

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

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Interviewee: **John Riley**

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Interviewer: **Sarah Schulman**

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ACT UP Oral History Project  
Interview of John Riley  
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**SARAH SCHULMAN: So you look at me, not at the camera. So the way we start is you tell us your name, your age, today's date, and where we are.**

JOHN RILEY: Okay. I'm John Riley. I'm fifty-seven years old. Today is January 2<sup>nd</sup>, 2013. And this is New York City.

**JAMES WENTZY: Just a second. Okay, thank you.**

**SS: Actually, we're in Harlem. And I went to that restaurant across the street and every single person in it was white.**

JR: Monkey Bar. Yes.

**SS: No. Cedric's.**

JR: Oh, okay.

**SS: I was like, "Wow." I guess things have changed.**

JR: Yes, the whole neighborhood is really changing a lot. It's about, I don't know, 50 percent white, almost. It's scary.

**SS: How long have you been living here?**

JR: For five years. When we came it was totally different and then it changed.

**SS: So where did you grow up, John?**

JR: I grew up in Iowa. I grew up on the shores of Lake Okoboji, which was a resort town in Northwest Iowa. It was a very beautiful place. It has a beautiful blue water lake there. I loved the summers there, but the rest of the year was not so good.

**SS: Was your family involved in tourism business?**

JR: No. My father was a podiatrist and my mother stayed at home and took care of us.

**SS: So were you raised with any kind of particular value about community? Did your parents belong to a church or did they do community work?**

JR: Well, my father was Catholic and my mother was Lutheran, and they — one struggle that my mother was involved with that I think influenced me was it was kind of a commons issue where there was a lot-owner association that had three beaches that everybody that was a part of the association shared. It was all written into the deed. Three tourist industry facilities tried to take them over and to try to drive us out. So my mom fought very hard against that and eventually sort of won.

**SS: So if you went there today, is it still owned by the —**

JR: They still have access to it. The tourist industry didn't get it proper. Instead, the city ended up taking it over, which is not bad because it means more people can access those beaches.

**SS: So you were born in 1955, right?**

JR: 1955.

**SS: As you're growing up, when you're ten it's 1965, you're growing up through the Civil Rights Movement, the Black Power Movement, the war in Vietnam, but it's all on television.**

JR: Right.

**SS: What kinds of discussions were taking place in your family as those events unfolded?**

JR: We were Democrats in a completely Republican county, and Democrats were considered to be like Communists. My mom was actually on the Central Committee of the Democratic Party for the county, and she was active in that way. She was probably in the left wing of the Democratic Party even there.

00:05:00 But as I grew older and I got closer to draft age, we started having discussions about the war. We were talking about me going to Canada if need be. My sister started dating a man, who was a conscientious objector, and he really brought home a lot of issues. It was really great. He was really thought-provoking. He raised my consciousness. He asked lots of questions about the Catholic Church that I couldn't answer. I. And I was raised Catholic and was a very devout Catholic. He raised all these questions about the church's teachings on many things, including sexuality. The more I thought about it, the more I realized that he was right. He was an atheist, and I soon decided I was an agnostic.

Even in rural Iowa, the movement penetrated, and so the anti-war movement was becoming increasingly visible in the newspapers and in our school. When I was in high school I refused to stand up for the flag during Veterans Day. I thought it was a complete glorification of war and that it was really something I didn't really want to support. I got a lot of flak for it.

**SS: So when did you start doing organized political work with other people?**

JR: I guess I would say in the late seventies.

**SS: So not in high school?**

JR: Not so much in high school. I mean, there, a student — I ran for Student Council. I had what, for Iowa or for Milford, Iowa, was a radical platform. I called for a student newspaper that was not controlled by the administration. I called for various student-power kind of things that were very low level. The administration did not want me elected. They got somebody to run against me in a three-way race and so I lost.

But it was one of those things I did pretty well and one of the other people that ran realized he'd been used and came to me and said so. I think I raised a lot of issues that people had thought about but had never expressed before and it was worthwhile. A newspaper did come out of it, but the administration somehow had their hand in it. But they did let us say what we wanted, but then they would put in their own reactionary articles to balance it.

**SS: And where did you go to college?**

JR: I went to college at the University of Iowa. I majored in botany and was in school till the late seventies.

**SS: In Iowa City?**

JR: In Iowa City.

**SS: Well, that was like a hotbed of radicalism at that point, right?**

JR: Right, right.

**SS: I mean it was infamous Iowa City.**

JR: Right.

**SS: Just from the Feminist Movement I remember the Iowa Women's Health Center and there was the women's presses and all this.**

**So were you openly gay in college?**

JR: Yes, I was not out to myself for quite a long time. It was driving me crazy and completely homophobic. I sort of knew, but I didn't really want to admit it. But I kept falling in love with all my best friends. I was like, "What do you do?" you know.

I ended up going into radical therapy. I don't know if you've ever heard of it. Claude Steiner was one of the people who developed it, was using transactional analysis, and they were trying to develop sort of a people's therapy. But they used a lot of the techniques of the Women's Movement of consciousness-raising in order to raise your consciousness about how you're oppressed in society. And it was through that group that I eventually came out.

**SS: In Iowa City?**

JR: Yes. It was a mixed group of straight and gay people. But it was amazing what you can do in consciousness groups.

**SS: But there was a lot of gay infrastructure in Iowa City, right, like there were bars and there were progressive gay people?**

JR: Absolutely. When I got there in 1973 in the fall, there was a Gay Student Union, and they were having their first gay dance, I think, in the Student Union there. And I saw it. I was like, "I saw the sign," And my heart started palpating and I started getting hot, and it was like, "Oh, my God, does anybody see me?" And I wrote down the number to call. Then I called the number and I had a sort of a typical overreaction of just like worried that other people would find out that I was calling this Gay Hotline.

I wasn't ready then, but luckily, my roommate was, and he came out as gay. Soon I was immersed in a gay culture as sort of a closeted gay person but around all these gay people. I think that also kind of helped in the process of coming out. That led me to get into this consciousness-raising group.

**SS: What was the relationship between the Gay Movement and the Left at the time that you were just coming out?**

00:10:00 JR: The Left at that point in Iowa City had kind of had this, sort of shattering because SDS [Students for a Democratic Society] had more or less disintegrated by '73, at least on campus at Iowa City. I looked for their local chapter. I didn't find anything. There were remnant groups that were still around, like the Attica Brigades, which was what later became the RCP's political project. And there were — that was there. Then there would be some broad coalitions like the Committee to Throw the Bum Out, which brought in a wider variety of forces.

**SS: Which bum were they trying to throw out?**

JR: Nixon. 1973, Nixon — he was on the eve of being impeached and people were furious and there a demonstration of like twelve, fifteen hundred people on a couple of occasions, calling for his ouster. I was at those demonstrations where I heartily agreed.

Then through that and my gay friends, I started to meet people that were gay that been involved in the anti-war movement, and they started telling me stories about gay and lesbian exclusion from political leadership within the anti-war movement and how people that were prominent leaders, as soon as they came out as gay, that was it.

**SS: Can you remember who some of those people were?**

JR: Who the leaders were that were —

**SS: Yes.**

JR: No, I don't. It's been a very long time. And he was telling me sort of third-hand. He himself was involved in the Gay Movement.

**SS: Well, David Dellinger famously was gay.**

JR: Right.

**SS: And there was — what's his name? He's like eighty-something years old now. His name is David also.**

JR: McReynolds.

**SS: McReynolds, yes, right. I was wondering if there was anybody else you had in mind.**

JR: No. These were local people and the stories about what went on in Iowa City were incredible from the anti-war period. Dow Chemical came to recruit, I think, people on campus to work for the corporation at the height of the Vietnam War Movement. They were the manufacturers of napalm and there were mass demonstrations against them. It was a very active movement. The police attacked it. There were a lot of what the newspapers called riots, but of course, they were police riots. But, anyway, that was that.

And in terms of what Iowa City was like, politically the Lesbian Movement was very strong. It was also separatist, largely, but as time kind of went on, the doors started opening a little bit in terms of willingness to work with other forces. And I think I wasn't there for the history to know why separatism existed and it took me a while to figure all of that out, that that in itself was sort of protection against male

supremacy within the Gay Movement, even. But relations became better over time between what was then the Gay Liberation Front and the Women's Resource and Action Center and various groups associated with that.

