# A C T U P Oral History P R O J E C T

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Interviewee: Risa Denenberg

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### SARAH SCHULMAN: Okay, so we start, you just tell me your

### name, your age, today's date, and where we are.

RISA DENENBERG: I am Risa Denenberg. I am 58 years old. Today is July 11<sup>th</sup>, 2008. And we are in Kunkletown, Pennsylvania, my home. **SS: Your home; you're soon to leave.** 

RD: I am about to go to Seattle, yeah.

SS: Okay. So where were you born, Risa?

RD: I was born in Washington, D.C. I went to public schools in

D.C.

### SS: What did your parents do? What brought them there?

RD: Oh, they were born in the area. Actually, my dad's parents came in through, I don't know, some circuit through Connecticut, and my mom's family settled in Baltimore, and they ended up in D.C. My mother lived in D.C. all her life. My dad was there most all of his life. My mom was always a secretary, and my dad – neither of them went to college. My dad did different things; whatever he could do. And he died young. He died at the age I am now, so – he was selling houses for the last years of his life.

### SS: So your grandparents were born in the United States?

RD: No. All of my grandparents were born in Russia, in eastern Russia, and came over in the late 1800s, at various ages. My grandmother came over in her teenage years, and went right into the sewing shops. They just survived. And they were both big families. And I still have huge extended family.

### SS: So I didn't realize there were a lot of Jews who were born and raised in Washington, D.C. I had no idea about that.

RD: I never knew otherwise. Although it's funny, because I didn't know any other Denenbergs in the D.C. area, and there are a whole bunch of them in New York. And I found there were quite a few of them in Philadelphia. I worked there for a while.

### SS: So did you live in Washington itself, or in a suburb?

RD: We lived, I grew up in D.C.; I went to D.C. public schools; we were literally the last non-black family to move out of the neighborhood I grew up in, which is a very nice lower-middle-class neighborhood.

### SS: What was it called?

RD: Um – I don't know. Lamont. Northeast D.C. Big yards, kids in the street, playing. I had a great childhood. Everything fell apart in my life when we moved to the suburbs. But I really loved living in D.C. You could ride the buses. My brother and I used to go down to the Washington Monument after school. We'd climb it, climb back, and come home; not tell anyone. We thought that was a hoot.

### SS: So was your family particularly community-oriented?

RD: My mom was an activist. She was a pro-integration activist. When the Boy Scouts wouldn't let black kids into the Boy Scouts, she and another mother, who was a black woman, started the Chameleon Club. It was an integrated club. She was definitely not just liberal, but she was an activist. And I didn't make the connection, I guess, until later in my life, that I got that from her.

My dad was more conservative, and a little uncomfortable with my mom, and very uncomfortable with me. But she definitely gave me the values that I have about living in this world with other people.

### SS: Did she bring you along to any kind of political events, or –

RD: She didn't go to demonstrations. It wasn't like that. It was just local community stuff. Whatever she did, I didn't get dragged along. It wasn't that kind of stuff. It was just her values, and the fact that – even the fact that we just didn't flee, you know, was different than most of my other Jewish friends.

### SS: Did you have a Jewish education?

RD: Oh yeah. I went to Hebrew school; I was bat mitzvahed; I was –

### SS: You were bat mitzvahed; that was brand-new at that time.

RD: Yeah, I was bat mitzvahed. We had to be bat mitzvahed on

Tape I<br/>00:05:00Friday night. We weren't allowed on the bimah on Saturday. But yes, it was<br/>new. It didn't feel new to me, because it had happened for a few years before my<br/>bat mitzvah. And then I went on, I guess, for another couple years, and got<br/>confirmed. So I had a very good Jewish education, in a Conservative shul.

SS: Do you remember the topic for your *drash*?

RD: Yes. I talked about the – oh, you mean the topic for – no. No. I know what I gave a little talk on.

### SS: What was it?

RD: You could give a little talk on something you were interested in, and I talked about my perspective on the difference between Ashkenazi and Sephardic Jews in this country. So I kind of looked at that. And I vaguely remember some of my haftorah.

## SS: So when you were in high school, were you politically aware?

RD: When we moved to the suburbs, I just kind of turned around a hundred and eighty degrees, in terms of the way I saw things. Being 14 when we moved — so I was in junior high for a couple years, and then in high school — I just, I just felt like my parents were sellouts. Instead of really understanding the complexity of their decision to finally move, I just thought, well, okay.

And I felt like I met white kids for the first time, because really, all I knew were Jews and blacks. And they didn't put me in the appropriate classes, and I think that's because I came from D.C. schools, and it took a while before my mother realized that they had sort of low-classed me, in terms of academics. So I met a lot of hoods. And I started, even in — whatever it was — eighth grade, I was dropping, skipping classes and doing stuff like that. And just became more rebellious than politicized. And in high school, I – I got kicked out of high school, so I didn't

even finish high school.

### SS: What was the offense?

RD: It was probably a string of things. I got in trouble a lot. But it was for not ratting on someone who was selling drugs in the school.

### SS: Okay. So then what did you do?

RD: Well, during that same year, which was 1968 – I had an illegal

abortion.

**SS: In Washington?** 

RD: In D.C., yes. I got kicked out of my home.

SS: Wait, can we talk about that for second?

RD: Oh, sure.

SS: What were the circumstances around that? How did you get your abortion?

RD: I didn't – it wouldn't have occurred to me to get an abortion. The guy absolutely insisted, with threat of violence. I remember feeling very despairing of even finding an abortion. I had been kicked out of the house – not because I was pregnant, but because I was just fighting constantly with my dad. So I was living – and I was crashing somewhere. I had a job at a restaurant. And I remember sitting on DuPont Circle, sitting on the grass at DuPont Circle in D.C., and, little flower child, me. And just sort of, as people would come by, I'd ask them if they knew anybody who did abortions. Well, there was a doctor in D.C. who did abortions. And I went to

him. And was in the waiting – and I had been examined, he was going to do it. I was in the waiting room. The place got raided. He was arrested.

SS: What was his name? It's 40 years ago, so –

RD: I don't remember.

SS: Oh, okay. So you were in the waiting room and the police

came in?

RD: Yeah.

SS: In uniform?

RD: Yeah.

SS: And it was his regular waiting room, but he was doing abortions in his normal office?

RD: Yeah, yeah. And he was arrested, and everybody else was taken down for questioning. And I just remember being so proud of myself. Because I had whatever it was, the two hundred dollars, in my pocket, in cash. Which was, I was a kid, and that was a lot of money. And I was like, none of your business, none of your business, none of your business. And – was I even 18? I don't even think I was 18 yet. And I just wouldn't tell them who my parents were. I just didn't give them any information. I was convinced that they couldn't arrest me for sitting in his office. And I just remember being really proud of myself, because I felt I was hearing people around me, kind of caving to the pressure to give whatever information.

And he was doing abortions again a few months later. But I didn't get an abortion from him. Then I was sitting on the grass, asking people. Because I remember feeling, okay, now I don't have to have an abortion, which was a great feeling. But it went forward, in terms of this guy being very insistent. And I was sitting on the grass, and asking people, and somebody gave me a number.

I ended up getting driven, or driving, being driven by this guy. His name is Roger. Roger comes up, to pick me up, to take me out for an abortion, on Tape I 00:10:00 a motorcycle. And I just remember thinking, I don't think you want to go for an abortion on a motorcycle. So I made him get a car. {LAUGHS}

> We went somewhere way out in the suburbs, to a woman's home. She was probably not even a nurse. She was a black woman with a lovely name that sometimes I remember — many, many syllables — who didn't even really examine me. She just slid something through my cervix, into my womb, and – she was nice enough, but she really didn't give me much information. I left there thinking; so was that done; is it not done?

So I went back to work the next day. Two or three days later, I started hemorrhaging.

SS: Right.

RD: And I went back to the place I was crashing. I aborted there. SS: So you didn't see a doctor.

RD: Never. And I don't know if I had complications or not. I did have a baby afterwards. But after one child, I never got pregnant again. I don't know if it had anything to do with that. One is enough anyway. {LAUGHS} But I did try to get pregnant after that, and I didn't.

SS: So what happened to you after – did you ever go back to school?

RD: I did go back to school. But I had a baby first.

### SS: Okay. So how old were you when you had your son?

RD: Nineteen. And in terms of the abortion question, and in terms of my involvement with abortion for many years, I still have to say that having an abortion doesn't cure any young girl of having a baby. It may delay it. I hadn't thought about it before then. I had always insisted, up through the years, that I'd never get married, never have children. There was nothing I could think about after the abortion but –

### SS: You wanted to have a baby.

RD: – I wanted a baby. And so I got pregnant by a guy that I was living with. We weren't really in love. But we were living together; we were crashing together. And I went back to Miami with him, when he was going back to school. And we ended up traveling from the summer before Misha was born, until after he was born. We traveled overland. We were in Denmark, and we traveled overland as far as Nepal. And we were coming back. He was born in Afghanistan; he was born in Kabul. I had him in a hotel room.

And those two experiences were, I think, real pillars of why I went into healthcare, and particularly was interested in women's health. Because there was so much myth about all of this; about abortion, about birth, about – and it really was something that I, I got it: women could be in control of this stuff; a youngster could be in control of it, and manage it, without the help of doctors. So that was a very fortifying experience for me, in terms of the rest of my life.

So I came back, and we were in Miami, and Dave went back to school. And I went over to the junior college. And I said — with baby on hip, because everywhere I went was with baby — and I said, so what do I do? I want to go to college now.

And they said, fine.

