ACT UP
ORAL HISTORY PROJECT

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Interviewee: **Iris Long**

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Interviewer: **Sarah Schulman**

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Interview of Iris Long
May 16, 2003

SARAH SCHULMAN: The way we usually start is if you could say your name, how old you are, today's date, and where we are?

IRIS LONG: My name is Iris Long. I'm 69 years old, and today's date is the 16th of May [2003].

SS: And where are we?

IL: We're in Astoria, New York.

SS: Iris, where were you born?

IL: I was born in New York City.

SS: Where did you go to high school?

IL: In New York City – Washington Irving.

SS: And when did you first start getting interested in science?

IL: In high school. I took a Chemistry course, and I decided I wanted to go and get a degree in Chemistry. And, I majored in Chemistry, from the very beginning.

SS: Where did you go to school?

IL: Hunter College.

SS: And then, did you go right to graduate school?

IL: No. I worked and went to graduate school at night and got my Master's. Actually, it was quite late – 1964.

SS: You got your Master's in Chemistry?

IL: Yeah.

SS: From where?

IL: Hunter.

SS: So, what was it like to be a woman in the sciences in the early '60s?

Were there many?

IL: No. I didn't really have that many role models, except that in the school – Hunter College – there were a lot of women in Chemistry. There wasn't a lot, but there was a number.

SS: Was it an all-women's college at the time?

IL: The year I went, I went up to the Bronx – Kingsborough or something – and they had a unit up there, and that was the first year they had men. And so, there were a handful of men in the Chemistry Department. So, that was it.

SS: What was your maiden name, by the way?

IL: Doerr.

SS: What's the ethnicity of that?

IL: It's German.

SS: So, when you started working in the field, how was it being a woman, trying to get a job in chemistry?

IL: I would say it was difficult. My first job was in a hospital – Columbia Presbyterian Hospital – baby hospital, actually. It was a neighbor, actually, that helped me get a job at Sloan-Kettering – that was my next job. And, I stayed there 11 years, actually.

SS: What did you do there?

IL: I was an organic chemist. They had a small research division at Sloan-Kettering for cancer drugs. In fact, as you later find out, AZT was the type of drug that I was developing nucleosides, which is very close to AZT. That's the drug class – nucleosides.

SS: Were nucleosides originally developed for cancer? Was that their first intention?

IL: Right. Because they were the building blocks of DNA or RNA – deoxy-nucleic acid, or ribonucleic acid. So, you either made nucleosides or you made – we say, purines or pyrimidines. Some of those were active, like 6-mercaptopurine or something like that, was active against cancer.

SS: What year did people start working with nucleosides for cancer?

IL: Well, it all had to do – in 1953 – with the discovery of the DNA and the
00:05:00 role of DNA – the helix, and everything else – which was about – not quite 10 years later – they were making these drugs for cancer – nucleosides – the building blocks of the DNA. They were using those to make the cancer drugs.

SS: So, AZT existed already?

IL: We were fooling around with all types of ways to put in groups – sulfa groups. AZT is – I can't remember the exact word – but we were fooling around with that type – trying to put those groups into a position on the nucleoside or the pyrimidine or purine, and fluorine groups – things like that, chlorine. We tried all types of derivatives. As a chemist, you try everything. And then they were tested, some of them. They were tested at different places. They may not have been tested at Sloan-Kettering. They were tested, first, in some sort of a screen – a non-human screen. And very few of them really went to the final stage that they would be tested in humans. And I knew about Burroughs Wellcome was up in Westchester, actually – Tuckahoe – and our group had association with Burroughs Wellcome, actually.

SS: Now, were any of these nucleosides successful with cancer?

IL: Yeah.

SS: Which ones.

IL: Well, they were fluorinated purines – USL, for example – and this nucleoside – they were active.

SS: But was AZT successful with cancer?

IL: We did not test AZT. That was discovered by another researcher – Midwest – and I can't remember his name, but he made that. He was an organic chemist, and he made that. And I don't know the testing that it actually went through. And, at the time, I don't think we discussed that drug that much, or that compound. And it was only when it was picked up – 10 years or so later – even 20 years, almost, that they had a screen for it. And, from what I read – I just read it the other day – that it was found, NCI and Dr. [Samuel] Broder – he later became the head of NCI.

SS: What's NCI?

IL: National Cancer Institute. And, he actually had some screen. They were looking for drugs against HIV. And, he had a screen, one of the early screens. So, there was always this argument between Burroughs Wellcome and who actually discovered this, and whether this was really in the public domain, and somehow, Burroughs Wellcome was able to get a patent on it.

SS: So, first Dr. Broder went back to this discarded cancer drug, and found that it could be applicable?

IL: Yeah, well, one of the ways they do a screening laboratory – they would start to screen many compounds and ask different laboratories for the compound. Now, they did get it from Burroughs Wellcome, from what I understand. So, they had it on

00:10:00 their shelf. So, they sent a number of compounds for him to test. And this one came up.

SS: And, at that point, was AZT useful for anything?

IL: No. As I say, chemists can make many drugs, and very few of them are active.

SS: Okay, so once they realized that it was potential patient group, then they went and got the patent after that?

IL: Right.

SS: That's very interesting. What year would say that happened?

IL: In the '80s

SS: Just in terms of your own chronology – when did you get your Ph.D.?

IL: About 1972.

SS: And you were still at Sloan-Kettering?

