That's what I mean by AIDS chic. When ACT UP came along, they reinvented it. In other words, it was now very stodgy and very bourgie to go to these GMHC events, because now what you should be doing was you needed to wear your \$10 t-shirt with the pink triangle and you needed to put on your jeans and go out in the street. And AIDS chic transformed itself into a much more proletariat and a much more activist model. So, all of a sudden — I remember at times I got it from both sides, you know. People from ACT UP would look at you distrustfully if you worked at GMHC early on. And also, I remember editing footage from the first ACT UP demo where a lot of GMHC board members got arrested. Rodger MacFarlane got arrested. Larry was an organizer — well, he was a former board member at that time. But Richard Dunne, the then-executive director of GMHC came along and said, "Did you shoot that on GMHC's time?" So, the

assumption was that the mission of ACT UP was entirely different than the mission of GMHC. So, on both ends, that's what I mean. It was unnecessarily acrimonious.

**SS: What do you think was the core ideological conflict?**

01:30:00 Well, there are two things going on here. First of all, it was a contest for who was going to control the discourse around AIDS. Was it going to be in an increasingly professional model, like "We're going to care for people. We're going to set up this whole professional organization to manage the care and advocacy of people living with AIDS," which was the GMHC model. Or was it going to be, "The rules are fucked and nothing's going to change until we get out there and we change them, and we advocate." So really the two messages should have been complementary and not competitive, because there was a need to have an organization that was managing care for people with AIDS, because the changes did not happen automatically. And GMHC lessened the suffering and continues to lessen the suffering of people with AIDS. But at the same time, without ACT UP there would be no changing of society. ACT UP changed the health care delivery system. It changed the way drugs are approved. It changed the very way people conceive of gays and lesbians in our society.

**SS: And how is that? In what way?**

JC: I think it did an enormous amount to really shake people up about their homophobia: "Are you so homophobic that you're really glad these folks are dying?" I mean, you'd have to be pretty out about your homophobia, or you have to be so misguided by religion to really think it's God's will or God's punishment that somebody suffers.



**SS: Do you remember particular instances of people that you knew who were sick, who experienced homophobia either from people they knew or from institutions?**

JC: It's hard to think of anyone who didn't experience some kind of homophobia on one level or another. Haven't you ever had a case where you've tried to tell your family that you were grieving over someone who was just lost and they don't take your grief seriously because that person died of AIDS? I know I have. I've experienced it personally. I remember seeing the trays on the floor because people wouldn't bring them into the bedrooms or the hospital rooms. So yeah, I think homophobia — like I said in the beginning, homophobia was the issue that really brought me to AIDS. Especially in the beginning, it was just so overwhelming in the Reagan years.

**SS: Were you involved with people who were dying, who had no family support around their illness?**

JC: As recently as a year or two ago, my friend Michael Parsons — he's one of the guys who didn't react well to the cocktails. He ended up dying on Christmas Eve two years ago in his best friend's arms. His family wasn't really there for him.

**SS: Was that common?**

JC: Yeah, of course it was. It was more prevalent than families who embraced their children. That was my experience of it.

**SS: Did you interact with people's families when you were involved with friends who were dying?**

JC: I tended to interact with the families more when they were really cool. I put Ray Navarro's mother up when she came in. And I have such respect when a family

member is willing to take responsibility on the level that she did. She came in and she basically organized all of Ray's friends so that we could give him round-the-clock care. But she's really special, and she's an activist in her own right. In the case of someone like Patricia Navarro, being involved with the family was quite easy. In the case of others, they weren't giving you much to work with. If they're not accepting their own child, it's very hard for them to accept a friend of that child. You're hanging by a thread of a thread.

**SS: Why did you leave ACT UP?**

JC: You know, I didn't make any conscious effort to leave and just say, "I'm through with that place." I never did that. I just got really burnt out and sort of withdraw from life in general for a period of time. A lot of that was about the cumulative amounts of deaths that happened. I just got really introspective.

**SS: When would you say that was?**

01:35:00

JC: Around 1993/1994. That's also when I left GMHC. You know how many tapes I made around the issue of AIDS? Just an enormous amount. I still make tapes about people with AIDS. I still make tapes around the HIV/AIDS pandemic. But I have to do other things, too. I got burnt out to the level that I needed to infuse a little other reality into my life.

**SS: I remember back in the day there was always this discussion of, for those of us women who were so committed to the issue of AIDS, people used to say, "If the shoe was on the other foot, none of those men would do anything for you."**

JC: I've heard that a lot.