I never took a GED. They just let me enroll in classes. So I went through two years of junior college, and then there was a break. I went to Florida State University, in Tallahassee for a few years. But I majored in dance there, believe it or not, for a few years. Took another break; and then started working at the Feminist Women's Health Center. And during that time, managed to get my bachelors in nursing and my license as an R.N.

> **SS: So were you a CETA worker at the health center?** RD: A CETA?

### SS: C-E-T-A? No; was your salary paid for by the federal

#### government?

RD: No.

SS: No. Okay.

RD: We were a collective that ran a women's clinic.

### SS: Right.

RD: We were one of the feminist women's health centers, of which there were eight or nine at the time, around the country. We were the people that went around, showing our cervixes, and showing women how to use a speculum. And we did abortions. And I myself — and I think some other individuals through the network — also learned how to deliver babies. And we funded ourselves by doing abortions.

So we did abortions once a week. And we would then do other things.

I started a prenatal clinic while I was there, which was something I was really proud of. But we made our money doing abortions. And the abortion thing was a real controversy in Tallahassee, Florida. And a lot of stuff happened eventually. We ended up not having a doctor, because of all this pressure, and we ended up suing the five local OB/GYNs and the Board of Medical Examiners. And because there was some interstate commerce involved, it was a federal lawsuit. So there was a lot of legal stuff that went on.

There was also, at a later time, there were demonstrations in front of the clinic. We got arrested during a demonstration, and not the demonstrators, one time. So all kinds of things happened. It was pretty out there. Doing those medical services really had this huge political context in this small Southern city.

SS: Now can you tell us a little bit of the history of the Feminist Women's Health Center in Tallahassee?

RD: Yeah. The history is that three women — Linda Curtis, Lynn Heidelberg and Kelly Patterson — went to a self-help presentation by Carol Downer and Lorraine Rothman, the two women who started sort of the self-help movement out in California. Or they came through. But they ended up going out there, and training, and coming back to Tallahassee, where Linda Curtis had lived. She had grown up in Gainesville. Lynn, I think, lived in California, but came with her, and formed a small group of women, using the model of the L.A. FWHC. They started an FWHC.

I came on board because they came out to the Health Department, where I was working as the dental assistant, to talk to the nurses. And I was like, whoa, can I work here? And very shortly after that, I became part of the collective.

We were laywomen. And we were determined to learn everything we could. We had this slogan, that you – you can teach a feminist to do anything, but you can't necessarily teach a woman to be a feminist. So we did our own. I learned to do the accounting and the payroll. We did everything. We eventually became a little bit more professionalized. I wanted the nursing degree, so I went after it. It wasn't really something that even I got a lot of support for, because of the whole concept that we could do it without being in the system at all.

### SS: How many people were in the collective?

RD: It varied at different times. It was usually not less than 10, but sometimes it would be as many as 20. People came and went, and there was a core. And then there was a big changeover when women came – the two women. Brenda Joyner and Frosty Grey – Linda Grey – came down from North Carolina. And Linda Curtis left, and came up to New York, and got involved with whatever that party is.

### SS: Which one?

RD: The one with Fulani.

### SS: Oh yeah; the New Alliance Party.

RD: The New Alliance. And she's still with – I've Googled her recently, and that's still what she's doing.

The deal when Brenda and Frosty came — and they were a couple — is that this was the first time we had some black leadership. And we actually moved, because we were at the end of a lease. We moved into the black community. So there was a huge shift in what we did. It was actually there that I started doing prenatal care. And we did a lot of things to kind of make sure that we were welcome in the community, which we very much were.

SS: Was there a doctor doing the abortions officially, or -

RD: Yes.

SS: – really?

RD: Yeah, there was always a doctor doing the abortions. We learned to do abortions in self-help groups, and we called them menstrual extractions. But in our clinic, we always had a doctor doing the abortions. I mean that really. {LAUGHS}

### SS: How many abortions did you do a day?

RD: We did them once a week; that was our pattern. And we'd do anywhere from 18 or 20 to sometimes as many as 30 or 35.

### SS: And were they Medicaid-funded, at that time?

RD: Most of the women paid in cash, but we did take Medicaid. Medicaid did not pay for – no, Medicaid did pay for abortions, right up until whatever. So yeah. And then they stopped, and then we would bill for pap smear and this and that, and we'd put together enough so we could at least give them a lower price. But yeah, we lived through that time, when Medicaid stopped paying for abortion at all.

### SS: So how long were you there?

Tape I

00:20:00

RD: I was in Tallahassee for about 16 or 17 years, and I worked at the health center for 14.

### SS: Fourteen years.

RD: Yeah, I know.

### SS: So what was the relationship of the health center to the rest of the activist reproductive rights movement, as service providers?

RD: Well, it was – it was sort of a, everything was fractious, because in my collective — and I was a little bit of an outsider; I was really focused on doing healthcare. But it was – it was, we ran an abortion clinic, so we could be out there and doing the political work and doing the demonstrations and doing stuff like that. And I think that we were even a little out there for the women's movement. We were to the left of the women's movement. So sometimes things weren't – well, things were fractious anyway. Everything was very competitive and very fractious in terms of who was doing what, when, and where. And there was the whole issue that we were basically — and not entirely, but basically — a group of lesbians, providing healthcare to straight women. And that was an issue to the lesbians. And there was a big lesbian community in Tallahassee. Naiad Press came out of that. And Dorothy Allison was there, during the years I lived there, and I never met her.

Because we weren't – we were somehow tainted, by this heterosexual activity.

### SS: So name names: who criticized you?

RD: I don't know. I'm not going to –
SS: How did you get that message?
RD: Because we, because our communities didn't mingle.
SS: I see. So it's not like there were articles about you, or

### people saying things to you.

RD: There may have been. There may have been. And there were articles that were sort of on the meta-level. There was Robin Morgan, and there was this, and there was that. And I don't remember. But it felt, to me, like – we never got together with – we were very isolated, no matter what we were doing. And I knew that the lesbian community, the larger lesbian community, was not isolated in little clumps. We weren't all a bunch of little clumps. It was sort of us and them, and that's what it just felt like.

### SS: Now, were you a lesbian at this point?

RD: Yeah.

SS: When did that happen? We just left you with Dave and Misha.

RD: I think I knew I was a lesbian, even when I got pregnant the first time. And then there was the wanting the baby. So that was good. I never really thought things would work out with Dave, although we did try to have a relationship. But I left him, and came up to Tallahassee. He was violent, and he was an alcoholic, and I was kind of crazy, and things got a little nuts between the two of us. So I took the baby, I went up to Tallahassee, and then I could come out.

And it's not that I knew in high school, but of my five closest friends, four of us are lesbians. We didn't have sex, we didn't talk about it; it wasn't – but it was very clear that on certain occasions, when my friend had an opportunity to kind of go out with her boyfriend or hang out with me, she'd choose me. And I really did have very close girlfriends. And I didn't really have a boyfriend in college, I mean in high school. A little here and there, but it just wasn't a happening thing for me.

SS: So what was the sexual culture of the women's health center?

RD: Well, the sexual culture of the women's health center, in some ways, paralleled the sexual culture of ACT UP in a certain way, in that sexual relationships formed alliances that formed leadership that determined how things would go. And I noticed that in ACT UP too, because I had really seen it. And it was on a much smaller scale; and people were just having sex with each other, and some things would turn into a coupled relationship, but usually not. And so there was, it was pretty ambiguous, who was with who.

The woman that I had the first relationship that I had, whose name was Libby Brice, killed herself, at some point. And there were a number of suicides or hard-to-understand deaths in women in the Feminist Women's Health Centers.

### SS: How do you understand that now?

RD: Well, I understand it on a lot of levels. One thing was, I understand that we were lesbians taking care of straight women, and we were not taking care of ourselves. I didn't have any – Frosty didn't have health insurance; she died of breast cancer. I felt a lump – right before I was leaving, I did a breast exam for her. I said, you got to get this rechecked in three months. She did nothing. Four years later, she was dead. And it was clear, because the work was 60 hours a week; it was more important than we were. And she didn't take care of this.

And, I still suffer from not being able to take care of myself. It's – I get accused at work of crying too easily.

Tape I 00:25:00 And it's – But it's, it's a real – {SIGH} – it's a real problem in movements.

### SS: Do you think it's a lesbian problem, or do you think it's a

#### problem in movements?

RD: I think it's a problem for women. I can't speak for men. I don't think it's as much of a problem for men. I think in the women's movement, it was a problem, in general. The more activist people are, the more strident they become, the more focused they become on issues; and you get all kinds of things that interfere in your ability to kind of listen to what's going on. And that definitely happened for us, working there. I mean, when you say, 14 years; I can't believe, and most people I know; they think, well, you do that for a couple years, and then you go on with your life. But it was like that, for those years.

SS: And it was a collective the whole time, 14 years?

RD: Yeah, yeah.

## SS: That's amazing. What were the relationships between all of the different Feminist Women's Health Centers?

RD: They would vary. The Feminist Women's Health Centers out in California wrote some books, and we felt very left out of that. There were leadership clashes. But we would come together. But then there would be big fights over — I don't know — in retrospect, probably very silly things.

# SS: Well, you had autonomous leadership, or there was national leadership?

RD: No, we had autonomous – we were an independent feminist women's health center in a federation, we called it.

SS: And were you guys part of Reproductive Rights National Network?

RD: No.

### SS: No, okay. What happened to the clinic?

RD: Well, the clinic went on after I left. I left in '88 – '87? – '88. Came up to New York City. Reached escape velocity by applying to graduate school. And it went on for a few more years, during which time several women who had left the health center over some kind of dispute started a clinic that was much more conventional. And eventually, there was really, not very much reason for the health center to stick around, or, however you want to see it, it got lost in this other business enterprise being more successful.