**SS: And were you a part of the Gay Liberation Front?**

JR: I didn't really join until — I wasn't really a part of it. I didn't really completely come out. First I came out to myself and then I had some relationships and considered myself bisexual, started a bisexual support group. And then people that were from the Gay Liberation Front approached me about working together on projects. So I did.

**SS: That's interesting. They wanted to do a Bisexual and Gay Alliance type of thing or did they consider bisexual to be part of the Gay Liberation Front?**

JR: They considered us just a wing that needed to be brought in, which was great. We did need to be brought in.

**SS: So where did you go from Iowa City?**

JR: From Iowa City — I stayed in Iowa City for quite a while. I got a job. I was working as a research assistant after I got my degree in biology or in botany in particular, but I worked in the physiology and biophysics department at the University of Iowa Medical School. And so I stayed there for a number of years and then went to China for a year, studied Chinese, and then came back to Iowa City and stayed there more or less until 1991. Then I moved to New York.

00:15:00

**SS: So then you were in Iowa City during the beginning of the AIDS Crisis. How did that unfold in that environment?**

JR: It was horrifying. There was very little information. We did get some information from *Gay Community News* that came out of Boston. That was kind of our lifeline or at least it was my lifeline in terms of having an expansive discussion on AIDS. Even though sometimes I didn't agree with it — with the articles.

**SS: Do you remember what, for example?**

JR: I think that there was a certain amount of denialism about what AIDS actually was. But I thought that there were other things that I really liked, at least parts of, like Cindy Patton's book, *Sex and Germs*. I thought that was very thought-provoking.

**SS: But denial about what AIDS was biologically or socially?**

JR: At first they weren't that concerned about the epidemic and I disagreed. I thought it had horrendous implications. Of course, I had no idea about transmission and I was constantly going to the medical library and trying to look up the latest articles, and was constantly disturbed by the way they always framed everything as being it was the disease of gay — essentially gay white men, and then eventually they added Haitians into it.

But I felt somewhat isolated. I think we talked some about safer sex within the bisexual support group. And then when I came back there was a Shanti Project, a chapter that was set up, and that was like a good way, I think, to sort of desensitize about feelings about it and the sort of horror about death and dying, and to express it in a group setting. I thought it was an incredible growth experience.

**SS: When did it start to reach people that you knew?**

JR: Well, probably '88, '89. I knew people that were positive, and then within a few years some of them were full-blown AIDS. One person died in '93, I think.

**SS: There was this idea, right, early on that if you weren't in New York or San Francisco you were going to be okay.**

JR: Right.

**SS: Or if you didn't have sex with people from New York or San Francisco.**

JR: Right.

**SS: So it took longer for actual AIDS to become visible, right, in the middle of the country.**

JR: Right, right.

**SS: Your concerns were conveyed through media, but not necessarily through immediate experiences at first.**

JR: Right. And I did meet people with AIDS various times. I went to California for six weeks on a motorcycle trip and stayed in San Francisco, went to Gay Pride there and hung out with people at the Bisexual Center and met some gay people through that, so that had AIDS.

**SS: Where was the Bisexual Center in San Francisco?**

JR: I can't remember, but they had a building that they did programming out of.

**SS: And did you decide to get tested at some point at that time? Did you feel personally endangered?**

JR: Yes, yes, I was afraid of having had it because I'd engaged in risk behaviors and it was unclear how long the virus had been around. I really didn't believe

all the stuff about New York and San Francisco. I believed it was a virus and it was happenstance whether or not you encountered it.

**SS: But were you willing to get tested even when there were no treatments?**

JR: Actually, I took part in a gay and bisexual men's health study, and that's how the tests happened.

**SS: In Iowa?**

JR: In Iowa, University of Iowa.

00:20:00

**SS: So what made you decide to move to New York?**

JR: A man. John Berryill, who was a writer, came to Iowa City. He came to finish a novel. He had some relatives that allowed him to stay in their house. So he finished his novel and took about six months. We dated basically from pretty much the beginning of him being there and then he left and we stayed in touch somewhat. He invited me to move to New York.

And so at a certain point my job ended. It was a grant position and the professor I was working for was moving out of town, so I needed to find a job. So it was the perfect time to travel and then I figured after travel I'd return to New York and see if that could work. Actually I went to El Salvador and Guatemala before coming to New York.

**SS: Did you go as part of an organization?**

JR: I went with CISPES [Committee in Solidarity with the People of El Salvador], so I was on a human rights delegation, and that was, like super intense, because death squads were — you know, they were not happy that we were there, and

they threatened us, and we went into the zones of control where the Freedom Fighting Army was — the FMLN [Farabundo Martí National Liberation Front] that was seeking a more just society, where they had military and political control. We met with some of them and we met with a lot of people that were just in ordinary organizations like unions and women's organizations and mainly people that were under threat of death by the death squads.

**SS: Can you just explain for viewers who were not around at that time what was the relationship between gay politics and El Salvador solidarity work?**

JR: I think Central America, like CISPES in particular, had tried to develop a relationship with the AIDS Movement, and they kind of united under a general slogan of "Money for AIDS, Not for War," so they were calling for defunding of this death squad government that was running El Salvador, that was completely backed by the U.S. and would not be able to maintain its rule without U.S. backing.

So I went to demonstrations that they organized. For example, ACT UP Chicago had a demonstration at the Federal Building with CISPES under that slogan and they did a number of demonstrations there. I believe in New York that was also the case.

**SS: There were a lot of gay people in CISPES also, although they were positioned differently than they would have been today, right? It wasn't like openly gay solidarity work. It was like gay people working in a movement with a certain kind of muted gay presence. Would you agree with that?**

JR: I'm not sure how muted it was, but they certainly did a lot of consciousness-raising groups with people that were — like prostitutes and doing sex education and things like that

**SS: So when you got to New York, how long —**

JR: And they were openly gay. They were completely openly —

**SS: They were openly gay.**

JR: They would do openly gay organizing and they were doing a lot of HIV education and they were actually fighting with the FMLN about making sure that these people were not excluded from the movement there.

**SS: Did you know Jeff Gates at ACT UP?**

JR: No.

**SS: Sorry. He was involved in Nicaragua. I was hoping to get some information.**

**So you came in '91 and how long did it take before you got to ACT UP?**

JR: So, I left Iowa City in '91, in May of '91, went to El Salvador for three weeks or something like that, two or three weeks, then went to Guatemala and actually studied Spanish then for about five months, then returned to El Salvador on my own and actually was there for the day that the Peace Accord was signed, which was fabulous in terms of, like, it was a real victory, and not complete victory, but it was pretty good. It stopped the fighting anyway.

00:25:00

Then my first sort of regular ACT UP meeting was in January of 1992. I had been to a previous meeting in November '90 when I came to visit John Barryill, as a

part of sort of scoping out New York and figuring out would living in New York work for me.

When I came to ACT UP, this was the thing that I really — it's always hard to transplant relationships, and I thought, "John, you really need to think about, like, why are you wanting to be in New York, because if you just go for a relationship and the relationship doesn't work out, you'll be very disappointed and maybe this wasn't the right move for you."

I was just thinking about the things I wanted to do, and one of them was to become active in ACT UP because I'd seen ACT UP before at the national —

**SS: The March on Washington?**

JR: Yes. Wasn't there one in, like, '89?

**JIM HUBBARD: '87.**

JR: Or eighty-seven, yes. It was just after ACT UP was formed. Was it in the fall?

**JH: Yes, October '87.**

JR: Yes.

**JH: And then there's one in '93.**

JR: Yes. I remember I had helped organize a bus-full of people to go to that march, because I was working with a student group there or a couple of student groups that did the organizing for it, and I remember seeing what looked like an army. They were all dressed in white and black t-shirts with "ACT UP" emblazoned across it, and I was, "Oh, my god. Oh, my god. Thank god." You know, I just felt incredible hope, because in Iowa City it was so isolating. People were very afraid to disclose HIV

status. Anyway, to see this group that was openly fighting for the rights of people with AIDS was fabulous.