IL: No, I'd left Sloan-Kettering. I got my Ph.D. at the University of Connecticut, in the Department of Pharmacy. And my Ph.D. was very similar. I was working on nucleoside or analogs – not exactly nucleosides, but they looked like nucleosides, shall we say. And it took quite a while, I would say. It takes quite a bit of time. Then, I had some jobs after that, and I actually left science, and I was home, and I wanted to do something else, actually. And I got involved with ACT UP. First, I was looking into amfAR, and I thought I'd maybe volunteer for amfAR. And I was interested in drugs. I was interested in all the different type of drugs that were needed to treat AIDS. It wasn't just an anti-viral. There were so many opportunistic infections and so forth. So, I contacted them, and they told me I should – ACT UP wasn't in existence, at that point. It was just going to be in existence. And I went to different meetings in lower

Manhattan.

SS: When did you first become aware of AIDS?

IL: I'm not certain of the exact time. There were a number of personal things that I had to take care of – people getting very ill, and this and that. My mother was ill, another friend was very ill, and I was taking care of those people. And then – I'm trying to figure out, exactly, the time. It was in the very beginning, because I was involved with CRI. That was before, and CRI was established a little before ACT UP, and I knew Dr. [Joseph] Sonnabend and Michael Callen and a number of other people. And I was involved with the AL-721.

SS: How did you get involved in all of this AIDS activity? When did you realize that something was happening?

IL: Well, I was reading different scientific things. I was always interested. I kept up with my reading in science, and I probably said that this was – I knew about it, and I decided to find out more about it, and I was interested in getting involved.

SS: So, you read some of those *New England Journal* articles?

IL: I don't know if it was in *Science*. I get *Science*. I was probably getting *Science*. I was a member of the American Chemical Society, and they have scientific articles there. The fact that AZT – of course, that attracted me, because I was a nucleoside chemist, so I knew about that. And I was interested in the drugs that were being used for the opportunistic infections, when I said, well, you need somebody here.

00:15:00 This is something I could do, and I would be looking at other uses of drugs for various other diseases. So, this sort of interested me, because essentially my background was almost entirely in nucleosides and things. That's what I did the most.

SS: It's interesting that the groups you approached – C[ommunity] R[esearch] I[nitiative], amfAR, ACT UP – these were community-based organizations. They weren't simply science. What made you choose those types of groups?

IL: Well, they seemed to be more in front. First of all, I knew what the hospital settings were about. After I got my Ph.D., I worked at Long Island Jewish. I worked at various other places, and I knew what the scene was in a medical institution and they do not take volunteers, number one – a volunteer like myself – if you want to go and see the patients and so forth. But that's not what I wanted to do.

SS: You're saying that you had worked in hospitals and you knew that that was not the place.

IL: Right. And, I had worked in institutions – Sloan-Kettering – and I didn't see myself – it would be very difficult for me to get back into that situation. I had difficulties getting jobs, and my experience with helping people – I had decided that I wanted to help people, and do it one on one, not through an institution.

SS: Had you been involved in any kind of community work before?

IL: No. Not that much, no.

SS: Have you ever been politically active before?

IL: No.

SS: Did you have any personal knowledge of people who had AIDS?

IL: No.

SS: So, it's really from the science –

IL: Right, the science drew me in – but, also, my feeling that I wanted to help

people, because I did. I don't know if it was the same time – I did work, go where people with AIDS were. I went to a hospice in the Bronx. I was there for a time. So, I wanted to understand the people, and what was going on.

SS: So, where did you go first? Did you go to the hospice before you went to amfAR?

IL: I'm not sure, I'm not sure. It may have been at the same time. Because I really did not go to amfAR. I contacted them, but I didn't –

SS: Wasn't Matilde Krim involved in some of these early cancer drives?

IL: Yes, and she worked at Sloan-Kettering, actually. I knew her by sight. I don't know if she knew me – at Sloan-Kettering. She worked with a doctor I knew and worked for, actually, at Sloan-Kettering, the downtown branch, because I was up in Westchester, actually. They had the Walker Laboratory in Westchester.

SS: What was the name – I forget it now – of the cancer drug? Interleukin? Interferon?

IL: Interferon.

SS: That was the thing she had done.

IL: Yeah. She worked on Interferon. Interferon has probably been around

00:20:00 quite a number of years now, in various forms. And she did research on it. I don't know about her research, exactly, but Dr. Sonnabend, also, worked on Interferon.

SS: At Sloan-Kettering?

IL: No, not at Sloan-Kettering. But, later, after she left, at amfAR, they both worked in the Interferon problem.

SS: So, were there a lot of failed cancer drugs that people tried to apply to

AIDS?

IL: No. They just didn't take cancer drugs. They took other types of drugs, too, but they did try cancer drugs – to look for a certain activity. And, with the initial screens they had – there are much better screens now, for these drugs. Of course, they have the virus; they didn't have the virus then. So, that's another area to look at – to see what the history was about that.

SS: What did you do at CRI?

IL: Well, I remember there was getting the AL-721 – getting batches of it, and people would come to buy the preparation.

SS: What was it about AL-721, that you thought might be potentially –

IL: I didn't think too much of it, but it was one of the things that people wanted, so I gave my services to the effort of getting it distributed.

SS: So, how did you get to ACT UP, initially?

IL: Because of my work with CRI and –

SS: Did someone come with you to the first meeting, or did you just walk in the door?

IL: No, no, I probably came with the group who I was with – I mean, one or two of the group. I sort of can still remember where it was. I think it was on the second floor somewhere on 13th Street – the school.

SS: So, when you got there, what did you see?

