

# **A C T U P O R A L H I S T O R Y P R O J E C T**

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Interviewee: **Herb Spiers**

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ACT UP Oral History Project  
Interview of Herb Spiers  
July 2, 2008

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00:01:10

**SARAH SCHULMAN:** Start by saying your name, your age, today's date, and where we are.

HERB SPIERS: Okay. I'm Herb Spiers. I'm sixty-two. We're at my home at 43 East 19<sup>th</sup> Street, New York, New York.

**SS: And today's date?**

HS: Today's date is July 2, 2008.

**SS: Okay. Great. I was going to say we're really happy to have the opportunity to interview you. Thank you so much.**

HS: Thank you. My pleasure.

**SS: So where were you born?**

HS: I was born in Columbus, Ohio.

**SS: In the city itself?**

HS: In the city itself.

**SS: And are you from a long line of Ohio people?**

HS: Yes, on both sides of the family.

**SS: Do you know when they got there?**

HS: I don't know the exact date that the Spiers side of the family got there, but we had one relative who was in Jamestown and fought in the Revolutionary War, and they eventually migrated from there to Pittsburgh and then into the Central Ohio area, and this would have been back in the 1800s, early 1800s.

**SS: Were your grandparents farmers?**

HS: Not my grandparents. My grandparents on my mother's side were first-generation Swiss. My grandparents on my father's side, they were the ones who had been here for a long time, and originally the further you go back, they were farmers, yeah.

**SS: And so what did your parents do?**

HS: My dad worked for the county government in the engineering department, and my mother was a housewife.

**SS: So when you were growing up, did your family try to instill in you any kind of sense of accountability to a community or responsibility for others?**

HS: Indirectly, I would say. Since my father worked for the Franklin County Engineers, the chief engineer was an elected position, and as a result, his job depended on the Democratic Party continuing to hold the position of county engineer. So we would go out and help in voting drives or handing out leaflets and things like that. The only closest answer that we would have ever got instilled in us a sense of community responsibility would have been through the church, and that was more strictly related to community obligations of the Catholic Church and its policies and predilections.

**SS: Was there any kind of discussion of social justice that accompanied that?**

HS: No, no, not really. In all fairness, no.

**SS: So what was it like being gay in high school in Columbus, Ohio?**

HS: Extremely difficult, extremely painful, as I'm sure you've heard countless times, particularly for men and women in my generation. Every aspect and every detail of my life had to be hidden and to be careful not to slip up, because, you

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know, commonly used word after, what, the fifth grade, sixth grade, was “queer,” “faggot,” and it was a term of use. I went to an all-boys’ school, too, which was a Catholic seminary preparatory, and so I was surrounded by boys that I had the hots for, and I just really, really had to be extremely careful. And for me it was difficult because my mother had this notion that I should be an actor or a dancer, so instead of after school playing basketball and things like that with the boys, I had to go off to acting classes and dancing classes, and so I had the label of being a sissy. I also, sort of as a compensation, had the reputation of being a daredevil, that I’d try risky things, physically risky things. So that sort of covered it up, but it was very, very difficult.

**SS: Were you having sex with other boys in high school?**

HS: No. No.

**SS: Were you aware of anyone else being gay?**

HS: No. No. Furthest thought from my mind that anybody else could be gay. Well, of course, back then when I was in high school, I’d never heard the word “gay.” Gay meant happy. It was queer. It wasn’t even the word “homosexual.” It was queer, faggot, derogatory words.

**SS: So when you were in a theatrical milieu, you had no exposure to gay men?**

HS: The first time I think I had exposure to gay men was when I did a play, *A Winter’s Tale*, and I played the prince, and it was a production of Ohio State University, and since it was through their theater arts department, I came across a number of gay men. But it was more a sensitivity than an intellectual awareness, because I was only in the fourth grade then.

**SS: Now, this kind of primary alienation from the place that you're growing up in, do you feel that ultimately it freed you from that place? In other words, if you had been straight, do you think you would have ended up living there and living out that life?**

HS: Yes. If I were straight, I think that I would have wound up perhaps a professor or perhaps involved in local politics. I would have married my oldest friend in the world who still lives there, named Patty Ryan, who is – oh, I shouldn't say that – my oldest friend in the world, and I think we'd have been married and had a family and probably would have, both of us, been in politics, something like that.

**SS: So when did you start plotting your escape?**

HS: I thought I'd never escape, first, but it happened when I was in a graduate school and I drove up to Toronto several times with a friend. At one of those playtimes, I met a young boy and we fell in love, and the decision was, well, would he live in Columbus, Ohio, or would I live in Toronto? Well, for me there was no choice. I could never ask anybody to come down to Columbus, Ohio. Toronto, in comparison, was a far more liberated place, at least for me. So that was my mode of escape.

My first escape was through a great friend named Tom Rossetti, who's still a very close friend, when I moved from my parents' house into my own apartment, and that's when I was free to come out. They helped me see a psychiatrist who suggested the revolutionary idea that I could be a happy homosexual, and to me that was – I can still feel the chill going up my spine at this concept that there could be such a creature. So it was Tom then and his wife, Carol, that helped me along the path, and I started having sex

with men and meeting men in Columbus and finding what gay life there was and things like that. And then in Toronto it was a whole different ballpark altogether.

**SS: What was gay life in Columbus, Ohio, at that time?**

HS: It's probably like most places. It was sequestered, covert. What gay bars there were, the main one that I went to, you had to go in – you parked in the back and went through the back door as opposed to the front door. There were a number of private parties that were thrown by people. There were after-hours places that you would go. All of it was very sequestered, very hidden.

**SS: Were most of the men married, or were people living a gay life?**

HS: Most of them were single. Maybe a few were married, but most all of them were single.

**SS: So when you went to graduate school, that was at Ohio State?**

HS: I went to graduate school at Ohio State and then I went to graduate school at the University of Toronto.

**SS: And what were you studying?**

HS: Philosophy.

**SS: So then you moved in with your lover in Toronto?**

HS: We moved into a household where he was living with his current lover. It was little romantically convoluted, but there were four of us living in this small second floor of a townhouse, second and third floor of a townhouse in Toronto.

**SS: And what year was that?**

HS: This is around 1969 or 1970.

**SS: So, I mean, this kind of communal setup, was this like a gay liberation household?**

HS: No, that was not. David, whose lease it was, and he was the lover of my boyfriend, Grant, was connected – in Toronto, a subterranean group of gay men and what we would call now lipstick lesbians, who were professional women, very beautiful, very glamorous, and they would have special parties that you were invited to or not. Of course, there were some gay bars in Toronto and we went to them. But our connection was mainly through this group of private individuals. But I did get involved for the first time with gay liberation in Toronto.