Then in 1990, around Thanksgiving, I was in New York visiting John, we went to my first ACT UP meeting, and it was in Cooper Union. And the impression that I had was just — I couldn't believe it. There were four hundred people in the room, and there was somebody had gotten up from the floor and was bitterly complaining about how low attendance was and we should be able to fill this room up. And I was like, "This, I've got to come back, because this is the kind of movement I want to be a part of." Just the energy and the vibrancy was incredible.

When I came back to New York, the first meeting that I could, I went to the ACT UP meeting and completely —

**SS: And how was the attendance?**

JR: It was actually a little bit — probably similar.

**SS: About four hundred?**

JR: Yes, maybe. But for me, you know, if we got three hundred people at a demonstration in Iowa City, we thought we were doing good. So to have people involved in ongoing organizing of four hundred is like — this is a powerful movement. So I was thrilled.

**SS: So where did you put yourself inside ACT UP?**

JR: Well, first, I was just trying to figure out what to do, so I was just trying to absorb as much as I could. I went to the literature tables and scooped up everything. And actually on my third meeting, I came across this guy that was about 5'11" and kind of skinny, and he was passing out these leaflets about Dhoruba [al-

Mujahid] bin Wahad, who was a recently released political prisoner that had been framed by the FBI. It had all kind of come out in the court records after being in prison for nineteen years. And when I saw this leaflet it was like, “Oh, I was wondering when this court appearance was going to be,” because I heard him in Chicago when I had gone to visit. And the person that was handing me the leaflet was Bob Lederer, who I’m lovers with now. That’s how I met him.

**SS: Right and you just had your twentieth anniversary.**

JR: And we just had our twentieth anniversary.

**SS: Congratulations. So were you part of that same formation that he was part of — the May 19<sup>th</sup> Prairie Fire Group?**

JR: No.

**SS: You just happened to be interested in political prisoners.**

JR: Yes.

**SS: So you weren’t part of any kind of —**

00:30:00

JR: No, I wasn’t in that organization.

**SS: Were you in any kind of —**

JR: I wasn’t, no. No. But I did a lot of reading.

**SS: So you met and fell in love over a political prisoner. That’s so**

**ACT UP.**

JR: Well, we met and just started dating. Actually, we didn’t start dating immediately because I went then to the court hearing and we went out to a lunch afterwards. Then he asked me, “What brought you to New York?”

And I said, “Well, I came to move in with my boyfriend, who I’m living with right now.” And he was crestfallen.

But anyway, actually within a couple of months, that relationship was not going so well. He had to move for a job, John, and so we kind of at that point, we were not a couple anymore. So I then went out with Bob.

**SS: That’s a great story.**

JR: Yes.

**SS: So where did you go in ACT UP? What was your first sort of positioning?**

JR: Well, the first thing that really caught my eye was Campaign ’92, and there was a presentation by Jack... Frank? Was it Jack Frank?

**SS: Jack Frank? Never heard of him.**

JR: I’m trying to remember. It was a presentation by several people about following the candidates around.

**SS: Can you just explain what Campaign ’92 was?**

JR: Yes. Campaign ’92 was an attempt to inject AIDS into the presidential campaign. In the 1980s, we couldn’t even get President Regan to say the word “AIDS” until about 1987 and President Bush didn’t do much better. He basically did very little during most of his administration. Campaign ’92 was designed to make sure that every candidate had to talk about AIDS so that it would become a part of the national dialogue. Pretty much immediately different working groups were set up around various candidates based on people’s, I don’t know, dislike of the candidates, ranging

from Pat Buchanan and Clinton and the entire host of candidates at the time. One of the targets was the —

[CELL PHONE RINGS]

**JH: That's probably mine.**

**SS: Whoops, stop.**

**JW: Start with the —**

**SS: That's ok, we'll roll anyway. I think I know who you mean. Jack.**

**He had a little beard? A skinny guy? Jack Ben something.**

**JH: Jack Ben-Israel?**

**SS: Could that be it?**

**JH: That's the only Jack I —**

JR: He traveled around all over the country and kept coming to ACT UP with requests for money to do that and he used the "What About AIDS?" image that was silkscreened on signs.

**SS: So which candidate did you choose?**

JR: I was very excited about the Republican primary, which was up in New Hampshire, Manchester, New Hampshire. So we went up and we zapped all of these different candidates. I was most interested in President Bush.

I was completely new to the whole concept of direct action the way ACT UP did it, so I was just trying to kind of feel my way along. But there were two buses that went up. It was frigid cold. We were told when it was time to go to the President Bush's speech that we should be careful to not clump in groups because it would make it easier for them to identify us and that at a certain point we would interrupt his speech.

00:35:00 And I went in with all these people, and since I was new, I didn't really have any friends, and so it was very easy for me to go to — to just be by myself and to just sort of focus in on what was happening on the stage. But I did look around from time to time, and I didn't notice — I don't really notice any of the people that were on the bus. Could that be? Maybe I just didn't remember them. But as it turned out they were all being snatched up by Secret Service and being removed from the room. At a certain point I felt like maybe I was the only one left.

**SS: You're the only one middle-American enough to get through the Secret Service.**

**JAMES WENTZ: In drag?**

JR: I ended up trying to disrupt, to say something about "What about AIDS?" And there was no response. And I was like, "Wait a minute. There should be a response." But then nobody did anything to me, so I thought, "Oh, well, maybe somebody will say something, interrupt later. Maybe there's still somebody left," and sure enough, there was. They started chanting and they knew exactly how to create a big scene. It did make a good scene that got some media attention.

**SS: What did you do? Did you say, "Excuse me, Mr. President, what about AIDS?"**

JR: No, I just shouted it out.

**SS: "What About AIDS?"**

JR: I wasn't afraid to do it, but I was hoping that others would join in, and nobody did, so —

**SS: I just want to ask you about the mechanism of this type of thing. People would say, “We want to go to New Hampshire and do this.” So ACT UP would pay for the buses?**

JR: Right.

**SS: And they’d pay for the hotels? Did you stay in hotels?**

JR: On this one, I don’t think that there were hotels.

**SS: Where did you stay?**

JR: I think it was a one-day thing. I think it was like one of those horrible trips that you were on the bus for a very long time.

**SS: You’d go up and then you’d zap Bush and then you’d come back.**

JR: Right.

**SS: And so by the time you came back, had you made friends in ACT UP, spending a day like that, like all the bus ride and everything?**

JR: Started to, but, you know, it took a while. But, yes.

**SS: So did you continue with Campaign ’92?**

JR: Yes. I eventually went to Houston with a contingent of ACT UP members. Houston was where the Republican National Convention was and it was in the Superdome or something like that. There was ten of us, included People like James Learned and Scott Sawyer and Kim Edwards, Ben Thornburg or Thornberry, David Falcone, and a few other people who I can’t remember their names right now.

**JW: I was there.**

JR: And you were there, yes. I thought it was one of the most exciting, exhilarating things I’d ever been involved with. We hooked up with then-new Queer

Nation of Houston, which was having phenomenal success in organizing. There was one big public meeting where hundreds of people came in preparation for a march that was to go to the Convention Center. This was actually on the night of Pat Buchanan's famous "culture war" speech in which he said that there was a culture war and, "We must fight these homosexuals and women that want women's rights and the feminists" — the entire enemy list for the Religious Right.

We were marching on our way to the Superdome to have a demonstration outside of it, and it was one of those things that it didn't get completely planned. People didn't really have an in for what the demonstration would look like when we got there, so people improvised. Somehow, somebody, I think, lit their sign on fire, and pretty soon a lot of the signs were going into fire. And, of course, all of the signs had images of George Bush on them, and it was like "What About AIDS?" And then somebody else that had a puppet of George Bush, took the puppet and had it dancing in the flames.

00:40:00 At a certain point, the police attacked the demonstration and I believe there were police on horses. And some people were hurt. As soon as it was over, somehow I got in a car and the radio was on. It was the live broadcast of Pat Buchanan's "culture war" speech — it was eerie. It was like the battle had already started and we were on the front lines in terms of getting attacked.

But Campaign '92, I think, was brilliant in that it really did inject AIDS into the national conversation and it so irritated President Bush that he called out ACT UP by name and said, "We have to stop these people."