IL: Well, there was a lot of people there. It was standing room only, at that point. And it was very interesting. I liked what was going on, and what was happening. People were looking for the drugs, and it was very interesting. I guess Larry Kramer was

there.

SS: So, where did you start working in ACT UP?

IL: I think it was really when Larry Kramer – when I brought in the information about the clinical trial was done at the AIDS clinical – at NIAID – and that they were all – the majority of them, over 80 percent were AZT, that they wanted other drugs being tested. That was the main focus, that we had to do.

SS: So, you brought that information to ACT UP?

IL: Yeah.

SS: How did you get that information?

IL: Well, I had to contact the NIAID – National Institute of Allergy and Infectious Disease. And, somehow, the information was available in the usual form of the trials that were being carried out with AZT, mostly.

SS: So, given your familiarity with AZT, when you realized that the NIAID trials were 80 percent AZT, what was your assessment of that?

IL: Well, it wasn't what people with AIDS wanted – number one. And why this was going on, why they were just testing one drug, when there were these other
00:25:00 potential drugs out there. Everyone could name these drugs. It didn't seem right to me or anyone else, so I said, well, okay, this is where we have to go. This is the government, this is what the government is doing. We have to put pressure on them, to expand their program to other drugs.

SS: Let me ask you a couple of questions about this. What was your feeling about AZT at the time?

IL: Well, it was a potential drug. It had gone through all the steps to get to the

testing in humans stage, but it didn't seem like – the drug was no miracle drug. It wasn't going to give you a cure. That was certain. But, people wanted it, and, obviously, there were side effects of the drug. People were becoming anemic and things like that. They were very toxic drugs – any cancer drug – I mean, cancer patients go through the same thing. The drugs are very cytotoxic. So, it was obvious that a lot more work had to be done, or we had to find better drugs to prevent these toxic effects from occurring. Plus, the drug wasn't getting rid of this virus.

SS: You said, this is not what people with AIDS wanted. What is the attitude, in science, that you were trained with, regarding what the patient wants?

IL: I wasn't really trained, since I was a chemist. I wasn't really trained to say what the patient wanted. This was all new to me, with respect to interaction with the medical community, even though, I worked for – they were mostly Ph.D.s. I did go to meetings where they discussed other things – the drugs in rats and whatever else. We didn't talk that much. The meetings that I went to, I don't think were that highly medical, because they were mostly scientists – they could be biologists or whatever – they were more in the science area, and not medical science – even though, there were some doctors there. But they were mostly interested in the laboratory science. So, you know, that's why I didn't really interact. How I knew you had to fight for whatever you wanted was because my own experience with my mother and another person who had strokes, actually, and how you had to be an advocate. And I was the advocate for these people. So, being an advocate, I knew that you had to be an advocate – whether it was for yourself or other people. You had to stand up and fight for the medical – actually fight – for care and drugs.

There was another woman – she influenced me a lot, too. She came down with Lou Gehrig's disease – ALS – and, in a short time, she was completely incapacitated – got lost in the street, one terrible snowstorm. And, obviously, she needed an advocate. She died shortly afterwards, within a few months. So, I knew at that time in my life that if you want drugs, you're going to have to fight for these things. You're going to have to fight whatever bureaucracy is there. I didn't really understand the whole bureaucracy thing completely – with doctors and institutions – the grants and things like that. I really didn't have much knowledge in that area, but I knew it was probably – this is something you had to know about.

SS: So, when you say you brought this information about the trials to ACT UP, did you just stand up in the middle of the room and tell everyone, or did you go to somebody?

00:30:00 IL: I always wrote some paper, with the data, and I made the presentation, yeah. It was very easy.

SS: So, you put the papers out on the table?

IL: Yeah, probably. And Larry Kramer was there, at that time. And he immediately jumped on it. I would say, one reason why I'm here today is because of Larry Kramer.

SS: What year is this?

IL: The beginning of ACT UP. I couldn't have been any more than a few months after I joined it.

SS: So, you joined it at the beginning?

IL: Yeah, I would say – not the exact beginning, but within a few weeks. It

was March of '87.

SS: How did you find out about it so fast?

IL: Well, I was working with CRI.

SS: Oh, okay. So, you were right on the frontline there.

IL: Yeah, so when I went to that meeting –

SS: And when did you bring in this NIAID information? You're saying, right after you got there.

IL: Well, already I was working on issues of treatment, probably, and thinking about these different drugs and stuff. So, it couldn't have been more than a few months.

SS: How did ACT UP respond to this information? What did they decide to do?

IL: They essentially accepted it and put it on their agenda. That was it. It was on the agenda.

SS: What were the drugs that people wanted to have studied?

IL: I can't remember all the drugs, but there were at least five or six drugs. They all have the letters and stuff. I can remember the AL very clearly, because I helped distribute it. But the others –

SS: Did any of them turn out to be valuable?

IL: No, I don't think so. But some of them were cancer drugs, too. They were not in the nucleoside area. They were not that type of a drug, but they were cancer drugs.

SS: Where did you fit in, in ACT UP? Did you get into a committee? Or did you start a committee?

IL: Yeah, I started a committee. It was going to these meetings. It wasn't just going to ACT UP. There were meetings after ACT UP, after the general meeting.

SS: So, Monday night, after the general meeting?

IL: Right, right. There were meetings at people's houses. I can't remember his name – Herbert – you probably know who I mean – I don't know – you're probably interviewing him. Herb – anyway, he made his house available, and people went to his house, and we all discussed what we should do next, with respect to treatment. And actually – I can't remember the names – a little guy and I – we decided we needed a treatment committee, and he said, no, we need treatment and we need data. So, it became the Treatment Data Committee. So, we formed the committee and that was –

SS: Who were some of the people on the Treatment and Data Committee?

