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Interviewee: **Rick Loftus**

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ACT UP ORAL HISTORY PROJECT

Interview of Rick Loftus

April 24, 2003

SARAH SCHULMAN: If you could say your name, how old you are, today's date and where we are?

RICK LOFTUS: This is the orientation test?

SS: Mm hmm.

RL: So, my name is Rick Loftus, and I am 33 and it's April 24th, 2003, and we're here at my apartment on State Street in San Francisco.

SS: Great. Where were you born, Rick?

RL: I was born in Detroit, Michigan, in 1969. My brother and I are twins, and we were the first children of my parents.

SS: And what made you come to New York?

RL: I wound up in New York because – well, I had just graduated from Yale, and my partner at the time had gotten a job at the *New York Times Magazine* group, which was kind of a shock, because it was the pit of the recession – 1991 – and I thought that there was no chance in hell that we would ever get a job in New York City in publishing, but he did. And so, I helped him move there the summer after I graduated college and went back home to San Jose to decide if I was also going to move to New York, and it took me a little while. I worked for a newspaper in San Jose, while I was trying to make up my mind. And initially, my parents were really against me going, and then all of a sudden, they just changed their minds and said yeah, actually, that wouldn't be such a bad thing for you to do. So right around the time that the newspaper I was working for noticed I actually had any talent – isn't that always the way – I'd already decided that I was moving out to New York. So, I joined Arthur in New York and was

living in Alphabet City, as of the fall of '91.

SS: Now, when was the first time that you heard the word AIDS? Do you remember?

RL: The first time I heard the word AIDS – yeah, I must have been, I think, in 8th grade. And I remember, there was a story in *Newsweek* magazine about GRID – Gay Related Immune Disease or Deficiency, or whatever they were calling it – and, at that point in time – I mean, I was a pretty precocious kid. I think by the time I was 8 years old, I'd figured out that I was queer, but I was raised in this Irish Catholic family – kind of conservative – nice, but conservative. And I was in a Catholic parish and, you know, there weren't any gay people anywhere, for miles around. So, I wasn't really exposed. But, by the time I was 8, I had figured out that I was gay. And then the story came out in *Newsweek*, and I remember thinking, oh no, I wonder if that's something that's going to affect me someday? I remember thinking that. And it was a lot later – sometime in college – when I was doing some stories in the college paper about AIDS prevention, and I came upon that same *Newsweek* article when I was doing some research in the archives in the library and it sort of jogged that memory, and I remembered I saw it as a kid. So, that was the first time I'd ever heard of AIDS.

SS: So, was AIDS discussed openly when you were in college?

RL: Well, at that point in time – it's interesting – I worked – I was the editor of my college weekly paper, the *Herald*, and I remember, as a junior editor, we did a couple of stories. This would have been in 1987-88, something like that. And I remember that there was a story about how AIDS was affecting the campus, and I remember talking to one of the editors who was writing the story, and he said, you know, there may even have

been a graduate student here and his girlfriend, who got diagnosed with HIV, and that was like, a big deal. It was a little bit scandalous – like, wow, we have people with HIV, right here at the University – ooh, ahh. But that’s kind of the level that things were at. You know, for most people at the University at that point, it wasn’t something that they saw as directly affecting them, personally, and there was still that stigma – that sort of drama around an HIV diagnosis.

SS: So, there were no students or professors who were openly HIV?

RL: Absolutely not.

SS: How about openly gay?

00:05:00 RL: No. I mean, John Boswell was there – and I think most people kind of figured he probably was queer. But I don’t think it was official. I don’t know. I think we sort of had -- we didn’t have a gay studies program, but we sort of had a few people who were kind of rallying for that. We had our share of queer radicals. And, Yale had the Gay and Lesbian Co-op, which had probably 30 active members. So, there definitely were gay and lesbian activists on campus at that time. But I was very removed from that part of the campus universe. I was not out – although trying to – certainly knew that that was something I would have to do at some point, but I had a lot of personal stuff to sort out, before I was ready to do that. So, my position in the campus world was as a journalist, and I worked on a newspaper, and I wasn’t out to anyone, and I kept assiduously away from political activists of all kinds, just because I didn’t relate to agitation at all. A journalist is an observer. That’s kind of how I saw myself. Things changed later.

SS: Do you remember speakers coming to Yale to talk about gay

liberation or AIDS?

RL: Oh yeah. We had BGLAD [Bisexual Gay Lesbian Awareness Day] Days – once a year, in the spring. And in fact, part of how I came out was in my junior year – this was after I had finished as editor in chief of the *Herald* – I joined a bunch of different other editorial projects, because my time was free, and I had a lot of expertise. And I helped put together the BGLAD magazine that came out in conjunction with the events of the week and gave a program of speakers and whatnot. I think I might have, sort of very quietly – last row – sat in on a couple of lectures or guest speakers at the previous year’s events. But at that point I wasn’t, again, officially out. So, junior year was when I came out on campus, and that was really during BGLAD week. And it was funny, because I remember the head of the Yale political union – or former head – also came out the same week, and so she and I bonded, as these people that everyone knew as being very prominent in a completely different setting – these campus leaders coming out as gay. And that was like, kind of a secondary thing for us. It was like, “Oh, the editor of the paper is gay, and the head of the political union is gay,” and all of a sudden, people started to realize that gays and lesbians weren’t just like those activists down at the Co-op, who are always agitating about something – that they saw once a year in the spring, at BGLAD events.

I remember Douglas Crimp came to speak. He was the author of *AIDS Demographics* which was a book about Gran Fury and some of the other artists collectives that helped draw attention to the AIDS epidemic early on, through some of their artistic projects and some of the things they created for demonstrations and whatnot. And he spoke, and I remember he was talking about how the epidemic had affected gay

culture and was sort of mourning the changes that were being wrought, and sort of the atmosphere of fear and sort of alienation that people felt. It was very somber. It was a scary time. And I think, looking back on certainly my early days of involvement with ACT UP, from a medical point of view, everything was so horribly grim. I mean, we were trying everything. Shortly after I had joined ACT UP, we went to the Berlin meeting and they announced the Concorde Study results – that AZT monotherapy wasn't effective after a couple of years of treatment which, in hindsight now of course that's a no-brainer, but at the time it was devastating news. That was the treatment that we had been relying on. And certainly, even before that, people were just desperate. We had nothing. There were so many people dying. So, it was a very hard time. But I think that one of the benefits, certainly, of the epidemic, was that it instigated an awakening of gay and lesbian political activism and of culture, in general. So, there was sort of like this blooming of activism. And certainly, I had a personal awakening. I sort of refer to my involvement with AIDS activism as sort of like a conversion experience. And I used a lot of religious metaphors in trying to explain to people what it was like.

And my best friend in ACT UP New York was Beth Stroud, who now is a minister and I remember at one point in time, she borrowed some stuff from me. I had this magazine that I'd helped put out on campus, during BGLAD days, when I came out – had a piece about my personal issues growing up as an Irish Catholic, in a very conservative community and having to deal with creating an identity for myself as a gay man. And it talked a lot about religion, and sort of wrangling with a religious heritage that wasn't accepting of being queer. And she used that, because she was studying at Union Seminary at the time, and she was working on a project about the religious

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background that many AIDS activists brought with them, and I think she felt they had been important and why they become AIDS activists in the first place. There was one really prominent member of ACT UP New York, BC Craig, who I think had started her activism working with Christian social justice groups, if I remember right. So, there were a number of people who had brought some kind of religious experience into their activism or it was a framework, from which their activism grew. But for me, becoming an AIDS activist was like a religious conversion, in many ways, in terms of the passion and self-discovery and creating a new identity.

SS: I just want to ask you one more question about the Yale thing. So, there you were, and you were this editor and then you came out.

RL: Very serious, very nerdy, well-liked, but very low-key editor.

SS: How did these other people who you constructed as the “Co-op People” – how did they respond to you, after you came out?

RL: You know, it’s funny, because in a way, I didn’t feel isolated because Rachel, this other person there, was also sort of like this bigwig on the campus who also was coming out simultaneously.

SS: What was her last name?

RL: What was Rachel’s last name? I knew you were going to ask me this. This is the one person whose last name I didn’t bring to mind before the interview. I can’t remember Rachel’s last name. I remember thinking well, I’m not the only person who wasn’t an activist who’s now come out as a gay person. It was funny, because at that time, a lot of the people who did publicly identify as gay were doing so because they were activists. And I think what happened in the years after the beginning of the AIDS

epidemic was – as I was saying – this sort of secondary effect of the awakening of gay and lesbian culture – was that a lot of mainstream closeted gay people came out of the closet. So, in a way, maybe that was kind of my initial niche – as somebody who didn't cast myself as a queer activist. I was just somebody who had this other thing that I did, but I also was gay, and it was part of my identity that I was claiming.

And I remember my senior year – I was out on campus, and I did go to a Co-op meeting at the beginning of the year, because I think every gay person on campus went to the Co-op meeting, for the first meeting, at the beginning of the year. And there were probably 100 people there. And that was the first and last time I went to a Co-op meeting. But I remember, there was somebody there from Texas, who was coming to do grad school and he was astonished. He said, “You know, the gay and lesbian group at my whole University – which is three-times the size of Yale – had six people in it. And here, you've got 100 people in this room.” He was thrilled. And I guess my feeling at that point was – I certainly supported the gay and lesbian activists on campus and appreciated the work they were doing. It just wasn't what I saw myself doing. I was in a senior group – sort of like a sorority/fraternity kind of thing, but it's a one-year thing, and one of the other members of that group was one of the big activists on campus.

SS: Who was that?

RL: Isabel Velez, and Isabel had been one of those people had gone to one of these – you know, she'd confronted Reagan, Bush officials when they came to speak, about their neglect of AIDS, and she did all kinds of stuff to agitate for gay and lesbian rights and recognition on the campus. And she was a firebrand and awesome, and a wonderful activist. We got along great. I had enormous respect for those folks. It's just

– like I said – it wasn't something I felt comfortable doing for myself at that point. But obviously, things changed a little over time.