**SS: In public?**

**JW: The debates.**

JR: The national debates with Bill Clinton. I hollered when he said that. I knew we'd really had an impact for him to say that.

**SS: It's also interesting, because it shows that ACT UP refused to take part in electoral politics. They would never endorse a candidate. I mean, that was really the politic that underlined that whole campaign, right?**

JR: Right.

**SS: And was that controversial inside ACT UP?**

JR: Not endorsing a candidate?

**SS: Mm-hmm.**

JR: No, I don't think anybody wanted to endorse them. I think people had their own preferences. It was pretty clear who they might vote for on Election Day, but it was more, "We're against these horrible policies and we're going to fight like hell to make sure that the policies change."

**SS: And in your view, what was the impact of Clinton's election on ACT UP?**

JR: Well, I think just taking a step back, the impact of Campaign '92 on Clinton was profound, because it forced Clinton to have a meeting with ACT UP in which ACT UP had five demands that it wanted out of Clinton. Three of which he agreed to in some form, one of which was to have a Manhattan-style Project to find a cure for AIDS, something that he actually didn't do. But it did have an impact on him and I think it put AIDS on his agenda. He had to deal with these people and he didn't want to deal with us. And I think the in-your-face kind of action that Bob Rafsky did, I think it was in March of 1992, I think had a big impression on Clinton. So what was Clinton's impact

on ACT UP I think is more — he had a lot of effects, one of which I think a certain number of people went to sleep. It wasn't the majority of people, because ACT UP meetings were still well populated in 1992, '93 and '94, but also ACT UP had undergone a split and I think some of the people that might be the closest to the Clinton administration actually had left. Perhaps I'm wrong about that. I was new to ACT UP. I didn't fully understand everything behind the split, but it was clear that a number of people in TAG had close relationship with the Clinton administration.

**SS: So in hindsight, now that you understand better, what is your explanation for the split?**

JR: Well, one of the things, just to sort of place where my understanding started, my understanding started right — I think it was in January of '92. One of the items I scooped up from the literature table was an attack on Maxine Wolfe and —

**SS: By who?**

JR: I think it was written by somebody in TAG, but I'm not sure. But it was basically thought she exercised too much leadership and that — yes, that she exercised too much leadership, she was HIV-negative and that she should be more deferential to people with AIDS.

And I really — it took me a long time to kind of try to sort out of all of the issues, but in hindsight, I think people in TAG were really well-motivated. They were very personally affected. Most of them — well, I don't know about most of them, but many of the leadership were people with AIDS that thought it was very likely that they were going to die and I think they were trying to do the best they can. And I think they were pretty well connected within the political establishment and so it was easier for

00:45:00 them to fall into alliances with drug companies and politicians. I don't think that they fully understood that the only way we were going to get anywhere was to have an in-the-streets movement that could fight and that too close of an alliance with politicians was a bad idea. And that the pharmaceutical company — it's not really about having alliances; it's basically we should be making demands upon them.

**SS: I want you to be really, really honest. Why do you think Maxine was a target?**

JR: I think she was too Left for them and that she brought up a lot of issues among women and HIV that — I really can't say exactly — that just weren't the priority for TAG at the time. It wasn't like they were completely opposed to those issues, but I think it was mainly that she had — and I think also later she would be kind of the voice of critiquing the drug companies, and she was heavily involved in the creation of the AIDS Cure Project, which was a proposal to create a Manhattan-style Project funded by the federal government to find a cure for AIDS, and in that she put forth a number of radical ideas, like that there shouldn't be conflicts of interest by researchers.

For people that don't understand that much about how research is done in the United States: NIH funding is done by panels of scientists and the panel of scientists vote on whether or not a grant will be approved. Many of those scientists have had involvements with drug companies where they receive honoraria or payments for doing lectures, talking about drugs that the pharmaceutical company is making, and how to use them. That builds in sort of a conflict of interest into their thinking, so they're much more susceptible to voting for things that will advance drug company interests and it can be kind of an insidious thing where they don't even fully realize what's happening; it just

seems like the right thing to do. And while scientists try to operate on the basis of rationality, scientists also are human and they can be influenced by perks and those kinds of financial arrangements.

Maxine was a strong opponent of that kind of thing and I think a lot of the people in TAG were becoming very familiar with the research community and I think they were threatened by proposals like that.

**SS: After the split, you decided to stay in ACT UP.**

JR: Mm-hmm.

**SS: And why did you choose ACT UP? Why did you choose to stay?**

JR: I actually never attended that many Treatment and Data meetings. I went once or twice, but I wasn't that interested. Even though I have a science background, I was more interested in sort of political action, because I thought that would be more useful. So I wasn't really in the orbit of TAG. I was never invited by TAG to join and —

**SS: Because they were invitation only, right?**

JR: They were invitation only. But I didn't feel left out by that. I mean, I thought ACT UP was the right place to be and I was disappointed that they left, because it was clear that they had incredible knowledge. But I think, in retrospect, I think that there was no way that a split could have been avoided, because there were too many differences. And ACT UP continued to exist afterwards as a very strong organization for a number of years. It exists to this day and we've made a lot of contributions in the intervening twenty years.

00:50:00

**SS: Let's talk about some of the campaigns that you were involved in after the split. What stands out for you as significant or —**

JR: I think I worked a little bit with City AIDS Actions.

**SS: Can you explain what that was?**

JR: City AIDS Actions was a working group within ACT UP. ACT UP had about twenty to thirty working groups at any given time in that period and —

**SS: This is like '90 —**

JR: This was like from '90 — what was that?

**JW: '94, '95.**

JR: Yes. I think that the assault — in 1994, Mayor Giuliani was elected, and the first action that ACT UP took was on the first day that he was inaugurated because he'd already made noises about cutting the Division of AIDS Services' funding, and the Division of AIDS Services was a way that people with AIDS in New York City could get access to a variety of services with sort of one-stop shopping, and he was going to cut back on that. And so, there was a huge demonstration that was outside of the inauguration.

A few months later there was, I believe — I think it was in March or something, march across the Brooklyn Bridge of about three thousand people. There was civil disobedience.

I was not in the center core of this, by any means, but I would go to working group meetings and try to contribute to the extent I could. I thought that they did excellent work and very brave individuals that were willing to get arrested. I really admire them.

I think another area of work was in 1995 in the run-up to Clinton's reelection. Clinton organized a White House Conference on AIDS and basically we saw it as an attempt to try to get the gay and AIDS community to sort of declare him to be the best person and try to rally their support. We thought that it was dangerous to get too close to the Democratic Party in that kind of way.

We brought down two busloads full of people with signs and demonstrated outside of the meeting. Actually one of the organizers of this demonstration — I helped organize the buses, as did Bob Lederer. Bob had worked at organizing our press conference outside to explain why we were opposed to the conference and then he actually went inside. He had a press credential with *POZ Magazine* and he had ended up using that as an opportunity to have a back-and-forth with Bill Clinton about AIDS and the lack of progress on AIDS issues that had been evident in the administration.

Clinton at one point said something about needing to do more studies and Bob just said, "There are just ample studies. There's no reason to do a single more new study. Why haven't you implemented the recommendations of the AIDS Advisory Council?" It continued the pressure campaign on Clinton.

**SS: Did he end up ever doing so, implementing those recommendations?**

00:55:00 JR: He did some stuff. I think a little bit later we eventually ended up getting some things around needle exchange out of him, but not the full program.

**SS: And is that — what you got out of him, is that was Obama defunded? Is that the same funding?**

JR: No, no.

One of the things that — the AIDS Commission that Bob was talking about was actually Bush's AIDS Commission, so these were not particularly radical proposals, but ACT UP had been involved in pressuring Bush's AIDS Commission, so a lot of the recommendations were good or at least decent.