IL: Jim Eigo, of course, was in it. But he came a little later. He was at Herb's
00:35:00 house. He was there. And there were a number of other people. I can't remember their names at this point. David [Z.] Kirschenbaum was the other. And so, we formed a committee, and it met every week, and we worked on it. I worked on it all day long, actually. We were calling drug companies and things like that – finding out, here's a drug, let's find out where it is, how can we get it? And so forth. So, we had a list of drugs that we were working on – the DHPG. Then, we had an action in Washington and so forth.

SS: What was the action?

IL: The action for DHPG was at a hearing.

SS: Let's go through the whole trajectory, so people can understand how the whole process worked in ACT UP. So, first you identified DHPG, and were

there any trials for it?

IL: I would say there were trials for it, but they probably were very small.

SS: Let's say what the drug was for, also.

IL: It's for CMV retinitis. So, the idea is, number one, it should be an approved drug. Before we even had this Treatment and Data Committee, we had had sessions where we started to learn what the FDA was all about. And I can remember a group of us trying to teach one another what the FDA is about, and how the FDA works to approve drugs. That was a very key part of the whole thing. It wasn't only the testing of drugs, the clinical trials – but how these drugs would be approved, and would they be approved in a timely way? Because they were not being approved in a timely way. And DHPG was one of the drugs.

SS: So, you felt confident that this was a drug that definitely merited approval.

IL: Oh yeah, everyone said that it definitely merited approval.

SS: And what held it up? What was the problem?

IL: It was the whole process of the FDA.

SS: That they had no –

IL: It was the bureaucracy of the review. On the application they have tons of paper they have to go through, and so forth. They have committees that will review the data and so forth. An anti-viral committee would review it. It would have to be put on a calendar. They would have to look at the data, make presentations. But the whole process was very slow. And, the drug companies agreed, everything was slow. They agreed too, so they had an ally in us.

SS: Who was the company?

IL: I can't remember. I guess it was –

SS: Glaxo?

IL: Burroughs Wellcome? [Hoffman-La Roche] I'm not certain.

SS: So, what would be the process? So, first you would go to the FDA?

IL: Because there was another new, purine type compound.

SS: So, first did you go to the FDA and say look, this is ridiculous, how can you speed this up?

IL: Well, there was contact with the –

SS: Who were the people there that you were in contact with?

IL: Ellen Cooper, and different people.

SS: What was their response?

IL: They met and we had to put pressure on them. There was constant pressure on them. It was not only us in ACT UP New York. There were other people putting pressure on them, too.

SS: So, this action was part of that pressure?

IL: Yeah, that was at a meeting – at an advisory committee meeting – and I can remember we had clocks – made clocks. Paper clocks or cardboard clocks, to show
00:40:00 that the time was going by and so forth.

SS: So, after you disrupted a meeting at FDA about DHPG – had you ever done anything like that before in your life?

IL: No, but everybody was gung-ho on doing it.

SS: Did you feel scared?

IL: No. A little. Not much.

SS: Were they angry?

IL: No. They were somewhat I would say stunned.

SS: So, how long after that did DHPG get released?

IL: I really don't know the exact time, but it was made available and some key people got the drug. They were key – Michael Callen – a number that I knew.

SS: So, Michael Callen's sight was saved –

IL: It wasn't Michael Callen, exactly, but a friend of his, who had CMV retinitis.

SS: So, were you involved in ACT UP's restructuring of the FDA approval system? The parallel track system? Can you tell us a little bit about who thought of that, and how it was implemented? What it was?

IL: I've talked about it so much. I can't figure out right now. I talked about it – I can remember talking about parallel track, but right now, I can't think –

SS: You can't remember what it was?

IL: It's getting the one drug – I can't remember how it went, at this point.

SS: Was that Jim Eigo's project?

IL: Yeah. He talked about it quite a bit. We all talked about it.

SS: Why did ACT UP have to think of a way for the FDA to be more effective? How come the FDA couldn't deal with it?

IL: They had their bureaucracy – the way they did things, how they got doctors. I mean, you know – within their ranks, there – they came from major medical

centers. They weren't looking to make the system work better. That wasn't their job, number one. They would say, that's somebody else's job. This is what developed for them. They didn't think of making the system more effective, I don't think.

SS: How do you think that people in ACT UP got to the point, where they realized that they had to and could be the people who were going to restructure the FDA?

IL: I don't think they thought that they were doing this, but they knew that they had to put pressure on the FDA and change the FDA – how they did business, because the drug development system was just taking too long. There was too much bureaucracy. Trials couldn't be done, because of the FDA. Drugs couldn't be approved and gotten by the public or whatever because of this long process. The compassionate use was not an effective way to get drugs.

SS: Was compassionate use another ACT UP –

IL: Because the compassionate use – yeah. The whole idea of getting the drugs before they were approved and expanding them to communities, before the exact approval date, that they knew the drugs were working and the expanded access thing.

SS: And do you remember who thought of that?

00:45:00 IL: It's hard to say one person, because we were all working on this together, and we just said, well, this is what we have to do. We have to get these drugs sooner. They have to be available to people – people who have no other choices. They have to be available. So, it just sort of mushroomed and developed. I can't remember the exact person who had this idea or that idea, because we were working on various aspects of it. We knew FDA was key. We knew that NIAID was key. And there were people who

were putting a lot of energy in each one of these segments of the puzzle.