SS: And does that other business still exist?
RD: I think it does.
SS: So there still is abortion in Tallahassee?
RD: Yeah. Yeah.

SS: So, '88. So AIDS, we date from '81 or '82; I don't know when it was first visible in Florida. But when did you first become aware of it?

RD: I was aware — and I'm not sure of the year — but it was a couple of years, probably, before I left. So let's say it was around '85. I was aware of AIDS; I didn't know anyone with AIDS; but I knew, because of my connections in the public health community, that the Public Health Department, the Leon County Public Health Department, was doing HIV tests. So it was probably as soon as there were tests available, whenever that was. And they weren't doing anonymous testing. They were doing confidential testing; but they weren't doing anonymous testing. So of course, that wasn't good enough. And we decided to do testing at the health center anonymously, so that, as we thought, gay men could come in, and be tested for HIV, and we were doing that for awhile. And this was very pivotal for me, because our first positive test was a woman. She was a poor black woman, who was doing crack, and probably selling her body, and who had come – and she was someone I knew well. She had come in for many services; she was someone I liked, and who liked me. And I thought she should have an HIV test. So I recommended it to her; she didn't come for it. And I was just absolutely floored. And of note, she took the test, but never came back for the results.

So I learned all of that before I came to New York.

SS: Now when you started testing there, what did you tell people, when they tested positive? What was the counseling?

RD: Well, we didn't have any men test positive before I left.

SS: Oh, okay. So you only had this one person, who was the only positive.

RD: Yeah, I mean, we were doing testing; it wasn't a huge number of people who came to us. But we were, we were always trying to connect with the community, and this was something that we could do. And we could do it better than the Health Department, because we would do it anonymously. But we didn't have any positive tests, at all, before I left, other than this one. And it was a woman.

SS: Now I'm asking you this question because we're basically the same age, and we have basically the same history. So I'm just putting

## that on the table. How did you feel about gay men, at that time, when you were working in the clinic?

RD: The women that I worked with – some of them just hated men; really. And some didn't. And gay men were not really separated out. I didn't have gay friends, gay male friends, in Tallahassee. I don't think I had any gay male friends in Tallahassee.

> SS: But you had lived through the Anita Bryant thing, right? RD: Yeah.

## SS: And had that made you have contact with gay men? Or did you guys deal with it in a separate way?

RD: I don't remember having contact with gay men in Tallahassee. I might be forgetting. But socially, I lived in a world of women. And I lived in a world of women, some of whom really, really hated men. And I think one of the things — and certainly not all — but even to have that in your midst is – it's a pretty profound reality.

### SS: Do you think it's fair to say that -

RD: I was around when they were trying to decide whether boy children could go to the Women's Music Festival in Michigan.

### SS: Did you go to the Michigan festival?

RD: No. But, and I didn't, it's not that I wanted to go. But that's, those were the kind of conversations that were happening; that little boys were not welcome.

SS: Do you think it's safe to say that when gay men became people who needed healthcare in a crisis level that your attitude towards gay men changed?

RD: Well, yes, but how? By the time, my attitude towards gay men changed by joining ACT UP, and being around gay men.

SS: But I mean the decision to offer HIV tests, or the idea of going – there's an attitudinal shift about who needs your attention, right?

RD: Right. Yeah. And you're right; we made that shift because there obviously was a community. It's hard for me right now to separate out whether you're asking me personally or politically about my feelings about gay men. And I just think I hadn't thought about it that much. I didn't know a lot of gay men.

### SS: Okay.

RD: It's like, the years I lived in Tallahassee, I sort of forgot that I was Jewish. I just wasn't – it wasn't on the – on the screen. I just didn't hang around with Jewish people; I didn't know Jewish people. I didn't hang around with gay men; I didn't know gay men. I hung around with feminists, some of whom really shaped some of my attitudes. And in some ways, I had to reshape my own attitudes.

SS: And being in a world of women only, what did you get from that?

RD: That women are just as bad as men, and –

### SS: That's not true! {LAUGHS}

RD: – just as duplicitous, just as power-hungry, just as backbiting, as men. I got other things.

### SS: Well, what are the other things, though?

RD: That women are very interested in sex; that women don't necessarily settle down into monogamous relationships. And that was, you kind of have to be in a community to really see that. There were some wonderful things about being in a community of women. And there was community. But it's not something that I kept the warm, toasty memories from. The memories I have have to do with working too hard for too long, not taking care of ourselves, and the consequences of that; and trying to be sure that I didn't forget that. So I've carried that more steadily through the rest of my life, than the good parts.

SS: So in a way, the picture that I'm getting from you is needing women sexually, and needing to be with women sexually; but the women that you need to be with are carrying all kinds of baggage from the damage that they've lived. So that's what creates this kind of – a community that you could stay in for 14 years, and then not carry the warm, toasty memories from. It's a dynamic contradiction.

RD: Yeah, it's a good way to describe it. Yeah. I'll go with that.SS: It's interesting.

RD: Yeah.

SS: Before we get into the whole ACT UP thing, just on that one question: what was different between that, and the relationships of lesbians inside ACT UP?

RD: Nothing. It was same-old, same-old. It really was.

SS: Okay. All right. So, then you came to New York to go to grad school, in '88. Where did you go to school?

RD: Columbia. I did a nurse practitioner program. It was '88 to '90. And then I graduated from that. When I moved to New York, I moved in with Marion Banzhaf.

### SS: Because you knew her from –

RD: She worked at the Feminist Women's Health Center in Tallahassee. And she had grown up in Florida; she had had an illegal abortion in Florida. And she and I were friends; we were good friends. And I had maintained some contact with her, and I was looking to her to help me find a place to live, and she was looking for a roommate. So I moved in with her. And naturally, came to an ACT UP meeting, probably within the first week that I was in New York. Because she was very much already going every week.

SS: Now at Columbia, at that time, there was a lot of HIV stuff going on, in the public health school. Laura, I forget her last name – but there were people – and Carol – what is her name? She was like a – Carol Vance!

RD: Yes!

### SS: Yeah.

RD: Right.

### SS: Were you involved in anything there?

RD: If you even try to imagine being in nursing school, whether it's baccalaureate or masters, you probably couldn't imagine how conservative and paternalistic it is to go through a program like that. You'd think it was somehow enlightening, to go to Columbia. But their nursing school was really repressive. I learned very little there, in terms of the skills that I already brought with me. And the nursing school certainly didn't connect me with anybody progressive. So if I did meet any of those people or work with them, it wasn't through being in school there. And of course, it was a different campus. Although the School of Public Health was up there – wherever – the northern campus, and not down at Morningside. So –

### SS: So it was like a day job.

RD: Well, I had a day job. {LAUGHS}

SS: It was your second day job.

RD: It was an ordeal.

### SS: Oh, my god.

RD: It was a real ordeal. I've never done well in school. I got kicked out of high school. I got in trouble in graduate school, because I have opinions, and felt like I had – wanted to have some input into how I was being taught. And that didn't go over.

So I didn't really like the program. I'm grateful to them for the degree, I really am. Because it was the first family nurse practitioner, FNP program, they did, and all of us, all six of us, had scholarships, which is really why I selected Columbia. And so I am grateful. I'm grateful for the education. But it was, they were just starting, and they were very conservative – conservative medically. I could do all kinds of things that they would have been horrified to know that I was doing, as a nurse.

I also walked into, because I walked into the Center to go to ACT UP, I walked into CHP, Community Health Project, and I did that. I did both of those things within the first few weeks I was in New York, long before I started school, or even got a job. And I remember going into CHP, and saying: Hi, I'm interested in doing women's healthcare here. And being told, oh, we don't, we don't have a women's healthcare program. And I had been told it was a gay and lesbian clinic. So I came back. I said, I'd like to do women's healthcare here.

Well, we don't have a women's healthcare program.

I said, hello? I'd like to do women's healthcare here.

And they heard that, and I started seeing women at CHP. And I'm sure I was not the first provider seeing women at CHP. But there hadn't been somebody in a long time. Now, at the same time, somebody was there, whose name I forget, doing HIV stuff with women, even already. No; what was she doing? I don't know. There was somebody doing stuff, but it was more education. SS: Now were they started for HIV reasons?
RD: No. CHP had been around for a long time.
SS: And they had no –
RD: CHP was around from the time St. Marks, the St. Marks

Women's Collective was around.

### SS: Oh, my god, '79.

RD: So they were an STD clinic, but I think St. Marks broke off

from CHP. I don't know, because I wasn't around, but that was sort of the sense I

Tape I<br/>00:40:00got. And that sporadically, someone showed up, and said, hello. But when I<br/>showed up and said hello, it did eventually lead to a women's healthcare program<br/>at CHP.

### SS: And is that still in place?

RD: I think so. I think so. We did, I think that we did some amazing work around women's health during those years. They hired a coordinator, who was Dana Greene. And she was there for a number of years. And we put on a lesbian health fair, year after year, starting in, I don't know, '92, ninety – I don't know. I did it for four or five years, and I think it went on for a couple years after that.

JAMES WENTZY: Excuse me, we have to change the tape. Hold that thought.

SS: Okay.

RD: I think that they were just busy at the, by '88, they were dealing with a lot of men who were very concerned. They needed every exam room every night. They had plenty of volunteers. So I think that they were telling me that they were reluctant to give me space because they were already overwhelmed, and it was just the whole reality that the prominence of this issue was very obvious.

SS: Okay. So you're saying it was a consequence of the AIDS crisis.

RD: Yes.
SS: It wasn't – okay.
RD: At least when I walked in, definitely.
SS: Right. Okay. So you come to New York. And where was

### your paid job?

RD: I worked at Beth Israel, 16<sup>th</sup> Street, in the ER. Where I got my real education to become a nurse practitioner. So I worked in the ER; I was going to graduate school; and then I was a volunteer at CHP, and coming to ACT UP meetings.