**SS: How did that happen?**

HS: I heard about a meeting of an organization called the Community Homophile Association of Toronto, and it was meeting at a place called Trinity Church, and I said to Grant, “I want to go to this,” and we went to a meeting. I found it exhilarating, and much to my surprise, I stood up and started talking, and I must have said something or said it in such a way that noted the attention of a lot of people, because afterwards people were just surrounding me. And then I got involved with that and I got involved with a very radical group that I became the convener, I think we called it, called Toronto Gay Action. It was direct radical action informed by the Gay Liberation Front of London, England, of all places. Eventually that led to the founding of the first gay liberation newspaper in Canada, one of the earliest in North America, called *The Body Politic*.

**SS: For which we're all very grateful.**

HS: Yes. I was at the first, the collecting meeting that organized it, and I've been involved in it for many, many years afterwards until I moved here down to New York, and there were many firsts connected with that in Toronto in terms of our gay liberation activities and the publication of *The Body Politic*.

**SS: Okay. I want to get back to the homophile organization, because from its name, it sounds like it was not a gay liberation organization, it was from the old school gay rights movement. Is that right?**

HS: Yes, and it was amazing, Sarah, that you would go to these meetings in the church, and there were sometimes three and four hundred people, and by the questions, the debates, the comments, you could see the divide almost right down the middle, between those who wanted to work within the system and that argued you could bring change in the current system by appealing to democratic processes that were supposedly in existence, and those who took a contrary view that said, no, the system would never give and you couldn't work into it; you had to go outside of that. So there was this internal debate, very vociferous, divided people along personality lines and things like that. And yet at the same time, curiously enough, there was a commitment from everybody that the Homophile Associate was something unique and something important that was bringing in huge numbers of people, relatively speaking, to identify themselves as gay, to be willing in some rudimentary way to come out, not the way we would think of coming out today, but at least to themselves and being involved, to come to the dances that we organized, sometimes to go on marches, very polite demonstrations, like Frank Kameny and the original group used to have.

Being in Canada, we were all very aware of us, those who were professional homosexuals at the time, were very much aware of what was happening here in the United States and with groups like that. So it attempted to be a mainline main road, and I was on the board of directors of it, and I was also the convener of the activists group, and so I was seen sort of as a conduit, a way of each group talking to each other without getting terribly divisive or hysterical.

**SS: Let me just ask you, do we need to ask these guys to be quiet?**

**JAMES WENTZY: No, they're fine. I just have to tweak this mic.**

**SS: So the mass organization was the homophile organization, and the gay liberation was the vanguard smaller group.**

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HS: Very small, yeah.

**SS: And what attracted you to gay liberation? What did it speak to in you that homophile movement did not?**

HS: Well, when I was living back in Columbus, Ohio, and I thought that I would never escape from that environ, I, of course, had read about Stonewall, and I imagined that nothing could be better than to live in New York, being a gay activist and doing something. It was very imprecise thought and feeling. It was more feeling than thought. So when I got to Toronto and there was there before me, it just {SNAPS FINGERS} took me up like that. There was never a second turning back. It caused the end of the relationship with my lover, Grant, because we went out on demonstrations and sit-ins, and I remember one we went to a straight bar to do a kiss-in, and we were chased out with beer bottles and all that, and it just frightened him profoundly, such that he couldn't deal with that, and so we eventually split up. But even then, staying in a

relationship with him or being involved with the principles and the philosophy that I adhere to, but more importantly, I think, the people that I was meeting and was sharing a life in, there was just absolutely no choice. There was its own Weltanschauung, if I could choose that phrase.

**SS: I don't know what that is.**

HS: It's a world view, a whole way of being. It was a totally consuming. It informed every aspect of my personality.

**SS: I want to ask you about sexuality and sexual values, the difference between the homophile movement and gay liberation, because you were in a non-monogamous couple. You were living collectively, even though Grant was more conservative and afraid to be out, but you had a more revolutionary sexual value system.**

DH: Well, Grant and I technically were monogamous. We were only living with our ex-lover, his ex-lover, and another roommate. At some point along the line we decided that – I probably said – no, I remember once on the street I told him I didn't think I could be monogamous, and he became hysterical right on the street. And I said, oh, my god, if he's going to be like this, I'll be monogamous. No big deal. But eventually that just changed.

Once Grant and I moved, moved out, one of the gay liberationists moved in with me, and then we moved into a little commune in a place in Toronto called Kensington Market, and we were all gay liberationists there, and there was one woman with a little baby, and that marked a difference where promiscuity was heralded and monogamy was considered unnatural.

**SS: Can you explain for people much younger than us what was the relationship between non-monogamy and sexual liberation?**

HS: Hmm. Well, sexual liberation at its core meant for us sexual freedom, the right to do and dispose of your own body as you chose, and that any conventions, be they legal statutes or mores that dictated against that, were wrong. I could go into a whole bunch of philosophical and theoretical arguments that centered around a critique of the nuclear family at that time, but I don't think that's necessary. It was just the feeling that sexuality from the history, certainly in Western history, had been constrained, and anybody who was, to use John Rechy's term, a sexual outlaw had been prosecuted, persecuted, you know, terrible things happening to him, that now was the time that in our own personal lives to live by the values that we espoused for what we considered to be a better society.

**SS: So gay freedom was considered the opposite of the nuclear family.**

HS: Yes. I think it's hard to see that now with so many GBLT people wanting to get married, wanting to raise children. It's almost like the re-nuclearization of the nuclear family. At that time, the word was used was "smash the nuclear family," and it was meant almost literally. Of course, none of us were smashing up our own nuclear families. Well, in some ways they were, by coming out, and some people, as happens today, I suppose, lost their relationship with fathers and mothers and sisters and brothers and things like that. But gay freedom meant that which was totally diametrically different from the traditional nuclear family. Remember, most people felt that their oppression derived from the nuclear family. You could still love your brothers and sisters, your mother and father, but they unwittingly had participated in your own

oppression by not noticing that you were different, and, if they did notice, trying to correct it.

**SS: Right. So where did the embracing of direct action come from? You said that in the gay liberation organizations that you were in, people used direct action. Where did they learn about direct action?**

HS: Well, in our own particular case, my own particular case, there was a chap named Paul Macdonald, who lived in London for a while, and the Gay Liberation Front in London was very, very active and took direct action. What its antecedents were—and of course there were antecedents, everything has an antecedent, by and large, I think—I'm not exactly sure, but we were greatly influenced by when Paul came and other people who had this history with gay liberation in London started to tell, "Well, we've got to go to the streets. We have to really demonstrate. We can't be nice about things. We've got to be in your face," which was unusual because Canadian society generally didn't have a tradition of direct action, as opposed to, say, the United States did in women's militancy or in labor union movements or certainly in the Civil Rights Movement, those parts of the Civil Rights Movement which were the very proactive and engaged in civil disobedience and things like that.