SS: Now, when ACT UP did its famous action at the FDA, did you participate in that?

IL: Yeah.

SS: What were the demands?

IL: Well, it's a long time ago, and I can't remember the demands.

SS: Was it related to compassionate use and parallel track? Or were they already in place?

IL: It wasn't one issue. It was many issues. We made a flyer – and it was many issues. I mean, we put down a number of issues.

SS: Did you have an affinity group with that action?

IL: Yeah.

SS: What was it?

IL: I can't remember.

SS: Did you get arrested?

IL: No, I didn't get arrested.

SS: Do you remember anything about that action?

IL: The buses, a lot of people there, people on top of the – someone having a banner on top of the projection of the building.

SS: Iris, how much of your life was involved with this?

IL: Quite a bit.

SS: Ask your husband?

IL: Yeah.

SS: Would you say every day?

IL: Yeah, every day. Every day, because I was either making calls – initially, there was no Internet or anything, so you had to make calls to find out about different drugs, drug companies, whatever. People would call sometimes, find out, I need this drug or whatever.

SS: People with AIDS would call you?

IL: Yeah.

SS: And ask for advice?

IL: Yeah, that was going on, yeah.

SS: And did you feel comfortable giving advice?

IL: They were trying to get drugs, or – what the problem was with getting drugs. Actually, I was even contacted during the TB, by a patient who needed – because drugs were cut off, for some reason. They couldn't get the drugs anymore, because the FDA banned the drugs, because they were contaminated or whatever, or they didn't like where the drugs were coming from – for TB, certain TB drugs were unavailable. So, I helped a woman get drugs from Canada. She needed streptomycin – a very simple drug – one of the first drugs she needed. She only had one lung, and she needed this drug. It was part of her cocktail, and it was no longer available in this country.

SS: What did you friends and family think? That you were spending all your time on AIDS?

IL: Well, I had new friends, that's all.

SS: Did your relationships change because of the work you were doing?

IL: No, I don't think they changed. Maybe. I would have been doing

something else, if I wasn't doing this.

SS: Were you talking about AIDS all the time – like, if you were getting together with your family, were you talking about AIDS?

IL: No. That was a time when I wouldn't talk about AIDS that much. I would say what I was doing, but it wasn't a long, drawn out thing.

SS: So, what about all these gay men? All these gay people that you're spending every single day with – had you ever had gay people in your life, to that extent before?

IL: No.

SS: Had you had any gay friends at all?

IL: Not that I know of, no. It was very closeted, so it was very hard to say
00:50:00 whether you did have a gay friend or not.

SS: So, how did that affect you? What did you think about that, at the time?

IL: I sort of just accepted it, that's it. I said, this is what I'm doing. These are the people I'm involved with. I like the people. It's a whole different thing I'm doing here, and I think I'm doing the right thing, and I'm very interested in what I'm doing. So, that's another thing. It's getting drugs for people, and also, the whole idea of interacting. I was always a laboratory person, and now, interacting with people, it was completely different and something I had never done before. I was not a joiner before, at all. But, I was a fighter type person, that would fight for somebody's rights.

SS: What happened to you when people started to die – your friends?

IL: Well, it was very hard on everyone – myself, the group. There were

funerals, meetings, memorial meetings for people, and it was very moving, to see all the people that came.

SS: Did you have any particularly close friends, whose deaths you recall?

IL: Well, one – I can't remember his first name. His name was Bohn. He was a Quaker, and then another woman who died.

SS: From ACT UP?

IL: Yeah, I think it was ACT UP, because I did get involved with some people – through someone in ACT UP, with a group of women in Brooklyn – it was a help group for women with AIDS – making them trainers and so forth. So, yeah, it was very moving, you know? To see people dying of this disease – knowing that they soon would not be here. There were a lot of people like that.

SS: You were the founder, I believe, of the AIDS Treatment Data Network?

IL: Treatment Network. It was called ATR – *AIDS Treatment Registry*, and then the name changed a number of times. Then, it went *AIDS Treatment Resources* or something – AIDS Treatment.

SS: What was the need that that responded to?

IL: Well, you didn't know where the trials were. I mean, my working with this one woman – the one woman who affected me, was this woman with ALS, and attempting to find the drugs. Now, in that disease – there's no drugs for this disease. I even doubt if there are any drugs now. They were using cyclosporin or something. She went to Germany – she was German – there was nothing there. She came back and died shortly after. But I know that this was an area that was not properly covered. The

hospitals do not – or the doctors do not get information about clinical trials out to people. And there was a barrier, it seemed. You couldn't give medical information, if you weren't a doctor. There was all this stuff that you couldn't do.

SS: So, you mean, individual hospitals would just be constructing their own trials, and nobody would know what anyone else was doing?

IL: Well, it was another system that was set up – that didn't work very well.

00:55:00 It had to do with the doctors – the doctors in certain fields, whether they were in cancer or whatever. And, they would have to be research doctors. They would have to have certain qualifications and fill out the forms – the FDA forms, to be a principal investigator. Then, there were the drug companies involved with these doctors, too. If it was a drug company trial, there were payments made for these things. And they seemed to like to be under the covers.

SS: Why?