SS: So you like a lot of responsibility.

RD: Well, I don't know how I did all that. And I remember when various friends of mine – they would either find out I was working, or they would find out I was in graduate school, and they would kind of be, like, really?

### SS: Just one more question before we get to ACT UP: what was the AIDS situation at Beth Israel emergency room?

RD: One of the nurses – well, the doctors were great. I loved the docs that I worked with there, particularly because they taught me things and let me do things. But we had a great policy about all kinds of social issues. I learned about AZT, for example, because guys would come in. And the docs were happy to give them blood transfusions in the ER, and send them home, which nobody would ever do now. But they were just responding, okay? You're on a drug, it's causing anemia, we'll give you some blood; go back to your doctor on Monday.

But we also — which is why I loved working there — we also had a real policy, and I don't remember what we called it. But we had a little name for homeless people who we would bring in; give them a shower; give them a new set of clothes and a meal; and let them sleep – not overnight necessarily, but at least for several hours. And we had some way of justifying that. I don't remember the little name we used. But I loved that we did that, and I loved working with people who thought that was important.

SS: Because I remember going to the emergency room at Beth Israel with someone who had AIDS — and I can't remember who it was —

## and they had a special entry system; that if you had AIDS, you could get on a fast track to see a doctor.

RD: It wouldn't surprise me. Because it was a very evolved group of doctors. When I was working in the ER, one of the nurses that I was working with early on — so around '88, '89 — died. And he was a very beloved nurse. And so I think that may have had a big impact on the staff.

### SS: Okay. All right, so let's get to ACT UP. So Marion brings you to ACT UP. You walk in, and what do you see?

RD: I'd been living in Tallahassee, Florida for 16 years. I was just, whoa. And I was very impressed, of course. And I was very – a little threatened. And anything you might imagine feeling, walking into a room that was at least almost as crowded as it ever got. And I immediately just knew I wanted to come back. So I was just very impressed.

## SS: How did you first enter into the organization? What was your first activity?

RD: The first activity was working on the women's teach-in. That was the first thing I did. We did the women's teach-in and the alternative teach-in kind of together. And I did both, I worked on both of them, so I don't know which one I did first.

> SS: Let's start with women's teach-in. So who worked on it? RD: All the women? I don't know.

### SS: You have any names.

RD: I mean, Heidi [Dorow] and – Marion and – anyone you can 00:05:00 name was probably there. Maxine [Wolfe] and –

#### SS: And what was the substance of it?

RD: Well, I think that the substance of doing a teach-in was — I mean, this is just my perspective — but my feeling, walking into ACT UP, with my background, and this – there was a lot of stuff going on, but there was this message of drugs into bodies. And I don't know when the FDA demonstration was, but that text, of drugs into bodies, was very shocking to me. Because I had been at the FDA in '74 or '78 or something, protesting against DES, and this experimentation of drugs on women's bodies, and not testing drugs sufficiently. So I was just kind of shocked. And not in disagreement, but just like, oh. So it was refreshing to think, things aren't always the way you think they are. At the same time, I was scared for men who were thinking that this was fine, to just experiment on their bodies. And I think it was those of us who were in women's health who were most, probably, vocal about being concerned.

Also, just the political issue was that these men, despite the fact that they were gay men, felt very privileged, and felt like they could do anything, and didn't have a real sense of history, most of them, of movements or of health movements. And so they were kind of like the blind leading the blind. They were doing amazing things, but we knew other movements at other times, and how things had evolved, and we thought, those of us who'd come out of the women's movement, and particularly the women's health movement, thought a little more historically.

SS: Can you be precise about something that they did not understand, or information that they didn't have, or how the privilege was expressed?

RD: I think that they just didn't understand and it was, in some ways, good not to understand how hard it is to change things, and how much resistance you're actually going to have to confront, and how many different kinds of strategies you're going to have to use. It was just more – also, not taking any lessons from other movements, whether it was political movements, civil rights, women's movement, antiwar movement; or the health movements, which had included a gay and lesbian health movement that spun off of the women's health movement. And there were other health movements. There were the free clinics, and there were migrant health.

So there was all of this stuff. And what we knew about was the women's health movement. So we were, it was a mix. But I think that the thrust of it was to talk about the women's health movement, and try to get across what were the issues and what were our strategies, and what can you learn? And my analysis, even at the time, was that what we did was so important, you just couldn't overlook it if you were really trying to move beyond it.

And I think what we did was give women a sense of body ownership. That was just – if you don't remember, if you don't know, you can't even imagine. But if you have teenage nieces and nephews or whatever right now, if you talk to young women, even up into their thirties; they have no idea what life was like before just that shift. No, this is my body; you can't just do whatever you want to me, whether it's medically or physical violence or whatever. So that shift was – it was there. And so what could you do with that? I mean, you needed to know it was there, and that it hadn't been there before.

That's just an example, but because that's kind of theoretical, but it still was really something that I think that we felt like these gay men didn't know.

SS: So would you say that the women in ACT UP who had experience in the feminist movement were contributors to the articulation of the PWA empowerment ideology?

RD: Sure. I would say that. I would say that it was very mutual, because there already was both a sense of this is horrible, what are we going to do? All this oppression; and empowerment, kind of all sifting together at the same time. But yeah, there was that to learn, from the fact that there is a sort of empowerment that takes place, that takes root, when concepts change about things that are as basic as who has control over your body.

So if it came up to something like drugs into bodies, it was just nice to kind of have that perspective. You couldn't even have this discourse if this hadn't happened.

SS: Now, how was a teach-in – was it mandatory? Was it – RD: Well, nothing was mandatory in ACT UP.

Tape II 00:10:00 **SS: Was it held during the Monday night meeting, or was it** – RD: No.

### SS: – separate event.

RD: It was a separate event. It was very well attended. We put together a booklet of a lot of historical information. I can't even say I still have one, and I wish I did. But we put together a lot of information. We sat at a table. We talked, we answered questions. There was a lot of dialogue. My overall impression was that the men that came to it loved it, and felt very grateful for that sharing, and learned from it. Now, you could maybe even see that, over the course of the next years.

SS: Now was the alternative sector of ACT UP already in place when you came in?

RD: Yes. I think so.

### SS: And then you went in to work in that?

RD: My entree into alternatives was partly just my own interest. I had learned a lot about herbal stuff in women's health. I had dispensed a lot of herbal and alternative information, as a healthcare worker, up to that point. I don't think I would have gotten drawn into that group if I hadn't met Jon Greenberg. I just wanted to be around him, so –

### SS: So tell us about Jon.

RD: Jon was a beautiful man, who was really a difficult guy, and that I, for whatever reasons – we just meshed, we just got along, we were like, I

felt he was my best friend, for the years that he lived; that whole time I was in New York. And he – some of the things that he talked about were so out there, so revolutionary, that people wouldn't even talk to him. He was feeling like, well, I have these organisms in my body; and this war concept is really offensive to me, and I'm going to learn to live with them, I'm going to make peace. And he wrote something called *The Metaphysics of AIDS*, which is this lovely treatise. He wrote a number of things that I have that I don't know that they've ever gotten published. I'm simplifying it. But he was very smart. And he wrote about these things in a very compelling way. And he, a lot of people congregated around him.

### SS: So a kind of acceptance of the virus, would you say?

RD: Yeah.

### SS: And how did he come to that point?

RD: He had received acupuncture from — I believe I'm saying this correctly — in a clinic where Susan Rosenberg worked. And she was later arrested.

### SS: Oh, the Lincoln Hospital Acupuncture Clinic.

RD: Yeah, yeah. And so he was introduced to alternative healthcare, I think, before he knew he was HIV-positive, because he was having a lot of problems; problems that his doctors, or whatever, couldn't figure out. And so he really learned the philosophy by being a patient, by being a consumer. And he was just naturally skeptical, in a very similar way, the way I and other women were just naturally skeptical of the medical profession. And so he was one of many men, for better or worse — in his case, maybe for worse, I don't know — who would never have taken AZT. He thought it was poison. And I had patients that didn't take it for that reason, but later were able to go on the cocktail, and do better, because they hadn't taken it.

#### SS: Right.

RD: So there were various reasons why people didn't go on AZT. But to him, it was poison. And he believed — and he was in and out of the different alternative communities — but he believed that he could manage this. It Tape II wasn't too different from the idea that I could manage a home birth. It was like, 00:15:00 he could manage it, he could figure it out. He was wrong, but he really believed that. And he really worked on it. And he had a lot of people listening to him. And he had a lot of really good ideas.

#### SS: Do you remember some of them?

RD: I just feel the whole idea that AIDS itself is a metaphor for breaking down barriers between different groups who are naturally seen as being at odds. He'd watch what happened in ACT UP as women got integrated, or people of color got integrated, or, to the extent that those things happened; and he'd see that as a metaphor, and he'd talk about it.

And he would talk, like a lot of men talked, about how AIDS was this lesson. But it was very, I just found him very compelling and very profound. He was very smart. So he could talk about things like that, and not make you think, oh my god. You had to listen. And it was just stuff like that, that he could take a metalevel of what was going on in ACT UP, or what was going on in the treatment community, or what was going on here, and branch it out into a philosophy of how we could achieve world peace, or how people could learn to live together. So the learning to live together – the learning to live with the virus was about people learning to live together. I'm not nearly as articulate as he was.

SS: That's okay. But being in ACT UP for a long period of time meant engaging a lot of possible outs for AIDS, right? Whether it was dextran sulfate or Compound Q, or visualization. There were a lot of different ideas of things that people became invested in and tried that didn't work.