The next thing I got involved with was around ADAP [AIDS Drug Assistance Program]. In the fall, in that same fall of 1995, George Catraves, who I had met earlier because of the bridge and tunnels action, came to ACT UP. George was a person living with AIDS and a long-term survivor of AIDS. He came to ACT UP with a letter that had come from the AIDS Drug Assistance Program and that letter said that his drugs, two drugs that he felt that were absolutely essential for his health, were being cut off. Those drugs were, I think, Epigen and Neupogen, and these were blood-boosting drugs. They were very expensive, but he felt that they were enabling him to tolerate the toxic drugs that he was taking. That was the era before the protease inhibitors, when people might be treated by one or more of the AZT-like drugs. And he was taking some kind of combination plus all of the prophylaxis. He said that many people with AIDS that he knew said, "How is it that you can take all these drugs? Because they would just wipe me out if I was taking them." And he was convinced it was the Neupogen and Epigen that gave him enough strength to survive on those.

He came to ACT UP at the time that we were just organizing for the Clinton AIDS Conference and a lot of people were interested in working on this, but most of them were tied up with organizing for this December conference. We said, "Start work on it now yourself and then we'll have a committee meeting right after this action,"

which we did. And he came to a few of those meetings. However, he eventually dropped out because of health reasons.

But we, together with him, helped plan this campaign that was a multifaceted campaign that involved demonstration, Sunday in the Country with George, where we went up to the summer home of Governor George Pataki, who was then calling for cuts to welfare, Medicaid, and ADAP, or at least no more funding for ADAP. I don't know that he called for cuts, but he wasn't in favor of more funding.

We were able to mobilize hundreds of people from ACT UP, Housing Works, Welfare Warriors, and other poverty organizations to go up there. We invaded this little town of a couple hundred people with three hundred people marching through the streets, doing civil disobedience in the middle of the highway. We got incredible press from upstate New York media that had never seen such a thing before. Sunday in the Country with George was a play on the title of — there was a popular play at the time or movie at the time. Then we also did a series —

**SS: It's a Stephen Sondheim musical.**

JR: Yes.

**SS: What kind of faggot are you, John?**

JR: Culturally illiterate, obviously. Not a Broadway queen.

**JW: Never too late.**

**SS: What was the outcome? Were you able to retain the —**

JR: Well, we had to do zap after zap. We went to the New York State Assembly, a group of us, and tossed leaflets from the balcony onto the floor while a couple of people did a banner-drop calling for full funding for ADAP. I was part of a

01:00:00

group that went to the Green Room and did a sit-in in the Green Room and it made a huge impression on the state legislature, state legislators. The Green Room was a part of the State Senate and at the time it was divided between Republicans and Democrats. The Republicans had the State Senate and the Democrats had the New York State Assembly.

That wasn't enough, so GMHC organized a postcard campaign, sent thousands of postcards demanding more funding for ADAP. And this was on the cusp of the release of the protease inhibitors and saquinavir, which was kind of the worst of the protease inhibitors was released, I think just at the end of '95, at a fantastic price of, like, \$6,000, so the —

**SS: Six thousand dollars per year?**

JR: Yes, per person per year. 5,900 — something like that.

**JW: Stadhanders —**

JR: Then there was, shortly thereafter, Crixivan, and then there was Abbott's drug. All of these drugs were very hard to get a hold of.

Anyway, we were looking at gigantic prices and already the ADAP was not able to handle drugs like Neupogen and Epigen. SP what was going to happen to all the drugs when these drugs became available? Because people with AIDS need more than just antiviral drugs in order to survive.

Anyway, GMHC launched their postcard campaign and then they also did lobbying days in May and then in June there was a civil disobedience action that I was a part of. There were six of us, including Jennifer Flynn, Jeanne Bergman, Bob Lederer, myself, and Anonda Levida from Housing Works and New York City AIDS Housing Network and the organizations as well as ACT UP.

We went to Senator Joe Bruno's office and Joe Bruno had referred to the ADAP program as a Cadillac program — that there was no better ADAP program in the country. Of course, he would not fund any more money for ADAP. And we went to Bruno's office with our AIDS Drug Assistance Declaration that had a picture of him and it said "AIDS Drug Assistance Declaration." It went through all the reasons why he should support it. And we had a place at the bottom for him to sign it and our demand was that Joe Bruno come and sign the AIDS Drug Assistance Declaration saying he would fully fund this program.

We walked into the offices and we immediately started putting up posters all over the place, making ourselves at home, and it took us a minute to figure out where was his actual office. When we got into his office, people started chaining themselves to the furniture.

So anyway, they were freaked out and their chief of staff came in. One of them kind of threw me to the ground and I just did the nonviolent passive resistance and stayed there until he moved on. Then I went back to my telephone-calling.

At a certain point, they had all left and they had shut the doors, but before they left, they had put up newspapers over the glass windows that normally would allow people to see in. And we had organized our press person to go to the office buildings, over to the press pool and brought the press over, so we had all of these cameras that were outside the door. Of course, they couldn't see in very well, but then they'd see these little cracks and then they'd put the camera up against the crack so that they could film what was going on inside. And that was out of us doing telephone-calling, faxing, calling different media outlets, doing interviews.

01:05:00 Then at a certain point I walked back to Pataki's desk and I was just looking it over and I noticed that there was a phone. On the phone there was a hotline button for Pataki's office, Governor Pataki's office, and I thought, "Oh, wow. I wonder how this works." So I pressed the button and I called, and the person at the other end was one of his administrative staff, and she said, "Hello, who is this?"

And I said, "I'm one of the six protestors that's taken over the office of Senator Joe Bruno demanding full funding for the AIDS Drug Assistance Program, and I'd like to speak to the governor, please."

And she said, "Who is this? Who is this? How did you get this number?" So eventually she hung up on us.

A little while later I noticed that the light blinked, the hotline blinked, and I thought, "Oh, I wonder what this," and I pressed it. And it turned out that it was Pataki talking to Senator Joe Bruno, because Bruno had two offices. So I said, "Hello, I'm one of the six protestors that's taken over the office of Senator Joe Bruno demanding full funding for the AIDS Drug Assistance Program."

And Pataki said, "Joe, let's get on a different line."

Everything seemed to be going fairly well and finally we get another call and I was asked to take it because everybody else was chained to furniture. And so I took it, and it was Joe Bruno, and Joe Bruno said to me, "You don't really think you're going to get anywhere doing this kind of stunt, do you?"

I said, "Yes, I do."

And he said, "I'm in an important meeting with Sheldon Silver and George Pataki and we have important business to conduct and you're disrupting that."

And I said, “Well, be sure to tell them that there are six protestors that have taken over your office demanding full funding for the AIDS Drug Assistance Program.” And he was just beside himself.

We hung up and then a little while later his chief of staff came in and said, “Well, we’d like to negotiate with you, so we’d like to do the negotiations down the hall with two of you,” or something.

And we said, “Well, we couldn’t possibly do that because we weren’t one organization, we were several organizations, and we always negotiate together, and we can’t know what everybody else wants, so that would be ridiculous to do so. So you come to us and we’ll negotiate in here.”

So here we were, talking with the chief of staff of Bruno and most people chained to furniture. And he said, “Well, we think — we’ll just consider this advanced lobbying if you leave right now.”

**SS: Advanced lobbying?**

JR: We said, “Well, really, we want him to sign this AIDS Drug Assistance Declaration and we’re not leaving until he does.” We were arrested and taken out.

**SS: So what happened finally with the funding?**

JR: Within three weeks — it was really amazing. Sheldon Silver had previously been sort of waffling on it; we had heard that through the grapevine. Publicly he was saying that he was strong on ADAP, but privately he was considering negotiating away his points on ADAP. We had earlier stormed his offices demanding that there be no backing off on ADAP.

Within three weeks, both Bruno and Pataki had decided that they would support an \$8 million additional appropriation for the AIDS Drug Assistance Program. That was completely thrilling. And George Catraves was at the time still alive and we were hopeful that he would remain that way. But, unfortunately, what had happened was his health had deteriorated so much that he was in a downward spiral. He died either that August or early in the fall of that year. It was very disappointing for us in that sort of personal outcome, but we were still happy that we saved — helped to save a lot of other people from having similar fates.

**SS: What's the current status of ADAP funding?**

JR: The current status is constantly in flux. I think New York State is in pretty good shape, but around the country last year, before the ACT UP twenty-fifth anniversary action, the nationwide ADAP list was up to 4,600, and then as we —

01:10:0

**SS: Forty-six hundred what?**

JR: People. Forty-six hundred people were on waiting lists in the United States in February of 2012.