IL: One can imagine that they felt comfortable with that system. They were getting paid in some way, shape or form. And they didn't want people to understand what was going on. It seems like this is what was going on. So, it was very easy to say, well, okay. I started to look at cancer trials, just to see what kind of data base there was – a government data base. And I did find some stuff. But I didn't think it was very good or up to date or anything. It was very hard to get. So, we said, well you have to have this type of information. This is crazy – keeping information from people, about where the drugs are being tested. That was the idea, it took off. Everybody was working on this – Bob Huff, everybody. We had meetings – that was another meeting – that was not Treatment and Data. And, it actually became overpowering, because the amount of work

you had to do on this thing –

SS: How many clinical trials were there at a given time, that you would track? Like, in an issue of ATR or whatever?

IL: Well, we got more and more, as the years went by. The first one – maybe there were 30, 40 or so, in the first book. One of the first books was in 1990. Then, it became more about pushing them. We got more trials. We were getting more trials. More drugs were being tested. When we pushed and finally got the ACTG, the AIDS Clinical Trial Group going, they were doing more trials, also. And then, we found out, it was very hard to get drug company trials, because that was more secret, because of all these payments probably going by, to the doctors. And finding – we were contacting each of the hospitals that were doing these trials, and you had to find the key person that would tell you what was going on there, in trials for AIDS. And it was usually the same people that were doing the ACTG trials, actually. Some hospitals that are not ACTG sites – you had to make contact with the AIDS doctor there and find out what the trials were. Or some coordinator.

SS: So, if you started out with 40 or 50 in 1990, what did you have by –

IL: I don't know. I don't know when I left ATR, but there were 60 or 70 trials.

SS: And how often would ATR come out?

IL: Initially, it came out – I don't know if it was every quarter or whatever. We came out more often, and then we cut down because it was very intense. I didn't like the fact that it was cut down. Nowadays, you can have it on the net, but we had to have hard copy, and it was very difficult.

SS: So, like, every three months, you're coming out with a list of 60 or 70 trials. And, how extensive were the descriptions? Did you evaluate the trails? Or did you just try to say what they were?

IL: No. All we did was give the entry criteria – for people who could get into
01:00:00 it – blood work they had to have, and the sites where the trials were going on.

SS: So, this revolutionized AIDS research, because it democratized access to the trials – or at least information. So, ACT UP was running this also?

IL: Yeah. ACT UP was a nucleus of this happening, and it gathered the people who were going to work on this project. This became more intense I had to leave ACT UP somewhat – I had to leave Treatment and Data and only do this, because it was so intense.

SS: You left Treatment and Data to do the ATR?

IL: Yes.

SS: Do you know what year that was?

IL: I can't remember. Maybe it was '93, or '94. No – it was before that. Probably, it was about '90 – probably when the first directories came out.

SS: In 1990. And how much longer did you stay in ACT UP after that?

IL: Well, I continued to go to ACT UP.

SS: Do you continue to go now?

IL: No, I don't.

SS: You continued until when?

IL: Well, I sort of – I don't know how many years – it was about 1996 or '97.

SS: So, you spent about 10 years in ACT UP?

IL: Right. 10 years, definitely 10 years.

SS: Okay, so you left T&D and you went to the ATR, around 1990. And then, you work on that for a few years.

IL: Right.

SS: And that was your major focus in ACT UP?

IL: Right.

SS: Did you work on anything else, later, in ACT UP? Or did you stay with the Registry?

IL: I pretty much stayed with the Registry. But I was involved. I went to the meetings and stuff and was still involved.

SS: Can you describe, a little bit, how the introduction of the protease inhibitors or the ideas about the protease inhibitors – how they were received in ACT UP? And, when people first became aware of this direction?

IL: Protease – yeah. I remember the first protease, which was a very small trial in Boston or somewhere. It was – essentially, it didn't really give very much. I don't know what protease it was, but it wasn't that successful. But I can remember that there was this small trial. I don't know – it may have been at Johns Hopkins or somewhere, and everyone wanted to get in it. It maybe had 10 spaces. And, any new drug was really sought after, and people wanted to try it, get into the trial, whatever. And that was, I would say, the beginning – that small trial of a few people. And the protease probably is not around anymore. That was the model, and that's what I remember was the first protease. And, of course, that was on Treatment and Data's agenda – was the protease inhibitors, after that.

SS: When did you start to think that this could really be a turnaround direction?

IL: Well, with the protease inhibitors, it just seemed to fall into place, all these things. This company makes it, that company made it; some other company made one.
01:05:00 And it just fell into place. And then, the nucleosides are still there, having cocktails. So, it's the better use of the drugs – finding better ways to deliver what the dose should be. And, of course, measuring the viral load. Those are all the things that made sense with the drugs – reducing the side effects.

SS: Were you involved with the campaign to change the CDC definition of AIDS?

IL: Yeah.

SS: Can you describe, a little bit, what that situation was?

IL: Well, I can remember going down to the CDC – a rainy day, whatever it was, raining buckets – and changing the definition. And one of the things that I helped to change there was getting TB as an opportunistic infection, I guess it was. And the women's issues that were there, also. And I was always interested in the women's issues – the access to women in the clinical trials.

SS: How were women excluded from clinical trials?

IL: Well, they were excluded by the rules of the FDA, again. And the doctors – the research doctors. I can remember – this was before I even came here – this one doctor, when they treated rats, they only wanted male rats or something. So, it was very ingrown, with respect to – they felt that women's bodies would affect the results in some way that they didn't want because of the hormone cycles and everything – that they

would affect these drug cycles and stuff. Like, no one else had these problems of hormonal things going on.

SS: And it was really that vulgar? Those were the reasons why women were excluded from the trials?

IL: Well, they didn't say it like that, but that was the rationale they talked amongst themselves, I'm sure.

SS: So, how did that get that changed?

