AAHP
AIDS Activist History Project

Interview Transcript 57

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Interviewee:	Maggie Atkinson
Interviewers:	Gary Kinsman Dani Normandeau
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Persons present:	Maggie Atkinson – MA
	Dani Normandeau – DN
	Gary Kinsman – GK

[START OF TRANSCRIPT]

GK: Do you have any memories of when you first heard about AIDS and what you might have heard?

MA: I remember hearing about AIDS. I think it was probably around '84 or '85, and I remember hearing that there was some illness affecting gay men. I was at university at the time and very busy with my life there. And I just remember hearing something vague about that there was some disease affecting gay men—mainly in California, or something—and didn't really pay too much attention to it. Except, I guess it was the summer of '85. It's a little complicated but in '84 I slept with a close friend of mine who was gay. I guess you could say theoretically he was bisexual or practically he was bisexual, but really he was gay and I knew it at the time. I didn't think anything of it at the time I slept with him. I slept with him in the fall of '84 and then in the summer of '85 he confessed to me that at the time we had slept together he had been worried that he might had been infected with HIV or AIDS and that he could have infected me. At the time there was no test available and, from what we had heard, if you got infected it would take 7-10 years to show up. So I kind of put it out of my mind. I just thought "Oh well, if it shows up I'll worry about it then." Subsequently, in the fall of '86, I overheard some people talking about HIV and AIDS and they mentioned the fact that you could be almost like a carrier; that you could be asymptomatic and that you could pass it on to someone else. At that point a test was available. I thought "Oh my goodness. Maybe I am infected. I could have passed it on to somebody else and I really should get it checked." So that's when I decided to go and get tested. Did you want me talk about getting tested?

GK: Sure.

MA: I went to Hassle Free clinic in Toronto. Ironically, it wasn't hassle-free getting tested. It was far from it. When I went there the counselor said to me—I told her that I had slept with a gay man—and she said she didn't think that put me at risk for getting HIV. Then I thought "Oh! That's not working." So I tried to make my history seem worse. She still didn't want to test me. Finally she agreed to test me when I said I wanted to get pregnant. When I told her that I had slept with someone who was gay and she said that wasn't a risk, she said that no woman had tested positive at their clinic. I thought "Well no wonder they haven't tested positive because you're refusing to test anyone who comes in!" She finally did agree to test me and told me the results would be ready in 2 weeks. So for 2 weeks I was very nervous, thinking "Oh my God! Maybe I have HIV." At the end of the 2 weeks I phoned to make an appointment to get my results. They said "Your results aren't ready. Call again in another 2 weeks." Then at the end of that time I was told I had to come in for an appointment. I just thought it was a formality. When got there I met with a doctor, and she told me my results were positive. At first I thought positive, that must be a good thing. She said, "You've got antibodies to the HIV virus" and I realized that's not a good thing. She said they didn't know what to do for me, that they'd never had a woman test positive there before me. She said they didn't have any treatments available. She said that all she could tell me was to look after my immune system, to eat well, and to get enough rest, and to avoid stress. They put me in touch with The AIDS Committee of Toronto, which was a fledgling organization back then. The next day, I guess, I had an appointment at The AIDS Committee of Toronto in their location on Wellesley Street , above The Kentucky Fried Chicken.

GK: Oh yes! I remember that well. I was one of the first three employees of ACT. But that's '83.

MA: Oh were you? Oh '83. This would be '86.

GK: It was still the same location. Just to tell you 1 quick story. When the staff—there were three staff—and we'd have the people come in for the board meetings and they'd all come in with Kentucky Fried Chicken. [Laughter] So we secretly would say that we were conducting a research study on the relationship between HIV acquisition and Kentucky Fried Chicken.

MA: I remember when I went in Yvette Perreault was there and Theresa Dobko. They were the only people I remember being there at the time. Just the two women in this room. I remember I told Theresa my story about how I thought I was infected and she didn't believe I could have gotten infected that way either. She picked up the phone and she called Stan Rea at Toronto General—or was it Sick Kids at the time, I think it was Sick Kids—anyway, he was an infectious disease specialist treating people with HIV at the time. She arranged for me to go and see him. I went to see him. He said "I think we should test you again." They tested me again to be sure and sure enough it came back positive about a month later. That's how I found out I was positive.

GK: What did you do about this? Or did they offer you anything that you could do about it?

MA: Well that first day that I got the news from the Hassle Free Clinic doctor I was kind of in shock and kind of stunned, even though I had been thinking maybe I could be in the back of my mind for that month I had been waiting for my results. I remember on the way home that day I stopped and bought some fresh fruits and vegetables because it was the only concrete thing I could think to do that could help my health. Stan Read gave me pretty much the same advice that that doctor had before. He said "We don't have any treatment for this disease yet. The only thing that we can do is monitor you and treat any infections as they happen." He just said the same things: that you should look after your health, eat well, get rest, and avoid stress. I remember saying to him, "I am in second year law school. How am I supposed to avoid stress?" He said, "Just do your best."

In those days there were so many unknowns about HIV, but I had a lot of confidence in Stan and I felt like if he didn't know it was reasonable not to know. Definitely that was one thing I came to learn about HIV, is that nobody really knew very much of anything back then. Also another thing is that HIV seemed to cause atypical manifestations of illnesses. So if you got something it might appear not in the normal textbook way that an illness would appear. I still find that to this day. For example, about 6 weeks ago I got an eye infection and went to see I think it was three or four different doctors and their conclusion was "We know you have an eye infection, but we're not really sure what it is. It's an atypical presentation." That's so typical of HIV. Because nobody knew in the beginning, I think that was one of the things that led the AIDS activist movement to get involved in helping to try to find answers, and digging.

In the early days, after I found out about it, initially I wasn't involved in the HIV community. I was too busy looking after myself and trying to get through law school. Because at the time, from what I had read, I thought I could maybe die within the next 2 years or maybe I might live another 20 or a normal life span. I don't know. But I thought in case I live longer I might as well finish law school, because I might need a career to fall back on. I thought it was best to continue. I am glad I made that decision. Actually while I was at law school one of my courses was Health Law, and so I had the opportunity to do a paper on HIV. My paper was on whether HIV should be considered a disability under the Ontario Human Rights Code. I argued that it should be and my professor didn't agree with me. Fortunately the Ontario Human Rights Commission did agree with me eventually. Under the guise of doing that paper I was able to do a lot of research on HIV, as much as we knew back then. So that was actually very good because it gave me the time and opportunity to do a lot of reading. That was one of the reasons why I thought there's a good chance I might only live another two years.

One of the reasons I knew that my outlook wasn't as good was because I had what they think was a seroconversion illness shortly after I got exposed. At the time we didn't know what it was. I had gone to the University of Toronto Health Clinic because I had been so ill. I had what they called a mono-like illness, mononucleosis-like illness, with swollen lymph glands, fevers, night sweats, and fatigue. I had actually gotten a medical note to have my exams postponed that year because I was sick for about a month. In a way it was good that I had gone and got that because it helped me identify the time I had been sick with that. Also, when my T-cell count was first tested, it was much lower than we would have expected given that I was exposed in '84. My T-cell count was first tested around '87. You couldn't actually get it done normally, but Stan Read slipped it in to a research study they were doing at the time. So he tested it. I remember him calling me with the results, and my T-cell count was below 300, which was a real shocker. At that point AZT was available, had just become available. He said "You could go on AZT now, but I don't recommend it. Let's wait until we feel you really need it." I am really glad he made that suggestion because if I had gone on AZT then, I would have been in the position of being on serial monotherapy. And I probably would not be alive today if I hadn't postponed going on AZT. I feel like I was very lucky, or very fortunate in the medical advice I got over the years. I really do feel really fortunate. There are a number of times I got advice from doctors or researchers over the years that really helped keep me alive. In the case of Stan Read he was my doctor, but other instances later on there were people like Dr. Bill Cameron, from Ottawa, who I got to know through the Canadian HIV Trials Network. It was because of my knowing him through that over the years and in the Canadian Association for HIV Research that he provided me with important advice. I remember running into him at a conference in Copenhagen. I didn't know him very well at the time, but he took me aside and he told me that he was working on research on Ritonavir with Saquinavir. And he told me "Don't take any of those protease inhibitors when they first come available. Wait for the results of this study. I think that's going to be the key to take both of them together." I really feel that that advice definitely helped keep me alive. I'm sorry I feel like I'm jumping all over the map.

GK: No, that's great. Maybe just to return to a little bit earlier. Many people bring to AIDS activism experiences in other movements and struggles. When you find out you're HIV positive, you're in law school, but were you involved in any social movement before?

MA: No.

GK: So AIDS was the first thing that you got involved in?

MA: Yes. I mean, my mother was a school trustee in Toronto, Irene Atkinson. When I was growing up she was first a member of the local residents' association. Then she became a school trustee. Actually first, my mother was the kind of person who if she saw a problem she felt she should do something about it. That was really her motto for us growing up. She would say "If you're unhappy about something you should do something about it." So when I came along there were no good nursery schools in the area, so my mother started a nursery school. Then when I entered the public school system she wasn't very happy with it, so she decided to run for school trustee. I think that in the back of my mind I had that motto, or that attitude that you should do something. But, no, I didn't have any involvement in political organizations before that. I had been involved in student politics at U of T, so I was on a number of committees. So at least I was aware of committee structure and meeting structure and so on in a more formal sense. But, no, I had never been involved in any demonstrations or anything like that. It was all new to me. My first kind of involvement in the community was probably the support group that was started for positive women through Hassle Free Clinic and The AIDS Committee of Toronto. Our two facilitators were Theresa Dobko and Bonnie Benedik from The AIDS Committee of Toronto. We met at the Hassle-Free Clinic, upstairs in a backroom. Do you want me to talk about that?

GK: Sure. I think Darien mentioned in her interview that group as well, but we don't have much information on it, so if you want to mention some more.

MA: Darien was in that, with me, at first. I think that there were 10 of us in that group. That's the number I have written down. I don't know if that included the facilitators, or if there were 10 women. I do remember being there that first night. First of all I should tell you that I heard about there being support groups around for men, but there were no support groups around for women. I was frustrated by that. But they told me they didn't have enough HIV positive women, or women who had tested positive, to form a group. So finally I got a phone call from ACT, or maybe it was Hassle-Free, to let me know that finally they did have enough women and that they were going to start this group. I think it was a couple of years after I had tested positive that this group finally started. I remember that first night going to the meeting and looking around at this circle of women and just being kind of astonished, or blown away, by how normal everybody looked. Because I think I had internalized the attitude that HIV only happens to women who are IV drug users or prostitutes or both. I guess I thought that I was kind of the odd person out here. But looking around at the other women in the room, I realized—and learning their stories—that I really wasn't the odd person out. There were two women in there who probably got it through IV drug use but they were housewives from Scarborough, you know? I think there was some support for the idea of having the support groups because there had been a study, which showed that support groups have helped women with breast cancer live longer. That came out in '89. Originally there was a study earlier, of the same women, and it had showed that it improved their pain management and stress or something—their quality of life. So there was definitely some evidence that support groups were a good idea. Certainly it was really great having the support group. I believe we met once a week. We would have our check-in at the beginning of the group. That took up most of the time we were there, talking about our issues. I belonged to that for years, until we disbanded actually. We eventually disbanded because we had lost enough members that we couldn't really sustain the group anymore. But the group did meet for years.