So that was the immediate factor, people like Paul, and we'd have people from GLF of London come over, and they'd stay at various houses and stay with people and talk with people and urge us on. Then there was also just the plain argument that if you wanted to really to make change, you had to do things differently. You couldn't ask, "Oh, please, we're nice people. Will you do this for us?" Because that wasn't going to

work. You had to make a demand and insist and be vehement and vocal about it, and so the logic of it, philosophically for me, made sense, you know, as a tactic.

**SS: Was the GLF of Toronto and the GLF of London the same GLF as New York?**

HS: No. It wasn't called GLF in Toronto. It was called Toronto Gay Action, TGA. What had happened, a few people had been in London, as I mentioned one person's name, Paul McDonald, he had gotten very much involved with them, so that was where the influence, but there was no direct connection. There were very few direct connections in those days between various organizations, or hardly any, I think, at all, but they influenced each other. People traveled, they read, there were broadsheets written and things like that. In fact, I think there was a famous document written by the groups in the London GLF, but I can't remember the name of it, which sort of set forth a body of principles or arguments about the demands for gay men and lesbians.

**SS: But did you see yourself – I mean, the LF part stands for Liberation Front.**

HS: Yeah.

**SS: Right? And that was at the time of countries trying to overcome colonial rule. So did you see yourselves as a left-wing organization?**

HS: Absolutely. Absolutely. Anybody who was involved in TGA I would say was a socialist. Perhaps some were communists. I don't mean necessarily they were members of the party, but they shared a Marxist critique of the system. That was absolute, and in *The Body Politic*, that was the same case. Most people were very, very left-wing.

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**SS: What does TGA stand for?**

HS: Stood for Toronto Gay Action.

**SS: Oh, okay. Oh, I see. TGA. Now, were other left-wing non-gay organizations willing to work in coalition?**

HS: It was interesting. There was a newspaper in Toronto, or in Toronto back then, and you'll have to excuse me, I can't remember the name of it. It was a straight newspaper and it said something the word "guerilla" in it. They covered the actions that we would engage in, and I remember they had one column or editorial that I thought was very backward in terms of its understanding gay liberation. I wrote them a letter, and I got back to me that this had created a great stir and they were upset, and there was a general meeting between the gay activists and this Toronto guerilla action group that published an underground paper. And from that, there was some coalescing around issues. There was never any formal integration or anything like that in terms of organizations.

**SS: I ask you that because I know just from my own experience that left-wing gay organizations often were unwelcome by straight left organizations who had conflicting positions about gay liberation, and I'm wondering if that was the case in Toronto.**

HS: As I remember, no, that wasn't the case. I may be wrong about this and my memory may not be serving me well, and others up in Toronto may remember this more than I do, but there were Marxist groups and study groups and things like that, and generally they took up the issue of gay liberation and took it up as a serious question that they had to deal with, just as they had to take up the question of feminism and deal

with in a very significant, liberated way, because many of those organization had oppressed women and had a traditional view of women, and they had to reformulate their thinking on that. In the same way, they had to reformulate their thinking, particularly in the face of militant gays who were willing to confront them and go face to face, as we did in this one case I just gave you about writing this scathing letter to them saying, “Hey, you got this all wrong.”

**SS: So how did women and men work it out at *The Body Politic*, gay women and gay men?**

HS: At the beginning and for a number of months, perhaps even a year or longer, there were no women involved in the collective, and then gradually one or two come in. The most prominent I can think of was a woman named Chris Bearchell, and by the dint of Chris’s personality, she just said, “I’m here, you’re going to deal with me, and you’re going to deal with the issues that I bring up.” There’s another woman named Pat Murphy, and Pat’s girlfriend. I forget her name right now. So there were a couple women who just by the dint of their forcefulness said, “You are going to deal with lesbian issues. The issues of gay liberation don’t just apply to men.” The oppression that women feel in some ways is a paradigm of sexual oppression, or women experience – I shouldn’t say feel.

And having the critique that we did on *The Body Politic* as a collective, there’s nothing we can do but say, “Yeah, you’re right about this. We have to try to sort this out.” We were always trying to get, in the early days, women to join the collective, but as you understand, women were doing their own thing. They were dealing with their own issues. They were forming their own organizations and try to make them cohesive

and forceful and be able to speak to the issues of women per se. In Toronto there was a lot of stuff going down. Of course, it's like every place else, there were consciousness-raising groups where you'd have gay men and lesbians getting together and lesbians say, "Oh, you're just a sexist pig. All you think about is the issues pertaining to your cock. Well, let me tell you, there's issues pertaining to my body that are different from yours." So there was a welter of activities that were going on like that.

**SS: Now I think, please correct me, that *Body Politic* famously went down over the intergenerational sex issue.**

HS: No, not really.

**SS: No?**

HS: *The Body Politic* lived a long and honored life, and it was eventually done in by financial pressures.

**SS: Okay.**

HS: The organization, people in the early days were smart enough to form a holding company called Pink Triangle Press, which owned *The Body Politic*, and eventually it brought out a bar rag called *Extra* and raised money. But for financial reasons primarily, but other reasons, *The Body Politic* published and announced that "We're publishing our last issue," and that was the end of it.

**SS: Because I do remember this huge, huge discussion, I guess, that took place based on *The Body Politic*'s position on intergenerational sex and age of consent.**

HS: Well, that happened actually early on when Gerry Hannon wrote an article, "Men Loving Boys Loving Men." And it was picked up by the straight press, and

eventually it led to the Supreme Court decision where the Supreme Court exonerated *The Body Politic* for any laws that the government said it had broken. But there was always this tension, because *The Body Politic*, you're right, was very progressive on the issue of intergenerational sex, and Jerry Hannon, I think, wrote another article, I forget the title of it, regarding intergenerational sex, which resulted in the police raiding *The Body Politic*, and then the whole legal process and policy that dealt with that. But, yeah, sure, there were many critics. And also within *The Body Politic* collective in itself, who had a different point of view than, say, Gerald's, on intergenerational sex. Some of them were very nuanced differences. Some of them were quite radically different from his view.

**SS: But when you were raided, was it for child pornography laws?**

HS: That's what they tried to use, yeah. I was living in New York by then, so I was no longer involved actively in *The Body Politic* on a day-to-day basis. I can put you in touch with –

**SS: No, that's okay.**

HS: – Gerald Hannon if you need to know, and people that really know that history. But that's right; they did use those sorts of laws, child pornography, obscenity, things like that.

**SS: So basically, and we'll get back to you coming to New York, but the things that defined gay liberation at that time, sexual freedom, living outside of a family structure, critique of the family and the state, sexual freedom for children and teenagers, all of these issues have become the anti-Christ of the contemporary gay movement. I mean, it's gone in entirely the other direction.**

HS: Do you think so?