**SS: And how many people were being served?**

JR: I don't know.

**SS: So 4,600 people are waiting for — is it like 10,000 people are being served, 100,000 people are being served?**

JR: I'd have to look that up. I don't have that number off the top of my head.

**SS: Because there's 1.2 million Americans with HIV, right? So I'm wondering how many of them are getting ADAP.**

JR: I don't know. Housing Works' website has a specific website. There's a box for it. They could give you that statistic.

It's a political football, so by the time election day came, most of the ADAP waiting list was gone. ADAP stands for the AIDS Drug Assistance Program. I didn't explain that at the beginning. And the AIDS Drug Assistance Program is designed for working people with HIV/AIDS that make an income below a certain threshold, and in New York State at the time it was something like 42,000.

**SS: When you say "working," you mean they have to be employed to get ADAP or you mean working-class?**

JR: Working-class, yes. Yes, they don't have to be employed. But it is something that keeps people working, so, yes.

**SS: Now, one thing that I share with many, many people in New York City is that every once in a while our phone rings and we hear, "Hello, this is John Riley from the ACT UP phone tree." How did you get to be the voice of ACT UP?**

JR: Well, when I came in, somebody else was actually doing it. It was a person with AIDS that had gotten sick and —

**SS: Who was it, do you remember?**

JR: I've got it somewhere in my records, but I don't have it handy. And he had a list, but there was no machine, and at that time it was a completely 100 percent volunteer-staffed group. So, basically the way it worked is he would generate a list of ten or twenty names and give them to as many people as could do the calls. It was kind of a hard job, but a lot of people did do calling. It was fairly effective in turning people out.

I did it for a while doing the same method, but I did find that sometimes people had conflicts and were unable to complete their phone calls. And I had discovered that there was a machine that could actually do automated calls. So I thought I'd get the machine to kind of do the spot fill-in stuff, so we'd have complete coverage. So, I got the machine and started doing that, but as time went on, people thought, "Well, if we've got a machine, why do we need to do it?" Because it's a lot of work to do it. Politically it's better if people call, and so I was somewhat disappointed in that, but that was kind of the trend of history.

**SS: So how many numbers are called every time you activate the phone tree?**

JR: Hundreds. I don't usually talk about that publicly.

**JW: Do you still call Bruno?**

JR: He's in federal prison.

**SS: Bruno's in federal prison. There you go.**

JR: Or maybe it's state prison. I think he's in state prison, I'm sorry. Correction. Or at least he was for a while.

**SS: Now, I just want to talk about the introduction of AIDS in Africa as a factor into ACT UP politics, and this is during your era. And it became very complex, how this was carried out. Can you tell us sort of the story of that from your point of view?**

JR: Yes. Well, it was a logical outgrowth of some of the other work that we were doing. We were doing the drug-pricing work and I just talked about the situation with ADAP and how the ADAP programs all across the country were being just

01:15:00

oversubscribed because of the exceptionally high price of the AIDS drugs. That had been an ongoing concern of ACT UP for a while and it goes back to the very first demonstration that ACT UP had on Wall Street where ACT UP was protesting the then stratospheric price of AZT, which cost \$10,000 per person per year. Through a grassroots campaign was able to get that price lowered dramatically, so that by the mid '90's the cost of treatment was somewhere around 25 to \$3600 a year for the price of AZT.

We continued that fight when the protease inhibitors came online as part of the tenth anniversary of ACT UP, and we were protesting the very high prices of all the protease inhibitors and all the other drugs. We were able to bring seven hundred people to Wall Street and have a demonstration, a civil disobedience of about a hundred people. We did continue that work throughout the next few years.

One of the related issues was around drug accessibility: the expanded access programs that had provided free drugs to people before the drugs were actually approved by the FDA. These sort of expanded access programs allowed the use of drugs that were shown to be at least having gone through a minimal amount of safety studies and showed some efficacy. Throughout '87, '88, '89, we did a series of demonstrations demanding that the drug companies continue these programs, as the drugs were eventually rolled out to keep the prices as low as possible.

In the course of doing some of the work around drug pricing, we encountered people like James Love from the Consumer Project in Technology, who was later to become very important in the whole struggle to get AIDS drugs to Africa and the developing world. One of the key figures to emerge was Dr. Alan Berkman, who in 1989

went to the International AIDS Conference in Geneva, Switzerland. Alan was a very political person. He had been involved in SDS. He had been involved in —

**SS: He was from Bob [Lederer]'s former —**

JR: Political circle.

**SS: Yes, exactly. I remember him from the Bronx acupuncture clinic, whatever that was called, Lincoln Hospital.**

JR: Yes, possibly. I don't know Alan's complete history, but I do know that he was involved with Wounded Knee, he was a medical doctor, and he treated Native Americans during that period of the occupation of Wounded Knee. And then he was a very radical person and was eventually jailed for treating somebody who had been shot with a gun and not reporting that as the law required. And he was involved in a radical political circle, the May 19<sup>th</sup> organization.

He was then in prison for twelve years, and when he got out, he wanted to do something meaningful with his life, so he became an AIDS doctor and he got his license back. He was the kind of person that — he's the only person that was ever prosecuted under the law that — I can't really tell this story, so I'll just drop it.

**SS: Just finish that point, because I'm interested in him.**

JR: Okay. Do you remember Mudd? Dr. Mudd was the person that treated John Wilkes Booth following the assassination of Lincoln.

**SS: Samuel Mudd.**

JR: So a law was generated afterwards, criminalizing treatment without reporting or something like that. And Berkman was the only person that ever actually was prosecuted under that law —

**SS: And who was the patient?**

01:20:00

JR: — at least at the time. So the patient was someone who was —

**SS: Shakur, right?**

JR: No, it was a white woman that — Marilyn Buck who was —

**SS: Who just passed away.**

JR: Who just passed away and was involved in an armed expropriation of a Brinks truck, in which a couple of people were killed, a couple of guards were killed.

That was how he came to be involved in prison. In the '90's he became an AIDS doctor and in '98 he went to Geneva. When he came back, there was a lot of talk, he said, about getting access to the third world for people with AIDS for these new drugs, but there was absolutely no action. It was just all rhetoric.

He came to Bob and me because he knew us, knew we were involved in ACT UP, and said, "What is the possibility of doing some kind of campaign for getting treatment for people with AIDS in these poor countries?" And we thought there might be some possibility, but we really needed to check. So we went — we said, "We need to talk to Eric Sawyer. We should have a meeting with Eric Sawyer and see what he says."

Eric Sawyer is a fabulous AIDS activist that has for years championed international view of AIDS, so he had incredible connections going back for, at that time, a decade. And we all went out dinner and we all discussed it and decided after a couple of dinners that we were going to call for a meeting, a broader meeting of people in the AIDS community to see what could be done.

In January of 1999, we had the meeting. It was at the offices of AIDS Treatment and Data Network, and we had invited ACT UP Philadelphia because they

were very powerful still, able to mobilize large numbers in demonstrations not only in Philadelphia, but also in Washington, D.C. John James, from AIDS Treatment News; Richard Jeffries from AIDS Treatment and Data Network; and then James Love from the Consumer Project on Technology; and a number of people from ACT UP New York, Bob, Eric, myself, and some others.

At that meeting, James Love played an incredible role. James Love was a part of the Consumer Project on Technology, which was a Ralph Nader group, and he brought with him these cartons, these little cartons where drugs or bottles of drugs are put inside, and one of them was AZT, and he said, "This drug was made in India by a generic company called Cipla, and a year's supply of this drug will cost \$80." That same drug, AZT, in the United States would cost maybe \$3,500 by 1999 for a year's supply. We knew, like wow, what we'd always suspected, that these drugs are very cheap to manufacture, and what's expensive is the profits that drug companies charge.

Then he passed around the 3TC box, and he said, "This costs like \$110," and then one for like this drug D4T, and that cost something similar. And we knew that for about \$300 we could put together a treatment regimen for people living around the world and that it was a completely doable kind of campaign, because while it'd be a lot of money, it was not \$10,000 per person per year, and it was much less.