SS: So, how did AIDS come into your life?

00:15:00 RL: So, I guess – I'd already acknowledged part of me always felt that this disease – which was increasingly, clearly a holocaust for gay men – was something I felt certainly posed a threat to me. I remember, actually – when I came out junior year, one of my close friends on the newspaper said, “The one thing that I have to say in reaction to what you're telling me is, first you're my friend and I love you and I don't care, you're still my friend – this doesn't change anything – but, number two, I don't want you to get AIDS.” And that was kind of where the public U.S. populace – their perception of what AIDS was about at that point in time, was reflective of that. They thought that AIDS was this gay disease, and here I was, telling all of my friends who had always known me as just Rick – I'm still just Rick, and I'm gay – for a few of them, it was like, oh God, I hope he doesn't get AIDS, now that he's gay. So, I guess I always felt, personally, there could be some threat posed by AIDS. I think any young, gay man at that point in time felt that way.

SS: Did your family say that?

RL: No, although I remember having a conversation with my Dad at one point about the epidemic. But I think – you know, my parents had such a time adjusting to my coming out to them, which happened during my senior year – I think that was about as much as they could handle – was just kind of coping with me being a gay person. But I think, getting into the whole thing of, could he be at risk for AIDS – they never said, “Well, we hope you're practicing safer sex.” That was not part of their vocabulary at all.

Probably, in the backs of their minds they must have known that that was something that could affect me, as a gay man, but it never came up – I think, just because they could barely articulate their worries over me coming out as a gay person and having to still relate to them and their very conservative Catholic world. So, it wasn't something I ever talked about, I don't remember. But ultimately, as I got involved in AIDS activism, as a treatment activist, I started to be able to have conversations with my parents about AIDS and how people reacted to the epidemic and how men were coping with having partners who were sick or whatever. I think they probably, at times, found the whole thing just completely overwhelming and hard to believe. I think it was hard to believe for people who were right there, in the middle of ground zero, living in New York City in the early '90s. That certainly, I think, counted as being at least at one of the epicenters. It was either that or sub-Saharan Africa. But I think it was overwhelming and surreal for people who were there, and I think my parents – it was just all too big and scary, probably for them to know even what to ask me.

SS: When you started living as an openly gay man, and you started having sex and boyfriends and whatever – did you find that safe sex was common or the standard? Or was it not common?

RL: You know, it's interesting, because I had a boyfriend in college, senior year, and we went and got tested together. And I certainly wasn't worried, because at that point I was a virgin. So, I was just sort of going through the motions. But I remember at that point, the doctor at the clinic said something about, "If you guys are just having sex with each other, you don't necessarily have to use condoms, once you've both tested negative." Which I found kind of surreal, because at that point, it went against

what the dogma was about safer sex. I mean, certainly at that point on campus, the safer sex message was getting out. People were getting the basic messages about how HIV was transmitted and that information was available. And I found that a very weird point of view. And now, thinking back on it – I mean, I think that’s probably a more practical perspective for a clinician to take. I mean, I certainly know a lot of the patients I see in my clinic – couples – are mostly not using condoms. It’s couples that have been together for a long time and are monogamous. But there was a point in time when that was a very controversial thing to say. I mean, there was nothing that would clear out a cocktail party faster than people talking about whether they use condoms or not with their partners. It was just a hot button topic. But I think that safer sex was certainly the norm, at that point. There was certainly a ton of awareness, and that was really when I think safer sex was really growing in strength. That was a point in time where gay men were demonstrating they were bringing infection rates down dramatically because of adhering to safer sex.

SS: So, who was the first person in your life who had AIDS or HIV?

RL: Yeah – I think the first couple of people that I remember – the partner that I moved to New York to be with – Arthur – was good friends with a couple of people here in the city, who had AIDS, and one of them was a friend of his who – he was part of a sort of group of friends who sort of rotated going over and spending evenings with him. He was very debilitated – Gary – and Gary was –

SS: What was his last name?

RL: No – I don’t think I ever knew Gary’s last name. Gary – I remember Art and a bunch of the other friends of his would take turns staying at his place at night,

because he was so sick. And I just remember – you know, I only met him a couple of times, because I would go over with Art to say hello – and he was – had had horrible wasting syndrome, and so he was very thin and he was always perched on his couch. I remember he was a big opera person, and he knew the opera singer Leonie Rysanek – she was a personal friend of his, and he knew all these opera stars. So, that’s what he liked to talk about. He was an opera queen. That’s what he would talk about with people when they came over. And of course, I knew bubkes about opera. And so, I would just sort of listen and appear interested, although I had no idea what they were talking about. And I remember – probably, like the first time he met me – as we were leaving, he remembered – I remembered that he said, “And boys, remember, be careful – you know what I’m talking about.” He waved his hands like this. And as we left, I said, “Art, that was really weird. Was he saying practice safer sex? Was that his way of saying, don’t get AIDS like I did?” It was very – it was kind of grim. Gary died right towards the end of that year. It was the springtime of my senior year, because I remember writing Art about sort of coping with his death. But I’d met him a couple of times when I’d been out here. And it was very hard for Art to go through that. And for me, I hadn’t known him that well. He wasn’t a personal friend of mine, but he certainly was exemplary of what it was like, living with AIDS at that point in history. There weren’t any treatments, and people did get horribly wasted and had horrible infections and chronic diarrhea – all of which he had. And it was just horrible, prolonged suffering until the end. And I remember, he got a little bit toxic to deal with, and that was a lot of what Art and I talked about – what it was like to give support to somebody who was so angry all the time. Because he was, like so many people, dying young, and had so much to live for, and instead was having

this horrible suffering and death. It was the story that got repeated so many, many times.

Another friend of Art's – Scotty was his name, Scotty Johnson – I knew for a longer period of time. And he came out – after we moved to New York – he came out and visited us and stayed with us. He was a waiter at Star's, and he was a part of that whole foody scene. He was such a lovely person and a talented painter, and just a lovely, lovely guy. And he wound up getting Kaposi's Sarcoma of the lungs. So, he'd been very healthy for a long time. I remember one time he came to visit us in our apartment in the East Village, and he'd left all his HIV meds at home. And Art was livid and insisted that he call his doctor in San Francisco and get a prescription called into the pharmacy down the street, and we took him to the pharmacy. And I remember later – many, many months later – finding AZT pills stuffed under the rug – insisted on taking a drug holiday while he was visiting us.

SS: How did you deal with people's anger about being sick?

RL: With difficulty, initially. It made me uncomfortable. I felt sorrow that they had to suffer. And I think there was probably also a mixture – there was probably some dread – I hope this isn't something that I will have to go through some day. I had a lot of respect for Art and these other friends that were supporting these folks who were ill. Later, when I turned on as an activist, I think I manifested a lot of my own anger, too. I mean, there was something horribly unjust about people going through all this, and the medical system was just so inept. Although – I wouldn't say, wholly unwilling. I mean, there were certainly parts of it that were just dead weight, that needed to be completely jettisoned or re-structured, and the activists made sure that happened. But there were certainly a lot of well-meaning medical people – a lot of heroic doctors who would give

00:25:00 the shirt off their backs and worked their fingers to the bones, doing everything they could think of – but there just wasn't anything. They weren't really going to be equipped to help. And that made me angry – not so much, angry at any particular person or entity, but just – it just seemed so horribly unjust, and so I think eventually I sort of got in touch with my own anger.

I remember at some point, during one of the – during the Pride March in New York one year, I remember the ACT UP slogan for that particular year's march was: "Where's Your Rage?" Because it was sort of at a time when things were kind of winding down a little bit with activism, and people felt like AIDS was being forgotten in the wake of the – I think it was around the time that gays in the military became very prominent. It was right after Clinton came into office, and I think people sort of breathed a political sigh of relief – or many people had – certainly not the ACT UP crowd, we were always suspicious. I remember telling people I thought Clinton was not going to help us, and they were outraged that I would say this, but I was a little more radical than the other people I was hanging out with, outside of my ACT UP crowd. But yeah, I think eventually I did kind of turn on to my own rage at how unjust it was. I made a good friend in New York, Michael Safdia, and Michael, I think, came to Treatment and Data committee meetings like, maybe, once a year kind of a thing. I don't even remember how I wound up making friends with him. He lived in my neighborhood in the West Village, and I would go over and hang out with him, and he was sick a lot. So, I was putting a water filter on his sink so that he could drink his water without getting parasites and helping him when he started on his Crixivan figure out how he was going to eat and take his medicine, and not violate all the eating rules with Crixivan, at that point in time.

And I remember the first time we ever talked about my activism my stuff. Oh, I remember he was saying, “What meds are you on?” And I said, “I’m not on any meds.” He said, “You’re not? That’s living dangerously.” And I said, “No, I’m HIV-negative, Michael, I don’t have to take any HIV meds.” And he’s, like, “You’re negative? Why the hell are you doing all this AIDS activism then?” And I said, “Michael, we’re all living with AIDS, whether I have HIV or not. This is all of our problem.” And he was really moved by that. But to me, that just felt so self-evident.

SS: Where did you get that message? Where did you hear that idea?