**SS: I don't know.**

HS: I don't know. I don't know either.

**SS: Marriage and children and –**

HS: Yeah, I think that all of those issues, though, were nuanced. One of the curious things that I find is that I'm an addict sometimes, too, NYPD Sexual Victims Unit.

**SS: *Law and Order*?**

HS: And it's all really interesting when they have a show that deals with some form of pedophilia. One way or another, they often will bring up NAMBLA, National Association of Boy-Men Love [North American Man/Boy Love Association], and they always have the bad guy give some sort of speech about how "We're misunderstood. We're the majority. You are wrong. Society will come to see that." And I've often thought, that's interesting that Dick Wolf would present that. So I find that very, very nuanced, that there is some degree of fluidity in this discussion of children's sexuality and at what age is it appropriate that they make their own decision and at what age does society say, "No, they are not fair game. This is predatory."

I don't think there's anything anymore that's called gay liberation. I think you're absolutely right on. That driving energy which marked the beginning and the early days of ACT UP, as far as I can tell, is gone, and I don't mean by that to besmirch the still number of people who are working and are and consider themselves gay liberationists and AIDS activists, etc., because there are people still out there, but as a societal phenomenon, it's gone.

**SS: Do you have a theory why?**

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HS: Well, I think part of the reason is a lot of what – one of the things we did in Community Homophile Association of Toronto and the Toronto Gay Action and other groups in Canada was we wrote a petition, and I wrote it, along with a man named David Newcome, but I really wrote it, and it was called “We Demand.” I think there were a list of like ten demands. There was a demonstration up in Ottawa, the capital of Canada, presented there. Well, if you look at those ten demands, every single one of them has been instituted by the government of Canada. While we aren’t that progressive in the United States, a number of the demands either explicitly demanded or implicitly have come to fruition. I think it’s incontrovertible that the social milieu for coming out, for example, is greatly improved since the seventies and the early days of gay liberation. So I think that has part – is our own success.

We also found acceptance as mainline organizations. We started raising vast sums of money. We were successful in having our own lobbying organization, all of which I think are very positive. But I think the downside of that was that as society has ceased to be so overtly oppressive, the impetus for young women and men to take up great militancy and willingness to engage in civil disobedience and other forms that we identify activism has dissipated.

**SS: Okay. So what brought you to New York?**

HS: Sex. Oh, yes. I used to say to my friends when they asked me when I was moving, “Why are you leaving Toronto? You live in this wonderful commune. You’re part of a group that is held up by esteem by everybody else. You guys are famous for having a cooperative that works, where you like each other, you talk to each other,

you do things together. You're involved in political activities. Why could you leave that?"

And I said, "Because I never got laid."

**SS: {LAUGHS}**

HS: You laugh. It's true. So a good friend of mine, Jim Steakley, had lived in Toronto, a very prominent historian of gay liberation in Germany, moved down here, lived in with a friend. They invited me to come down. This was during the seventies in New York, which was just absolutely fabulous because it wasn't in the Disney-fied New York that we live in now in Manhattan. It was the dirty, gritty, slimy. There was still a sense of coyness to gay sex and things like that, and you had wonderful clubs, and there was Fire Island. There was all this sexual freedom, and it was just wonderful. For a gay man, it was like dying and coming to heaven.

But there's another dimension that was more profound. All my life, I wanted to live in New York City. It was dream. And that's because I had a great-aunt who lived outside of New York, and as a kid in Columbus, Ohio, whenever she'd fly in in a plane, "Oh, my god, she's on an airplane." She would give us each a dollar, and she would tell us about New York and all that, and I thought, "Wow, this has got to be fabulous."

After I graduated from high school, her gift was to come to New York and stay with her, and I just – wonderful. So when the opportunity presented itself, I had finished my Ph.D., there were absolutely no jobs to be found in philosophy, so it was a relatively easy choice to move down to New York and enjoy the group of the beautiful men that existed here.

**SS: Where were your hangouts?**

HS: Oh, well, at first I'd hang out, as everybody did, in the bars on Christopher Street and in that area in the West Village, on the piers, when we still had the warehouses. Then there was the dance clubs. Shortly after I arrived here – well, before. Well, eventually I got involved with Flamingo, which was a dance club, and then, of course, there was Fire Island. I also worked at – a friend of mine opened a store which ostensibly sold leather goods, but it mainly sold dildos and poppers, and I worked for him one summer here in the city and out on Fire Island, and that was just absolutely fascinating for me, being trained in philosophy and all that, to see these women and men come in and buy their dildos, buy their handcuffs, and then, of course, always buy the poppers, last thing. And in fact, I made a journal. That was one of the fun things. It was 180 degrees different than being a professional philosopher, and it was quite fun. It was quite different. So I did the normal things. Those were the hangouts where this certain set of gay men hung out.

Tape II  
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**SS: So when did you first become aware of AIDS?**

HS: I suppose that famous day when the *New York Times* on its front page wrote a story about this mysterious disease that seemed to be killing gay men. That was the first awareness, and this was on Fire Island. I also was aware, I'm not sure if it was exactly that same day, but certainly thereafter when Larry Kramer and some other people were out at Fire Island handing out fliers about gay cancer, this gay disease, and something needed to be done.

**SS: And what was your reaction, do you recall?**

HS: Well, I think the reaction was, “This is strange. How could cancer be a gay cancer?” There was an intellectual objection. Okay, sure, there could be a cancer or diseases that would affect gay men, but certainly they could affect other people, too. So it wasn’t one of disbelief that there were certain cancers killing gay men, but that it would also, all things being equal, affect any other people. So to call it a, quote, “gay cancer” was, for me, as a trained philosopher, a misnomer. But then I guess I would keep involved or kept aware when I would see things written either in the mainstream press or in the not a mainstream press, and then with the organizations that – well, I guess there weren’t any organizations who were dealing strictly with it until ACT UP got formulated.

**SS: When did it become real in your life?**

HS: Well, a friend of ours in our little circle of friends was one of the first to die. That was before –

**SS: What was his name?**

HS: His name was Larry – I can’t remember Larry’s name, but I remember visiting him in the hospital, and he had a rare disease that birds only got, and he died relatively early on. This was like in 1980 or something like that, 1981. So that personally affected me, and then you’ve heard this a million times, the story then it just was a snowball effect, more and more and more people getting sick.