GK: Because people left the group or because…

MA: They died. Some people did leave the group. It wasn't for them. They just didn't feel that comfortable with it or whatever. I think one person was asked to leave the group, because she had some other issues that were kind of overwhelming. She was being threatened by an abusive husband and so on. It threatened to kind of overwhelm the dynamics in the group. She was asked to get one-on-one counseling for that elsewhere. But on the whole it was because people were dying off over time. We tried bringing in some new people as time went on, and that worked relatively well. Eventually they felt they couldn't continue to do that. It just wouldn't work really with the dynamics of the group. So we eventually disbanded. However, to get back to going to those meetings, when I would go I would pick up a copy of *Xtra* Magazine mainly to read about HIV news. I started reading Chuck Grochmal's column, which I loved—I couldn't wait to read it every time I got the copy of *Xtra*—and followed his illness until he died. I attended the memorial at the 519. I think that was around February of 1990 … I think it was 1990. By that time I had finished law school, I had articled, and I had been called back by my firm to work, and I had finished the bar admission course. I was just starting to work as a lawyer at Borden and Elliot, a law firm downtown with 200 lawyers, 400 support staff, so a big firm.

GK: A big one, yes.

MA: I just started working there. I had worked there before as an articling student. Just come back to work as a lawyer. I went to this memorial service and as I was wandering around the room looking at the artifacts and so on, I was shocked to see Alan Cornwall there, who was a lawyer at my firm. He was probably shocked to see me there, too. The strange thing was that he had been assigned—he was a couple years ahead of me at the firm—and he had been assigned as the young associate to mentor me. It was just an incredible coincidence that the two HIV positive lawyers at this firm could be put together like this. I think he had already taken me out to lunch once, or something, to kind of get to know me. He called me the next day after Chuck Grochmal's memorial. I think at the memorial he told me that he was a member of AIDS ACTION NOW!, I had read about AIDS ACTION NOW!. I was surprised, because I just assumed that anybody who was with AIDS ACTION NOW! would be HIV positive. I didn't find out until later that about half of the members were HIV negative. The next day he phoned me. We went out for lunch and, first of all, he divulged to me that he was gay, which I didn't know because he was totally closeted about that at work. Only one or two people at the firm knew he was gay. Maybe people suspected but he was actually very straight seeming at the firm. He was a very different seeming person in his personal life. He had this very straight persona at work. Because there was such homophobia in the legal profession then. Maybe there still is today, I don't know. At the time there were 600 members at this firm and nobody was openly gay at the firm. Even partners who were permanent bachelors—there was no discussion that anybody was gay there. Alan divulged to me at lunch not only that he was gay, but then he told me that when he first joined AIDS ACTION NOW!, a few years before, that he didn't know his HIV status. But then when his partner Paul Meagher tested positive, he got tested as well and found out he was positive. I was very surprised that he would be this open with me and tell me he was positive. So I told him "I'm in the same boat as you are." He said, "What do you mean?" And I said "I'm HIV positive, too," after looking around the restaurant making sure nobody could hear. His jaw literally dropped. He couldn't believe it. He really couldn't believe that somebody like me could get it.

It was really fantastic having somebody else in the firm who was positive. Because we would call each other and share our concerns. We were both terrified that the firm would find out that we were positive. Because even though they were nice people, we thought that they'll probably let us go. They wouldn't come right out and say they were firing us, because for legal reasons they wouldn't want that. But our performance reviews would go from "Excellent" to "Poor" and they would find some way to get rid of us. And also the economy was quite bad. There were a lot of bankruptcies at the time. Around '92-'93 the firm had to start letting lawyers go, which is very unusual. At that time with the financial climate a lot of firms were having to let lawyers go. We thought "Oh my God." You didn't know when you might come in and maybe you would be let go. We didn't want HIV to be the cause of that.

Shortly after that, I got approached by another friend, Bill Harris, he was head of Barclay's Bank in Canada at the time, but he had friends who were in the gay and AIDS community. Somehow he had found out that AIDS ACTION NOW!, or actually Mark Freamo at AIDS ACTION NOW!, had applied to the government for some funding to start a legal aid clinic for people with HIV. He said to me "You're a lawyer, why don't you get involved in this?" He knew I was HIV positive, as well. He was a friend of a friend. Actually he was friends with the young man I got HIV from, so he knew about the whole situation. He said "Why don't you get involved in this (starting this legal aid clinic)?" So I attended the first meeting of this very small committee. I think there were five of us. Alan Cornwall was one of them, I was there, James Thatcher, Mark Freamo, and I don't know if there was anyone else there at the first meeting. We met first at Alan's place, then we met at James', then Mark's, we'd meet at my apartment, and so on. We ended up hiring a young lawyer, Gerry Heddema, to start running this fledgling clinic though ARCH, the Advocacy Resource Centre for the Handicapped. That started probably around 1991. I think it was in '91 that we hired Gerry. That was kind of my beginning of getting involved in the AIDS community. Through that committee I met James Thatcher, who I became friends with. I guess partly because of

James—I know I had attended one big general meeting that AIDS ACTION NOW! had held before—and James had spoken at it. This is before I knew him. It was only after I met him again that I knew who he was. I remember being very impressed because this very preppy looking guy stood up, and well-spoken. I thought "Oh good. Some people with AIDS could be actually people I could feel comfortable with."

I started popping in to some AIDS ACTION NOW! meetings, usually near the end because I just really wanted to go out for dinner with James, or go for a drink or something after work. I knew the AIDS ACTION NOW! meetings were happening on a Tuesday night. I think they went from like 8-10. I dropped by and I saw this big room of people. I probably thought I was inconspicuous just coming in near the end and sitting in a chair. Little did I know that everybody knew everyone and anybody new coming in was pretty noticeable. That was my original going to AIDS ACTION NOW! meetings. I was very impressed with these people because they seemed so knowledgeable and they were all well educated, but they also some of them had connections with government and with government organizations. They seemed to know what should be done. I was very impressed with all of that.

But I didn't really get involved with AIDS ACTION NOW! until later. I think it was around '92-'93 that I… I should back up a bit. Earlier than that, I think it was around '91, it was the spring of '91, that I heard through the women's support group that there was going to be this general meeting for HIV positive women that Darien was starting Voices of Positive Women. Darien and another woman were working on this anthology, as you heard about. When they applied for funding for it they were told "well we can't give you funding for a book, but why don't you start an organization?" So they had this general meeting and I think there were probably about 25 women there at the first meeting. And it was really a wonderful experience being there. In a way we were all fumbling our way through this situation. I remember that there were some HIV negative women who had come, as well. Some of them were support women for these positive women who were there—like had driven them there, or whatever, helped them be there—but we decided we just wanted HIV positive women at this meeting. We had to politely ask these other women "Could you please go out and wait? We'll let you know when it's okay to come back." We made decisions about the organization that we wanted it just to be HIV positive women, by and for HIV positive women. I became a member of the first steering committee, and I became the Chair of the first steering committee of Voices of Positive Women. That was definitely a learning experience. Darien was really the mainstay of that organization because she was the staff person, so she was running it on a day-to-day basis. I had involvement with the AIDS community through that. I should go back and say that one of the reasons that started was because the AIDS Committee of Toronto had made it very clear that they didn't provide support for HIV positive women. They said, "We do prevention work for women and we provide support for HIV positive men, but we do not provide support for HIV positive women. That's not part of our mandate." Leslie Gaynor was working there at the time doing prevention for women, but unfortunately support was not a part of their mandate. That was really why the organization got started. It was because there wasn't really a place at ACT or at the PWA Foundation. And also women felt they didn't want to go to what was known as an AIDS building. That was why it had to go to the building on College Street—for anonymity. Women were so terrified about people finding out they were positive.

Through that I started to get involved in some other things. This was while I was still working and also trying to set up the HIV and AIDS Legal Clinic and starting to run Voices of Positive Women. Plus I also started to run another legal aid clinic at the 519. I was approached by some people at Osgoode Hall Law School. They had a legal aid clinic, and they wanted to run a satellite legal aid clinic at the 519. I gave up my Saturdays and then would go in there and train students to do wills and powers of attorney for people with HIV. So I did that as well.

GK: It sounds like you were very busy.

MA: Yes. It wasn't really until after I finished I guess my first year working as a lawyer I felt "Okay, finished my first year. Now I can start to do more things in the community." But also, I was living this double life because I was terrified that people would find out I was positive. It was really kind of a fine line, because I was known in the community, I was on these committees, and Voices, and so on. And yet I didn't want the firm I was working for to find out. It was tricky and it was stressful. But I felt I had to do these things.

In '92, while I was at Voices, we were contacted by the Canadian HIV Trials Network. They said that they wanted an HIV positive woman to be on their steering committee to provide advice. I thought, "Hmmmn…" I think it was Darien who had said to me that she thought—I think she was involved with TAAR (that's AIDS ACTION NOW!'s Treatment Access and Research group or sub-committee)—she had said to me "I think that the future of AIDS activism is in treatment." And I thought that makes some sense. So when this opportunity came along I thought maybe I should get involved in this. It would certainly force me to learn about treatment and get more involved. I applied and was accepted. The first meeting wasn't until the spring of 1993. It was in '92 that I was asked to be on the committee. I remember Brian Farlinger, who I think was becoming Co-Chair of AIDS ACTION NOW!. Somehow he got the message to me, probably through Darien, that they felt that I should become a member of TAAR at AIDS ACTION NOW! if I was going to be on the Canadian Trials Network. So I became a member of the Treatment Action and Research Committee and started attending the AIDS ACTION NOW! Steering Committee meetings. At the same time my health was declining. In January of '93 my T-cell count fell below 200. Actually it was surprising it stayed up that high so long, because it started at around 300. Anyway, it fell below 200, which at that time was considered full-blown AIDS, at least by the Americans. Which was quite a shock actually. I guess I hoped that whatever I was doing for my health would help stave off the progression. I could see myself that my health was declining.