**SS: At that point, how many people were living with HIV around the world, do you remember?**

JR: Twenty million, something like that, and the death rate was mounting. It was already past a million.

01:25:00

**SS: So for \$6 billion, every person with AIDS could get a drug regimen for a year.**

JR: Yes. I don't know the exact figure.

Anyway, but the question was could we generate enough political pressure in order to do it? Here again, James Love was extremely important because he laid out what some of the targets were, and he talked about this thing called TRIPS, the Trade-Related Intellectual Property policy, which was created by the World Trade Organization, which was then only about five years old. And this particular treaty, which had 100, 150 signators around the world, allowed for in a public health emergency the use of essentially eminent domain to — or not eminent domain. It's basically to break the patent on a drug for public health good.

That became a very critical point for us politically to lobby around, as well as there were provisions that allowed for what was called parallel importing, which just meant that there could be no restrictions on importation of drugs based on, like, a direct relationship with a drug company. So for example, if South Africa tried to buy AIDS drugs, they would have a certain market, right? It would probably be a fairly small market at the time. This was before the complete explosion of HIV in South Africa. But Germany had a bigger population of people under treatment, so if South Africa were to buy with Germany, they would get Germany's discount, and so it would make it much cheaper. Almost any drug could be cheaper this way.

This is what Jamie was explaining to us, and then he put forth the idea that we should come to an international conference that he was organizing with Health Action International and Doctors Without Borders that was going to be held in Geneva in

February of 1999. And so, Eric Sawyer and I and one or two other people from ACT UP New York flew over there, and there was this big assembly of players from all across the world in AIDS. ACT UP Paris was there. There was also — who else was there?

**SS: Was TAG there?**

JR: I don't recall. They might have been. But certainly World Health Organization, UNAIDS, and some of the malaria and TB public health scientists and doctors were also there, which was kind of a new addition to the movement and a very important addition, as it would turn out a few years later.

That was a very exciting meeting, ACT UP Paris. What was most exciting about it was it was a big assembly of people without the drug companies, and the drug companies were going crazy when they heard about it. It was like, "Well, we'd like to come too." And James Love, I think, just said no, and they just begged him and begged him. Finally he talked with his partners, and they ended up allowing somebody from International Pharma to come in. Then I think it's when International Pharma came in that ACT UP Paris did a disruption of his presentation. Anyway, it was a very exciting meeting and it helped make connections internationally between AIDS activists and scientists and the World Health Organization and UNAIDS.

The next big demonstration that happened was the AIDS Drugs for Africa demonstration, the Hope for Africa demonstration that ACT UP New York and ACT UP Philadelphia organized. We went to Pharma's headquarters in Washington, D.C., and demanded that they lower the price on AIDS drugs.

01:30:00 One of the backdrops to all of this is that the Clinton administration was still in power, and the Clinton administration had decided that they wanted to create this

thing calls TRIPS Plus, which was to use the TRIPS accord as sort of the basis, and then the Plus would be to negotiate away a bunch of rights that were present under TRIPS.

They essentially wanted to get rid of this clause that allowed for the —

**JW: Generics.**

JR: — generics to be created.

**SS: What's TRIPS?**

JR: TRIPS is Trade-related Intellectual Property agreement, and that was from the World Trade Organization discussions. This was a treaty, and Clinton wasn't satisfied with it. This is going to be a strain that we'll see, or a string that we'll see all the way through the storyline, because successively the Clinton administration, the Bush administration, and the Obama administration have tried to weaken these protections for generic drug production over the last decade and a half.

**SS: Thereby undermining the availability of cheap treatments.**

JR: Right. Completely undermining that. But we haven't lost it yet. It's a constant struggle to try to keep it open, and the way this plays out is that the U.S. will do these side agreements with individual countries or groups of countries. For example, right now there's the Trans-Pacific partnership, which is being negotiated, and they're trying to take away this generic drug production within that, or limit it, limit it to old drugs, so that people with AIDS that are poor, you know, in five years will not be able to get the new drugs that could keep them alive. And, of course, with AIDS, AIDS is a disease where the virus mutates and can get around the existing drugs, and so that's why you always need a new generation of drugs to keep ahead of those mutations.

We marched on Pharma in April of 1999. I was a part of a civil disobedience action with about ten other people from ACT UP New York and Philadelphia. We were also marching for a bill in Congress called the Hope for Africa Act, and that was introduced by Jesse Jackson, Jr., which would have been a less draconian version of a NAFTA-style agreement. It would be a better version of it.

**SS: What became of that?**

JR: It never passed.

**SS: Did it ever come up for a vote, or did it just die?**

JR: I'm not sure. I can't remember.

**SS: So what is your agenda right now? What are you working on in ACT UP right now?**

JR: Basically one of the things that I'm working on now is the Robin Hood Tax Campaign.

**SS: The Robin Hood tax.**

JR: And so, The Robin Hood Tax is our proposal to create a financial transaction tax on Wall Street trades for stocks, bonds, derivatives, and currency speculation. It's a very tiny tax, it's only .5 percent, and it could generate up to \$350 billion per year just in the United States, and it's the kind of tax that a lot of economists think would not have a negative effect on business, and, in fact, it could help prevent the kinds of bubbles that we've seen in the U.S. economy over the last ten years.

**SS: That's a big agenda there. That's not going to be so easy, John. What's your strategy?**

01:35:00 JR: The Robin Hood Tax was not invented by ACT UP New York. Robin Hood Tax is a part of an international campaign that was put forth by NGO organizations in Britain, and the thrust of it is to create a fund, to fund global goods. For example, AIDS. The world's governments have been completely slack in fulfilling their commitments to making sure that people with AIDS around the world have treatment access. In 2005, the G8 governments agreed that they would try to have universal access to AIDS drugs by 2010. 2010 came and went and still nowhere near universal access.

At the present point, we've got about 50 percent of the population that desperately needs AIDS drugs, on these AIDS drugs, and we need to get the rest on. It's one of the ways that we could actually end the AIDS epidemic. A study came out last summer that showed that people that are under treatment are much less infectious if they're being treated with AIDS drugs. And so, the more widespread these drugs are in terms of availability, the more we can limit the growth of the epidemic. That's one aspect of it.

Then there's also environmental organizations have called for creation of a fund to make sure that poor countries can develop alternatives to greenhouse-emitting gases, in terms of electrical generation, and there's also calls for poverty reduction.

What ACT UP is doing is kind along the same kind of line. We don't have, like, sort of a central plan that's completely identical. These plans are all created on a country-to-country kind of basis, but we think that it's politically possible to do so.

There has been a financial transaction tax in the past. From the early part of the century up until the sixties there was one. It had various rates depending on the time. And currently this international campaign has yielded some results. The

government of France has announced that it has a financial transaction tax, and part of the proceeds from that tax will go to fund Global AIDS.

It's not completely beyond the beyond, but it is something that will take time to get, and it will require a big coalition to get. It's going to take a lot of political energy. In Europe, they're ahead. Eleven countries have gone to the European Commission and said, "We want to have a financial transaction tax." All the details about where that money will go, that's not all worked out because it's all done on a country-by-country basis. Wherever these Robin Hood Tax coalitions are strong, we're going to do better.

We're trying to create such a coalition in the U.S. Already we have National Nurses United behind us. We have groups like Housing Works support us. And there's a number of labor groups that have expressed in having a financial transaction tax. Their goals are much less ambitious than ours. We want a higher rate, and we want to make sure that AIDS is not forgotten, and we want to make sure that this isn't all for deficit reduction or something like that.

Part of our frustration is that over the years the administration's constantly saying, "Well, we just don't have the money. We just don't have the money because of the fiscal cliff," or because of this or that.

And we're saying, "Okay, this is how you can generate a lot of money. It won't be that noticeable by the people that are paying it, and it'll help stabilize the stock market." So there you go.

Obama himself has said that he's open to it, at least according to insiders in the White House. Ron Suskind wrote a recent book called *The Confidence Men*, and in

there he details that Obama expressed openness to it, but his treasury secretaries have not expressed the same openness to it. Neither [Timothy] Geithner nor [Larry] Summers has done it. We are hoping that the — not just hoping, but pressuring the Obama administration to appoint somebody that is supportive of the Robin Hood Tax, which is a bill in Congress.