**SS: When you started to hear that it may be sexually transmitted, given your sexual liberation background, did you mistrust that?**

HS: Yes. I remember Larry Downes, who was my doctor at that time— Larry’s now deceased—he was further down on 19<sup>th</sup> Street, and I remember having a conversation with him, and he told me, “Oh, you know, now antigens have been found in

semen,” and I wasn’t exactly sure what the implications of that – I mean, biology isn’t my strong suit, but he pointed it out to me. Yeah, initially it was something that I questioned, given my sexual liberation background, along with a lot of other people who questioned it, too.

**SS: Sure, big debates all over about that it was –**

HS: Yeah, big debates, huge debates, and they only got bigger.

**SS: So what persuaded you to accept that it was sexually transmitted?**

HS: I can’t put a time or place on it. I think it was a gradual process. I think that I accepted it, along with a lot of people, that if it was sexually transmitted, that the more sex you had, you increased your odds of making contact with whatever this antigen was, virus, whatever. So a lot of the debate was over the issue of abstinence, cutting down the number of partners, safer sex.

I remember I got involved doing a calendar for GMHC with a guy named Jim D’Eramo, who I don’t know if you’ve interviewed Jim or not, but you should at some point. And we tried to introduce the idea of safer sex and using condoms and making it fun, and we did a whole photo shoot and developed a calendar and things like that. So I think it was a slow process that was an epiphany, oh, my god, yes, just had to accept by the din of logic that the more people you had sex with unprotected, if there is a biological agent, that you were increasing your odds of getting it.

**SS: When you had to adjust to safe sex, did you feel a sense of loss?**

HS: Hmm. Loss. “Loss” may be a strong word. No, I can’t say I ever felt that there was a sense of loss. Certainly using condoms wasn’t – it was a trifle inconvenient, but it wasn’t a great inconvenience. I mean, you could get pretty proficient

pretty fast in using condoms, so, no. I know some people did, therefore refused to do it, but that wasn't my personal experience.

**SS: Now, did you become politically active in any of the AIDS movements before ACT UP?**

HS: Were there any?

**SS: Well, there was David Summers and the PWA Coalition. There was GMHC.**

HS: I was involved with certainly GMHC, as I said, with my friend Jim D'Eramo, who was working at GMHC, who was, I think, in the educational part of it. Then there was a chap, now deceased, named Mitchell Cutler who started the Buddies Program at GMHC, and I was involved with the Buddies Program. But remember, GMHC wasn't a political organization, and they strove all the time *not* to be a political organization. And the one man, god knows I forget his name, who they hired as the executive director and lasted not very long, who did actually show up at ACT UP meetings and things like that and tried gently to steer GMHC into a little more activism or supporting it, they got rid of him really fast. {SNAPS FINGERS}

**SS: Who was that? Was that Tim?**

HS: I cannot remember his name. He was from Canada. And I just cannot remember his name off the top. But he didn't last very long.

**SS: So you were a buddy.**

HS: Yeah.

**SS: How many buddies did you have?**

HS: Can't remember that now. Several, though.

**SS: And what was that experience like?**

HS: It was very moving, very, very – it was hard. It was hard to see these men who were strong and healthy and vigorous going downhill and needing help and knowing what the outcome was going to be. It was very hard and touching, and it required, I think, a lot of strength and fortitude.

**SS: Do you think that people really accepted that they were dying at that early point?**

HS: I certainly think Larry knew that he was dying. He's a person I mentioned earlier. And, yeah, at least the ones I came across, I think so. There were a lot of Louise Hay. In fact, she was in town quite often and was right around the corner from the Gay and Lesbian Center at that church there. I forget the name of it. So there was a lot of talk and discussion about denial and the processes of dying and things like that. But obvious there'd be some people who were in denial and didn't think they were. But the ones I knew, yeah, I think they knew that they were dying. That isn't to say they accepted it.

**SS: So did you have discussions with your buddies about their deaths?**

HS: Yeah, sure. Sure, yeah, if they'd want to bring it up.

**SS: So you became savvy to death very quickly.**

HS: Yeah. Mm hm. When I was a child, when anybody died in our family, there was usually an open casket in the home, so the little child, and death was always explained. It wasn't tried to be swept under the table or too young to know. I remember as a little, little kid being held up to look in a casket. "Oh, this is Great-grandmother Roth and she has died and she's gone to heaven. You can put something in

the casket, and she'll take it with her." So at a very early age, we're familiar with death. So I think that served me well when AIDS came along.

**SS: Right. So what brought you to ACT UP?**

HS: The same old story. I forget, was it Nora Ephron? Somebody was supposed to speak that night at the Community Center, and I was interested in what the topic. She got sick. Larry Kramer was there. He got up, did his famous "Everybody stand up. This half of the room sit down. The rest of you are going to be dead within--," the usual Larry technique, and Larry's statistics were that "Half of you were going to be dead." I don't know what came from. And I was sitting in the audience with my friend Jim D'Eramo, who I'd worked with, and it was decided that the next week the group would meet again, and I think that time Tim Sweeney acted as the facilitator, and then groups were broken down.

I remember I went with a group that was charged with trying to come up with a name for the organization. I can't remember. I was trying to think of the name of the young man. He lived in New Jersey. Steve something or other, who said, "Oh, I always thought the name ACT UP would be great." And I thought, "ACT UP? Oh, what a horrible name." But when it was brought to the floor, everybody, "Oh, yeah, that's it. Love that," and I was wrong. Obviously I was totally wrong about that.

So I think from my background in gay liberation and *The Body Politic*, I was already there. I was all ready. One of the problems was, nobody knew much about anything. I mean, there were some people who had knowledge about the medical issues, based on what was known to that point, but we didn't know about how do you form a political organization around this issue. What I mean by, for example, how did the FDA

work? How did new drugs get applied? How did the Centers for Disease Control work? Who was in control? Who did they answer to? How did they set their policies? How did you influence their policy? We had to find this out, because why should any of us know that? It never came up before.

So one of the first committees that was formed was the Issues Committee, and we had a young man who was the first chair, but he only lasted one or two, and then eventually I became the chair of the Issues Committee, and we held the Issues Committee here for a long, long time. And I think it's fair to say it was a very influential, important committee, that there would sometimes be thirty people here for a meeting, and we'd report back to our findings. I think what's really important for that, it served as a place of gestation for what later became the AIDS Treatment Committee [Treatment & Data], for which Mark Harrington and Peter Staley and Jim Eigo and a whole list of other people emerged, and they became very precise and very accurate and very knowledgeable about the biology and the science of AIDS so that we could go and talk intelligently to these various committees, the FDA, the CDC, the honchos who ruled them.

I met here a couple of times with Burton Lee, I think his name was, who was President Bush's AIDS czar, and he would come here a couple times just to talk to me privately to try to get a handle on the issues and how the community perceived the Bush administration's either acting or not acting, and Burton Lee, despite he was castigated, did personally try to understand. Of course, he was the Surgeon General—that's who he was—was constrained by the politics of the situation.