I was going to back up and tell you that the summer before, in 1992, my friend, Douglas, who I got HIV from, he died of AIDS. I had gone out to see him. He was living out in Victoria at the time. I think while I was out there I also attended the Canadian Association for HIV Research annual conference. I think it was their 2nd conference they'd ever held. And they held it out at the University of British Columbia. I stayed out there in the residence and attended this meeting as a representative of Voices of Positive Women. I found that being a member of that organization was a great place to be. It gave me the backing of an organization. There were some things that were said about women with HIV, at this conference, that I didn't like. So I carefully looked up on the abstracts who the researchers were, and on behalf of Voices of Positive Women, I wrote letters complaining about this. I remember one of the letters was to Catherine Hankins, the researcher from Montreal at the time. She took it very seriously and wrote back to us and apologized for their tone and the attitude they seemed to be expressing. It helped start a dialogue. It got Voices of Positive Women at the table to be a representative of women with HIV in Canada. That was my first introduction to AIDS research really—being at a research conference like that. It was a good introduction. People were very friendly and interested.

As I said, I first went to that conference. I was gradually becoming more and more ill in the fall. Then in January I took, at my doctor's recommendation, 6 weeks off work, which my supervisor wasn't very impressed about. I carried around with me at work at all times a little slip of paper from my doctor, from my GP, which said "Margaret has AIDS. She needs to leave work immediately for health reasons." Because at that point things were really bad with the law firm letting people go, and so on. I was afraid I could be let go at any point. And also, being more and more public, I was worried they would find out. So I used to carry this around with me. I had planned on leaving work to go on disability.

I should mention that James Thatcher had died the year before as well. Apparently one of the last things he spoke to Doug Elliot about, his friend, who was also a lawyer, was, he said "You gotta get Maggie to go on disability." So Doug approached me and talked to me about it. I went into his office and spoke with him—and so did Alan Cornwall as well, because we were both in the same boat, had similar contracts with Borden and Elliot—so we got some legal advice from him. I remember him saying to me, because I said—he was asking what life was like—I said "I get up and it takes all my energy to work and then I go home and I'm so exhausted I just go to bed right away." He said "You don't have to live like that. There's more to life than just working. You have a right to have some quality of life."

My parents were encouraging me to leave work too. They knew I was positive at that point. They were worried. They said "Look, if you got fired, for example, if you got let go then you wouldn't have any disability coverage. It would be better to leave now, while you have coverage." I was waiting because my supervisor was supposed to be having surgery and she wanted me to oversee her files while she was recovering. Then she told me, it was in April of '93, she said that she had decided to postpone the surgery for 6 months. I thought I can't wait another 6 months. That's when I made the decision to go in and tell her.

She was very good. She was quite shocked. She had me go and see the head of the firm, the chairman of the firm. So I had to go and tell him too. They decided, or they recommended to me that I come clean. Instead of just sending some little anonymous note "Maggie is leaving the firm for personal reasons," they decided it would be best if I said that I was HIV positive. It was funny because, talk about prejudices and stuff, my supervisor said, "You know, otherwise people might think you had a nervous breakdown, or something." I guess she felt it was better to think that I had HIV than I had a nervous breakdown. I don't know. That letter went out after I had already left the firm, packed up my boxes and left that night.

The firm actually left my office open for me for a whole year afterwards. Thinking just in case I was able to come back, with some rest and stuff, I might be able to come back. But I realized I couldn't come back, because, as a matter of fact, I got full blown AIDS the following year. But I got an outpouring of support from people at the firm. When they found out, people wrote me letters, cards, phoned me at home. There was really a lot of support. The firm was great. The poor firm, just a few weeks later Alan Cornwall decided to leave too. So I think they were totally in shock. They were just reeling. They just thought one person was bad enough, but then another. And then a support person, too, at the firm, he also came out as being HIV positive. The firm went on to have fundraisers for the AIDS community. They really were great. And they provided me with support over the years. They gave me a computer to use at home. They even had somebody come to the house and fix the computer if it broke down. They provided me with office supplies. To this day I still get medical coverage through them. I was very fortunate.

I left the firm in, I think it was, April of '93, and right around the same time was the meeting of the Canadian HIV Trials Network Steering Committee that I was on. It was being held in Montreal. They also said to me "Oh. By the way, while you're here for this meeting, we've decided to establish a Community Advisory Committee to the Canadian HIV Trials Network, would you be on it?" So I felt, I guess I should be.

The Community Advisory Committee had representatives from across Canada and different disease groups. For example, they had someone from the Canadian Hemophilia Society on that. It wasn't James Kreppner, it was somebody else. [possibly Pierre Desmarais.] Anyway, they had representatives from pretty much every province and different disease groups. I went to that first meeting of the Community Advisory Committee and ended up getting elected Chair. I was really kind of thrown into the deep end. First, I'm on the Steering Committee. Then I'm Chair of this fledgling Community Advisory Committee and we have to work out our terms of reference and everything. We're reviewing research protocols, which was—I mean, I hadn't done science since grade 13—I had a background in Classics. I did Latin, Classical Greek, and German at university, and then law school. The good thing about studying Latin and Greek was it helped me understanding medical terminology. So that was one advantage. I was really thrown into the deep end having to learn how to read and understand research protocols and so on. Oh! And also someone said to me, if you're going to be on the Canadian HIV Trials Network you should really go to the International AIDS Conference in Berlin, that's taking place next month.

All of a sudden I got funding. I think it was from Burroughs Wellcome, as it then was. Someone had given me someone's name. I think James Thatcher put me in touch with Russ Read. So I didn't get it through AIDS ACTION NOW!, because AIDS ACTION NOW! wouldn't take money from drug companies. But I could get it through Voices of Positive Women. We could accept money from drug companies. I got some funding from them and went to the Berlin AIDS conference, which was an amazing experience.

Also, within probably one month, I think there might have been the Canadian AIDS Conference, I think it was that year in Montreal. That's right, there was the CAHR meeting, there was our Community Advisory Committee meeting, and there was also the Canadian Association for HIV Research were also holding their meeting. They used to hold it at the same time as the Canadian Trials Network. It worked out well for funding for bringing people into the meetings. Catherine Hankins was the organizer of that annual meeting. So I stayed on for that meeting as well. There was a meeting there in the evening and I got up and asked some questions at the meeting. It was a meeting for community in Montreal. As a result of speaking up at that meeting I got asked by Norbert Gilmore—he approached me and asked me if I would come and speak at McGill for their World AIDS Day event on December 1st of '93.

And also, around the same time, I was approached by Ken Logue. He was one of the co-chairs of the Toronto Primary Care Physicians' Group. He had said to me—he was on the Steering Committee of the Canadian Trials Network at the same time, that's how I met him there—and he said "You know, James Thatcher used to come to our Primary Care Physicians' meetings, as a representative of AIDS ACTION NOW! and as kind of a liaison with the community and the activists" and he said "Since James died we really haven't had anyone. Why don't you come to our meetings?" So then suddenly I was the AIDS ACTION NOW! representative to the Toronto Primary Care Physicians' Group.

As I said, within about a month suddenly I was involved in all of these different things. And there were other committees as well. I think the thing is once you've gotten onto one thing, then people saw you and asked you to get involved in something else. And there weren't that many of us who were out there. And because I had left work all of a sudden I felt, now I can be open about being HIV positive and that gave me more freedom. I felt a strong responsibility to do what I could. I think we all felt at that point that our time was limited and that we could die probably very soon and that we really didn't have very much time to accomplish things. So we had to kind of give it our all.

Plus you had examples of people like, for example, with Brian Farlinger, who was the Chair of AIDS ACTION NOW! at the time. I mean, he was a bit of a tyrant. I loved Brian and he became a good friend of mine but he was very demanding. You would go to a meeting with him at AIDS ACTION NOW!. It would end at 10 o'clock. I can't remember if it was 7-9 or 8-10, but anyway it would end fairly late. He would hand you a document, some dense document or some letter he wanted you to review, and he said "Oh. Can I have your response or your comments by 9 tomorrow morning." I would just look at him like, "Oh God, Brian!"

I've written about this before. I was asked to write about Brian for *Living* + publication [Living + News and Treatment Information from the BC Persons with AIDS Society January/February 2003/Issue 22]. I remember when I got PCP pneumonia in the summer of '94, the International AIDS Conference that summer was in Yokohama, Japan, and Brian was going and he said "Why don't you go?" I said, "I'm not going because I've got PCP." And he said, "Oh come on." As if it's no big deal. Just bring your medication with you. Because he travelled to Yokohama, he was going through intravenous treatment for CMV retinitis, and so he was on Ganciclovir intravenous drip. He had to take bags of medication with him and his IV pole and everything and was doing his drip while he was in Japan. Having something like PCP, as far as he was concerned, was nothing, and no reason to stay home and not go to a conference. There were certain expectations that you would basically continue until you dropped. Anyway, that's how I got involved in the activism.

GK: Right.

MA: I wanted to tell you, too, how when James Thatcher died in '92 and I went to the memorial, which was great—were you there?

GK: No, I was in Nova Scotia then. I played the video that he did before he died for my class when I was teaching sociology at Acadia. I did know James but not that well.

MA: His memorial was held at Hart House in this huge big room full of people, probably a couple of hundred people in there, all milling around. It was like a cocktail party. They had a quartet playing. He had left instructions for what he had wanted done for his memorial. So there was a quartet playing and they were serving champagne, Moët & Chandon champagne, and his favourite rum, a Cockspur rum—he was from Barbados, originally. There were people like researchers there, drug company people had flown in from across the Canada to be there for this event. He was so well respected and liked.

GK: I was wondering about returning to a couple of topics: Voices of Positive Women is one; your involvement in the various treatment committees is something that other people haven't really told us that much about, so that would be very useful to have.