IL: Well, Terry McGovern – and there were lawsuits against this. I can remember being called about women not being – one of the drugs, Ampligen, didn't work very well, wasn't a good drug, but the woman wanted to get into the trial, and couldn't get into it. And Terry McGovern sought these people out, and she worked as an advocate for these people.

SS: So, why did you finally leave ACT UP after 10 years?

IL: You have to move on. First of all, I did the AIDS Clinical Trial Group. I thought that was very important, to have a good Community Advisory Board – CAB, as they called it. And, I was always associated with Mt. Sinai, and I thought the CAB wasn't going anywhere, so I thought I would take it over, and I became the Chair there. So, it was quite a bit of work, actually.

SS: What were some of the projects that you did there?

IL: Well, the whole idea was how you have a meeting every month and how you find out what's going on, and also – you have to run – this is supposed to be a Board, and there's supposed to be certain information given. Now, the investigator sometimes wants to give you his information. He'll talk about – not AIDS clinical trial, not the

01:10:00 government trials, but some other trial he wants to do. So, there's a problem in what type of information, and also, how you train people, how the whole organization works and what influence you have at the national level. So, that took up a lot of time, figuring out that, and trying to – the CCG – the Community – do you know what it is? The CCG – it's like the CAB on a national level – Community Constituency Group – that's what it is. And it's supposed to be made up of representatives from the CABs and stuff, but that never really happened exactly that way. People may come from other areas. And so, there's somewhat of a disconnect that I felt was a disconnect, between the CCG and the CABs. And there's a lot of issues – getting more members to CABs and getting them to meetings and all these things. And I tried to work in that area. I tried to drum up more activism in the CABs and help them get to meetings.

SS: Who was in the Sinai CAB? Who were some of the other people?

IL: There was Holly Horn of ACT UP, and David – I can't remember their names.

SS: David Gold?

IL: No.

SS: David Barr?

IL: No. I can't remember right now. I have a whole list upstairs, if you need to know – Sandy Baker, who was a patient at Mt. Sinai. I built it up pretty good. Finally, there was even the woman who's now in the CCG. What's her name? Ann something. She works for the city. She's a nurse, and she worked for GMHC, also. Holly acted as the Vice President and Secretary, and I was the Chair, and we had minutes at every meeting. I think they were too long, at this point, now, from what I know about minutes.

But we tried to record everything that was said at the meeting and we had good discussions. I was the Chair for two years there, and before that time, I was also involved – there was a man who had HIV, and he was a Chair. I just acted as a Secretary at that time, but I was sort of doing the work. He was not too well. And I thought we built it up pretty good. We had regular meetings. There was never a meeting missed.

SS: Now, when TAG separated from ACT UP, why did you stay with ACT UP? Or did you also go to TAG?

IL: No. I never went to a TAG meeting.

SS: Why was that?

IL: I don't know. I just felt – I didn't feel – there was some sort of animosity between certain ACT UP people and TAG. I wanted to go, but I never pushed myself to go.

SS: Were you ever in direct conflict with them?

01:15:00 IL: No, not exactly. Meetings are a dynamic. And you can either feel wanted at a meeting or you don't. And I felt that some of the meetings, later on, were not very friendly. In fact, I saw one woman, who was a friend of mine – she was trashed. This had to do with peptide-T, and she was at the meeting and really made to feel not very welcome. So, I wasn't comfortable with TAG. And there were other people, also, that were not comfortable with TAG.

SS: Right, so you stayed in ACT UP?

IL: Yeah, I stayed in ACT UP. The people are fine – [Gregg] Gonsalves and whatever, the others. But there was a little ruthlessness. I don't know what it was, there was something that was not just right.

SS: We interviewed Rick Loftus – do you remember him?

IL: Yeah.

SS: And he said that he felt that the T&D committee of ACT UP, after TAG left, was still a superb, excellent committee. He said the people were working at a very, very advanced level.

IL: Well, I went to a few meetings after they left ACT UP, and I didn't think that was quite so.

SS: You didn't think that was the case. So, you think that the split really hurt ACT UP, in terms of information?

IL: Yes.

SS: So, you just basically stayed with ATR?

IL: Right. Well, I may have left ATR at that time, too.

SS: What did you do after that?

IL: Well, I was concentrating on the ACTG.

SS: That's right.

IL: And the CABs.

SS: And that was in your capacity as a person in ACT UP?

IL: No.

SS: That was not your ACT UP work?

IL: No, no.

SS: That was after you left ACT UP? Or, while you were still in it, but it was separate?

IL: It was separate, because the people in the CABs – the people at the

hospital – may not know what ACT UP is. It was a different clientele there. It was not the same people.

SS: What was the difference?

IL: Well, there were different organizations. There were African-American there. There were people coming from – you can say, you want to know about ACT UP? No. You had to concentrate on the hospital, what they were doing, what the ACTG were doing – you just couldn't bring anything else into the – I mean, I didn't know how to do it.

SS: Was ACT UP involved in the creation of the ACTG?

IL: No, but they were involved in the CCG – that's what they were involved in.

SS: And, who initiated the creation of the ACTG? What body created the ACTG?

IL: The National Institute of Allergy and Infectious Disease, NIH.

SS: And you don't think that that was in reaction to community –

IL: No, because those trials – that first list of trials, which no one knew about, was already in existence. It was in existence in 1987, actually. It wasn't that it was that new. Maybe there wasn't a reaction, but no one in the community knew about these trials.

SS: So, CCG was the response to the community?

IL: Yeah – the Community Constituency Group.

SS: What was the impact of ACT UP on the creation of the CCG?