Tape II  
00:15:00

The other thing that the Issues Committee did that I think was of significance is we were responsible for drafting the document that went to the AIDS

meeting in Montreal, that famous – oh, what do they call the big AIDS meeting every year that they have? It was in Montreal, and ACT UP took over, and it read our demands. I wrote those demands. I thought I should have delivered them, too, but, anyway, Eric Sawyer did, and we were joined by Tim McCaskell of our Canadian – they had a group up in Toronto, AIDS Committee of Toronto. But that was important because it helped to focus what exactly were the demands.

**SS: Do you remember what the demands were?**

HS: I don't remember them all now. I'd have to go back and look. But you can imagine what they were, more funding, more political laws protecting, no ban on HIV people from the country, the usual sorts of demands that there were at that time.

**SS: So let's go back to the beginning of the Issues Committee. What were the first issues that were identified?**

HS: The issues were really what are the issues? I mentioned the FDA, for example. How did, we asked ourselves, a new treatment make its way through the FDA? What was this process? How did it happen? How did pharmaceutical companies develop a drug that went through the FDA that got approved that could get out to the community? And we had to do research into that, so various people went out and went to the library, called people, and then we'd come back and share our information, and then we'd try to find out if it was accurate or not. Then we would pass along – I think we had every – was it Monday night or Tuesday night? Monday night the general meeting at the Community Center, and each committee would make its report, and we'd try to report on "This is what we found out."

One of the importance of it could be that when we would find issues that, “Hey, this shouldn’t be this way,” or it should be easier, or it should be more transparent, that that would give us a reason for demonstration, for acting, and for threatening to demonstrate, and involved how the pharmaceutical companies operate. Are they strictly driven by profits? Are their profits outside? Why aren’t they pushing the FDA and the CDC to allow them to expedite, bringing new drugs to the market that can help people?

**SS: So at the beginning, what was the problem in terms of drug development?**

HS: Oh, slow.

**SS: And that was because –**

HS: Well, it’s because the FDA, the CDC, had never ever before in their history been challenged about how they went about reviewing the data that was submitted to them by pharmaceutical companies on whether a drug should be pursued or not. There was never seen to be any urgency. There was never any group that – perhaps there were some groups. I may be leaving something out. There may have been some women groups that had raised issues like this. I think, in fact, there were. We weren’t terribly aware of it until it was pointed out by the large number of women who were involved in ACT UP. But that was really an important issue, and the issue became, well, how do you speed this up? Who’s dragging their feet? Is it the pharmaceutical companies? Is it the FDA?

**SS: Who was dragging their feet?**

HS: Both.

**SS: Now, why would the pharmaceutical companies be dragging their feet? Didn't they stand to make more money?**

HS: Well, because they had to play by the rules that the FDA set for them, and they didn't want to rock the boat. So if they played by the rules of the FDA, their chances of getting approval were greater. If they went and say, "Hey, there's a community out there who needs this drug. We've got to hurry up and get to it. There's a certain sense of urgency," this could be seen as contaminating the data, that these issues were irrelevant, that the only thing that was relevant was the data generated by the clinical trials. Later on, as ACT UP matured, it got very good into looking at – Treatment and Data Committee did this – looking at the nature of clinical trials, how to speed up clinical trials, how to do smaller clinical trials, smaller group-size clinical trials.

Tape II  
00:20:00

At that same time, Michael Callen had developed the Community Research Initiative, CRI, and eventually I sat on the board of that, so there was attempt at that level from the medical level to push at the community level to expedite the development of drugs which would treat HIV and AIDS.

**SS: By doing the research ourselves.**

HS: Trying to. CRI didn't have a laboratory, so what it basically meant is either raising money to support trials that would be going on at different locales, that CRI would be involved in the administration of, sometimes doing some trials actually on site, small trials. I'm sure you probably have interviewed Joe Sonnabend.

**SS: No, we haven't.**

HS: Oh, you must interview Joe Sonnabend. In my opinion, he's one of the great unsung medical heroes of AIDS. But, Joe was very much involved in the

medical side of how can CRI help conduct small clinical trials which can prove safety and efficacy and result in a speedier development of getting some sort of medication to people with HIV or AIDS. Gosh, there were just a number of different ways of trying all in all to expedite the process, get new drugs in the pipeline, to get people to access them, particularly people who had failed whatever drugs were out there, AZT and whatever was coming along. We didn't even use the words. How did you salvage these people? You'd hear about a drug that was in the pipeline or being tested or it showed signs of success. How do you get that? I mean, one of the arguments was, well, why can't you give these to people who were dying anyway? How can it possibly hurt them?

**SS: And what was the answer?**

HS: The answer was basically what you always get from bureaucracy, "Well, it's not our intention, but you have to realize this could make things worse." You know, basically doubletalk. They couldn't deal with the issue. How can you adversely affect a dying person's life who willingly knew that there might be deleterious side effects but still wanted to say, "Yes, I want to try"?

**SS: Now, what was your first personal experience having communication with the FDA?**

HS: I don't think that I had any direct, myself, personal, because I was sort of organizing a lot of the people that would go out and do this piece of – Bill Bahlman, for example. I don't know if you've interviewed Bill. You probably have. But Bill would go out and do a lot of research and gather information, and then they would bring it back here, and we would all talk about it and try to refine it, and then I would try to put it together. Often I would give the report as the chair of the Issues Committee to the

general meeting. I don't want to take credit for being one of the frontline researchers in that.

**SS: You had brought up before that ACT UP would make its demands or try to negotiate with these institutions and then it led to our actions, because they were not responsive.**

HS: Mm hm.

**SS: So with the FDA, of course, that's one of our most important actions. Can you lay out what the steps were that made us have to have that action in order to get –**

HS: The steps were the inaction by the FDA. You wouldn't get any response. Or I remember – this may be off the track. I'm not sure I'm answering your question. CRI did this amazing proposal for funding, either with the CDC or the FDA about a clinical trial, and all the feedback was very positive, and then at the last minute, it was denied. And it was like, "What? How can you tell us all along this is going to be approved, and then denied?" So you would try to get at the basis of that, and you'd really get the runaround, such that the decision was political. That itself didn't result in a demonstration. It's hard for me to give an exact answer to that because so many people were involved.

The thing about ACT UP, you have to remember, it wasn't a top-down organization, although sometimes it had appearances of being like that, but really it was not. To get people to move, there had to be a groundswell of a feeling of injustice or wrong, and that was usually somebody from the Treatment and Data or Issues or Action Committee, wherever it came, or just an individual who had done some research and say,

“Hey, did you know this? There’s drug X that Merck is toying with, but they’re not doing anything with it.” Okay, why not? People would outrage that from the floor.