RD: Yes.

SS: And would you say that this was on that continuum, or was it in a different realm?

RD: It was in a different realm. I, because I was associated with the alternative, the group, got a lot of requests to do various things for people. I did a lot of [Compound] Q infusions for guys. In fact, I had a little group, once a month, that would meet at a guy's apartment, and I would do Q infusions for all of them. And they were very – this particular group, in some ways, was very timid in their expectations, and timid about having any broader understanding of why they were doing it. It was not desperation, but it was closer to that.

And Jon was very thoughtful about what he would do and what he wouldn't do. Jon was someone who would take a Bactrim if he felt short of

breath. We lived in the same apartment house, on the same, fifth floor. If he got short of breath on the third floor instead of the fourth floor, that day, he'd take a Bactrim. He paid a lot of attention to what was going on in his body.

He did things wrong, as I said. But he did everything thoughtfully. And I think a lot of the guys who were rushing to do this and rushing to do that were some variant of desperate. Not to lump things together, but it just felt qualitatively different. Or maybe just because I got to know him so well, and it was just so compelling.

And he gave me a real sense, too, that I've carried with me, of what it means to die. And – he, he just said, you can't save lives. That was Jon's line. You can't save lives; everybody dies. It's so obvious. But he would say it in ways that startled you, it made you think. What are we talking about here?

And he didn't want to die. But he was very aware that he was going to. And he didn't have any illusions about that until he was dying, at which time, he threw everything out the window, and – didn't want to die.

SS: At the end, he didn't want to die.

RD: Did not want to die.

SS: What do you think it was that changed, that made it possible for you to have such a close primary relationship with a man at that time in your life, when before, you lived in a women-only world?

RD: I don't know. I think it was Jon. I think it was Jon. I don't know how close I necessarily would have been to other men, although I got, I had

good relationships with gay men, and continue to. But I think I fell in love with him. He was just so – charismatic, for me. And so the relationship itself meant a lot, in terms of what my life was about. It was shocking. It was shocking to feel so drawn to a man. But it was also delightful. And it allowed me to think about things that were being thought about amongst the larger community of gay men and lesbians, trying to work together.

SS: Okay, I want to talk about Alternatives – the committee. What was their relationship to – did they have an antagonistic relationship to the pharmaceutically-oriented folks? Or were they –

RD: Oh yeah.

#### SS: Can you explain –

RD: I don't think it was antagonistic, though, in the competitive sense. It was just like, you're wrong. And there was also a lot of — this was not Jon — but there was a lot of sweetness and lightness about the whole thing that wasn't, so butting heads, in terms of expressing antagonism. But it was just like, you guys are wrong; this is just wrong. And we're, you're wrong about HIV, you're wrong about this, you're wrong about that.

But I don't know that there was anything particularly homogenous about that committee, and I did not go to their meetings. I helped them when it was time to put on the teach-in. I did a lot of writing; things that I could do to help. So that's why I was part of the teach-in. SS: Now, were there treatments that were advocated during that teach-in, or that were expressed, that later turned out to be very valuable and viable.

RD: No. I don't – correct me if I'm wrong: I don't think so.SS: Okay.

RD: And it doesn't debunk the whole idea for me. I think it gave a lot of meaning to a lot of people. I think that they were essentially right, not wrong, about the way they felt things were going, in terms of developing these drugs. I think they were right that these drugs are no panacea, even though they are life-preserving.

So they were right, philosophically; they were just wrong factually. And so I don't know where people scattered over time. I know that Jon didn't change his position soon enough.

SS: Do you think that he died because of his ideology?RD: Yes.SS: Is that true for other people, too?RD: Yes.SS: And how do you deal –RD: Although, I say that with some certainty that I really don'tpossess. I have no idea. But it's what I felt, because it had to do with the fact that

he was convinced that he could take Fluconazole for cryptococcal meningitis.

And it has a lot to do with the fact that we fought a lot during those months; and that when we finally got him on Amphotericin, it was too late.

#### SS: Now why would he take Fluconazole and not

#### Amphotericin?

RD: You'd have to ask him.

SS: Okay.

RD: It might have been – I don't know.

SS: Do you feel it was arbitrary? Do you think it was

#### dementia?

RD: No, no.

SS: No.

RD: Well, he was acting, he did have cryptococcal meningitis. And he did tell us, one day, that he had fucked God. He'd gone up on the – he had these – but at other times, he seemed perfectly lucid. And he would have these horrible outbursts. But he had always had horrible outbursts.

So I don't know how much was the disease; I never knew. Which itself was a great lesson, because I deal with a lot of people with disease, and I understand that you can't tell how much of anything is disease, and whether disease is something separate or integrated. He really gave me that understanding about disease. So I still don't know. I know it had something to do with his last few months; that kind of damage that was being done in his brain. He was having spinal taps every week, towards the end, just to let the pressure out. He was having horrible headaches, and we were trying to take care of him at home, and – and eventually, I said he had to go into the hospital, because he was having seizures.

The last period of time was not very good for either of us. It was obviously not very good for him, but he, that day, he called me a traitor. But I just couldn't count on his friends to take care of him, having seizures. And nobody was noticing. So I just, and I was working; I couldn't be there all the time.

We had a wonderful team, but it was the middle of July. He died Tape II 00:25:00 on the 12<sup>th</sup>; tomorrow will be the 15<sup>th</sup> anniversary. And as much as I tried to supervise his care, we were reliant on a lot of different people, so he could have round-the-clock care at home. And it was very hot. Which wasn't, it wasn't a good thing.

> So we just, I, you want to die at home? I'm here with you. He, no, I don't want to die; I don't want to go in the hospital. Gee, thanks. You're going to have to do one or the other. And then he went in the hospital, and died in the hospital.

#### SS: Now, did you discuss his political funeral with him?

RD: I didn't have to. He would talk to anybody about it. I remember one time, I was in the elevator with him, going to get either an induced sputum or a chest x-ray. But we were in a medical building, and there were other people in the elevator, and there was even a kid in the elevator. And he said his thing, well, when I die, I want you to burn me in the street, and eat my flesh. The things that he was saying at the end.

Although his idea of a political funeral was very different than the other political funerals. He did not want a political funeral. He would say that, too. Whatever that meant when he said it. But he was very active with the group of people who were planning political funerals, and he was very close with Mark Fisher and Tim [Bailey] and the other men who planned for political funerals. But his line was, I do not want an angry political funeral.

Well, okay; his line was, so you read it however you want to read it. I do not want an angry political funeral; I just want you to burn me in the street, and eat my flesh. So that was –

SS: So can you – I was there – but can you describe his political funeral?

RD: Well, we -

#### SS: How did you get the body back, first of all?

RD: We – well, we had him taken to, if I'm not mistaken, the name of the place was Fisher's, and they were very used to dealing with people with AIDS. Of course, so he went there from the hospital. And I just made, I just made the arrangements. I told them what we were going to do. But I didn't plan what we were going to do. We came together. We were at Barbara Hughes's apartment.

#### SS: At whose apartment?

RD: Barbara Hughes's -

#### SS: Barbara Hughes.

RD: – apartment; and they were in an affinity group. They were the people that went into the TV station. That was that affinity group. I don't remember what they called themselves.

#### JW: The Marys.

RD: The Marys, right. And we sat down, and tried to decide: well, what did he mean? What would he want? There was the in-the-street thing. Well, that's, we were near Tompkins Square Park. Let's do it this way. And once people had decided – and it terrified me; because I knew it was all going to dependent on me arranging it; because nobody was going to talk to anyone else. Somehow I was the person, who people thought was his spokesperson.

#### SS: You were the widow.

RD: I was the widow, exactly. But it was really not that hard to arrange. And I remember being terrified at this meeting: oh my god, what if I can't make this happen? But I went over there, and told them what we were going to do. They, of course, didn't want to be involved in it. But they agreed to bring his body to a certain place in a hearse. And we took it out.

#### **SS: Houston Street?**

RD: Yeah. Whoever took it out — I wasn't carrying it — took it out, and carried it right up First Avenue, and across at Seventh, and over to a place that we had pre-selected. And I called John Kelly and asked if he would

sing, and various people were prepared to speak. And it just all came together. The piece of getting him there was not really, as much as it terrified me as to whether they would do it or not, it really wasn't that hard to arrange.

And the coffin was closed, as we carried it through the street. But we did open it there. And I selected the clothes that he was in, which was drag. Which, he wasn't really that into drag. But I had some pictures of him in drag, so I thought, he'd like this. And then we, then I had him cremated.

#### SS: And what'd you do with the ashes?

RD: Well – as it turns out, some of the ashes went to his family. And the other ashes I had, and one year later, on the first anniversary, I went out to – the beach; the island. What's the island?

#### **SS: Fire Island?**

RD: Fire Island; where I had taken a place before. No, I don't even think I had a place there. We just rented a place; went out there; invited his Tape II 00:30:00 closest friends. And we had this little thing, where we threw them, threw his ashes, and threw some flowers and stuff into the ocean.

But I asked everybody to eat some of the ashes, to taste some of the ashes. And not everyone would, so I put some into the cole slaw. {LAUGHS}

#### SS: You made his wish come true.

RD: I did my best! I did my best.

SS: Okay, thank you for telling us about that. Let's go to Compound Q.

RD: Okay.

SS: So can you also – we all remember the famous day when Larry Kramer came to the meeting and said, they're dancing in the streets in San Francisco! The cure has been found! Compound Q!

So what is your history with Compound Q, and how did it get introduced into our community?