MA: I think I still have all my minutes from the TAAR committee meetings from back then. I did want to tell you, though, I was starting to tell you about his memorial, James Thatcher's memorial. There were a number of speakers there. Tim McCaskell read James Thatcher's last words. I think it was Tim McCaskell read it. Actually it was reminding me of Brian Farlinger's memorial service, too, which was also a really great memorial service. When I left that memorial service that evening and I walked out with Bob and Linda Gardner, who were members of the steering committee of AIDS ACTION NOW! —I had worked individually with Bob and Linda on different things. AIDS ACTION NOW! was seeming to be constantly setting up new subcommittees. I don't know if anyone else has talked about that. The problem was that we were always being confronted with new issues. People were bringing us issues, somehow we were coming up with them. For example, one thing was there was concern that there were not enough HIV primary care physicians out there. We decided to strike a subcommittee on how we're going to address this crisis or this issue of how to get more doctors involved. So we had a couple of meetings on that, I think with Bob and Linda and some other people there. It was a very small subcommittee. Eventually I think the AIDS Bureau took that issue on and started trying to address it with the OMA, the Ontario Medical Association. Also I worked with Linda and Alan, I remember that was when we were both at Borden and Elliot still, and Linda came to our offices after hours and we worked on a presentation to a subcommittee at provincial parliament. There was going to be a public hearing and we were making a presentation on behalf of AIDS ACTION NOW!, so Linda came to the offices and the three of us worked on a brief that we were going to present to this subcommittee. That was an interesting experience of having to try and put together a brief like that. That was one of the great things about AIDS ACTION NOW! is that it was not just kind of mindless protesting. I think that was one of the reasons that we were a well respected organization is because we had these public protests, but we also were involved in policy making, behind the scenes. We had something supporting our activism. In some ways, at least when I was involved in it, it seemed to me like our public protests and actions -- we used them as a last resort. It's like we would try lobbying behind the scenes. We would develop relationships with, for example, they were kind of nicknamed spec-asses, special assistants to the Minister of Health and so on. We would have a fairly close relationship with those people. Like you know, have their personal phone numbers, and be able to call them and talk to them about an issue, and try to get things addressed. And if that didn't work, and writing letters to the Minister—unfortunately that would get shunted off to the AIDS Bureau to answer the letter on behalf of the Minister—but if we felt we weren't getting anywhere then we would use the activism. You know like threaten to hold a demonstration and then if we didn't get what we wanted then we'd hold the demonstration, and so on. We realized you only have so much currency really of the public interest so you can't just hold a demonstration everyday. And also we found that the press wasn't necessarily interested. We had to become kind of canny. It's not like you could just get hundreds of people to show up at a demonstration all the time. We had to learn how to hook things onto other things. For example, we wanted Glaxo Welcome to provide a drug—it wasn't 3TC, it was a drug after 3TC—I think it was called 1592, originally, and we wanted them to provide compassionate access to this drug to people with HIV. They were refusing to give it. We had tried working with the company. They were steadfast that they weren't giving the drug out. We knew they were doing a plant opening in Mississauga so we decided to demonstrate at their plant opening because we knew there was going to be press there for the plant opening. So we would try to piggyback on other events like that. As I said: try to be smart with our resources, because we knew from experience that if we just sent out a fax notice, if Glen pressed his button and sent out his fax notices that we were going to have a demonstration or something, we couldn't expect that the press was necessarily going to show up. That was also one of the reasons why we had to do dramatic things like burn somebody in effigy, or have street theatre, was just to get the press' attention to an issue. Those were all things that I learned as I went along with AIDS ACTION NOW!

I remember when I left James' memorial and was talking to Bob and Linda Gardner, that I remember saying to them "How did James know what to do?" I felt kind of lost when he died. Like I thought "Oh my goodness!" He seemed to be so full of ideas of what they should be doing, because he was Chair at the time. I guess I didn't realize the mechanism of how AIDS ACTION NOW! worked that well at the time. I didn't realize, I guess I thought he seemed to be coming up with the ideas. I guess I didn't realize that it really was the Steering Committee, this group of people who, it was almost like brainstorming that they would come up with the ideas. I found that when I was Chair or Co-Chair that a lot of it did come from the Co-Chairs and the senior members of the steering committee, people with the most experience and so on.

I think at that time I was starting to think about becoming more involved in AIDS ACTION NOW!, and maybe becoming Co-Chair eventually. I just think I thought that's just way too much for me. I couldn't possibly do something like that. How would I even know what to do? So that was '92. In '93 I became so involved just all at once in treatment activism and AIDS ACTION NOW!. As I said, there were a lot of these subcommittees at AIDS ACTION NOW!. There was our Steering Committee, then there was the Treatment, Access and Research Committee—TAAR—and there was a provincial subcommittee. TAAR usually dealt with the research aspect, so we would meet and discuss the latest research on something. Usually it was Brian who was bringing forth those things. Brian and I were on it, and so was Darien. I think Kalpesh Oza was on it too. We would meet and discuss the latest research that we would have read about that had come up. And also, we would talk about federal health issues. But then for provincial matters, like treatment in hospitals and clinics—in Ontario that was considered a provincial matter—that was dealt with by the Provincial Committee. It was interesting, too, how things started off as subcommittees of AIDS ACTION NOW!. For example, that's how HALCO got started—the legal clinic–was because Mark Freamo went off on his own. People were annoyed with him at AIDS ACTION NOW!, I gathered, because he did that. He didn't follow the way it was supposed to be done. He had just written this letter to the Minister and somehow got this funding provisionally approved, so then they had to strike up this subcommittee at AIDS ACTION NOW!, which became HALCO. So then HALCO went off on its own. And PASAN started pretty much the same way, from what I understand. But they were almost a subcommittee of AIDS ACTION NOW! and then they went off on their own. So it is interesting how they started these things off.

GK: So did CATIE start that way?

MA: That's right, CATIE, was the TIE [Treatment Information Exchange] project at first. I was involved in some of the original meetings for CATIE as well. It was great to see how that happened. We have a lot to be proud of. For example, with the Trillium Drug Program, which isn't ideal, it's not perfect, but I'm always proud to tell people that it was AIDS ACTION NOW! that got that funding. That was one of the things I inherited when I was Co-Chair of AIDS ACTION NOW! was dealing with the hassle of Trillium and its growing pains. Paul MacPhee was very involved in that. He was my co-chair at one point.

GK: There's three different lines of conversation we could proceed with. One is going back to Voices of Positive Women. Another is more around the various treatment committees you were on. The one that probably flows most naturally out of what you just talked about is how you got involved as the Co-Chair of AIDS ACTION NOW! and what that was about as a learning experience.

MA: Okay. In '93 I got very involved in… I mean I already was part of HALCO legal aid clinic, which I stopped when I left work. I just couldn't continue. I was still a member of HALCO's board, but actually when HALCO got incorporated and became a board—I think that was around '95—Louise Binder might have joined the group, or maybe that was later she joined. I think when she joined I decided that's enough, she can do this, I'll step aside. In '93 I was involved with HALCO and Voices and then got on the Steering Committee of the Canadian Trials Network and the Community Advisory Committee. We met twice a year in person and we also had teleconferences as well. I became a representative on the Primary-Care Physicians' Group, which met quite frequently at that time. There were some other committees I got involved in too. For example, insurance issues that people with HIV were dealing with because companies were buying up people's insurance policies. That was an issue.

So the AIDS Bureau struck a committee to deal with the insurance issues. Alan and I and Brian were all on that committee briefly, and then just Alan and I continued on that. Then I got involved in the Unwilling and Unable Committee, kind of a strange name for the committee, but it was also struck by the AIDS Bureau in response to the whole criminalization of HIV issue. We had these ongoing meetings for years dealing with the whole issue of how should the Ministry of Health deal with people who are unwilling or unable to practise safe sex or practise safe needle injection. What we should do about that. I was on that committee for a number of years with James Kreppner and John Playter, from Hemophilia. They became good friends of mine from that experience.

I was involved in those things and, I was telling you before that my health was getting worse around '93, and I went on disability in '93. However, once I left work and wasn't having to work those 12 hour days, and was able to rest more, I found that some of my health issues receded a bit. I had more energy to do all of these committees and be involved. I found it very invigorating and interesting. Then in '94, in June of '94, I was in a meeting with government officials to do with coverage of HIV drugs and this was a great sign of the power of AIDS ACTION NOW! back then. We had managed to get an appointment with the head of DQTC, that was the Drug Quality and Therapeutics Committee, here in Ontario. They made recommendations to the Minister on what drugs should be approved, so a very influential committee.

I know that Anita Rachlis, she was my doctor at the time, she was also on the Steering Committee of the Canadian HIV Trials Network. She was in charge of the Toronto satellite of the Canadian Trials Network. I forgot to mention that when I met her in '93 at these meetings in Montreal, the Canadian Trial Network meetings, she said to me "The Canadian Association for HIV Research has asked me to organize the next annual conference in Toronto in '94" and she said "But I don't want to do it unless you agree to be a community representative on my organizing committee." I said okay. So then I got involved in organizing the next year's annual AIDS research conference. We organized it so that we had a protest. We were so fortunate, because Anita allowed us to put a flyer in the handouts that went to all the conference participants to advertise our protest that was taking place at lunch time one day as part of the conference. We had a speaker from each different track of research: basic science, clinical science, epidemiology, and social sciences, one from each track speak about the importance of getting more funding for AIDS research. We went around Hart House Circle and had all these stands and we spoke. So we had an activist speaker and a researcher. We had all these researchers come out and take part in the protest and it was really one of the first times that they had gotten involved like that—the researchers. I'm trying to remember if Mark Wainberg was—I'm sure he was there. Chris Tsoukas, Immunologist was one of the speakers. Ken Rosenthal from McMaster was one of the other speakers. I was involved in that in the early spring and summer of '94.

Anita had complained to me about the fact that the government was giving her a hard time about approving the use of certain HIV drugs. She said "Come on. I'm an HIV-AIDS specialist and they won't even take my word for it that a drug should be covered for a person." I thought we should get a meeting with DQTC and try to address this. I approached the government, the Ministry of Health, and got this meeting. I invited Anita to come to the meeting, and we had a primary care physician there as well to talk about the issues from their standpoint. Anita was shocked when she got my invitation to come to the meeting. She said "I've been trying for months to get a meeting with them and I couldn't get it." Yet we, at AIDS ACTION NOW!, could just say we want to have this meeting and got it. It really was quite startling that here's one of the top AIDS specialists in Canada and she cannot even get this meeting and yet we can. That was quite a learning experience to see that happen.

It was at this meeting—I was really not feeling very well, I started to feel terrible back pain and had a fever of about 103—it turned out I had PCP, pneumocystis carinii pneumonia, which I found out a few days later I had an x-ray and they discovered… I went for testing actually at Toronto General and had a bronchoscopy. At first they weren't sure exactly what it was, but they determined it was PCP. That was when I really got full-blown AIDS as it was known at the time. Overnight I quit everything. Because really I was extremely ill.

I do have to tell you that at the time I was Chair of the Community Advisory committee of the Canadian Trials Network, and we had a teleconference coming up. I phoned Robyn Sussel, who was our coordinator for the committee at the Trials Network in Vancouver. I said to her "Robyn I'm really sorry, but I won't be able to chair the meeting on the phone because I've got a fever of 103, I've got PCP, and really don't feel well enough to do it." She said "Oh please, couldn't you at least stay on the phone to be on it?" Because I had said, "Why don't you have Sean Hosein chair the meeting, because I can't do it." She said "Oh please, couldn't you at least stay on the phone?" I thought: how can you be so heartless. I mean you're in the AIDS industry. We'd been having people die like flies on our committee. It was just awful. We really lost a lot of people in a fairly short period. I do remember how I thought this is terrible. People have such high expectations of you in this field. It's not enough that you got the number one killer of people with HIV, and you have a fever of 103. Oh well, sorry, that's not enough.