IL: Well, New York ACT UP I think had a great role in making that CCG.

And, after that, I really don't think the impact of the CCG on ACT UP – there was that much interaction there. There were certain people – Mark Harrington was on the CCG – but, people were taken from all over the country, so it wasn't like this was a New York
01:20:00 thing or anything, and I don't think there was that interaction of CCG and ACT UP.

SS: After it was created?

IL: Yeah, after it was created. I don't think there was that much involvement of ACT UP in that, because, essentially, they are not – how you would meld that into ACT UP, I don't know. It's the same thing as the CABs. You're having people from all over the country. There wasn't a connection at that time. If there was Internet, and this and that, it may have been a completely different world, but that's not how it was at that time.

IL: I think that the CCG did, in the initial stages, did have an effect on ACT UP, because Treatment and Data was involved, and TAG wasn't formed yet, whatever, or was in the process of being formed. And therefore, there was treatment information given to ACT UP.

SS: It's interesting, because you said, and I know that that's absolutely true, that most of the people with AIDS in the city, who were involved in AIDS, had no idea what ACT UP was. And yet, they seem to be beneficiaries of so much of ACT UP's work – parallel tracking, so much of the work that you did. And yet, they seemed unaware of the organization. Why do you think that was?

IL: It's communication. I mean, you have to have a newsletter. There were

some newsletters of ACT UP, but not that many. They have to get to other communities. I don't think – it's a big city. There was no Internet. So, I don't think people, really – it's like, you go 20 blocks way, it's a completely different world. You go to a different community, it's different.

SS: What's your assessment of where AIDS is at today?

IL: Well, it's better treatments, better detection – your status is known, your viral load. There was nothing like that. There was only T-cells. So, the prognosis of people is much better, with respect to – there are still access problems, all around the country, with respect to the drugs – whether they can get the drugs they need or get the testing they need.

SS: What is the obstacle to access?

IL: Well, it's still partly information, information, being tested, whether prevention work is still necessary. And it seems to go in waves. People are aware, and then they're not aware. Things happen, and then they become aware again. Well, of course, the international scene is now treatment activists all over the world – and, in Africa and so forth – getting drugs to those countries. But also getting prevention messages out. So, the research has gone ahead quite a bit – the research on human diseases, in all types of areas. Some of them affect AIDS – affect the good treatment that
01:25:00 people might be getting. But there's still a lot of healthcare problems in access to care.

SS: Do you see a cure for AIDS?

IL: I see it can be a manageable disease. I don't know if it can be cured – manageable, which means you can live your normal lifetime, with the correct medication, but it's still much too complicated. On the new drugs – the T-20, and whatever – it's

very hard to live with that regimen – injection two times a day, plus you have to take all the other drugs and this and that. But I think that some of these barriers can be overcome – just like AZT wasn't given properly in the beginning, it was just a pill. I don't think there's going to be a cure. I'd like to be wrong, but I think that it will be a manageable disease. That's what I think.

SS: I just have two more questions, and then we're done. Looking back, do you think that ACT UP missed the boat on anything, in a dramatic way?

IL: Well, there were ACT UPs all over the country. Somehow, that should have been stabilized, rather than gone downhill. And with the Internet and everything, it could have become a national, viable organization. But there were a lot of – how I see – it's not so easy to form an organization. And later there was a lot of conflicts and things, and people were turned away. People don't like to go to meetings where there's some sort of tension or whatever, and there's fights and this and that. The TAG thing, obviously, didn't help. I'm interested, right now, in how organizations and meetings work. I looked into this parliamentary stuff, and it is very, very difficult, and I'm not sure that's the answer. But you sort of take a little bit of that and take a little bit of this – but, somehow, people have to be able to have better meetings and not be overwhelmed by organizational things, too much, but see that everybody is treated fairly. In the beginning, everyone was treated fairly. Everybody could be heard. Nobody was shouted down too much. And I feel that was lost. So, it does have to do with an organization or meeting-type thing. But, how you do that, I don't know.

SS: And then, finally, of all the incredible work that you did in ACT UP so much – what do you think has had the longest-range impact, broadly?

IL: I think that anyone can make a difference. And, that you really have to seek and listen to many voices. If my voice wasn't heard – and you have to really do a lot of research, a lot of research in finding out things – trying to figure out why this works this way, and why it doesn't work this way. What are the different pieces to make
01:30:00 something work? You have to reach out to all different types of people – whether they're doctors, different communities, churches, whatever. To get things done, you have to make a chart of where you have to go. So, there has to be some sort of a plan, too. You have to plan.

SS: Of all these specific things that you were involved in, like restructuring the FDA, *AIDS Treatment Registry*, any particular drug. Of all these different concrete things that you worked on, which one do you think affected – so many of them have affected so many people, but what are you most proud of, of your achievements?

IL: Helping people get the information, get the drugs, breaking down barriers for medicine – not only medicine, but how other patients talk to doctors – this, that and the other thing – all these things. This has to do with, well, you have to have certain knowledge, that doctors have to be receptive. If they're not, you have force people, you have to "act up." That's what you have to do. And, you have to – no matter what – they're not going to like this – okay, here it is. Here's the next letter or the next brochure or whatever, or the next action. And, if it's important enough, sometimes – I mean, you can't do this for everything. Sometimes, you have to walk away from certain things, but if it's on your agenda – this is what you think, this is what you're working on, this is what you're going to do, you have to go to every extreme to carry that out.

SS: I'm glad you did. Thank you, Iris. Thank you, so much.