RD: I guess I don't know. a lot of times, I just got pulled into things because I was a nurse, and I could do things. I did a lot of medical care in the home, over those years. And so I sometimes got called in or pulled into things that I don't really know how they got started. I don't know who – I don't even know who was doing these infusions when I started doing them for people, and I don't know who else was doing them. I just know that I kind of got brought in. Or I'd get called, and I'd go to someone's house and do an infusion, and they were on a monthly basis. At that time, that was the idea. And I sort of thought, well, why don't we all just get together, because I can't run around and do this. At one point, we had six; I had six guys that I was doing Compound Q infusions for.

And I really, I was just being of service. I don't -

SS: They were choosing medication and you were helping them

RD: Yeah.

SS: - have autonomy about their -

RD: Yeah.

#### SS: What was Compound Q?

RD: It was some kind of – pharmaceutically enhanced, or extracted plant. It came from some kind of melon, if I'm not mistaken. What was it? I don't know.

#### SS: What was it supposed to do?

RD: I don't know. I probably knew at the time, but I really don't remember how it was supposed to do what, because I don't even remember where we were in our understanding of what we were trying to do, or where the virus was, or –

#### SS: Well, what made people stop doing it?

RD: Well, I'll tell you, it was a hard infusion to give and to tolerate. When I had six guys doing it, it was a little hairy for me, because they would have palpitations, or high fevers, or things would happen during these infusions. And so they weren't pleasant. They weren't, sometimes they'd go smoothly; sometimes people would faint, or have a bad reaction. And a couple times, I came close to sending someone to the hospital.

So I didn't love doing them. And I think people eventually stopped doing them in part because it was hard to get; although there was a good source, apparently.

SS: How did they get it, do you know?

RD: They got it from some particular person who was in California that they'd send the check to, and it would come in the mail.

#### SS: Was it illegal?

RD: No.

#### SS: Okay.

tape?

RD: Not, not to my knowledge. But in that larger sense, what did it mean to me, doing it? I never even thought about it. It wasn't illegal, I don't think, for me to do infusions for people at home, of my own free will. And there was nothing illegal about it, as far as I know. And it came in ampoules. So it was some kind of extracted, pharmaceutically extracted, clear liquid. So it wasn't something I thought was weird, in terms of being able to provide a safe, sterile infusion for people. I felt comfortable with the way it was packaged.

# SS: So when did people start to realize that it wasn't going to do anything?

RD: Well, actually, I don't know. Because I, at some point, just was overloaded with things to do, and I turned the group over to another nurse. So, and those were my only contacts.

Did those people stop? I don't know. You've interviewed one person who was in that group. And he's apparently doing okay, but I don't know when he stopped.

SS: Okay. Okay, how much more time do we have on this

#### JW: Seven minutes.

SS: Okay. Because I want to get into a big topic.

RD: Oh, okay.

SS: So you were really, really involved in getting AIDS services for women with AIDS. How did you enter into that process?

RD: Well, I think I came to New York knowing that HIV was the underbelly of HIV was somewhere other people didn't know. It was in women, and drug users, and people of color, because this woman was a drug user and a person of color. And so I just came with the knowledge. And then I just found people who also had figured this out. And I, when I finished the graduate program, which was in '90, I looked at all of these programs, most of which were in the Bronx — although some of them, I'm sure, were in Manhattan — and I met the key people, just by interviewing for jobs. And you're going to ask me names, and I'm not going to remember. But they were all over the place. The doctors that became involved in AIDS were wonderful people; and started clinics in all the hospitals; and none of them could completely ignore the women's issue. But where there were women, it was more evident, and discovered, and dealt with a little more aggressively.

> So I went up to the Bronx, to Bronx Lebanon Hospital, and started working with Kathy Anastos, who is still doing women and HIV work. She was in the original study, the women and HIV; WIHS [Women's Interagency HIV

Study], whatever; study, that was funded by the federal government, and she's still doing AIDS research in Africa, and working with women and AIDS.

And what happened was, I was a nurse practitioner in a doctor-run clinic, so I was *the* nurse practitioner. Most of the providers were men. And all of them were, just felt like, well, why should I do the GYN exam? Let her do it. And everybody would send their women to me for the GYN exams. Plus, I'd been doing them over at CHP, and while I had mostly, worried-well lesbians, or lesbians that weren't at risk of HIV, I also was seeing some HIV-positive lesbians at CHP. So I already had a little heads-up about what we were going to see gynecologically. But then I had the added attraction of seeing all the women in this clinic. And all the women in this clinic was, at that time, at least 200 women. Because it was about a thousand people in the clinic. Just right at the beginning. It got bigger. Maybe 900. But it was huge.

So I was doing these GYN exams, and finding all this stuff, and other people in other clinics were finding all this stuff, once they started seeing women. One of the reasons that some of us didn't send women over to the clinic was because we were afraid that they wouldn't get treated well. And so we figured out a way for them to get their GYN exams. In my clinic, it was, well, send them to Risa; she'll do them. And so I got to know a lot of women. Because when you do GYN care, you ask certain questions. When I do GYN care, I would always ask about physical violence; I would ask about early sexual abuse; I would ask the appropriate questions to do an appropriate kind of conversation. So I learned a lot. Plus, when you have to talk to people about things that are difficult, you do develop an intimacy quickly, if you're going to get anywhere.

And so I really had a lot of opportunity to get to know women. Plus, if they had a lot of GYN problems, they'd come back to me. So I'd get to know them over time, and get to know them well.

So in addition to it being a wonderful experience for me personally, I saw the pathology. I saw it day in and day out. I could see what was going on.

#### SS: What was going on?

RD: You couldn't treat their, particularly their HPV-related infections, you just couldn't treat them. The warts, you'd freeze them, they'd come right back; the cervical problems, you'd try to get rid of them, they'd come right back. There was a lot of question about periods, there was a lot of irregular periods, heavy periods. I don't know that I saw that much of that, but I saw some of it. And there were just – sometimes it was hard to sift out whether or not this stuff was going on because of sex — lots of infections — or whether it was really HIV. But there was a lot of PID, pelvic inflammatory disease, that was hard to treat.

But the most profound thing was this, these abnormal pap smears, which I immediately started trying to keep some data on, which became the basis for doing this study at our center, because I already had a lot of data by the time they started the study. Pap smear results, and whether they made it to colposcopy, and whether we did this or that, and what was the next pap smear. And I decided right away — I mean, it didn't take me long — that these women need pap smears every six months. And since I didn't mind doing them, it wasn't that hard to accomplish.

 SS: Because you were seeing dysplasia, or you were seeing

 Tape II

 00:40:00

 rapidly accelerated cervical cancer?

 RD: No.

 SS: No.

 RD: I didn't see a lot of cancer.

 SS: Okay.

RD: I saw a lot of dysplasia; but dysplasia that acted differently than in women who weren't positive.

So I took the next step, and I got trained in colposcopy. So then I saw even more pathology, up close. Because colposcopy is the exam you do to look at the cervix, the vagina, and the labia under magnification. And part of the training is learning how to take the biopsies.

And again, it was because there was a backup trying to get these appointments for women for colposcopy; and there was also just the factor that I didn't want to send them to a gynecologist who might treat them badly. Although I did eventually form an alliance with one of the gynecologists, Laurie Solomon, and she precepted me to learn how to do colposcopy. And so that was something I learned to do. Tape III 00:00:00 So it just made me, you know, I just had the skills to do this kind of work, and to see what was going on. And what it was was just a lot of dysplasia. I really didn't see a lot of cancer, never. I did see some. But you do see some cancer, anyway.

#### JW: Can you hold that thought?

### SS: Okay, so there you are, in the trenches of service provision, observing that women with AIDS are having other kinds of symptoms and diseases. How did that translate into the activist movement?

RD: Well, actually, the activist piece, for me, what there was of it, actually came first, before I got up to the Bronx. Because I was between finishing grad school and starting a new job. And I had a month or so. And I don't know how I hooked up with Terry McGovern, but she found me, and asked me if I'd look through charts for her. So as she was building the momentum for the lawsuit that she filed, I was reading charts — which was fascinating — and looking at things that were overlooked as, obvious to me, obvious signs of HIV. And she was getting, she had these clients, as she described, coming to her; can't get disability, blah blah. But in order to build a case, she felt she really needed the piece of somebody having sort of a medical eye.

So I read all those charts. I learned a lot from that, too. Because these women were going over and over again, for UTIs, pelvic infections. Pap smears didn't even reach the surface. And we talked about cervical cancer. But by saying it didn't even reach the surface, I'm saying I read these charts, and nobody was doing pap smears on these women. Which is not because they were HIV; it was just bad healthcare. So it was a lesson also in a certain amount of bad healthcare that women were getting, when men were getting the range from good to bad healthcare, but at least some good healthcare. And the women that she was talking to were getting horrible healthcare. So there was that, too.

But I just picked up on a lot of things by reading those charts. So that happened the summer before I started seeing patients in the Bronx.

So I had a few patients at CHP who were positive, women who were positive. I read these charts; I got fired up by fiery Terry McGovern; and then I went and started seeing patients for the next six years.

SS: So how did the activist strategy around this issue evolve inside ACT UP?

RD: Did it? {LAUGHS}

SS: Well, there were all those coalitions, demonstrations –RD: Oh, yes, it did. You're absolutely right.SS: Okay.

RD: I think that I might misspeak if I tried to say how it unfolded. A lot of it did unfold around this lawsuit, I think. I can't think of anything else that was really a trigger for demonstrations, of women don't get AIDS, they just die of it. It had to do with the definition, which was a spinoff of the disability issue, which was where the meat was, in terms of being able to create or file a lawsuit. SS: Now were you involved in any of the activists' side, the street side, of that CDC campaign?