I resigned or took a leave of absence from everything, including Voices of Positive Women. My poor Vice-Chair at Voices, Marlene Freise, she was from the HIV-T group, the transfused group. She was Vice-Chair of Voices and all of a sudden she became Acting Chair, overnight. She wasn't too thrilled about that, but what could she do? I was virtually bedridden for about 9 months with PCP. Because unfortunately it didn't run as smoothly as Brian Farlinger might have thought it would.

It turned out I was allergic to some of the medications. I got one terrible rash after another. I couldn't tolerate the medications. I ended up on Mepron, which was a new drug at the time—or Atovaquone—but unfortunately I was allergic to it too and the only way I could stand being on it was I was to be put on Prednisone, which suppressed my immune response to the drug and then that led me to get pulmonary aspergillosis, a fungal infection of the lungs, which can kill you. I remember talking to a friend of mine, Ken Logue, who was a primary care physician at the time. I said to him, I told him over the phone that I had been diagnosed with aspergillosis, and I said have you had patients with aspergillosis and how did you treat them. Because at that point I was trying to figure out what drug to take for it. He said, "Actually they were so sick we didn't treat them." And I'm like "Oh God! That doesn't sound very good." And then I did some research on the illness and found out that most people die within 6 weeks. And I though "Jesus Christ! I didn't think I was *that* sick." Let me tell you - the drugs almost killed me.

That's when I became Anita's patient. Up until then I had just been treated by my GP, Donna Keystone. As a matter of fact, Donna drove my results over to Anita's house the night she got them. Anita phoned me the next day and she said "I'm cancelling a dentist appointment to see you today." I went in and she said, "Why do people always wait so long to come to see me?" You know, like it's almost too late for you. I thought, "Great." She really didn't have the best bedside manner.

She acknowledged the fact that we already had an existing relationship because we'd known each other from the committees and organizing the conference. But she said that we should be able to put that aside in order to be able to treat you. I said that's fine with me. She started treating me for the PCP and I was also overseen by another doctor who was a PCP specialist in Toronto, Dr. Charles Chan. He was known as Mr. Mepron because he had done the Mepron trials. She put me on IV Pentamidine and I went from feeling pretty good to feeling like death warmed over. You probably know people who have been on IV Pentamidine. It is a horrible, horrible drug. It is really a chemotherapeutic agent. I had to have the first treatment at Sunnybrook at their HIV treatment clinic, or room. Then after that they set me up with home care and they would come here. I would kind of lie on the couch and the nurse set me up with an IV pole and everything.

The homecare nurses were not happy doing this treatment because there was a risk that you die during the treatment. They might really need a crash cart nearby and so on. It was definitely stressful. I do remember, when I read all the potential side effects and everything the night before I started the treatment, I changed my will that night. That was one of the good thing about being a wills attorney is that you could do your own will. Pretty easily change it any time you wanted. Because Christ, there's a chance I could die tomorrow.

I remember I called James Kreppner because he had had this treatment. It was really great being able to talk to somebody who had also gone through the same thing and could reassure me. You know: 'Yes it hurt, and yes, you could feel like your veins were burning from this caustic drug in your veins. It's not that bad and you can get through it.' It was very reassuring to be able to talk to somebody like that. I miss him being around.

I forgot to mention I was in terrible pain with this illness. This was one of the ways they actually finally figured out it wasn't PCP. Well, I had PCP but then it morphed into this fungal infection because of the steroids I had been on. I developed crippling pain, just incredible. Also I got very low hemoglobin, and then I had to have blood transfusions for the low hemoglobin. Because literally, I did not have enough energy to walk across the room to get a Kleenex. I mean I was just really very… I was throwing up because my hemoglobin was so low, and so on. I was in terrible pain from the aspergillosis. I was complaining of terrible pain and they said "Well, PCP shouldn't be causing you any pain." Eventually they figured out that I had the aspergillosis, which can apparently cause cancer-like pain. They put me on morphine for that. The morphine, even though I was on the lowest dose, it was so strong for my system I guess that, literally, I was only awake about 4 hours a day. I could be awake to have some meals and my treatments and slept the rest of the time.

I did go to one AIDS meeting in that time period. It was in the fall and it was the Canadian Trials Network Meeting and it was in Ottawa. I really wanted to go to it. I remember talking to my aunt on the phone and I said I really want to go to this meeting. And she said "Well, why don't you? You could call a cab, take it to the airport, arrange for a wheelchair to be there at the airport. There are ways to do it if you really want to go." So I did that and oh my God, I was so weak. I was puking in the toilet the night before the meeting and the morning of the meeting because my hemoglobin was so low, which they hadn't actually determined at that point. But I did manage to make it to that meeting and I don't really know how I did it in hindsight. Oh! And I didn't tell my family. My family were around here pretty much all the time. My Dad was living downstairs in the house. It's a duplex. And my sister was here, too. My mother lives a few blocks away. Plus I had the homecare for the PCP and the aspergillosis. My mother was popping by almost everyday, bringing groceries and household supplies. I didn't tell my family that I had gone until I got to Ottawa. I called them and left a message. I knew they would have put obstacles in my way to going.

I was virtually bedridden at that time. I was on morphine and became addicted to morphine. Although they tell you there's no such thing as addiction. Well, excuse me, but you still get the same withdrawal symptoms when you try to come off it. I was on the morphine, became physically dependent on it, which I didn't realize until I tried to come off it. The reason I tried to come off it was because eventually, after about 4 months of treatment for the aspergillosis, the respirologist, Dr. Andrew McIvor , really great guy, said "I'm afraid you're not getting better." I thought, that's not good. I really ought to do something about this. I made an appointment to see Kenn Luby, the naturopath in Toronto. I went to see him. I can't remember if I had been to see him before that. I went to see him and he recommended a bunch of supplements for me to take. I remember I was leaving his office and I ran in to Glen Brown that day. Glen Brown invited me to a party he was hosting. In hindsight I thought I probably looked like I was at death's door and here's Glen inviting me to a party. I thought that's so like the AIDS movement. You know, people are at death's door but we just carry on.

I went home and I started taking these supplements that Kenn Luby had recommended. Lo and behold my aspergillosis started getting better. For me, when I started taking that medication, it was kind of a turning point. Maybe also I felt like I had to take control of the illness myself. Obviously conventional medicine on its own isn't working enough. I went back to see Kenn Luby about a year later. I walked into his office and he said "Oh my God! When I saw you the last time I thought you were dying. I thought I would never see you again." I didn't realize I had looked *that* bad.

Once the x-rays revealed I no longer had the aspergillosis and I was getting better I thought I had better stop the morphine. I don't really need it anymore. That's when I realized "Oh my God! I can't stop it." With the support of my family I was able to get off it. It was very hard to stop taking that. I went through a few days of hell, of really wanting to take that drug. Got off the morphine. Then, in the spring of '95, I started on AZT/3TC. I started to feel better within days. Really felt so much better. I was almost dancing a jig in the kitchen. I remember my mother being so shocked. There I was, the person who could barely walk around before and suddenly had so much more energy.

I decided to go back to AIDS ACTION NOW!. That was one of the first things I did, go back to AIDS ACTION NOW! and I went back to the Primary Care Physicians' Group meeting. I decided that I wasn't going to go back to Voices. I decided I only had so much energy and probably time. I felt that I wanted to devote my energies to where I felt I could have the most impact. Also, I knew not everybody could do activism. Not everybody can do that kind of in-your-face stuff. I felt this is something I could do. I could do the policy. I could do the protests. This is one of the things that AIDS CTION NOW! was based around the principle of creating systemic change. We weren't just trying to help person A or person B, we were trying to create change that would help everybody. That really appealed to me because I felt like I was going to get the most bang for my buck in terms of making a difference. Basically, recovering from my sick bed, I thought, "I want to go back to AIDS ACTION NOW! and I want to be Co-Chair." I started going back to the meetings and at the next election I ran for the Steering Committee and to be Co-Chair and that's what I did.

GK: And who were you Co-Chair with at first?

MA: Peter Amenta and then the following term after that, because I think we had it staggered, so Peter Amenta had been Co-Chair with the previous Co-Chair and then he was Co-Chair with me for one year, and then I was Co-Chair with Paul MacPhee the following year. I can't remember who he was Co-Chair with before that. It worked well the way we did it.

And I started going back to the AIDS conferences and hearing the research presented. Fortunately, I had a really good memory at that that time. I could remember things pretty much almost word for word. I could remember all the slides. I had a very good memory. I found that came in handy in dealing with drug companies and government and so on. For example, we had been approached by James Kreppner's partner Antonia Swann (Smudge), because James wanted to get access to a drug called Nevirapine and it was a non-nucleoside reverse transcriptase inhibitor. It wasn't available yet and he wanted compassionate access to it because he kind of ran out of all other options and he felt that he needed this drug. She and he had been trying to get access to it for him, personally, without success. So she approached AIDS ACTION NOW!. We decided to get involved. We contacted the drug company and lickety-split we had a meeting with Boehringer Ingelheim. They flew in one of their top researchers from Belgium to discuss the research with us and why they didn't think they should make this available under the compassionate access program. There were three of us from the community at that meeting. It was James Kreppner, Sean Hosein, and myself. We drove out to Burlington to the company's offices. The three of us met with them and this researcher. Actually I have to back up a bit. Our first meeting was held at CATIE's offices on College Street. Because AIDS ACTION NOW! didn't really have much in the way of an office. We didn't have any money, really. We always had our meetings, for example, at the 519 Community Centre. There was no fluff or frills, you know? We would all bring our own coffee or our own food, or whatever. We didn't provide anything, which I think was a good thing. We were pretty basic. We didn't waste money on things. So when we needed to have a meeting and seem like we were a little bit bigger than we were, we would do things like borrow a board room from CATIE. We did that when we met with David Dingwall, the federal Minister of Health at the time. I think we met with him around '96. With Boehringer Ingelheim, we met them there at a meeting room that CATIE provided. This researcher was trying to tell us why he didn't think he should make it available. But I had been at the previous year's World AIDS Conference and I had seen the research presented myself. And I could remember it and could speak to it and say "Wait a minute! What about X, Y, or Z?" Then they agreed to provide it. Then we had the meeting out in Burlington to discuss how that would take place and how we would set up this compassionate access program. I remember that Smudge was so thankful and I think, too, very impressed that she had been trying and so had James without success. They got AIDS ACTION NOW! involved and suddenly we got access to the drug. Not only for him, but for anybody else who needed it as well.

GK: So maybe we should just pursue the AIDS ACTION NOW! Steering Committee, and you being Co-Chair.