**SS: What is your feeling about that?**

JC: You know, I grew up an Italian-American working class woman. So, I can't tell you how many wedding gifts I've given, how many shower gifts I've given. I'm never going to get any of that back. So, the kind of sentiment that you have expressed in this anecdote about how many lesbians would say, "If the shoe were on the other foot, would the men come through for us?" — I can understand the anger and the bitterness behind this. But I never felt that what I was doing was totally altruistic. I felt, and I still feel, the essential changes that have come down are beneficial to me and they're beneficial to society in general. So, if the shoe were on the other foot, I think the men would be there.

**SS: Do you think there has been a transformation in power sharing between men and women, gay men and women, because of AIDS? Do you think that's been a permanent change?**

JC: Well, it's starting to swing back. It swings along with the political climate right now. From what I can see, yes there have been some advances. But right now the real power positions have basically fallen into the hands of gay, white men.

**SS: Let me just ask you, just to bring this to a close, because we have talked about a lot of things —**

JC: Yes, we have. I thought I couldn't talk for forty minutes.

**SS: What would you say were ACT UP's greatest achievements, and what would you say were its most disappointing errors?**

JC: I think ACT UP's greatest achievement was in providing a whole generation of people the sense that activism works, a sense that they could make change by advocacy and by resisting normalcy. That is an amazing general change. The way that

came down is we changed the way drugs are approved. We changed the price of certain drugs. We changed the way people talk about sex. We changed the way civil rights for gay people are administered for gays and lesbians. So, the changes have been extremely pervasive — all pervasive. It's failures — how ACT UP failed. I think ACT UP failed because people became impatient with the process and felt that, "If only we would just let certain people take control of the movement, ACT UP would get out of its morass." All of these endless discussions on are we fighting for treatment or are we fighting for general change in society — people became impatient with that. So, they started attacking people on either end. The movement just began to eat itself up from the inside, and that was painful to watch. I think it also came at a time when energy was low because so many deaths had occurred.

**SS: Can you be more specific about that debate? Can you characterize it with a little more clarity?**

01:40:00

JC: Well, I can. It's just one of those things where it's been talked about so many different times. I hope that I'm really talking about the issue and not talking about the gossip around the issue. But the discussion really centered around people who — when we really started to make change, when the drug approval process was changed, when the prices of drugs were impacted, there was a sense that we really could have a massive power in this arena. At the same time, people wanted to work on broader issues. They wanted to work on issues of concern to people of color, to women. They wanted to work on prisoners' rights. They really wanted to attack all of the phobias and all of the isms that are inherent in our society. That's a much more general message. And I think, for a lot of people — maybe the people who came from more conservative backgrounds —

they found themselves going further and further out on a ledge for issues that they cared less and less about. So, at that point, they retreated to a position saying, “Hey, why are we diffusing our message and our energies? Why aren’t we focusing on what we know works and what we’ve had success with?”

And on the other side, people really wanted to initiate change and really wanted to follow the big numbers in the epidemic. It was a struggle also between different individuals — visible individuals — within ACT UP. I know Maxine got a lot of heat during all of that because Maxine Wolfe was someone who was very visible on the side of “let’s make this a broader effort.”

**SS: What do you think were the long-term consequences of that debate?**

JC: Well, I think because so many people sort of spun off, it wasn’t a debate that engaged people. It was the kind of debate that sent people back into their own corners. So, one of the long-term repercussions of it was that it factionalized ACT UP. It sort of factionalized people. More and more the people who were questioning getting bogged down I think ended up in power positions, in powerful organizations, or at powerful companies. The people who had more of a social focus ended up, once again, going back to the periphery of the periphery.

**SS: And do you see any of that reflected in the current AIDS situation?**

JC: Well, the current AIDS situation just begs the question of why didn’t we follow the initial — let me start again. What we see in AIDS right now is all of the social messages that we were trying to get across have just come through with a vengeance. I mean, what we need to do more than ever is talk about social issues and we need to talk

about them on a global scale. You know, this kind of complacency, or this normalcy sort of sapped the energy of ACT UP is now — it's a deadly attitude.

**SS: Thank you, Jean.**

JC: On that last one, I know, I'm sorry, my energy is down but it's such an important part of it. All of the social issues that people were advocating for have come through with a vengeance.

01:44:48

**SS: Okay, thank you. You just talked for two hours. That's good.**