**SS: Now, 1,600 people died of AIDS in New York City last year. Why is that?**

01:40:00

JR: Why is that? Well, some of it is that people are not being diagnosed until it's really, really late in the infection.

**SS: And why is that?**

JR: Because they don't have access to healthcare. Sometimes there's stigma involved. They don't want to admit that they might be at risk, and so they never go to the doctor. And there are also some people that have a history of injection drug use that have more difficulty tolerating AIDS drugs, so their livers are not able to handle it, and so that can be very devastating. They can get to a point where they just can't take the drugs anymore.

But nationally there's like 16,000 people that are dying every year of AIDS, and we should be able to do better. You know, we could end AIDS, but we really need to do something different if we're going to do that. The HIV infection rate is just still just unconscionably high. It's a huge epidemic among young gay black men and in the black community as a whole it's going up and up.

**SS: According to Kevin Frost and amfAR, the number-one group getting infected are gay white men, actually. It was interesting because he told us**

**that the number-one group is gay white men. The second group is black women, which *The New York Times* just reported has decreased by 21 percent. The third group is black men who have sex with men, and the fourth group is gay Latino men. Basically AIDS is a gay disease in the United States, even though it looks like Gay Inc. has completely separated itself from AIDS. So how do you understand that, and is it worth reclaiming AIDS as part of the gay agenda from which it's been rejected?**

JR: Oh, absolutely. I mean, the biggest problem with the whole marriage equality fight is that it's eclipsed so much of the AIDS fight.

**SS: But isn't marriage — I mean, I think gay marriage is seen as an antidote to AIDS because it implies a certain kind of sexual practice that it doesn't actually mean, but in people's minds, gay marriage is clean and AIDS is dirty. So it's a psychological separation from AIDS. Because people don't stand up and say, "I'm marrying my boyfriend and we're both HIV-positive."**

JR: Right. There's too much stigma.

**SS: So AIDS is invisible with the gay marriage discourse.**

JR: Right.

**SS: It's interesting how they've been pitted against each other in that regard.**

JR: Don't you think a lot of that is subliminal? It's not stated so much. Have you really come across people that will publicly put it in that contradictory terms? I agree that there is a subtext there, but I'm not sure that there's that many people that are saying that.

**SS: No, but their actions, Gay Inc., the people who are running the gay marriage campaign, have separated from AIDS as an issue. I mean, even in film festivals, gay film festivals, there's like one slot for one AIDS film. It's considered something very marginal and peripheral to gay culture at this point, even though we're seeing that infection rates are completely implicating.**

JR: Right. You know, why is it 50,000 people are getting infected every year, 50,000-plus? There should be no reason for that.

**SS: And why is it? What is your understanding?**

JR: I think, what's the state of sex education in high schools? People still can't talk about sex. Condom manufacturers don't really want to talk about AIDS and condoms because they don't want to be associated with AIDS. They're still afraid of it. We still don't really have that much in the way of ads of condoms on TV. Occasionally you might see one, but it's not about disease prevention.

**SS: But even if there was all of that, wouldn't there still be a group of people that would get infected no matter what?**

JR: But I think that it's possible to make that rate go down. I definitely think it's possible to make that rate go down.

**SS: Men don't like to use condoms. I mean, women get pregnant all the time who don't want to get pregnant, right? So, I mean, that is a factor, regardless of how many condoms are available.**

JR: Right, there still is — I don't think that there's a magic bullet that we can say that will do everything, but we can make it easier for people to disclose. We can

01:45:00

make it easier for people to get treatment. The more people that are on treatment, the less likely — if people know their status, they're less likely to infect others.

**SS: Is that true?**

JR: I think so, yes.

**SS: Do we have statistics for that?**

JR: I think we can probably find statistics for that.

**SS: Okay.**

**JW: Especially if they're not in jail or have a house.**

JR: I'm sorry.

**SS: I only have one more question. Is there anything else that you think we need to make record on or that you want to talk about?**

**JH: Do you want to show that picture that you've been holding?**

**SS: Yes, what is that picture? Do you want to hold it up and we can**

—

JR: I don't know if I told you about that.

**SS: Is that you and Bob? That's you.**

JR: That's me and Bob. We're at Gay Pride.

**SS: Without a beard.**

**JW: He looks like an Iowan.**

JR: ACT UP did an eighteen-month campaign that started in about June of 1997, and the kickoff was a big demonstration during Bill Clinton's fiftieth birthday that happened here in Manhattan, and about a thousand people turned out for it. It was all

focused in on getting the Clinton administration to drop the ban on needle exchange, the federal funding for needle exchange.

We took this campaign and confronted Clinton on six different occasions. We confronted also the governmental officials that he had appointed, people ranging from George Stephanopoulos to General [Barry] McCaffrey, to task publicly about this. It was a great campaign, and in September of 1997 about a thousand AIDS activists descended upon Health and Human Services with a giant spine for Donna Shalala, because at the time the Clinton administration had within its power, just by saying so, to lift the ban on federal funding for needle exchange. Shalala was too cowardly to do so. That's why we brought a spine for her to use.

And then we did — at the end of the campaign, we were partially successful. April 20<sup>th</sup>, 1998, the Clinton administration had come to the point where they'd had too much pressure. We had really done a really good job. We had interrupted Clinton at a rally here in New York for Ruth Messinger's campaign. We had interrupted him at the Human Rights Campaign, a fundraiser in Washington, D.C. that fall — was it '97? So he felt our presence.

On April 20<sup>th</sup>, Shalala was about to issue a press release and do a press conference in which she was going to say that the federal government certifies that needle exchange is both safe and effective in stopping the prevention of HIV transmission. And at the time, Clinton was on a plane with General McCaffrey, who is then the AIDS czar — not the AIDS czar, the drug czar, coming back from South America, and McCaffrey told Clinton that, "If you do this, if you make this determination and allow federal funding for needle exchanges, that I will call you soft on drugs."

And Clinton caved, and he called Shalala up and said, “Change the press release.” They redrafted it, and when it came out, it said that, “The federal government certifies that needle exchange is safe and effective and we encourage state and local governments to fund it, because they know how to do it best.”

The AIDS community and the needle exchange community was furious about it, so a group of us from ACT UP and these needle exchange programs and, I think, Housing Works, went down and had a meeting with the AIDS czar, Sandra Thurman — she was the head of it at the time — and demanded that she basically criticize the Clinton administration for taking this cowardly stand and insist that the Clinton administration must support federal funding for needle exchange.

01:50:00

She refused and everybody got out their chains and lucked up. We took over her office. I was doing video for this action. I saw it all. And we had these beautiful posters of Bill Clinton next to a dirty needle, syringe filled partially with blood, and calling on him to lift the ban.

We didn't win completely on that, but we made some progress, and at least some municipalities and state governments had a little more courage to fund needle exchanges, not to the extent that they needed to be. It was going to take a decade till after the Democrats won in 2008. I think in 2009 they finally lifted the ban on needle exchange funding by the federal government. So that continued for two years until the Republicans took control of the House, and then they promptly reenacted it and Obama signed it into law. So it's one of those things that you constantly have to fight in order to keep what gains you get.

**SS: So here's my final question. So, looking back, what would you say was ACT UP's greatest achievement, and what do you think has been its biggest disappointment?**

JR: Well, I think that probably ACT UP's greatest achievement is its success in mobilizing thousands of people to fight for their lives and to fight for the lives of the people in their community, and that through, many, many things were possible, ranging from creating AIDS drugs that were scoffed at, even the possibility that they could create drugs to fight viruses, to worldwide distribution of the drugs. I think that's its greatest achievement.

In terms of the greatest disappointment, I'm not disappointed with ACT UP. I can't really say.

**SS: Great answer.**

JR: ACT UP may be smaller, and it is smaller, but I don't really even regret that it's smaller because our shrinking has been in part due to our success, and thousands of people were involved in that success and they've taken that spirit elsewhere, and sometimes they don't do much with it and sometimes they do a great deal with it. The heads of — I mean, there's dozens of spin-off organizations from ACT UP and so —

**SS: Okay, thank you, John. Good. Let's see, how long was that? Not too bad, two hours and fifteen minutes. That's good.**