MA: Okay. I have to tell you that I feel like I don't remember as much as I should. I feel like if I had more time and I reviewed some of my files I would remember better. Because as a matter of fact, I did an annual review each year that I was Co-Chair. I set out everything that we worked on and accomplished for each year, so I can give you a copy of that. I don't have it to hand right at the moment. I do know it is in my files. I feel a little bit inadequate that way. Like I don't feel too well-prepared to discuss everything. I can talk about some things, in general.

GK: What was significant for you, or what did you feel like you were mostly working on during that period of time?

MA: One of the biggest campaigns that took over AIDS ACTION NOW! for a lot of the time that I was Co-Chair—I mean there were a number of different things that were going on, there were all these different subcommittees, as I told you about. For example, we were working on the Trillium program. Before my time it had been approved in theory, by the NDP government, thanks to Brent Southin. Glen may have told you about that, about how they got…

GK: So did Brent.

MA: Oh! Did you talk to Brent? I didn't see his name on the list.

GK: It should be there.

MA: Good. I'm glad you talked to him. in part thanks to Brent, because I gather he was there with the NDP Premier and got it approved in principle. Then at AIDS ACTION NOW! we were stuck with trying to get the Trillium program up and running and then deal with all the myriad of administrative problems that we were facing. Paul MacPhee really was our go-to person on that. He dealt one-on-one with the government representative for the Trillium program and was trying to get the forms better and their reimbursement program better. We did a lot of work on that. At the same time, or around the same time, we were also working on the renewal of the National AIDS Strategy. Before we were told that the government was not going to renew the National AIDS Strategy. The National AIDS Strategy had been renewed in '93, that was before my time, and apparently they had a hard enough time getting it renewed in '93. But then it was renewed until March 31st '98.

Things were going along. Around '94 when we had a protest at the Canadian AIDS Conferencewith the researchers we were protesting to try to get more AIDS research funding. As I said, that was '94. Then in '95 I was asked to be on something called something like the National HIV Treatment Forum. There were representatives from all across Canada from the research field and some community members. We were talking about the future of AIDS research in Canada. This was being held in Ottawa. The Minister of Health arrived at the meeting, Diane Marleau. She said they were going to sunset the National AIDS Strategy. That it was not going to be renewed in '98. They were just going to let it go. This was shocking news. It was very upsetting news, too. I remember at the time Brian Farlinger was quite ill and I thought, how am I going to go home and tell Brian this? Here we were trying to fight for improved funding, now it's been taken away from us completely. It felt like the government was pulling the rug out from under our feet.

I flew home from Toronto that day, as I was supposed to, and Diane Marleau was going to be speaking at, I think, CATIE's offices that day. She was giving an announcement there. So I showed up at the office and I challenged her at her press conference about the fact that she was actually taking money away or that they weren't going to renew the strategy. I guess it wasn't a press conference. She was making an announcement to this AIDS organization. I remember when I phoned Brian to tell him about what was going on, he said "Why didn't you phone me from Ottawa? I could have arranged for protesters to have met Diane Marleau at the airport." I thought, 'Good God! There's no pleasing Brian.' [laughter] "Sorry Brian. I didn't think of that."

After that I went to the next AIDS ACTION NOW! meeting and I said to them "Look, this is really very important. This is, I think, more important than anything else we're dealing with. If they don't renew the National AIDS Strategy there's going to be no federal funding for AIDS programs or research. That's incredibly serious. It's going to affect every AIDS organization in Canada. I think that we just have to make this a priority." At first there was a little bit of resistance. I remember some people not really wanting to take this on, or not feeling that this was that important. I remember talking about this with some AIDS researchers and some of the people who'd been at that meeting in Ottawa. We, in the AIDS research community—and I kind of consider myself a part of that community—they were struggling with how do we make people aware of how important this issue is? I said "I don't know. All I know is I just went to AIDS ACTION NOW! and said 'Look, we just have to address this. This is just so important.'" We did start trying to do some things, like some press conferences and things like that. We started a campaign and Paul MacPhee was instrumental in this. Just as had been used when the CBC was facing a loss of funding, they had used a telephone campaign, getting people to phone their federal representative—their MPs— and get people to say that they didn't think they should reduce funding to the CBC. So Paul had the idea we should do something similar for AIDS. He was responsible for setting up this big telephone campaign across Canada.

That was another thing. In a way, AIDS ACTION NOW! spearheaded what became this national campaign. We realized we needed to leverage the AIDS organizations' person power across Canada. I would write briefing documents and give it to the OAN [Ontario AIDS Network] and CAS [Canadian AIDS Society]. We dealt a lot with CAS. I had a document at home that outlined where the National AIDS Strategy funding went to all these AIDS organizations across Canada. I looked at that document and highlighted who was going to lose what. So that was useful. Plus, we provided briefing documents to the Canadian AIDS Society. They sent out that information and petitions and things like that. I was drafting petitions at home. I remember being so weak and so tired. My mother was over here and she's going "Do another petition." I was like, I can't do another petition. I was trying to draft another bloody petition and my mother was taking it to people and getting it signed by relatives. We were sending it all over the place; all over the country these petitions were being sent. So people did a lot of outreach with these petitions. Taking it to people and meeting with members of parliament and so on. We even got invited to a breakfast meeting in Ottawa to speak to a parliamentary non-partisan breakfast meeting. I spoke at that and tried to… I realized, and I had been told this over the years that statistics don't really affect people. They should. Logic should move politicians. But it doesn't. What people need to hear is personal stories. I tried to think of how did I personally benefit from programs that were funded by the National AIDS strategy. So I spoke about that at the breakfast meeting.

We had been doing all these sorts of things. Also, Paul MacPhee also led a campaign to get funding to put a full page ad in *The Globe and Mail* leading up to the World AIDS Conference in Vancouver in '96. That was actually a very important thing that was taking place. We realized it. We thought this is a kind of a once-in-a-lifetime opportunity that the World AIDS Conference is taking place in Vancouver, in Canada, in '96. So the eyes of the world, so to speak, will be turned on Canada. This is a way we can shame the government into renewing the National AIDS Strategy. That was our plan. We knew that there would be a lot of media attention leading up to the AIDS Conference, so we gave interviews and talked about it. We had demonstrations out in Vancouver. It was a big disappointment that Chretien refused to go to the International AIDS Conference.

David Dingwall, who I can't stand—a real jerk—he was a bully. He threatened us as an organization that if we gave him a hard time at the International AIDS Conference. We had a meeting with him before the International AIDS Conference here in Toronto at CATIE's offices. He just threatened us. We went ahead and had our protest, which was very good. We couldn't have done such a good job on the protest if it hadn't been for the assistance of Martin Schechter, who was head of the Canadian HIV Trials Network. He was Chair of the CTN when I was there. Then Mark Wainberg became Chair around the time that I resigned. He was one of the Co-Chairs of that conference. He had invited me to speak as a keynote speaker. I spoke about compassionate access at that conference. He knew we were planning to hold a demonstration when David Dingwall was speaking, so he arranged for us to get front row seats—the AIDS activists. We were all in the front section, right in front of David Dingwall. That was very handy because had we been scattered right throughout this huge uditorium, it wouldn't have had an impact.

We had the protest. We still didn't have the funding. We thought "Oh brother, now what? back to the drawing board. I guess we'll just have to keep going." At that point we still had almost 2 years before the funding ran out. However, in early '97 I started to get phone calls at home from some of the researchers, like Martin Schechter. And he said "Look, this is becoming really serious because the problem is that we can't hire new people because the funding is running out in a year. So in good conscience, we can't hire somebody if there's no ongoing funding." That kind of hit home and I thought, "Now we really have to do something." We did have things. We did do a press conference with Martin Schechter. I think Mark Wainberg was at one of the press conferences we had. We felt that as activists we had to have the added weight and credibility of these AIDS researchers with us. Showing how important it was. I think that was helpful. But again, logic really doesn't win out.

We at AIDS ACTION NOW! knew the government was going to be having their federal election in '97, so we thought this was going to be our opportunity. We're going to have to dog the campaign wherever it goes and we're going to have to dog Chretien wherever he goes. Fortunately, one of the first times around the time there was going to be an announcement of the election, Chretien was in Toronto. He was at an event first in the morning down at the Canadian National Exhibition grounds. He was at that first and there was only a handful of us there for that. I remember I arrived first with my little placard, standing there. We knew he was going to be speaking at the Sheraton Centre Hotel later that day at a fundraiser, so we at AIDS ACTION NOW! had decided that we were going to hold a demonstration outside of the building and that we would pay for two tickets—one for Louise and one for me, Louise Binder—and that we would confront the Prime Minister at the luncheon. So that's what we did.

First we had the demonstration at the CNE grounds as he went into that building. And then we all scurried down to the Sheraton. I remember my mother was with us, too. And Louise and I were wearing suits. We felt we had to blend in with the crowd and also we felt we didn't want to look scruffy. I remember this is something that Bill Harris said to me once that he remembered turning on the TV once and seeing something about AIDS activists and that he was impressed when people looked… as if people can identify with these people. For example, when you see business people protesting it makes you look twice. You don't go, this is some rabble or something. I think the average person might take it more seriously when they see somebody in a suit protesting. You have to think about that. You have to think about the way things look. That reminds me, that was something Glen Brown used to talk about. He was one of our media experts. I remember him talking about how one had to be aware about how one presented oneself. So for example, he would wear his AIDS ACTION NOW! T-shirt with jeans, but always wore a black jacket over it, so he had that kind of mix of looking somewhat business-like with a suit jacket or a blazer and the AIDS ACTION NOW! T-shirt. As I said, we were very aware of how things appeared because we knew we had to get the support of people, voters, because that's the only thing that's going to matter to the politicians.

GK: Right. So you go in wearing suits?

MA: We're all in our lawyerly suits. Of course, Louise used to be a lawyer too, at one time. It was a little bit awkward, but we ran into people I knew from Borden and Elliot and they had some extra seats still available at their table. They said we could sit with them. They had no idea we were going to do this confrontation. I felt badly about that.

We were sitting at a table about 20 feet from the head table and the podium. We were quite nervous. We were sitting there trying to work up the courage to do this. It was nerve racking and there was tons of security. I guess partly because there were other protestors at this meeting. We were not the only protestors there. As well, there was a group protesting about access to day care.

GK: AIDS ACTION NOW! also had a picket outside as well?

MA: Yes. So we were first protesting outside and then Louise and I slipped inside with our tickets. We got seated at this table near the front. We had decided what we were going to say. As I said there was a lot of security in the room. I seem to recall the wall being lined with men in dark suits. We were worried that we were going to be arrested because we were both on HIV medication and, especially in those days, if we are arrested and put in jail and we don't get access to our medication this could be really serious for us. I had never been arrested. Any protest I had been at had always been very polite. And actually we had always been treated very well by the police when we had protests.