RL: I just always believed that, you know? Like I said, even as this 8th grader, looking at this magazine thinking, that is going to affect me and being sort of personally scared – like I hope I don’t get sick. But, I think, even then, I was recognizing this is something for all gay people to cope with. And certainly, being in ACT UP and seeing just the throngs of diverse people involved – and all of the women – the heroic lesbians, without whom none of it would have happened – who – virtually, none of them were HIV infected. And certainly, my role. I had kind of a funny experience being an activist and being an HIV-negative guy. I mean, in treatment – I was a treatment activist. I was a science activist. That was the stuff I was interested in, that was the stuff I got involved around. And, for Treatment and Data, I would say – I’m sure that more than half the guys were positive. But there were always people who were very, very highly involved who were negative. You know, Theo Smart was an example of somebody who was doing incredible work, and he wasn’t sick himself. And, I think in TAG, it was about the same. I was in the first group of people who joined Treatment Action Group as a new member. They sort of split off from Treatment and Data committee in ACT UP proper

and became their own organization of treatment activists focused just on treatment activism. And I was with the first group that ever got inducted in as new members of TAG. And TAG was kind of the same thing as Treatment and Data. I think, probably more than half the people who were HIV positive. So, for me to be involved as a science activist, as a treatment activist, trying to find better treatments and do whatever was needed to make that happen – whether it was working with scientists or pressuring drug companies, or talking to the FDA or whatever – you know, it wasn't because I felt like the clock was personally ticking for me. And my partner was negative, and so it wasn't like somebody that I desperately loved was visibly worsening in front of my eyes, either. But, I certainly had a lot of friends – a lot of whom I made out of ACT UP.

SS: How were you first exposed to ACT UP?

00:30:00 RL: I went to New York and was still doing journalism, and I did some pieces for *NYQ* – which then became *QW*. So, I was freelancing some pieces. I did some really funny pieces for them. I did one on piercings and – I don't know, I did some fun pieces. Mostly, I wrote news. But, I remember, I did a piece about AIDS activists and one of the guys commented, sort of incidentally – I think that I mentioned that I was a medical writer, because that's what I was doing. In New York, that was my job – I worked for this medical films company. And following the development of new drugs was part of my job, so I knew how to search the medical literature and knew where all the medical libraries were in New York and visited them routinely. And this guy commented, oh, you should check out our meetings – we could probably use someone like you. And I thought, you probably couldn't, but I was intrigued enough, after doing the story that I checked out the ACT UP general meeting. And it was totally overwhelming. It was this

huge mass of people.

SS: When was this, that you first came?

RL: This was October of '92.

SS: Okay, and was this at Cooper Union or at the Center?

RL: This was at the Center. This was roughly a year after I'd been living in New York. And I remember just awash in all this information and all of these people and this astonishing, endless array of issues being brought up and all these different committees. But I knew at that point that if there were any group I'd be involved with, it would be the treatment group. And so, I went to the first meeting, and that was – I'll never forget that first meeting.

SS: That was still T&D?

RL: T&D. So, it was that week. So, it was the beginning of October '92, and I went to the Tuesday night meeting of T&D and holy Hannah, I didn't understand anything they were talking about – and I was somebody who was not the average layperson. I studied drug development and worked with drug companies. I had taken a lot of science courses as an undergrad. I wasn't starting from total zero, but boy, I didn't understand anything they were talking about. They talked about fibrology, immunology, pharmacokinetics, FDA policies, this committee, that NIH group, and these scientists, and drug pricing. In just one meeting they covered such a broad array of issues. Everything was important at that point in time. God, even like red algae treatments. They talked about all kinds of stuff. It was just bizarre, but totally overwhelming. And I remember, kind of, at the end of the first two hours, sort of stumbling out the door, with my eyes a little bit glazed over, thinking, I don't know if I'm really going to be able to do

anything with this group because I don't understand the first thing that's going on.

SS: How many people were at the meeting of T&D?

RL: In those days we would get about 50 people, and there were maybe 15 people who were actively working on stuff and had projects and things to present. There was always sort of the second and third and fourth rows of people who were just kind of there to listen – and weren't maybe doing projects but were certainly interested in what they were hearing.

SS: Where did they meet?

RL: It was on the second floor of the Center – so, just over the big ACT UP floor area. So, that first meeting finished and I was kind of stumbling toward the door thinking – I don't know what I was thinking, thinking I could get involved in this group. I don't know what they're talking – I could never do this. And David Samuels was there, and he was kind of stumbling out for, probably, a cigarette break and saw me and said, "Hey, you're a new person, aren't you?" I said, yeah. He said, "You should come back, we need you." And that was all he had to say. Even in those days, David was pretty darn sick. He managed to live a couple of more years, but there's just something about this – and he was just – and there wasn't anything kind of sharp or – he was just, like, hey, you should come back, we could use you. And I believed him. I don't know why I believed him, but there was just something about that – having somebody say, we could use the help. And so, I hung in there, and it was the most amazing experience in self-education I've ever had. It certainly completely conditioned how I've approached my education on medical issues ever since, because I learned all kinds of stuff, on my own – immunology, virology, pharmacokinetics – all those things they were talking about that I didn't

understand anything about. I was reading huge amounts. It was like earning a Master's Degree. And I remember afterwards, just doing treatment activist kind of stuff and going to conferences and presenting at ACT UP floor meetings, and people would come up to me and ask me, "Hey, are you a doctor? Because, I just got this test result," blah, blah, blah. And I'd be like, "No, no, no, I'm not a doctor, what makes you think I'm a doctor?" But apparently, I'd learned enough medical-ese to sound like it. And there were a lot of people in Treatment and Data who had those kinds of experiences.

SS: Well, how would you know what to read, for example?

00:35:00

RL: Well, you know, I tell people these days that I was – we were doing Journal Club. That's what doctors call it. Doctors have this thing called Journal Club, where once a month, they'll get together and somebody will bring an article, and everyone will have read it ahead of time, and somebody will present it. And they'll talk about what the major points were and what we should learn from it – whether the research was valid or not. And this is something that physicians do all the time, to continue their education and keep current with the literature. Well, we did that times four, every week at Treatment and Data, but we didn't know that's what we were doing. And I remember – after finally entering UCSF, as a medical student and then as a resident – looking back and thinking – my God, we were operating at beyond Ph.D. level, in our routine discussions. That even applies – ACT UP Golden Gate, here in San Francisco – same deal. The kinds of things that people would bring up – the insights, the ideas. And then I would go back to my lab and say, well you know, blah, blah, blah, blah, and I would present something that some bartender had observed at a T&D meeting or treatment committee meeting, and you'd have this bigwig fronts-of-the-newspapers,

doctor scientist say, “Really? Oh my God, what an interesting idea – I’d never thought of that, but that’s true, isn’t it?” And I’d be like – a bartender came up with that, some lay person, at an activist meeting.

SS: What does that reveal, exactly?

RL: What it reveals is that education is what you make of it – that individuals are able to equip themselves. And this gets back to what I was saying about how I observed this mass of the medical complex. And some people would sort of – some of the activists, maybe, who came from a certain point of view would sort of view it with suspicion up front. You know, those are the conservative people. They have the power. They are the authority complex. You know, I didn’t view the medical system that way, but I certainly saw them as being really inept. I mean, here people were dying left and right. They might have known a lot, but they didn’t know enough. And I saw, on a frequent basis, activists way outstripping the doctors all the time on knowledge and insight about treatment options and the current research.

SS: But how come the doctors weren’t as up on it as the activists?

RL: Well, because it was all equally new to everyone. Because the doctors had all their other responsibilities and they couldn’t spend every free moment reading up on all the different articles, like we were in Treatment and Data. I was probably reading articles from 10 different medical journals each week.

SS: And how would you get these articles?

RL: People would bring them in. They’d bring in copies. And there were all the newsletters, which were blossoming at that time, that were put together by geniuses. I mean John James is an absolute hero of the AIDS epidemic. He’s probably saved

thousands of lives, and he's a journalist, but he's just an incredibly smart, savvy, good journalist, who's produced excellent quality information and put it out there as far and wide as he could get it distributed. And *Treatment Issues* was an equally excellent – and so they were like, probably a better read, word for word, than what was coming out of the *New England Journal*, or *Proceedings of the National Academy of Sciences*. People would come to these Treatment and Data Committee meetings bringing articles. Somebody would have an interest in virology research or malaria therapy for HIV – whatever. There was a lot of weird stuff that people would bring in, too. But we read all of it. And I read it voraciously, because it was all interesting to me.

SS: Did scientists come to your meeting?

SS: Did scientists or doctors come to T&D meetings?

RL: You know, there were some doctors who were involved – like Howard Grossman. He didn't come routinely at the time that I was involved – like '92-'95 – that period of time, but he was a member and he would show up every once in awhile and present something. And Greg Dubbs was a Ph.D. who worked with the Herzenberg Lab here in Stanford, ultimately – and he was involved in some research and he would give some presentations, too. And he was involved a little bit more frequently with activist stuff. But most of the people were laypersons. But, what we found – I think, certainly I was not aware at the level we were operating, until much, much later – looking back on it and realizing we were all functioning at the level beyond Ph.D. But, at the time, we just were trying to learn everything that we thought would be important, or potentially important in helping find better treatments. And everything was relevant. So, we learned

00:40:00 all kinds of stuff, and we certainly had an enormous motivation because either ourselves or people that we loved were very sick and the clock was ticking, and we knew there wasn't time to waste. And so, there was a sense of urgency. So, we educated ourselves and we didn't even realize how unusual we were – probably in many cases. I certainly didn't. You know, when people would come to me at the back of a floor meeting to say, I just got these test results and blah, blah, blah. And I would say, “Well, I'm not a doctor, but you should go talk to one.” It kind of shocked me that – I mean, I certainly wasn't trying to misrepresent myself, but I guess people just came to that conclusion, because all of this medical stuff was coming out of my mouth. And I think a lot of treatment activists had that experience. They would go to conferences and they'd be – you know, poets would be offered jobs as epidemiologists with the CDC, it was really amusing.

SS: Like who? Who was the poet and who was the bartender? Tell us some names here.

RL: I'm trying to think of – we're dipping into the mists of time now, so I'm afraid I'm not going to be able to give you specific names on those. But there was a poet who had – it was a story I was told as sort of a junior treatment activist, because this is someone whose name I used to know, who was a very important Treatment and Data Committee member years before, who wasn't involved at the time that I had joined but was still around. But I remember people telling the story about how he so well versed in the issues of the spread of HIV and the epidemiology that the CDC had offered him a job. So, certainly, those kinds of things happen. I remember one time, I helped coordinate a meeting. We had a situation where a drug company in New Jersey had –

SS: Which company?