RD: I was involved in ACT UP demonstrations to the extent that I could be, given that my full-time job included Friday, Saturday, Sunday. And that was how I worked full-time and still made it to classes. And so a lot of demonstrations were on weekends. I didn't make a lot of demonstrations. I've never thought of myself as having any political savvy. I'm just, because I'm interested in making sure the healthcare gets provided, I've been very useful to the movement.

But I did – and I do have, still, not just a trepidation, because I won't go to demonstrations anymore. But I did have the experience in demonstrations of just really losing it. It's just such a release of raw emotion and anger and stuff that you pent up for all kinds of reasons, that I just was very out of control at demonstrations. I spray-painted "ACT UP, Fight AIDS" on the capitol in Albany. What a dumb thing to do, and it's still haunting me, because I'm a licensed person. And that was not something I can pretend didn't happen.

00:05:00

Tape III

Tape III 00:05:00

And I can't even explain it, but I don't think I'm the only person that was hard to contain at demonstrations. I'm very well-contained in other settings.

SS: So were you involved in any of the organizing side?RD: No.SS: No. Okay.

RD: If people would come to me for information, or ask me to help with this or that, or I'd make signs. Definitely not in any kind of leadership role around political strategy or political – and sometimes I would just really be – in retrospect, I think I was kind of – I don't know if "timid" is the right word, but I thought this was just so beyond what I could imagine actually being able to pull off. And I would be amazed, time after time, that these things would get pulled off, that these demonstrations would happen the way they were supposed to, and people would come. And the arrests would happen, and the bail would be posted. The way, the machine of it, just amazed me. And just people taking those risks. Over and over again, I was just always awed by it.

#### SS: Did you get arrested?

RD: Yeah.

#### SS: When did you get arrested?

RD: I got arrested, I think it was at City Hall; I got arrested in

Albany. I got arrested whatever time it was when there was the strip search.

SS: Oh, you're one of the strip searches?

RD: Yeah.

SS: Can you tell that story? First of all, what did you do to arrested at Target City Hall?

RD: It was – sitting down in the street. It was – it wasn't acting out, or acting up. I was just sitting on the street with other people. We wanted to be arrested, according to plan. We were taken down to wherever. And the women matrons, whatever you call them, decided that it was normal procedure to strip search everyone who came in, and so they did.

Now my reaction to being strip searched was very different, I think, than other people's. To me, it was no big deal. Oh yeah, you want to see my pussy, you can see my pussy; I don't care. I've shown it to other people. I've shown it to, you know, I'll put a speculum in if you really want, and I'll tell you about it.

So because I had that attitude, I think that she was, the woman that had to work with me was fine. But I think when there was some angst about it, it may have escalated into something even worse. I don't really know. And it's certainly not a judgment about people who were really freaked out by it. But I wasn't. And in fact, when they decided to file a lawsuit, I didn't sign on to it.

#### SS: Why?

RD: I felt it should be a class action suit, and the decision was made not to go class action; that it would be enough of a political statement. Well, I really thought that was wrong that these particular women should get this money. I didn't care if, as a class action suit, anybody who signed on to it only got two dollars. I just thought that was the way to go. And I had been involved in a lot of this legal stuff back in Tallahassee. And I – no, no judgment; I just didn't think it was the right legal strategy. And I remember, when we went from because we'd have these meetings about it — I remember the meeting. I don't know where we were, but the meeting at which we went from class action suit to no, that's not going to work. And I never went back to another meeting.

#### SS: Okay.

RD: And I didn't get my eight thousand dollars. {LAUGHS}

SS: Okay. And so then you were arrested at Albany.

RD: Yes.

#### SS: Now what was the demand at Albany?

RD: We were there with the women stuff; you know the women's signs, the tombstones. I remember making those tombstone signs. I don't know. I don't know.

#### SS: Do you remember how many people were up there?

RD: A lot. A lot. I don't know; it could have been, I don't know.

It was a lot. Hundreds.

#### SS: And did you all have to go back to trial?

RD: A lot of us did go back. Now, I was the only person that got taken over to the penitentiary.

#### SS: What did you do?

RD: I spray-painted on the capitol. Dumb. But satisfying, in some ways. And so I was charged with some kind of misdemeanor that was different. And so they took me over to – and it was called a penitentiary. So they took me over there, and processed me, and I was there overnight. Everybody else, I think, got out that night. And I got out the next day.

Tape III 00:10:00

	SS: And when you got out, who was waiting for you?
	RD: John – whatever his name is.
	SS: What was his last name? Was his name Kelly?
	RD: No.
	SS: No.
	RD: But maybe his name was Kelly, and it wasn't John. Because
it wasn't John	Kelly, ha ha!
	SS: Do you know who I'm talking about?
	RD: A little guy –
	SS: The little straight guy, who was with Alexis –
	RD: Yeah.
	SS: – the guy with the beard.
	RD: Yeah.
	SS: I think his name was John Kelly.
	JIM HUBBARD: Isn't that John Kelly?
	SS: John Kelly.
	RD: Okay. Sorry.
	SS: He was waiting for you?

RD: He was there, my hero, get me out of this place. Although that night – and get me out of this place because I hadn't had any coffee. I was like, oh my god; they're not even going to bring me coffee? They brought me a baloney sandwich? And they wouldn't let me take a shower. Because I wouldn't put on their, the clothes. And they said, well, if you're not going to change clothes, you can't have a shower. And I was filthy. They were just, they weren't mean, but you know, it was just so stupid. And I was just really glad to get out. But I knew they'd come for me.

I got a check back from them, because they took my cash. So I got a check from them, that I still have. A little souvenir. But yeah, they took, they, he and someone — and I don't remember who it was, who the woman was — but, came and got me.

It was just so wonderful that these things were taken care of. I mean, and even in the extremis, that somebody would do something that they stupidly shouldn't have done, and made it that much harder for everybody else, and all of that. But they were right there, as if, as if it was perfectly natural that we would want to spray paint.

Now the neat thing was when we went to court. And we didn't all go. But because we had a court date, some people went, because we thought of it — and I went because I thought I needed to be there — we went because we thought of it as an opportunity to talk in a public setting about the issues.

And I remember speaking to the judge, directly to the judge, standing there speaking about what was going on in my life right around that time. And I remember him being absolutely captivated by what people were telling him, and being very conciliatory. I mean, these things stood. We were pleading whatever, no contest, or whatever. There were fines. It's not that there were no consequences. But he was great. I don't know what his name was. But I just remember that experience, of feeling, oh; you get how desperate this situation is. So that was kind of a neat thing – because we had to go back up to Albany.

I don't remember how many of us went. I think it was a small cadre, maybe 20, of the hundreds of people that -I don't know where they took all those people, because they didn't take me there.

SS: Now what about women with AIDS who were in ACT UP? As far as we know, there's only a couple who are still alive, and the one that we've approached has refused to be interviewed. Were you involved with them?

RD: I was involved with people as their provider. So I was a –

#### SS: Who were in ACT UP.

RD: Yeah. Some of them. Certainly I wasn't everyone's provider. But I did know some of the women because I took care of them in the clinic at Bronx Lebanon.

SS: And since they've died, and were active in ACT UP, can you tell us about some of these people?

RD: Well – I'm trying to think of – I'm trying to think of who – I'm trying to think of whether somebody in particular is dead or not: I don't know.

#### SS: Oh.

RD: I really don't know.

#### SS: Okay.

RD: But in any event, I found that these were unusual women in the group of women that had HIV, because most of the women that had HIV were married. In my clinic — I'm talking about a select population — were married, were non–English speaking, were completely confused about what happened, had no idea how they were infected; were not activists in any sense of the word, and were just really struggling. So these women just shone. Some of them had been in prison, and had been in ACE Out, or ACE [AIDS Counseling and Education], or one of these groups that had done counseling in prison. They had gained their activist stripes somewhere. They were mostly single. Some of them were lesbians, but not most. And they were just brilliant women, who were very brave. And I do remember some of them specifically. But I can't remember someone who's dead that I knew personally like that.

But I did have close friendships with a couple of women; not a lot. Mostly it was they either came, some of them had come into CHP to see me; some of them I saw in the Bronx. It was more that I was a resource that people knew was available for GYN stuff. But I also got very, very close with a couple of people who started out as patients.

Tape III 00:15:00

#### SS: Okay.

RD: But that didn't happen through ACT UP.SS: Okay. So now I want to open a huge can of worms.RD: Okay.

#### SS: The lesbian transmission issue.

RD: Um hm.

# SS: Can you sort of historicize that? How it came to be on the table, and how it was played out in ACT UP?

RD: It came to the table, I think, in a very reasonable way, because there certainly was a question. And at the same time, there was certainly a sense that, as was true in other movements, that lesbians didn't matter. And so there was some of that. And there was some of, I guess, sort of a wannabe thing, in a weird sense, that you were living through it anyway. This one step removed felt really weird, when this was your life anyway.

But there was certainly enough not known at the time that it became an issue to think that it might be an important issue. So it didn't arise out of some kind of political motive. It was a real question. And it became sort of a calling card.

It was also a way to introduce women to safe sex. We knew that women, like men — maybe more than men — were having sex with men and women, or were doing other risky things. So it was a way to introduce the larger question of safe sex.

There were some real good reasons to be talking about HIV transmission and lesbians. However, like other things — like the cervical cancer issue — it got blown out of proportion, in terms of how real an issue it actually was, when you really had enough information to look at it. And there was, of course, a reluctance to let go of any issue. There's always a reluctance to let go of things you've felt passionate about.