Chretien was introduced and he stood up from the head table and walked over towards the podium. Then Louise and I sprang out of our seats and in unison shouted "WE'RE DYING WITH AIDS! WHEN WILL YOU RENEW THE NATIONAL AIDS STATEGY?!" We didn't even have the words out of our mouths when these big, burly guys grabbed us and started dragging us out of the room. It happened very quickly. Fortunately, it was all caught by the TV cameras. So it was on the news that night.

They took us out of the room, out into the hallway. The head of security was there. There were RCMP guys and the head of security for the hotel. They took down our information but nothing bad happened to us. We didn't get arrested. The head of security from the Sheraton said "Never, ever come to this hotel again." [laughter]

GK: They didn't give you a trespassing ticket or anything?

MA: No, they just let us go.

GK: So that has no legal validity.

MA: No. But we were just relieved to get out of there. To be honest, I was so shaken up afterwards—I felt like I was almost trembling afterwards—it was not an easy thing for me. Later that night Chretien flew to the Maritimes and I believe he was met with some protesters there, as well.

GK: In the Annapolis Valley, yes. I think he was at a Girl's Guide meeting, or Boys Scouts.

MA: It might be. I can't remember. He had flown to something and I believe there were some AIDS protesters who had met him at the airport. So that was good. Good coordination. Then the very next morning in the, I think it was the Saturday *Star*, there was an article in the paper that said that Chretien's people had leaked the information and that they were renewing the National AIDS Strategy ahead of their formal announcement that was going to follow. We felt that was a real success that we got the $42 million a year to be continued because of what we did. Our strategy worked pretty well. I mean there was a lot of work that went in to it and we worked for it for a couple of years, but it all came together in a way with those protests. But really probably the most influential thing were the protests.

After the election Allan Rock became the Minister of Health, and then there were negotiations about what the renewal would be like—what the funding would look like. But I started to get less involved after that. I kind of got burnt out because I had pushed myself so hard. I was still recovering from the aspergillosis. I mean, there were times I would get up in the morning to go to a press conference and I would be coughing up blood and not sure if I was going to be able to continue. And plus, I was pulled in a lot of different directions. At the same time I was doing the renewal of the National AIDS Strategy and trying to run AIDS ACTION NOW!, I was also co-principal investigator of the Canadian Women's HIV Study with Catherine Hankins. That and some other committees I was on I just really felt overwhelmed and burnt out. I felt like I think I have done enough for now. I pretty much retired for most of my involvements. I had still had some involvement with AIDS ACTION NOW!.

Also, I think that AIDS ACTION NOW!, with the approval of the protease inhibitors and the coming around on the market around, I guess '96 or '97 they started to come out and become available. There was media coverage that made it seem like AIDS had practically been cured. That made it much harder to get media attention to HIV. It made it much harder to get people to come out to AIDS ACTION NOW! meetings. I think that people just didn't feel like AIDS was as important or as much of an issue. Sometimes I felt kind of bitter. I would go to these AIDS ACTION NOW! at the 519 week after week and I felt: here we are a handful of people busting our guts and I walk by all these people sitting, having coffee at the Second Cup, or something, on Church Street, and nobody is coming and helping us. We tried to do things to try and reinvigorate AIDS ACTION NOW! and get more people involved. It just really didn't work. I know that we went to more of a quiescent status, like having meetings when we needed to and so on. I think it was still useful having an organization available if you needed it. Certainly my experience with AIDS ACTION NOW! had shown me that companies and government won't listen to individuals, but they will listen to an organization. Even if you're just a tiny little organization and you really have almost no money and resources. So it's definitely useful having that organization available.

[END OF PART ONE]

January 19, 2018 [PART TWO]

Persons present: Maggie Atkinson – MA
Alexis Shotwell – AS
Gary Kinsman – GK

[START OF TRANSCRIPT]

MA: Actually, when I read over your list of questions last night, I thought, "Oh God, I really feel like I don't think I have that much to talk about." Because, well anyway, you can ask the questions.

GK: Yes, and then we'll see where it goes.

AS: Okay, so, officially we're beginning, and it's February 19, 2018. And we're talking to Maggie Atkinson, part two, in Toronto about Toronto.

GK: So, I'm assuming from the discussion we just had before we started, that there's nothing you really want to add in from the first transcript.

MA: No. Not really. Though there was one thing that came to mind when I read over the transcript, because one of the questions you asked was if I had any history of being involved with activism before I got involved with AIDS, and it did occur to me that when I was at law school I did belong to a women's rights organization. It was called Women and the Law. So, I did belong to that. We were dealing with some pretty serious issues of sexism and so on at the law school. For example, there were horrible anti-female graffiti that were in the men's washroom. Somebody went in with a camera and took photographs of it, and then they posted them in the hallways, and I think that the administration wanted to shut it down-- they said it was obscene. So, it was okay in the washroom, but out in public it was obscene. The men had drawn pictures of hanging women. It was terribly violent stuff. It was against the women who belonged to Women and the Law. So, it was really quite something. Anyway, but I never was involved really in activist organization and going to demonstrations and stuff like that.

GK: You said you were also involved, I think, in some student groups in university.

MA: Yes. I mean, it was student politics, yes.

GK: Yes, so that produced some familiarity with meetings and organizing and stuff like that. So, what I thought we could do is go back to AIDS ACTION NOW! and talk a little bit more about it, and then move into some of the other groups you were involved in, if that sounds okay.

MA: Okay.

GK: So, around AIDS ACTION NOW!, we didn't really talk that much about AIDS ACTION NOW! and women's issues and treatment issues. So, I was just wondering if you had any memories of when you were involved in AIDS ACTION NOW!, how it might have addressed those questions.

MA: It actually, I don't remember it being a really big issue at the time. I remember, I think that it was before my time that Darien was involved in doing a pamphlet on clinical trials and women. And so, there was an issue of ensuring that there was representation in clinical trials by women. Voices dealt with that to some extent. If there were any issues, then it probably would have come through the Treatment, Access and Research committee, TAAR, and then come to AIDS ACTION NOW!'s Steering Committee to be addressed. But over the years, I only remember a couple of issues where it came out through the research that things were different for women. That, for example, I vaguely remember that there was some concern about serious side effects with Nevirapine, and that women seemed to get worse side effects. So, that was one of the rare instances. Also, I came across something when I was looking through my papers last night, from 1999, that a couple of studies, including one from Ontario, showed that when men and women had the same CD4 count, women seem to have a lower viral load. It was the first time that there had been any difference shown. I mean, it was interesting, but you know, they didn't really know what to take from that.

But on the whole, I felt that the issue of doing research on women was almost sidetracking us from the most important issue for women, which was research on drugs that were going to keep us alive. Because the number one killer for men and women was PCP, for example, pneumocystis pneumonia. I felt that we needed better drugs, we needed early access to the drugs, and we needed them on the Formulary, we just needed to keep people alive. I felt that was our first and main concern. I felt that all research was potentially going to help women. Also, from what I understood, in many of the trials they couldn't get enough women to enter the trials. The numbers were so small that they couldn't do separate analyses. I mean, that seemed reasonable to me, and as I said, we were just fighting to try to keep people alive. I wasn't really interested in spending a lot of time and energy on addressing women-specific issues. Though, through Voices of Positive Women, for example, we did have a meeting… I think it was in the fall of '92, maybe, that we had… or maybe it was the spring, I can't remember, we had a meeting with doctors. It was called The Dialogue. It was between women and doctors, and it was breakout sessions and small groups, and it was very good about dealing with issues about women and HIV. Oh, and AIDS ACTION NOW! did put out a flyer on women's issues, and what women should be looking for and the issues like getting Pap smears done regularly. I found a copy of it yesterday. But I don't know the date of that.

AS: And do you remember- I mean, because in the US there was a lot of work that was basically trying to educate doctors about indications of HIV that would be more prevalent – you know, so like having frequent pelvic inflammation, or—

MA: Right. Yes.

AS: Was that part of the educational work that you were doing with doctors? Or was it—

MA: I mean, I do remember that, and I do remember the issue coming up about, that women may have different symptoms of full-blown AIDS—

AS: Yep.

MA: A little bit like the, what they say about women and heart disease now.

AS: Right.

MA: You know, that the symptoms may be different and that, therefore, the definition of AIDS may not be appropriate for women, it may not be inclusive enough. So I remember there was talk about that. But I don't remember how we addressed it.

AS: Yes.

MA: As I said, I know that AIDS ACTION NOW! did do this flyer. Actually, I think it was mainly *taken* from some other source. Voices published the same thing. But that was educating women on what they should be looking for.

AS: And I think that maybe that was also after, like, the CDC in the US changed the definition. And I think that maybe that flyer was one of the things that came after that, so that doctors in Canada could have been referencing the updated definition that had, like, T-cells and CD4 cells as part of the—

MA: Yes.

AS: So, it would be interesting. I should look at, I think we *might* have some other, someone else who gave us the flyer who had talked about—

MA: Oh, really?

AS: —what dates, so we should check it.

GK: Right. Yes, we can—

MA: You mind if I get up and—

GK: Sure. No. You can move around, you can do whatever you want.

MA: I think, I think I… [rummaging] Is this the one you're thinking of?

AS: Yes! That's right. Yes.

GK: Which one is that?

AS: Have you seen this one? You must have seen this, Gary.

GK: Oh, no. I haven't seen this one. I don't remember seeing it. I've, certainly I've seen other things from AIDS ACTION NOW! and women's issues, but not this particular one.

MA: Yes. Remember, that was a big controversy when they, when the United States decided to change the definition of AIDS to be a T-cell count below 200.

AS: Yes.

MA: But Canada didn't follow that. I mean, we still, in Canada it was still, you had to have the AIDS-defining illness.

AS: Ah-ha. Really?

MA: Yes.

AS: Can you say more about that? Just that it—

MA: I just remember that it was still considered an American definition. That AIDS was, see they did it for purposes of benefits.

AS: Uh-huh.

GK: Right.

MA: So it wasn't considered a medical definition. It was really just for ease of people getting access to social benefits. So, in Canada, I believe you still had to meet the definition of, like, you know having PCP or something like that, or I think it was like, was it oral… not oral thrush, but… esophageal thrush. Things like that.

GK: Yes. Because that change came about because of a long campaign. It involved other groups but, at the core of it, were this, a lot of activists from ACT UP New York City, trying to change that definition.

MA: That's right. Yes.

GK: So. Maybe we should talk about Voices and then move back to the ending of AIDS ACTION NOW! since we're talking about women and AIDS stuff. So, you'd left Voices, you'd been quite involved in Voices, you'd left it when you got really ill.

MA: Yes.