RL: The president of the company was Sim Fass, and the company – I’m trying to think of what its name was – BioTech[nology] General, which is a very generic kind of name for a biotech company, but at any rate, they were developing growth hormone, and they were involved in some patent disputes with other companies that were developing growth hormone as well in the United States, including Serono Labs, which now owns the patent definitively. But they were doing some studies of their growth hormone product in a couple of the hospitals in New York, and I remember they all of a sudden called the doctors and canceled the study. And patients who had been on growth hormone were getting cut off of the drug. And so, one of these doctors called me and said, “We don’t really understand what’s going on, but they’ve stopped the study.” And certainly, as an activist, I was outraged. The patients were getting cut off of therapies they were on, without an explanation. So, I called the drug company and I said, “So here’s the deal – you either come and have a meeting with these nice doctors and explain to them why you can no longer sponsor the study, and we work something out, or I’m going to bring a gang of green-haired yahoos and a Channel 7 News team to the front gates of your company, and you’re not going to like the publicity.” And you know what? At that point, ACT UP had done enough and had been in the media enough that they listened and they responded and they came to the meeting. So, I facilitated this meeting. We held it at GMHC. We went through the meeting. There were representatives from the two hospitals and the drug company officials and basically what they explained was – so, we’re in this patent dispute and we lost, and so we don’t really own the rights to this product any longer, but we have this other drug that we’re developing that could work for patients with wasting syndrome and AIDS. So, basically, they got the ball rolling in

starting up a new study. And we worked something out, where patients were able to continue. I don't know if they got growth hormone, or if they got the Oxandrolone, but they were able to get another treatment, and continue on that. We managed to broker a compromise. And at the end of the meeting, the drug company people came up to me and said, "So how long have you worked for GMHC?" And I said, "I don't work for GMHC, I work for a film company, and I have to go back to work now." And they were flabbergasted. And they said, "You mean, you're not a member of this?" And I said, "No, I'm a layperson." And they said, "Well, how do you know so much about medicine?" And I said, "Because I've studied and I've learned a lot from people with AIDS. That's who's taught me. That's my school. Those are my professors. They taught me."

SS: Who were the green-haired yahoos?

00:45:00 RL: Pretty much any motley assortment of ACT UPpers that you wanted. I definitely was somebody who appreciated early on that our strength as activists was our diversity. I look at activism as an ecosystem, and there were sort of the more, sort of pearl and tie type people, who would sit down at the drug companies and quietly discuss what they wanted them to do. And then, there were people who were street activists. People like Bob Rafsky, for example – is a great example of going up face to face with Bill Clinton, with that great picture from the *New York Times* saying: "You're dying of ambition and I'm dying of AIDS, what the hell are you doing about the HIV epidemic?" He was a great street activist, a great example. Maxine Wolfe is another fabulous street activist. These were people who understood the importance of making noise in the streets. A lot of what got ACT UP attention in the early day was that street side of

things. I think what I appreciated as a treatment activist was that both approaches were very important, and I didn't necessarily look like a street activist. I mean, I worked on Madison Avenue and I wore a suit every day, and that was kind of my shtick. But I certainly knew that our strength was in our ability to operate both facets, and I was certainly as willing to go get handcuffed in front of a drug company, if need be – and did, on a couple of occasions – as I was to sit down in a suit, in a nice quiet room, and make the drug company talk to the nice doctors. Both roles were important in moving the agenda along. And every once in awhile – well, not every once in awhile, probably all the time – there were always fights amongst people who were a little bit more street, and who were always looking for the next demo. And then, people who were a little bit more conservative, who didn't really want to go storming the gates of a drug company – and that wasn't their idea of fun and would much rather just see some results and kind of liked the quiet approach. But I think both were necessary.

SS: Can you remember a specific time that there was a conflict or a disagreement between those –

RL: Well, you know, I think more in terms of – certainly there were people who had disagreements over approaches, but it seemed like, when you looked at it closely, it probably wound up being about individual personalities. And, I mean, there were so many endless little squabbles between individuals, it would be hard to remember specifics. But one thing that I can talk about a little bit is – and this maybe sort of relates to that issue – is the schism between the science activists and the other kinds of activists. TAG, as I mentioned before was this group – they were the Treatment and Data Committee of ACT UP New York, and then they split off in January of 1992 and formed

their own separate group. There were a few people who stayed behind, as the continuing Treatment and Data Committee of ACT UP New York. It was a much smaller group. There were a few people, like Theo Smart, who would kind of continue to belong to both groups, and work with both groups.

SS: And what did you do?

RL: Well, as a new person coming to ACT UP, nine, 10 months after the schism – I got involved with ACT UP, because that was the group I'd ever heard of. I never heard of TAG. And I only heard about them at Treatment and Data Committee meetings, afterwards. Then, all of a sudden, TAG made it sort of known, that they wanted to recruit some new members, and I was interested, so I was part of the first half dozen people who joined TAG.

SS: So, this vibrant, alive, treatment group, that was so self-educating that you're describing, is the post-split? Is without Mark Harrington and all those guys.

RL: Oh yeah. No – there were still like, 50 people coming to Treatment and Data Committee meetings, you know? And, maybe that was because it was more approachable. I mean, TAG, definitely – people felt like they had split off and went off somewhere and were meeting behind closed doors – probably meeting with a lot of big lobbyists and people in suits. And, for a lot of common folks who were trying to just get educated about their treatment options, that didn't seem very approachable. And TAG I think, always – maybe still does have that sort of – I think they recognize it as a problem later and try to address it. But, I think they had this image of being the ivory tower. And certainly, the kinds of people who split off were people who were sort of Ivy-Leaguer background types. Mark Harrington was from Harvard, so people sort of perceived them

as being these sort of über-professionals. They were lawyers and doctors and well to do, and probably maybe would have never been activists, except that they got an HIV diagnosis, or somebody they loved was sick and all of a sudden they realized that they needed to be involved and do something, and they became activists that way.

My training at Yale was in environmental studies, but I studied environmental activism. And my thesis was, actually, in part, analyzing how environmental politics and activist groups operated and behaved over time. And there was this metaphor that Lois Gibbs, who worked with the Neighbors of Love Canal, came up with – the metaphor of the Buds and the Granolas. And it always stayed with me. And it was something that I had used in writing my thesis, and then afterwards, I realized I was sort of observing it, in the same interpellations and interactions of personalities in AIDS treatment activism – or, AIDS activism, in general. And so, the idea is Buds and Granolas. So, in Love Canal, there were neighbors who lived in the Love Canal area – it's a famous story of neighbors basically discovering that they were living over a toxic dumpsite.

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So, some of those people got organized and started agitating the government to bring some attention and resources to their neighborhood to help them cope with the fact that they were all living over these toxic waste sites. And Lois Gibbs, who was this little housewife, became this incredible environmental leader and activist. And now she works with – or she founded the National Toxics Clearing House in Washington and became a big environmental activist. So, her experience was the experience of being someone who was personally involved and became an activist through her personal involvement and those of people she loved. But she also described the Granolas, who were sort of the long-time activists – sort of leftist, sort of Birkenstock-wearing long-hairs, who would

come in, you know? Who had just left some rally somewhere else in the country to come to Love Canal and help agitate and march. They had a lot of very useful expertise and they knew how to do civil disobedience and not get injured while being arrested and how to hold a sit-in. They brought that kind of expertise and connections with big, environmental organizations. But, they didn't have the personal stake. And so, the Buds and Granolas sometimes viewed each other with a little bit of skepticism. The Buds – people in Love Canal – this was a working-class neighborhood. They were tow truck drivers and waitresses and kind of plain folks, and didn't meet eye to eye with these Granolas, who had a lot of suspicion of the government, and couldn't think of anything more fun than being in rally.

So that kind of division, I think, also existed in ACT UP New York – in that you had people who were – probably would have never been activists, except that they got some bad news from the doctor and they were getting sick and they realized they needed to do something. And they might have otherwise continued on as Wall Street brokers or whatever it was they were doing, and this changed everything. And their interest tended to be pretty focused on what is the treatment I need that's going to keep me alive and not let this virus kill me? And that was their orientation. What's going to keep my partner from dying this year? I need to find it. If it's in some company's vault, we need to get it into his body. That was the Bud-equivalent in ACT UP – was that constituency. And then you had the people who were doing needle exchange and agitating for housing and trying to change immigration laws and helping people not be discriminated against because they had HIV in getting jobs or whatever else. And all of those kinds of issues. Working with the schools – although, one of our activists, Kate [Barnhart]? What was

Kate's last name? HIV-positive teenager – it's been 10 years – she was positive, but most of the kids who are working on school education and condoms in the schools and that kind of stuff, they weren't infected. They were just trying to bring about a social change. So, there was that whole kind of group, and those people initially worked together. And then, eventually, those sort of different orientations became more important. The Buds – many of whom were sort of the core of the Treatment and Data Committee – who wanted to find a treatment that was going to keep them alive, just weren't as interested in needle exchanges and housing and stuff like that. They had homes. They didn't feel those issues pertained to their survival –

SS: But some of the “Granolas,” as you're calling them, also had AIDS or HIV.

RL: Right, right – this is not a perfect metaphor and people crossed over, right. But I'm just trying to describe crudely, how I saw the two major poles develop. And I feel like part of what explains why the science activists split off is because they complained that they had to deal with a lot of crazy personalities, which was true. The ACT UP floor meeting would have your share of really random announcements, and things that just didn't seem related, or people who were kind of incoherent. And I think they, oftentimes, sort of belittled some of the issues that other people felt were important. And so, they felt like they were wasting their time, and they were tired of being in five-hour long meetings that didn't focus specifically on treatments that were going to keep them alive. And so, they lost interest, and they felt their time would be better spent away. And so, that explains the schism there. I think a lot of people don't realize – that schism happened in San Francisco as well, resulting in ACT UP San Francisco and ACT UP

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Golden Gate, which was the treatment-oriented group.