“Let’s plan a demonstration against Merck. Let’s find out where they are. Let’s find out how much money they make. Let’s–,” blah, blah, blah, blah, blah, “And then let’s have a demonstration out there.” That’s the way it would work, rather than a group of people sort of sitting and plotting step by step. It was spontaneous, that’s the word I want, a lot of spontaneity.

**SS: Because you not only had to identify what the problems were, you had to propose the solutions, right? So things like parallel track or expanded access, those were ACT UP concepts.**

HS: They were ACT UP, and I think that a lot of the – at the stage when ACT UP started making suggestions or saying, “Hey, this could be done,” a lot of that came through the very hard work of Treatment and Data, because they really got down to the nitty gritty and made sure they had their facts right, and so that when they brought it to the general floor of ACT UP or had meetings with pharmaceutical companies or meeting with [Anthony] Fauci or whoever the head of the FDA was at that time, that they had their facts straight. And you couldn’t be back-doored by them saying, “Oh, you guys really don’t know what you’re talking about.”

**SS: Now, how did you come to understand that the same drugs were being tested over and over and that the trials were being duplicated? How did that get identified?**

HS: I think it got identified by just persistence of contacting the drug companies and saying, “Where are you with this? What’s happening with this?” And

then you'd start noticing a runaround. There were a lot of people—and this is why I say it's a grounds-up organization—there were a lot of people who took their own initiative to gather information. Some pharmaceutical companies got savvy and they said, “Hey, why don't we have a liaison person that can deal with organizations like ACT UP or GMHC or things like that, that we can talk to and let them in and maybe pacify them?” Or actually you have a real honest-to-goodness dialogue. It was just really hard, determined research from a whole variety of people who were committed to doing something, and then it got all put together, either at the Monday night meeting at the floor or other groups talking to other groups, individuals talking to other individuals. What I'm trying to say, Sarah, it was very fluid. There was a lot happening at the same time, and, of course, sometimes you get it wrong, too. The nature of the beast.

**SS: You mean like Compound Q or –**

HS: Yeah, or whatever or the whole debate, well, is AIDS caused by a virus? Well, no, it's not caused by a virus. It's caused by the lifestyle of gay men, and all of that. I guess that debate is even still going around today. So it was just such a fluidic and dynamic group and so many people involved for personal, intellectual, social reasons that the sum was greater than the whole of its parts. Something else was added because of this dynamic.

**SS: Now, within Issues Committee there were a lot of different directions and areas of focus, and some people were interested in social welfare, healthcare for all, universal healthcare, and some people really wanted to focus on the science of specific treatments. How did this play out, this split focus between social structure and science?**

HS: I think it played out by the people who wanted to focus on the science eventually establish a Treatment and Data, and that was their mission to really understand the science and the political aspects of the science. We had grown up, all of us, thinking that science was politically neutral, free. But, of course, it turned out that it wasn't, that there was all sort of biases in science, too, that's institutionalized.

Tape II  
00:30:00

That's how that eventually played out, by originally a Treatment and Data was a subcommittee in Issues, and it became more and more interesting. A lot of brilliant people joined it, and they started doing this type of hardnosed research, like they were great graduate students researching their master's or their Ph.D. topic and knew that they had to know what they're talking about. I think that's how it got played out.

The other issues, like universal healthcare, prevention, which was a big issue, women's issues, HIV/AIDS and the black community, and trying to make coalitions with different groups, they were always a little more difficult to deal with because they didn't have the precision that a committee dealing with scientific facts and information would have. So that that was always a more difficult way of trying to get prevention issues, universal healthcare issues, actually to formulate an action around that. It was much easier to formulate an action around a piece of scientific data that you could show and say, "Hey, this isn't being dealt with in a correct way," either by the pharmaceutical companies or by one of the governmental bodies, the NIH or CDC, FDA, choose the one you want to pick.

**SS: So you went with T & D when it first –**

HS: I wasn't really involved too much with T & D. I went to a few meetings, a number of meetings a number of times, but I was not really one of the people

who was one of the movers at T & D like Mark Harrington or Peter Staley or Jim Eigo or people who really had a good grasp and a good scientific background. I didn't have that sort of background so it's easy for me intellectually to wrap my thoughts around these issues. So I don't want to take credit where it's not due.

**SS: So where did you put your focus?**

HS: Eventually the Issues Committee sort of faded away, just as ACT UP still exists, but sort of faded away in terms of a presence. If ACT UP was a community, Issues Committee faded away into that community, and other people went on and did other things that were involved. Eventually, I just stopped going to the – and I think it came in when the cocktail came in and people started living longer, and the Clinton administration came in and there seemed to be more social and political activity regarding AIDS in a positive way. So eventually my involvement waned there.

**SS: So what years were you in ACT UP?**

HS: Well, let's see, I'm trying to think. When did it actually start? I can't remember that date.

**SS: Eighty-seven.**

HS: Eight-seven? Through the early nineties. I testified before a number of governmental committees on AIDS. I was on TV a number of times and things like that. But then I guess in '92, '93, with the general ebbing of ACT UP, I was part of that, the movement.

**SS: So what was your favorite project that you worked on in ACT UP?**

HS: Oh, boy.

**SS: Or one of them?**

HS: Probably was the demands that were presented at the AIDS conference in Montreal. I like doing that. I like being able to pinpoint issues and writing them up and giving the justifications for them. I like that. I liked personally hosting the Issues Committee, and I tried to make it – and I was criticized for this, I think, but I liked to try to make it a commodious experience for people, so I would have things to drink and little snacks to eat and things like that so people could feel comfortable and get to know each other, and there would be an environment where you could really sit down and talk. Our Issues Committees would sometimes last three and four hours, and people would actually get and talk. I enjoyed that personally a lot. Whether in the end it was productive, if it had been more regimented, I can't say. But I liked that.

Certainly I liked some of the people I met that I just had enormous respect for. What's her name? Oh, I can't believe I can't remember her name. She was a medical researcher and an older woman.

Tape II  
00:35:00

**SS: Iris?**

HS: Oh, Iris Long, yes. I adored Iris Long, for example, and there were a number of other people that on a human level was just really, really wonderful to experience and to work with and to feel that in some very little and insignificant way that I was part of a real community experience that wasn't something that any one person or persons could take credit for, but it was the whole, and that I was part of that whole, and it was really great to work in that community way. That was really, really wonderful. Go to the Monday night meetings with all the nonsense and dragging out and raising this

objection, that objection, and the stupidities that you would have to listen to, and all that, it was really quite wonderful and quite exciting to be part of that.

**SS: Now, were you involved in the action around the NIH?**

HS: Not too much, no.

**SS: No.**

HS: That was more – the person I identified most with that is Peter Staley, Peter and the group like that.