And there was also a general tendency in ACT UP, amongst everyone — the men and the women — to really overlook the facts if it was not in their polit-, and it was very frustrating to me. And at one point, for awhile, I stopped going to ACT UP meetings, because I just felt like so much misinformation was being spouted from the front of the floor, and I didn't know, should I correct it, should I, and what should I, and I just kind of stopped for awhile because I felt like this is a political thing. I don't know where this fit into my other sensibility. But it was like, this is a political thing. If people want to make an issue out of something that's not an issue, that's a political strategy.

So I fit into it as an educator, as someone who was concerned about women's issues and safe sex for women. I was particularly concerned, though, because there were, I had, I knew some, or I was taking care of some lesbians — and this was in the clinic, and they weren't activists — but I was taking care of some lesbians in the clinic who were with HIV-negative partners, and they came to me, and wanted to know what to do. And I was also dealing with other lesbian HIV-positive women who didn't know how to disclose, or were feeling isolated, and so on and so forth.

So those issues, I really connected with.

SS: But do you feel that you've ever seen a case of lesbian transmission?

RD: No. Is that in question anymore? I don't know.

#### SS: Just for the record.

RD: {LAUGHS} Not that I know of.

SS: So would you say that what happened in ACT UP was a kind of AIDS hysteria around that?

RD: No.

SS: No.

RD: No. I - no. I think it was much more complex than AIDS hysteria. I think it had to do with – women are important. And we need to investigate these questions too, and we can't just wait. So there was a sort of urgency amongst women who had been very helpful in all kinds of issues to taking a stand for our own issues, whatever they were, or weren't. And I wouldn't call that hysteria.

#### SS: Okay.

Tape III

00:20:00

RD: I think it was a quite legitimate question. We did not know the answer to it. I think many questions got carried along a lot further than the facts supported them.

SS: Okay. So what was the lesbian sexual culture inside ACT UP? Would you say it was more pleasure-oriented, or more relationshipand love-oriented?

RD: I think it was more power-oriented, actually, which was my experience in Tallahassee. I think people wanted to sleep with people who were

perceived as powerful, and would change their — I know I'll probably get into trouble for even saying this — but it was my perception at the time. Alliances had to do with leadership, and had to do with popularity. Kind of gradeschoolish. As well as pleasure; as well as the desire to talk about sex and to talk about all the sexual issues that there was no other way to talk about, other than by creating a sexual culture in which to talk about it. And I think it was also about partnerships and finding your true love, which some people maybe did. I don't know.

#### SS: I don't think so.

RD: {LAUGHS}

SS: I don't think there's any couples left from that time. Was it casual? Could you go to an event and end up going home with somebody? Or was it –

RD: Well, now, you have to understand; you're asking me. Could

SS: Or your friends.

RD: {LAUGHS}

I?

#### SS: Did you observe it, even if you were not –

RD: I think some people could. And some people were young enough and cute enough that anybody would probably be happy to sleep with them, myself included. But I – I don't know how – there wasn't group sex, to my knowledge. There were probably some ménages a trois. There was a lot of experimentation; there was a lot of partner-changing. And there was a lot of talking about sex, which was healthy and good.

SS: Do you think that that culture — this is my last question on this — was an extension of lesbian culture? Or do you think it was an influence of gay male culture?

RD: I think it was both. It was an extension of lesbian culture, but in lesbian culture, talking about sexuality was repressed because that era, like the women's health movement era, lesbian kind of activism – was there lesbian activism? – that was the '70s. And so the things that we could talk about in the '80s and '90s were extremely different. But it was very much because in ACT UP, women were sleeping with men. It was very much because of that. It created all kinds of luscious and amazing questions to ponder.

#### SS: Okay.

RD: A lot of conversation, because – and it happened all the time. I don't know if people know how common it was. Maybe they do. But it happened all the time. And a lot of the lesbians had some sexual encounters with men. That's another whole question, why did that happen? It's a fascinating question.

SS: But that's interesting, that you say it that way, instead of saying, a lot of gay men had sexual encounters with women.

RD: But then, I can't speak for gay men.

SS: Okay. So you're just looking at it from your point of view.

RD: Yeah. I think it's equally astounding; maybe more astounding. But I can't speak for gay men.

#### SS: Okay.

RD: I think those alliances, though, were as genuine as any alliances. I don't think that was just experimentation. It's like the way I fell in love with Jon. You just – you don't know what to do with those feelings, because at a certain time in your life, those feelings all feel sexual. So I think – but it was just kind of astounding to me. All of it, including my own behavior. It was all just, whoa; what are we doing here?

#### SS: Do you like who you were during that period of time?

RD: Yes and no. There were a lot of things about myself that I was uncomfortable with, that I'm no longer uncomfortable with. I didn't like the part of me that could be drawn into doing things that I didn't agree with. And that's what being in political organizations has always been like for me. And so ACT UP was really the last time I was interested in being a political activist within an organizational structure.

SS: Okay. I just have a few more questions. Is there any kind of realm that you think we've missed?

RD: I don't know. SS: You guys? Jim – JH: Yeah, a couple things. SS: Okay. **T&D**?

# JH: One is, I was wondering if you had any relationship with

RD: Yeah, I did. But – when and how, I'm not sure.

#### SS: Did you go to T&D meetings?

RD: I never went to T&D meetings. I had some interaction with Tape III people. You know what I felt like, was that I don't know if I was perceived this way, but I felt like anybody had access to me. I wasn't sectarian. I had a lot of medical information. I was willing to share it with anyone. I was willing to, I think, pretty much, be open to whatever issues people wanted to be dealing with. So I think people might have – I got invol-, I know what; I got involved with some of the clinical trial stuff. I wrote for that big book that came out every year, with the clinical trials.

**SS: What was that called?** *The AIDS Treatment Directory?* RD: Yeah.

#### SS: Okay.

RD: It is another whole aspect of my involvement with women's health and with HIV/AIDS, is that — and also the part of myself that I do like — is that my relationship with a lot of it was writing. It was just, and I did an amazing amount of writing during that time, that I'm very pleased that I did, and that was very gratifying. And it was good writing, about issues that other people weren't writing about.

I was not in a leadership role. I never wanted to be in a leadership role. But I did like having, not feeling like I belonged to, I wasn't in an affinity group. I was just sort of, whatever. And I tried – and I think that the writing is a very important piece of what came out of that time. The women's group wrote a book. We wrote –

#### SS: Women, AIDS and Activism.

RD: Yeah. And that was quite a project, to try to work as a collective on. And so much good writing came out of that whole period.

So that was just another whole piece of history. Hopefully that's being preserved, too. That's why I got some books out, and was looking at stuff to kind of remind myself.

Did I answer your question?

SS: Okay. Anything else?

RD: T&D. I was, I was involved in some minimal way with TAG.

#### JH: Yeah, I guess I was just thinking about alternatives -

RD: But, I was involved with TAG in the sense that I was girlfriends with Barbara Hughes at the time, and she was very involved. And I'm not even sure how she got pulled into it, except it made sense to her. It was sort of her personality. And I really respected the work that they were doing. I didn't feel antagonistic about what they were doing. I didn't feel they were off base using those strategies. You use whatever strategies you have. At the same time, I understood how it felt so disjointed. I understand how things fractured. There were too many things, and you couldn't do them all. And if you focused on one, you were saying other things weren't important. And so it was painful. But I don't think any of it was – unnecessary.

JW: And do you remember the relationship between A & H

### [Alternative and Holistic Treatment Subcommittee] and HEAL [Health Education AIDS Liaison], and how that evolved? Do you remember?

RD: I don't think I even have that information. I mean, I might be a little bit aware of it, but it didn't –

SS: Okay. Well then, I just have a few more questions. Oh, yes. Were you involved in the NIH action?

RD: Yeah, I was there.

#### SS: What was won at the NIH?

RD: I think it was a turning point. I think it was a big turning point, and I don't know if I'm correct timing-wise, but I think it was a big turning point for having access to those ears in a way that they had to listen, and that forged some of the relationships that later led to drugs. It's very straightforward. So I think it was a very important, pivotal thing, in terms of how trials went, how drug development went, and the fact that we have treatments now. And as much as I still think they're bad drugs, they're wonderful drugs. I have friends that are alive because of them. So, it was very important. It was the winning card. Who knew?

#### SS: Okay. So when did you leave ACT UP?

RD: I left ACT UP – I used to say, you couldn't go into the Community Center anymore after you'd broken up with your third girlfriend. It was just too painful. And I stopped going to ACT UP after Barbara and I broke up. And it was just, I, it was too painful.

At the same time, I was sort of outgrowing ACT UP. And I don't mean that probably the way it sounds. But I was just feeling I can't do activism. Tape III 00:30:00 It's just not good for me. And it doesn't, I don't need, people don't need my input. There's plenty of information here. At the very beginning, I felt I was holding information other people didn't have. And so I had a sort of sacred obligation to be there. And I just didn't feel that anymore. I felt like, people knew what they were talking about, and they didn't so much need me. And it was just too uncomfortable.

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

> > RD: ACT UP's greatest achievement, in the scheme of healthcare

SS: In its entirety.RD: – but no, but that's how I think of it.SS: Oh, uh huh.

RD: I think of the women's health movement as giving women body ownership. I think that ACT UP began, expanded and created the whole idea that people have a right to determine what healthcare they get. I think it's huge. I think people don't even know how ACT UP provided that for them.

And of course, a lot of things have happened. And everything has its belly side. I do palliative care now, and I meet with people who think, well, if I want you to shock me after I'm dead, I get to say. So people make bad decisions about their healthcare when you let them make decisions. But that right wasn't there before, and was there, some point, and thereafter, and it's something everybody benefitted from – everybody.

Disappointments? Eh, water over the dam. It's nothing worth talking about.

**SS: Okay. Thank you.** RD: You're welcome.

SS: Thank you. Wow, we just learned so much.