SS: Let me just ask you something – this post-split, ACT UP T&D, which you’re describing as beyond a Ph.D. level – can you tell me as many names as you can of the people who are in that committee?

RL: I knew you were going to do this. Well, I think Theo Smart is exemplary of somebody who just clearly operated beyond multiple Ph.D. level function. And he was certainly a role model for me of somebody who did incredible work and was an HIV-negative guy. So, I could kind of see – he was doing all this brilliant stuff, and it wasn’t something that he was personally dealing with at the time himself. It wasn’t about his picking his own treatments. He was just doing this work because it was important. So, he was somebody who I could sort of emulate in what I did. I’m trying to think of some of the other people – Kevin Frost is another example of somebody who was clearly operating on a very high level and eventually he became involved in research over at, I think, Cornell. And he was another role model for me. I’m trying to think of who else in the Treatment and Data Committee. Those were the two guys that I kind of saw as, wow, they’re doing incredibly cool work and I could be like them. And yeah, it’s true – of course, both of those people also happened to be working, as well, with TAG – didn’t give up their involvement with ACT UP, which I respected and appreciated about them. I mean, I think I was certainly somebody who – but their involvement with TAG got me very interested in what TAG was doing as well. And certainly, the caliber of information at TAG was at least as good – if not, at times, even more sophisticated than what was done at Treatment and Data.

SS: So, you went to both TAG and –

RL: Yeah, so, eventually, later in the winter of '92-'93, like December, January – TAG started doing an orientation for new members and eventually, I joined TAG. So, I was part of both groups. So, I was one of those crossover people. And part of why – as cool as it was to be able to sit in TAG meetings and hear people talk about meetings with the FDA and the NIH – I mean, certainly we had people in Treatment and Data Committee who did that kind of stuff, too. But I always felt it was important to continue my involvement with ACT UP New York because of those floor meetings, because that was where you'd have 100 people filling the room, who were not going to be sitting at an FDA committee meeting, and probably couldn't spend a lot of time, listening to a lot of jargonese about what had happened at that meeting. They just wanted to know – they would come and tell you, "My partner just got really sick, and he's on his sixth treatment for MAC and his doctor doesn't know what to do – what do we do?" That's where those people would come to you. They weren't coming to the TAG meetings. The TAG meetings were closed. And for me, as an activist, why the hell am I doing all of this? It's to help people like that. I guess that's in a way, a presaging of my work as a physician – it's just like, built larger, but that's the same thing I do as a doctor now. They come in and I have to treat them.

SS: Well, how did the community get access to the information that TAG had?

RL: Well, that became part of an issue that got discussed with TAG over time. And they were putting out their newsletter and then, certainly, there was some crosstalk because people like Kevin and Theo were coming to the Treatment and Data meetings and giving out information that they were maybe picking up at the TAG meetings. Or

they were doing their projects and they would give presentations at both meetings. You know, there were a couple of times – because I was involved in both groups and got along with a lot of people – there were times when I kind of wound up – I remember when the protease inhibitors came on the scene and TAG said, we need to have a big study to see if they work. And of course, most people just wanted to get access to them. They had already decided that they worked, and they weren't so interested in doing a big trial, where some people would not get therapy for maybe a long time, in order to prove that the therapies worked. The people who weren't on it would die, and that's how we would know they worked. Well, the mass of ACT UP was not thrilled at that kind of arrangement, and didn't want, didn't really support a large simple trial. But there was certainly a lot of scientific rationale for wanting to have that.

SS: I just need to catch up here – did ACT UP oppose any kind of placebo in a trial?

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RL: Well, there wasn't really an articulated position to that effect. But there was definitely – you've probably heard the phrase, "Drugs into Bodies." That was at times an official slogan at certain actions. There was a lot of pressure to get treatments into people, to get access as fast as possible. I mean, part of the work that treatment activists who were in Treatment and Data and then split off into TAG accomplished was the fast track system at FDA, for example – which I think these days is probably more responsible for accelerated cancer drug approval than for so many HIV drugs, although they're benefiting, as well.

SS: The conflict that you were just describing between TAG and ACT UP T&D – that was about the issue of placebo?

RL: Well, coalesced around the proposal for a large trial, to look at the protease drugs and prove that they made people live longer – and the thought was that we could do that by doing a huge study. And this was something that members of TAG came to appreciate, by talking to a lot of scientists, which they did. And was a model that had kind of been pioneered in cardiology. And so, I think that's where they got their insight into – you know, we should try to do this in HIV and do a big study and see whether these treatments are any good. And it was partly engineered – it sprang from – TAG had a lot of skepticism of these treatments, because they'd followed so many and so many had turned out to be worthless or not so good – you know, AZT monotherapy – no good after two years. And so, they were a little bit more willing to do whatever was needed to get valid information about what treatments actually worked – whereas I think the average layperson – regardless of whether they –

SS: I'm still on the placebo question – this trial would have involved some people –

RL: Not getting protease drugs.

SS: Oh, okay.

RL: Which, at that point in time, everyone had the sense were lifesaving drugs.

SS: But would have the comparative track been AZT? Or would it have been –

RL: It probably would have been combinations of nucleoside drugs, without the magic protease inhibitors everyone wanted. And, at this point, people had a sense that these drugs could be very important. And so, I was asked or agreed to – I'm sure I was asked because people knew that I still went to ACT UP New York, that people in

ACT UP proper liked me, that I got along with people, people trusted me that I wouldn't bullshit them. I said what I meant. And so, they said, could you go present this project. Gregg Gonsalves came with me. Gregg had this sort of similar – people in ACT UP like Gregg – even – they knew he was centrally involved in TAG. So, he came, too. And we presented this idea and boy, people were incredibly hostile to that idea, because they felt like it was putting the priorities of scientists and rigorously evaluating a treatment over the interest of laypersons, who just wanted a treatment that might keep them alive. And there's still that sentiment today.

SS: How was it resolved? What happened?

RL: Well, the idea was shot down. There just wasn't a lot of support for this idea in the community. And I think that was when – this was right around the time that TAG got around to writing its mission statement. And I'll always remember that meeting, because I spoke at it, and I felt that TAG's experience of coming up with this idea – of the large simple trial which, to them, made a lot of sense. Here, we'd been burned so many times. We've had these therapies that have been approved, and then we found out that they didn't work so well. Let's really find out if this is going to make people stay alive longer. They felt that was quite reasonable. But a lot of people in ACT UP would say things like, well those guys want to have a study and have some of us be put on placebo and maybe wind up dying, because we don't have access to these protease drugs. But you know, they're all going to get on treatment. They're not going to sign up for a study like this, they just want the rest of us to be in a study like this.

SS: Was that true?

RL: I don't know. At that point in time actually, a lot of members of TAG

weren't on any therapy at all yet. I think they had kind of, at that point, appreciated – I think they were the type of people who were kind of wait and see, let's get more information, and a lot of what we'd gotten was pretty disappointing. So, a lot of them had held off on taking treatment, until they saw something that really looked like it was making a difference. And, we didn't really start having that data until after I came out to San Francisco.

SS: Would you say that the people in the upper echelons of treatment activism – whether it was TAG or ACT UP – had access to advance treatments themselves that other people – either in the rank and file of the organizations or in the broad community would not have?

01:05:00 RL: No. I think they had access to information, in part because they could speak doctor-ese, or scientist-ese. But I think almost all of us – certainly TAG and T&D, equally, felt that it was our responsibility to get that information out. Some of us maybe took on that burden more than others or took it more seriously. It gets to be pretty tricky. I have the experience now of speaking doctor-ese at my patients and they go, what, what? “What did you just say? What are you talking about?” And I'll say, “Oh my God excuse me, I was speaking doctor-ese, I'm sorry. In English,” – and then, I'll start again. And I have to concentrate now sometimes to explain medical stuff to people in a way that they're going to understand and digest and use. And a lot of activists – any time you get involved in a special area of knowledge, you start picking up a jargon. And so, very quickly, activists started graduating into speaking this science language jargon, and it became an effort to find ways to get information to people that would help them. But there are groups – the AIDS Treatment and Data Network, for example, was a group that

did brilliant projects – getting very basic treatment education with folks with less than an eighth-grade education. Ken Fornataro and those folks understood that one of the central missions of treatment activists was to help people who needed it. And a lot of those people didn't have a Harvard education and couldn't just start reading the *New England Journal of Medicine* and get anything from it that would help them.

SS: Was that an ACT UP project?

RL: The AIDS Treatment and Data Network? Well, it was another kind of – I guess you would call it NGO that spun off of stuff that started – I mean, Ken was a member of the Treatment and Data Committee. By the time I joined T&D, he was just doing that, and I was aware of them, and I guess every once in a while people from that group would show up and make a presentation, but they were already cooking along with their organization at that point.

SS: So, let's get back to you. What specific issues did you work on in treatment?

RL: The first big project I got involved in was the protest against Hoffman-La Roche in February of 1993. And probably, other people have talked about it. It was like the last big mega-action, where we must have had a dozen groups chained to the fronts of different –

SS: All right, take us through the whole thing. No one's described it yet. What were the issues?

RL: So, Hoffman-La Roche was a drug company that was developing a couple of different treatments for HIV. They had a drug on the market, DDC, which is a horrible drug. We hardly ever use it now. So, they had a protease drug that was in development,

and it turned out to be the first one that got released. It was the first in human studies.

SS: What was that?