**SS: When we interviewed Jim Eigo and we talked about the Issues Committee, he said that – I mean, I'm really paraphrasing here, this is not totally accurate, but that initially there was a real interest in ACT UP towards universal healthcare.**

HS: Mm hm.

**SS: And a feeling, a conceptual understanding, that AIDS could never be addressed inside the structure of American healthcare system, and that this demand kind of changed over time and became focused on drug into bodies and specific treatments. Did you observe some kind of conceptual shift over the years in terms of what ACT UP's goals were?**

HS: I hadn't thought about it in that way, but certainly if even paraphrased I can see Jim saying that, and I think he's 100 percent correct, and I think there was probably some conscious process, and that may have been when the Treatment and Data became more and more influential and powerful, just saying, hey, we ain't getting universal healthcare anytime soon, and to press that as a demand for AIDS really doesn't address specifically enough the issues pertaining to AIDS and that are, what, how is the

treatment, what are the drugs that we can push? How can we actually help real live people who are living with AIDS and HIV to live longer, to ameliorate their suffering, things like that, the drug into bodies, you're saying. I think there was that shift. I hadn't thought about it right now, but Jim is exactly right, and it did come from people who made that very forceful argument.

I don't think that meant that people totally abandoned the idea of universal healthcare, but even today we can see that the analysis that if you try to push for universal healthcare, you're going to be screaming for a long time at the cost of really getting something specifically done to benefit people, like parallel track, the whole host of drugs that are now available that ACT UP was very forceful in pushing and instrumental in getting taken. I think that was a correct approach tactically.

**SS: Were you involved with fundraising?**

HS: Not a lot. I'm not a very good fundraiser.

**SS: Let me ask you a little bit about the culture of ACT UP. Here you embody the history of the gay movement in a lot of ways. Did you find that people were aware of that history?**

HS: Of my personal involvement?

**SS: No, no, in general, that the younger people –**

HS: No, they were not. In fact, there were a number of teach-ins at the Community Center about the antecedent Gay and Lesbian Liberation Movements, about Women's Movement, about other health advocacy movements, that a number of the other younger members wanted to know about but didn't, and people volunteered to do those sorts of seminars.

**SS: Did you present at those?**

HS: Did I present at those?

**SS: Mm hm.**

HS: No, I don't think I ever presented at any of those.

**SS: Were you surprised at how little younger gay people knew about their own –**

HS: I'm still surprised. I was at a cocktail party for Yale and Penn graduates the other day, and I was trying to tell them about Magnus Hirschfeld and his Sexual Institute and the burning of the books by the Nazis and the connection between them, and they sort of looked like, "Wow. Why is this guy telling us all of this?" I couldn't believe it. I thought, "Because you're gay men."

But in ACT UP, people who came to ACT UP and came back were interested, and a lot of them wanted to know. It was a generous curiosity, and it just wasn't there. So I was surprised at the ignorance, more gratified and surprised by, "Hey, we do want to know. Let's have these seminars or teach-ins."

**SS: So we'd like you to tell us about your bugaboo.**

HS: {LAUGHS} It's an interesting one. It's generally thought that there were founders of ACT UP and that Larry Kramer was the founder, and I really don't have a problem with using words and things like that. I guess mine is more of a process since I was there at that beginning. I think of it in terms of this. There was a wonderful political philosopher theorist named Robert MacIver, and he talked about causation, and there were precipitating causes which are different from a cause itself. There were antecedent causes. And I sort of think of Larry's talk as one of those, a precedent, a precipitating,

but not a cause in and of itself. I really felt that there were no founder or a founder, that it was truly, from my experience, a group of people sharing a set of common beliefs, common frustrations, common anger, that came together and really transcended any notion that there was a founder or founders or that there were important people or essential people, or if this had not happened on X date, that ACT UP never would have happened. I think it was, imagine, a matter of the spark. Larry gave the spark with his speech, absolutely, no question about that. But the fuel that was ready to explode was already there.

**SS: How do you think ACT UP affected your life now, the consequences of having been in ACT UP?**

HS: Hmm. It's a good question, Sarah. I think the influences are very subtle, some of which I'm probably not even aware of. Certainly it's affected how I see the issue of medicine—medicines—and how treatments are developed. I guess I hadn't given a thought to the fact that there was politics involved in this. We all knew there was obviously economics, but that there was politics, and that that politics could be affected by human beings, by people gathering together. So when I look around about any issue pertaining to health and treatment, things like that, I'm more readily – ready to ask, “What are the politics? Whose interests are these serving? What is the class relationship? Why aren't certain places and people being served and others are?” I think that is just one of the things that ACT UP brought forth.

I think the response to those, to medicine, has been moved forward because of ACT UP, what it did, the people willing to confront now governmental bodies, private companies, to organize, to make demands for treatments, for medications,

for clinical trials. For example, a good friend of my sister was just diagnosed with cancer, and before I think ACT UP happened and all that, it wouldn't have been thought that an individual can go around and find out about clinical trials and try to find, "Hey, what's happening? What's good ones? What's bad ones? What can be done?" And she did that. She went online and started doing her research.

I think a part a little bit of ACT UP might have influenced David Landay's seminal website. I don't know if you know about it.

**SS: No.**

HS: Survivorship A-Z. You should look into it. It's one of the most amazing sites for people with fatal diseases and their lovers. I think maybe in some ways ACT UP had an influence on David developing that. It's changed our way of looking at medicine, the culture of medicine, as you say.

Tape III  
00:05:00

**SS: Okay. Now, I don't have anything – is there anything else you guys want to ask Herb? Is there anything that you feel we haven't addressed?**

HS: No. I'm sure I'll think of a host of things once you leave.

**SS: Well, I have one last question, then. What do you feel is ACT UP's greatest achievement, and what do you think was its biggest disappointment, looking with the advantage of hindsight?**

HS: I think its greatest achievement was what I had just said, that there was an awareness brought not just to the American public but to the world public, if you will, that decisions regarding medicine and science could be affected by ordinary citizens coming together and making demands and doing something. I think that is tremendously

profound. I think that it will continue to grow in time, and I think ACT UP made a huge contribution, unintentionally, but a huge contribution to that.

I think the greatest disappointment is that there's still a great need for that activism, and it isn't there except for the few heroes whose names I don't even know, that I forget. Mark [Milano] may be is one of them who is still around, who's still fighting the good fight and who have seen, "Hey, everybody out there, listen, it ain't over. Yes, people are surviving more and longer, but it ain't over." I think that's the sadness.

**SS: Okay. Great. Thank you for your time.**

HS: Oh, my pleasure.

**SS: Thank you so much, and thank you for all your work.**

HS: Oh, thank you.

**SS: *The Body Politic* was really important for me, so thank you.**

HS: Thank you. Thank you.