RL: Saquinavir – which turned out, again, to be not a very good drug. And then they had a drug called a tat inhibitor, which was very important, because it had a completely novel effect on the virus – at least, in theory. And they seemed incredibly slow in getting it through the preliminary studies. And people wanted to get it into human trials. There were a lot of people who – very influential people – like Theo, for example – Theo Smart – who commented on it very favorably and were looking at it as something that might help at that point in time and could be an important new treatment. And so, there's a lot of interest in it. And they were just incredibly slow, in bringing it forward. And so, another thing that Hoffman-La Roche had at that point in time was PCR. And now, these days, of course, everyone knows that we measure virus levels in people's bodies with viral load tests. PCR is the first kind of viral load test we ever had, and Roche owned it. And they charged a boatload of money for it.

SS: Do you remember how much?

RL: Oh, I'm sure, at that point in time, a PCR test for a human being was probably in excess of \$200 dollars a shot, which is more than double what it is now. Of course, the reagents cost pennies, pennies – not the first time in AIDS activism, where we've had something that literally cost pennies to make that was being charged at thousands of dollars a shot. So, PCR was very expensive, to the point that it was difficult for scientists to use it and see how it worked and kind of learn to apply it. I mean, ultimately, of course, we now use it every day in the clinics. But, at that point in time, it was so prohibitively expensive that it was actually – the price was getting in the way of

the scientists making use of it and getting insights into the virus, by applying it. That was a problem, as well. There were all these issues with them. We want to get that protease drug into human studies faster. We wanted to get the tat inhibitor into studies faster. They were charging too much for PCR, and it was bogging down the scientists. We didn't like that, and they were not very forthcoming with information.

SS: Who was your contact?

01:10:00 RL: So – well, there was a Community Constituency Group for Hoffman-La Roche, and I think Theo was on it, and Iris Long from Treatment and Data – who was a founding member of Treatment and Data Committee ACT UP – was on the group, the committee, as well. And then, I think there must have been a couple of people in TAG who were also involved, of course. And Linda Dee, from Baltimore, and a few other people from around the country. And they were coming to our meetings and talking about – you know, they were having problems. They felt – not everyone on the committee, but a lot of people felt like Roche was dragging their feet, they weren't –

SS: Do you remember the names of the Roche people?

RL: Well, at that point in time, I think Gail Levinson had taken over as sort of the official spokesperson and contact. And there were a lot of scientists, but because I wasn't working on a science project related to Roche stuff, I never actually talked to any of the scientists directly. But people like Theo and Iris did, because they would go to these meetings and scientists would be there and present stuff. But, at any rate, this community advisory group – many of them started to feel – the majority of them started to feel like Roche was not being honest, not being a good public corporate citizen, and that they needed to get kicked in the butt. So, that resulted in a little Roche direct action

group starting. So, that's how I got involved, and I think Michael Marco was probably the point person, between TAG and ACT UP New York. He was another person who could kind of cross over easily. So, he and Barbara Hughes and Beth Stroud and I were totally new to ACT UP, at that point in time, and she wasn't really a treatment person at all. She did other stuff. But it was a direct action. And for me, it related to getting treatments available and sort of accelerating a science. So, that was my interest. So, we joined that committee, and Bob Rafsky was involved, too, because he saw it as being a priority for ACT UP New York at that point. So, we organized and – it all happened so fast in hindsight, but we wound up having this enormous action in February of '93, and basically, there was a series of escalating events – putting Roche on notice.

There was a sort of mini-action, during a presentation that Hoffman-La Roche made in New York – I think at the Marriott. And I was with some of the ACT UPpers who were there, and they were meeting with this official group of community advisory people. But I remember that we had decided we needed to make an announcement that time was up, and Roche needed to start being more straightforward in releasing information. And so – I remember, Larry Kramer was part of this little action. So, we went in, and Kim, who was a very soft-spoken guy was there, too, and I guess, they had actually gone into the meeting while a couple of us – this guy Keith and I ran around the hotel, throwing fliers out into the central air well of the hotel. It was this huge lobby, so it goes up 15 floors or whatever. So, we were running up and down different floors throwing fliers saying, “Hoffman-La Roche needs to change their policies” or whatever – bad, corporate citizen, blah, blah, blah, and listed all the issues. So, we just threw hundreds of fliers into the hotel, and they were drifting down 15 stories into the middle of

the hotel. And, of course, we were being chased by the police while we did this, so we were having to, like – it was very cops and robbers – like ducking around and jumping into elevators and trying not to get caught. And we managed to make it out of the hotel. While we were throwing all these papers, Larry Kramer and company went in – busted into this community advisory meeting and said, enough talk, you guys have to start coughing up some data and honestly communicate –

SS: So, you busted into a meeting that ACT UP people were participating in as a community?

RL: A couple of people were, and I think they knew that this action was going to happen. But, like I said, not everyone on the community advisory committee, felt that Roche wasn't being forthcoming, but they were the minority. And I think Iris Long was one of those, who was sort of an *éminence grise* of Treatment and Data, because she had helped create it in the first place, and she was very well regarded. I think she was someone who felt that Roche wasn't necessarily hiding anything, they just – things weren't moving because science is slow. And a lot of people disagreed with her on this. She certainly wasn't in support of this demo. But, anyway, they went in – Larry Kramer basically put them on notice that they needed to stop stalling and start giving more substantial information and communicating honestly with the community – that people were fed up. And then I think Kim –

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SS: Who's Kim?

RL: One of the other activists who was with him –

SS: Do you remember his name?

RL: I don't remember his last name. I knew you were going to ask me that!

Apparently, they had this elaborate spread of – I remember, shrimp cocktail, and all kinds of food laid out for this meeting, and they tipped the table over, and cocktail sauce went flying. This is what people tell me. I wasn't in the room, when they did this. And then, they all dashed out. And one of the ACT UP media activists – Shraga Lev – got picked up by the police, and I remember we were nervous, because he had taped us, talking about our plans for the bigger action that was going to happen in a few weeks, if Roche didn't respond. So, we were worried that the cops would review the tape and know what we were planning on doing. But, at any rate, a few weeks later, we did this big action at Hoffman-La Roche headquarters at Nutley, New Jersey, and there were probably a dozen different affinity groups of about a dozen people apiece, and each group was responsible for shutting down a gate. It was an enormous complex. So, I was the driver for my group.

SS: What was your group called?

RL: We had some great names. One group was Tales of Hoffman and then, Roche Motel, I think was our group's name. And – who was in my group? David Feinberg was in my group. I don't know if Beth was in my group or in another affinity group. Anyway – so, basically what it involved was, people as a group, chaining themselves together and blocking the gates – which was a much bigger version of what TAG had done at Astra Pharmaceuticals. And, it got enormous press, and there were helicopters flying all over, and it was very cold, and I remember Kevin, I think, almost got hypothermia – Kevin Frost – and I remember they had to warm him up in a bathtub in the hotel across from the drug company complex that became our headquarters. And slowly, people – different groups would be arrested and processed and people started

percolating into the hotel – where drivers and support people were staying. And unfortunately, I remember – as was all too often the case, many times – that the media only very imprecisely got the message. So, here we did this enormous action, with hundreds of people, shutting down a drug company for a day – their American headquarters – this huge pharmaceutical company. And you know, they basically said we were protesting the price of AIDS drugs. Well, no, this had nothing to do with how much they were charging. Certainly, that had been an issue at other points in the past, but we were there because we needed these drugs developed in a hurry, and we felt the company was going too slow and they weren't being honest.

SS: So, what was the consequence of –?

SS: So, what was the outcome of the action?

RL: Well, I believe the Community Advisory group was dissolved.

SS: No more shrimp cocktail.

RL: Right, exactly. But there was still – I wound up, actually continuing to speak on a regular basis with Gail Levinson, who would give me information about what was going on. So, I don't think they wound up having group meetings to disseminate information. Things changed, actually. I remember writing for the Treatment and Data newsletter that the price of PCR was brought down, not long after that action. Was it because of the action? I don't know. But I'm sure people within the company – even if NBC couldn't get the story straight, I'm sure they appreciated that we were making a valid point in talking about the pricing of their PCR product. So, I consider that a belated victory. That was probably three or four months afterwards. And as it turned out, tat

inhibitor was a total bust. We got the animal toxicity data was horrendous and I remember, afterwards, Mark Harrington saying that it might not have even been a tat inhibitor, actually. That the way the assays were set up, it might have had some other mechanism –

SS: The way that what was set up?

RL: The way the assay –

SS: What's an assay?

RL: A test-tube test of a drug. It's sort of like the most early stages of studying how a drug works. And tat is this protein in the virus that's very important, so if you block it, you can block the virus – to put it in simple terms. And, I remember Mark saying at a meeting that – he had a very sophisticated understanding of the drug development process and he had been talking to some scientists and thought maybe the drug didn't even work the way they thought it did – which, maybe means that it wasn't as important as we thought. So, that was disappointing. Saquinavir of course wound up, months later, having its first human study results announced at the Berlin meeting and it looked promising, but it wound up being ultimately within the field of protease drugs kind of a disappointment. It was extremely difficult to manufacture, and so there were continued tensions with the company later on, because they weren't able to make very much of it. So, the question was, how do we distribute it? And there was some question as to whether – because it wasn't a very strong drug, we had the choice of giving a lot of people a little dose, which probably wasn't going to be very helpful, or giving a smaller number of people what was, maybe, a more effective dose. And again, it wound up being a situation of “Drugs into Bodies” versus the more skeptical approach of why don't we

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see what works? And, I think I remember members of TAG saying, maybe we should use it in a smaller number of people and use a dose that we think will really work. And of course, again – not a very popular idea in the general body of ACT UP, as an example.

SS: How do you evaluate that now – looking back? That choice?

RL: I think – I do feel the overall – the involvement of activists brought enormous, life-saving changes in how drugs are approved and developed in this country. But there were some things that people were wrong about. The study looking, for example, at AZT to prevent transmission of HIV to babies and pregnant women.

SS: Right – 076, was that it?

RL: I think that's the number, yeah.

SS: Can you set that up?

RL: So, that's an example where the general body of ACT UP New York decided they didn't like this study. And I don't really remember – I wasn't – that all happened before I ever joined ACT UP, so I never witnessed those discussions, and I don't know what the reason for the opposition was, exactly. But I remember people were concerned about the toxicity. Even at that time, people appreciated AZT, as it was used then, was four times the dose we use now, and people had a lot of toxic side effects.

The people were not in support of that study. Well, lo and behold, in 1994-95, when the results came out and we found that it dramatically reduced the chances of a mother transmitting the virus to her baby – well, I remember one of the big activists who had rallied the floor in opposition to the study – and the study, of course, wound up happening anyway – came back and said, “Well, we were wrong. This works.”

SS: Who was that person?

RL: I can't remember her name, I'm sorry. But she wasn't coming routinely to floor meetings at that point, but she came to give the results and she, at least, admitted, you know – we called that one wrong. And I think – certainly now, in hindsight – knowing how quickly the virus develops drug resistance, all of this pressure to get people on treatments that were usually one drug at a time, I can appreciate now, wound up inducing all kinds of drug resistance. And those folks who were so avid about being involved as trial participants and being in study after study and getting one drug at a time, wound up developing horrible drug resistance. And then, when the protease drugs came out – the really strong ones, in the spring of 1996 – March 17th was when Crixivan was approved. I'll never forget that date. It's an important date in my history.

SS: St. Patrick's Day.

RL: Yeah, when the first potent protease inhibitor was approved. A lot of those folks couldn't benefit, because we have to use at least three drugs that are active, and if you've already used all but the one new drug, you can only get one new drug into your system, and then you're using a couple of other ones, that your virus knows how to get around. So, you're effectively on one drug, and we know that the virus can always get around one drug. So, some of that – it kind of all gets back to the whole business of – there definitely is, sort of the layperson's wisdom about a lot of things. And it's true, that sometimes eggheads don't see what's important, because they get lost in the stratosphere. But there were some things that seemed so obvious to laypersons. Well, duh, we need people to get treatment – that now, in hindsight – maybe it would have been wiser to hold off. Maybe it would have been smarter for people not to rush to go into those studies. But, of course, those volunteers had to be in those studies, so that we would have learned

01:25:00 about the treatments that we use today. So, those people were heroes to be research participants. But there's so much that we've learned now, in hindsight. I think we now know that protease inhibitor combination therapy saves lives. And we wound up learning that without a large simple trial, but with the benefit of studies that a lot of people, in the general rank and file of AIDS activism opposed, because they didn't want people being deprived of life-saving protease inhibitors. But part of how we appreciated how much better people were on protease inhibitors, was comparing them to people who weren't. So, I don't know – it gets tricky.

SS: But you already had that data. You already knew what happened to people who didn't have protease inhibitors, right?

RL: Right. And that gets into the whole business of science purism versus what seems common sense. Common sense would say, right, we already had that information, but the way we conduct clinical trials, we have to have a control, because there's the problem of what we call the "historical control." Well sure, we can look at a set of hundred people five years ago who didn't have protease drugs and look what happened to them and compare them to a hundred people we'd put on protease drugs today and how these people do much better. But is that because we also, in the five years, learned a lot more about how to manage AIDS and HIV? And maybe the reason these people are doing better isn't because of the drug, it's because of other things that have changed.

SS: Well, I do remember a debate in ACT UP about trying to use AZT – because it had been studied and studied and re-studied and that would be the control.

RL: Yeah, right, and for a lot of people just using one or two nucleoside drugs – we know those people didn't do that great. And so, that would have been depriving them of something that could have really helped them turn the corner. And certainly, throughout 1996, and afterwards, we saw example after example of the Lazarus effect – people who were this far from death's door who had dramatic improvement, and basically came back to life and were restored to health by protease combinations.

SS: I wanted to talk about Berlin a little bit. That was such a turning point. Can you explain what that was, and how you got there?

RL: Yeah, so I was part of the ACT UP group that went over to the Berlin conference.

SS: When was that?

RL: That was in the summer of '93.

SS: And what was this conference?

RL: It was the International AIDS Conference – which, at that point in time, was happening every year. Now, they happen every other year.

SS: Who organized it?

RL: Well, there's an international committee now of academics. But, at that point in time, they had already recognized that they needed involvement of community groups. And so, activists and laypersons had access to the conference and were encouraged to attend, which was not true for a lot of scientific conferences in the old days – and certainly, in the early days of the AIDS epidemic, having a lot of these laypersons and patients come to a scientific meeting and ask nosy questions and interrupt speakers was not something that the scientists were used to having. But, by this point in time, it

was considered expected that lay persons would be there, that activists would be there.

The Berlin conference was enormous. There were thousands of people there. There were hundreds and hundreds of sessions.

SS: How many ACT UP people were there?

RL: I think we wound up sending – from New York alone – about 60 people.

SS: And how was that paid for, by the way?

RL: We did all kinds of fundraisers and sold stuff. I remember when we were selling these little trinkets – I remember, they were like lanyards or the equivalent. They had ACT UP's name on them. And basically, we sold them. They were tchotchkes. But we were selling them with the idea that people were donating money to us and they sold for a dollar a pop or something. So, we sold a bunch of those, and we did a bunch of fundraisers. I remember we had a beer blast at the Crow Bar – little community events like that to raise money, to send the group over. And some of us just paid out of pocket. I mean, I did. But, then I wound up getting a scientist stay in some squat in East Berlin that was – people were using the hallway as a toilet. And I was like, I don't think I can stay here. This is a bit too much for me. So, I wound up staying with Dudley, actually, and a bunch of other people with one of the treatment activists from Berlin – from ACT UP Berlin, in his home. And I think Dudley Saunders was there, too. But anyway, there were a little group of us, and I stayed on the couch or the floor or something. It was only for a week or whatever. But part of my disappointment was that I had worked my butt off, doing all of these events and was paying for myself, so I was already covered through my own out of pocket expenses. And then, at the last minute, we'd added in all of these community activists who were not regular ACT UP members, but kind of represented

01:30:00 women's groups or other organizations or constituencies that we felt were under-represented. And I did feel it was important for those people to come, but I felt it was kind of disappointing that we were sort of adding them in at the last minute and paying for them to go, but they hadn't really been involved in any of the fundraisers, which kind of violated what we'd all agreed to up front, about people who wanted to go had to do the work – either paying for themselves or helping out with fundraisers – that kind of stuff.

But, anyway, it was a lot of effort to get all those people over there, and we're all staying in people's houses and stuff. I mean, it wasn't a lavish vacation or junket or anything. And it was an amazing experience for me to be at this conference and there were endless numbers of sessions, and there were a lot of protests and I remember, there was a protest at the Astra booth, and Brenda Lien stood up and spoke and there was – we did a big action against Rouche. There were two, actually. I worked with ACT UP Paris and we did one. Actually, I think that one targeted some of the health officials of Paris about their inaction on AIDS in France. But those folks were also involved in the Roche action, and we did a big action at the Roche –

SS: What was the issue?

RL: Well, with Roche, it was a lot of the same stuff as before – you know, just further pressuring post the February action. And, of course, at this conference, they finally did present the information on their protease inhibitor. So, we finally got that data, but they basically had – even with all the pressure – six months or whatever, five months – they still hadn't coughed it up and then they finally did present it. But, you know, at these conferences, it was amazing to me to go out into the main exhibit hall and to see all these incredibly lavish displays from these drug companies. And it really

burned me, because they spent thousands of dollars setting up these fancy booths with all of these glossy pamphlets and handouts and puffy pens and cups and crap like that. They spent so much money on marketing, you know. I mean, this money would all be better spent – I mean, hey, how about a reasonably priced drug, so that people don't go bankrupt trying to afford treatment. I remember that thought crossing my mind more than a couple of times. I was kind of disgusted by all of that.

SS: Did you have a treatment agenda when you were there?

RL: Well at that point in time, I think I was still sort of, one of the "Roche people," because I'd been involved in helping organize the February protest, and Roche was kind of my beat. And after the big action, most people stopped talking to Roche. But, like I said, I was still in contact with Gail, who was the spokesperson –

SS: How were you in contact? Would she call you at home?

RL: I would call her or she would call me at my office. I would call her with questions. I would be putting together an article for one of the newsletters and I would say, what's the latest information on the protease drug. Or, what's the deal now with the tat inhibitor. So, I wasn't going to any meetings and confronting company officials or anything, but at least I was still talking to Roche, and getting information about what was happening with their products – not nearly enough to satisfy most of the people who had originally decided it was time to do a big action against them and target them, but enough to be abreast on what was going on with them. And, eventually, that became important again. Eventually, people wanted to start talking to Roche again, and so it was helpful that we had kept a line of communication open. So, we had some big protests at the Berlin meeting. And, of course, the big news, as I mentioned before, was that the results

of the Concorde Study were finally announced.

SS: What was the Concorde Study?

RL: The Concorde Study was looking at AZT treatment. And, basically, what they had found was that using AZT by itself – in the short term, people did better, which we knew. Here in the United States, we had done some short studies. But Americans – you know, I don't know what it is about our culture, but we're always focused on the short-term outcome. And so, the Europeans, being a little wiser as they usually are, decided well, okay so they're doing better now. Let's keep watching. And what they found was that when you got two years out, those people who had gotten AZT and those who had not, the clinical benefit seemed to wane away. And, in hindsight, that's not so surprising, because what we can probably imagine now, knowing what we know, is that people got AZT, and it did squish down their virus for a little bit, and they gained some weight and they maybe reconstituted their immune system a little bit in the short term. And then, the virus got around it. And then, they were back as if they weren't taking anything.

SS: Who did the Concorde Study?

RL: It was a collaborative group. I know there were scientists from the United Kingdom and, I think, from France, as well.

SS: Why was it called Concorde?

RL: You know, I don't know.

SS: So, they just stood up and announced –

01:35:00 RL: So, they presented this. And, I think we'd had preliminary results already and so, we kind of knew roughly what they were going to say. But it was sort of official

notice that the treatment – one of the few treatments that we had – the way we were using it then was not all that effective. And so, people came away feeling sort of depressed. Now, in the meantime, we had this tat drug, that turned out to be killing pigs and monkeys and probably wasn't ever going to be put in human beings. And we had the first protease inhibitor, but, as I told you, that went from Roche – ultimately turned out not to be very strong. And so, while the results were hopeful, they weren't a slam dunk, super exciting. And, a lot of people, at that point, were, like, oh, this is going to be like all those other drugs that failed. There wasn't – we didn't have – we did have some information about some of the other protease drugs that were really going to make a difference, but it was very preliminary and we were still worried about drug resistance and that it would probably be a short-term benefit, like AZT turned out to be. They still hadn't quite gotten the insight. There were a few activists – I think, John James and, I think, probably David Barr and a few people like that, and David Gold – were talking about combination therapy. But they were a little bit ahead of the curve, in terms of saying, you know, using them together – using a few drugs at the same time, might make a difference that one drug at a time won't. And that's something that anyone who works in cancer or in tuberculosis knows, as a basic principle. But, I don't think people had quite gotten insight into combination therapy until a few years later.

SS: So, when you left Berlin, did you move on from Roche?

RL: Eventually, I wound up being more involved. Ultimately, my beat became immune therapies – things that were intended to boost the immune system – and other projects I worked on. So, there was that stuff. And, actually, the things that I most studied were drugs that suppressed a sort of immune chemical that occurs naturally in the

body called TNF, that we thought was probably bad. And the evidence was that people with HIV had a lot of TNF in their systems, and it was probably part of why they lost weight, and it seemed to feed their virus and make it replicate more. And, that if we could block TNF, we could maybe slow down the virus and help people gain weight. So, I studied those treatments. So, things that –

SS: Did that pan out? Did that turn out to be so?

RL: Yeah. There were a couple of drugs that worked to block TNF and we can still use them for HIV wasting syndrome. But, you know, I think a truism has emerged that the best treatment for almost any problem related to HIV is just put them on combo therapy. If we can get them on an effective combination, a lot of those other problems – people on effective triple therapy – if you squish their virus down to undetectable, generally speaking, the immune system comes back, at least part of the way. They recover from all their opportunistic infections and clear them – not all of them, but a lot of them. It certainly helps with things like AIDS lymphoma. Those patients do much better and, in fact, if they don't have an effective combination treatment, they probably don't do very well at all and they succumb quickly. They gain weight. Clinically, they're a lot healthier and their energy is better, and pretty much everything clears up, if you get an effective combination of HIV drugs. As a clinician now, though, I can say that I've got a lot of my guys now on combination therapy and their virus is undetectable, but their T-cells stall out. They go up a little bit and they just kind of hang out. And here they are, percolating along, and they're still undetectable, or maybe they start to break through a little bit, and I change their drugs to squish it back down. But they're not growing back a whole immune system. And that's what I study now, and that's what I'm

interested in working in, research wise. Much later in my path, I wound up becoming a researcher, and I worked with a group that ultimately has pioneered using growth hormone to stimulate the thymus, which is the organ that makes T-cells.

SS: What group is that?

RL: The McCune Lab – at Gladstone Institute of Virology and Immunology.

SS: So, when did you leave ACT UP New York?

01:40:00 RL: I left New York in the summer of '96. And, at that point, that was after having completed two years of pre-medical studies at Columbia. Basically, here I was, being an activist, working as a medical writer, and at a certain point, I remember I got headhunted by AmFAR to work on one of their newsletters as a medical writer. And, in going through the process of interviewing for that, I realized, what I really wanted to do was go to medical school. And so, I started off going to night school at Columbia, and taking statistics and chemistry and working my butt off. And, eventually quit my job, so I could go to school fulltime, and wound up working part-time as a researcher at Community Research Initiative on AIDS. And Joe Sonnabend was the medical director there and became my boss and mentor. And, when I left, I think Vincent Perrybone took over that position. But, I was there for a couple of years, as a research assistant – basically, helped do a bunch of studies on protease drugs and non-nucleoside drugs and studied some immune therapies that Joe wanted to investigate and helped out the group that discovered the Kaposi's Sarcoma virus – which we now call, HHV-8. We were giving samples of Kaposi's patients to their lab. So, we worked with them, and with Barbara Ensley of Bob Gallo's lab, studying treatments for Kaposi's Sarcoma. So, as a treatment activist to actually be involved in research was very cool. But I also – it was

very humbling to realize what an enormous effort it took to move things forward and how slowly everything moved along, even when you were trying to work as fast as you could. It just went very slowly, doing research. And that's the way things are, in science.

SS: So, looking back at your time in ACT UP, what were or what was the greatest achievement that you witnessed in ACT UP? And what would you say were some of the biggest disappointments? Let's start with the negative and end with the positive.

RL: So, looking back on it – yeah, it's funny – I mean, I think – a lot of times, I think about how, as certainly I regard everybody who was involved as heroic, for just being willing to put in the time as laypersons – to do whatever they could to fight the AIDS epidemic, because so many people were too afraid or apathetic or whatever. So, anybody who had the guts to say, I'm going to make time to do this, and to spend hundreds and hundreds of hours that people did – living and breathing, being an activist, I think it's heroic. There was a lot of negativity – all the ego stuff, when I look back on it. There was just endless squabbles between people and people whose motivation for being involved was, maybe, because they liked being on camera. I mean, I guess that's a truism in any active – I've since talked to anti-war activists here in San Francisco, and it's all the same stuff. The meetings look the same, they're just talking about different issues, with a little different vocabulary, but you always have that in activism, I guess.

But, in hindsight, there was just a lot of time, where I would just get so exhausted, having to be a go-between, between two people who weren't speaking to each other because their egos were too big or whatever – or not even realize – I would go do something and maybe forget to put – heaven forbid – somebody's name on some flyer.

And all I was trying to do was get something done. And then, I would get yelled at, because I hadn't gotten somebody's name somewhere that it needed to be featured. So, I wound up stepping on toes occasionally. So, that kind of stuff – you know, you look back on it and it's kind of like, well, that was sort of too bad. And there was a lot of that. Also, being somebody who was both, in ACT UP and in TAG, it was gratifying to be able to help facilitate communication between those groups when it was important to have that happen. And I was grateful for the opportunity to do something that seemed constructive in that way, but on the other hand, there were times when I felt like neither group really trusted me, because ACT UPpers would see me as this former Ivy-Leaguer, and I was just like those TAG boys. I couldn't be trusted. And then TAG would think that I was blathering all of their secrets to these crazy radicals of ACT UP New York, so they didn't think I could be trusted either. And, so it was, sort of like –

SS: So organizationally, what do you think was ACT UP's great achievement?

RL: Well, there were a few – the reforms at the NIH, certainly, which were, basically Mark Harrington and Gregg Gonsalves's brainchild.

SS: Like what, for example?

RL: Well, they –

SS: You mean, like fast track?

RL: Well, that's FDA. So, what they did at the NIH, in part, was to coordinate the efforts going on across the 14 different institutes that comprise the NIH that weren't really – nobody was kind of getting an overview of what was going on. And so, they helped create a central office to monitor that and kind of direct what was happening –

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rather than allowing it to all sort of chaotically burble around through the invisible hand of the market or whatever and hope that something good would come out of it. They insisted that there be some central direction. And so, that was one reform – major reform – that happened, thanks directly to the involvement of activists. And FDA – fast tracking drugs – which I think has had – probably wound up helping a lot more cancer patients even now at this point in time than people with AIDS. But a lot of patients with different diseases have benefited from those reforms.

I think the greater willingness for scientists and doctors to acknowledge the wisdom and expertise of patients; to involve patients in community groups in scientific and medical projects, and recognize their involvement as being important and valid. I think that's something that has changed in medical culture – at least in part, because of that. And that's a real change, and it was broad and it started, I think, largely with AIDS activism. So, I think there were a lot of big, sort of broad cultural changes that happened in science and medicine, because of AIDS activism. You know, it's commonplace for doctors to acknowledge that probably the AIDS patients will know a lot more about their treatments than the doctors will. I can tell you – I'm at UCSF, which is the number one AIDS center in the United States – according to U.S. News and World Report – for the last umpteen years. And that's part of why I wanted to be there. But, even in my medicine residency, which is one of the best in the country, most of the residents can't even name all the HIV drugs. I mean, it's only people who specifically make it a point to do that kind of medicine that learn that stuff. We don't really have an official training program for HIV practice at this point. It's not an official specialty. So, you kind of have to make it your business to learn it, which I guess has always been the case in AIDS

medicine – people learn as they go. So, I think AIDS activism has wrought incredible changes, and I felt really privileged to be involved in it. I mean, it's why I became a doctor. I would have never become a doctor – otherwise, I'd probably still be working at some newspaper somewhere.

SS: And still be in San Jose?

RL: Probably still be in San Jose. Yeah, working for *Metro* or the *Mercury News* – which, you know, some of my old college buddies now are doing, as a matter of fact. Certainly, being an activist – I mean, I think that's what turned me on to – having the experience of being in the back of an ACT UP floor meeting, and having some guy come up to me and say, "Hey, you know, I just tested positive for Toxo – what the hell do I do?" Or, somebody calling me and saying, "You know, I just failed my fourth combination for MAC, and I'm losing weight everyday and I'm scared. My doctor doesn't know what to do. What do we do?" Trying to specifically troubleshoot people's problems and help them, and going to the literature, and talking to drug companies and finding out what they had in their vaults, so to speak – all of that experience of directly being involved in one person, trying to help them, kind of turned me on to being in medicine – got me interested in being in medicine. And it's what's kept me going through all this period of time.

SS: Thank you, Rick.

RL: Thank you.