GK: Did you get reconnected with it, or…?

MA: No. No, I didn't. So that was, I got ill in June of '94 and then, so yes, I'd been Chair right up until then. After that, Marlene Freise took over. She was the vice-Chair. I believe that after that Louise Binder became Chair. So I didn't really feel any need to get back involved in it and, as I said, I really, it wasn't until this, well, I started recovering. I went on AZT/ 3TC in the spring of '95. I started going back to AIDS ACTION NOW! meetings then, and also the Primary Care Physicians Group, I went to some of their meetings. I got more involved in AIDS ACTION NOW! and got elected co-Chair, I think it was November or December of, '95. So I didn't really have the time and energy to go back to Voices at that point, and then I was so busy with things like, trying to get the National AIDS Strategy renewed and, *plus* we were working on so many other things. When I read over my notes, the end-of-year review I did in '97, and I thought, "Oh my goodness, we were working on *so* many different things." We really were kind of run ragged working on these issues. Like the *national* treatment issues of trying to improve the research, trying to get drugs approved, trying to get compassionate access to drugs, trying to improve the drug regulatory system in Canada, and then once drugs were approved, trying to get them onto the Formulary, trying to get them approved provincially.

AS: Yes.

MA: And then dealing with the Trillium Drug Program, so. And then, all these other myriad little issues that would come to us like, "Oh, we need access to, compassionate access to a drug from a drug company where the trials are going on." Another issue was we found out that HIV-positive women who were on benefits, they weren't getting free formula, for breast-feeding. They weren't getting free formula for their HIV-negative babies.

GK: Right.

AS: Oh…

MA: So they were in the position that, were they supposed to *breast feed* their babies and potentially infect them? So, so we got involved in that, in pressuring the government to cover that.

AS: Yes.

MA: And so, as I said, there were all these issues that you wouldn't even *imagine* that you would be dealing with, that you were.

AS: Yes.

MA: So.

GK: Right. For sure.

MA: So that's, that's more or less why I wasn't involved with Voices. I just didn't have the time and energy, and I felt that it was being ably managed by Louise.

GK: Right.

AS: Yes.

GK: That's great. So… Great. If we're talking about the late '80s, sorry, the late 19*90*s, and moving into AIDS ACTION NOW! becoming, I think you used the word "quiescent."

MA: Yes.

GK: How does that take place? I think at one point, maybe in—

AS: Well, before we talk about the quiescent period, I just… We haven't had very many people who can tell us much about the period that happens after '96. When all of a sudden, the whole situation changes. And you were just talking a little bit about the work that was happening in '96, '97. Like, sometimes we get this image, because people withdrew, often, when the drugs became better and people felt maybe a little bit less of a sense of active crisis.

MA: Right.

AS: So just if, I wonder if you could talk a little bit about how that felt in AIDS ACTION NOW! for you?

MA: Well, I think I did talk about it a little bit at the end of the interview, where I said I felt frustrated that, a handful of us were being at meetings and working hard—

AS: *Really* hard. Yes.

MA: And, I'd walk by *all* these people on Church Street and think, "Here we are, working so hard for, many of *you*. And nobody's coming to our meetings." And we did have interviews with Xtra to try to get the word out that, we really needed more people to come out. That *was* frustrating at that time. I guess there was a noticeable drop in attendance. But, actually, we still had quite a few people coming to meetings at *that* time.

AS: Yes.

MA: I would say it wasn't really until, say, '98, '99, 2000. That's when we had *really* small meetings. As a matter of fact, I was reading over some of the minutes I found from 2000 and, we'd have some meetings where there were maybe five people there. And it's just the hard core of us, the same old names, like… me and Paul MacPhee, and Greg Robinson, and Brent Southin, and, there'd be a handful of us there. At one point, we had an employee, too. Alex. So he was there, as well, taking the minutes. So, yes. Those days. I can see why it eventually fell apart then. But in '96 we were still, I think, pretty energized. There was still quite a good number of people coming to meetings. Actually, in '97 I think that was, I believe it was '97 it started, or maybe it was '96-'97, that Jim Wakeford started coming to meetings. And he was interested in a couple of issues. One of them was Wakeford's Wagons. I don't, have you heard of that?

AS: No, what was that?

MA: Oh. It went on for a little while. It was kind of like Meals on Wheels. But he wanted to have, like, gourmet food prepared for people and delivered to their homes. We weren't really involved in that, but he did approach us about some support for it. And so he did have that up and running. I don't know the details about it, but… there were other people supporting that. He had a committee, I think, helping run this Wakeford's Wagons. Also he wanted our support on medical marijuana. So we did have a medical marijuana, sort of, subcommittee. Jim took it upon himself to, he felt that we needed more funds, that our coffers were getting low. I mean, we didn't have a lot of expenses, but… Anyway. So he had our first, he organized our first ever fund-raising campaign, because he felt we had to kind of have this war chest. So we wrote to all the members who were on our mailing list, of AIDS ACTION NOW!, and… I think we got about ten thousand dollars from that. He had a few little fund-raising events. For example, we, we showed a film and actually… I'm trying to remember. I think that we, I think Pam Davenport, who was Brian Farlinger's sister, I think she did a screening of the film she did about her brother, Brian Farlinger, so that was a fundraiser for AIDS ACTION NOW!. That kind of thing. Anyway. So, yes, I would say there was still quite a bit of activity. I mean, there was lots of *activity*, but there was still quite a few people coming to meetings back then.

I think we did have a meeting – a stand-alone, day-long meeting, with break-out groups – I don't know if other people have talked to you about it. I think it was around the time of our tenth anniversary. It was to discuss the future of AIDS ACTION NOW!. I believe that was 1998. That was definitely when we were in trouble. In a way, I think it kind of only got worse after that. I mean, I was co-Chair with Greg Robinson and, I think it was Paul MacPhee, for the '98-2000. There were three of us – which was unusual, normally it was two co-Chairs. When I look at our minutes around 2000, there was definitely a fall-off in terms of how many people were coming to meetings. As I said, down to five or eight people. And sometimes, yes, in a way it must have seemed odd. I saw in the minutes that, I remember, we got approached by, oh, I can't remember his name. El-Farouk, or something?

GK: Yes.

MA: The lawyer? Anyway, he came to one of our steering committee meetings, because he, a friend or a client of his, wanted access to… I think it was Abbot's… an Abbot drug, I think? And something else. So, anyway, he came to our meeting, but there were only maybe four or five of us at the meetings. So he must have wondered, "Oh, this is AIDS ACTION NOW!'s steering committee?" I mean, considering we used to sometimes, maybe twenty-odd people there, and now we're down to only maybe four. Anyway. According to our minutes, I think Tim McCaskell took that on and decided to try to see if there was anything that could be done for him.

GK: I'm sure El-Farouk was quite happy. Regardless of how many people were there. Knowing him, anyway.

MA: Yes. Anyway. So, yes. I don't remember it really being as much of an issue back then. No, I think we had a pretty robust group back in, say, '96, '97.

GK: So '98 is when you're signaling things are starting to get more difficult?

MA: Yes.

GK: Do you want to just describe the next couple of years, from your vantage point? And at some point you disengage from AIDS ACTION NOW!.

MA: Yes… Well, I was co-Chair 'til 2000, and so I still attended some meetings into 2000 and maybe 2001? But then, after that, I mean I think I have *one* reference to a meeting in

2002, maybe. Actually, I believe, looking back at my resume, my CV, and my records of other— because I was on a number of other committees at the same time, like, for example, as I mentioned before, I was co-primary-investigator on the women's study, that was the Canadian Women's Study and it was run by Cate Hankins, from Montreal. So they were primarily looking at women and cervical cancer and, so I'd kind of been dragooned into being the co-principal investigator. She felt it would look good for the funding applications to have an HIV-positive woman as a co-principal investigator. So I agreed to do that, and it was primarily… I think it was, like, monthly teleconferences and all sorts of documents to read. I also was involved with the beginning of CTAC and also the Ontario HIV Treatment Network (OHTN). I was on the first board of OHTN for a little while. So there were a number of different things going on, and it got to the point in, I guess it was around 2000, that I just thought "I can't do this anymore." I remember Cate Hankins saying to me, "Oh *please* can't you stay on the committee," she said. "You know, you could just be on the other end of the phone." I thought, "I *can't* do one more teleconference." I felt as though *every cell* in my body was screaming NO.

GK: [laughing] Right.

MA: And so that's when it, I just quit everything. Overnight. And I just said, "I can't do, can't do…" Oh! Like, for example, another thing I was involved in was I was the community representative on The Canadian Association for HIV Research (CAHR). I was actually their first community representative. That ended in 2000. My term was up, thank goodness. I had been on through the Canadian HIV Trials Network, and I was also on their ethics committee for a little while. I just kind of put a halt to everything for a little while. Maybe it was about a year before I went back to a CAHR meeting. I don't know if I've answered your question. What was your question again?

GK: Oh, it was about what you just talked about. So that was good.

AS: Yes. And it was kind of, just reading your transcript, really… really made me reflect on the number of times that people say "I know that you're saying that you can't, you don't have energy for this, but just… be on the end of the phone." You know?

MA: Yes…

AS: As though that doesn't take any energy. There's also something just about that work of being the community representative, right? Who's expected to hold that.

MA: Yes. Actually, though… At the time, I was talking it over with some friends of mine and saying, I felt very torn about leaving the Women's Study. They were having a tough time getting funding. You know, a friend of mine who doesn't know that much about the AIDS movement or anything, she was saying to me "Oh, come on. Nobody's irreplaceable" and "So if you step down, somebody else will do it." *Nobody else did it!* The problem is they *lost* their funding. You know? That was the end of that study. And so… yes. I do, I feel a little guilty that I didn't do it. But… [laughing] But, anyway.

AS: It's like, how, how much can a movement *ask* of people? You know? In a certain way.

MA: Well, speaking of that kind of philosophical issue of, "How much do you give?" I think that when we thought we were going to die soon, we were willing to give everything. It's kind of like doing a sprint. That, when you think "Okay, the finish line's soon. I'll just keep going 'til I can't go anymore. I'm going to die anyway, so what difference does it make?" You want to make a difference before you die.

GK: Yes.

MA: But then after the protease inhibitors came out, we thought, "Wow! You know, hey, we might survive this!" Things felt different. You thought, "Okay. I don't want to go to the meeting, because I'm feeling sick. Because I want to get better." Whereas before, you'd go to the meeting when you were sick, because you think, "Well, what difference does it make?" You know? So I think that some of us began to feel a little different that way, that you were trying to save yourself for the future because you knew that, maybe, the future was possible. But I definitely was burnt out. Also, I felt that there was no balance in my life. That my *whole life* had revolved around AIDS ACTION NOW! and the AIDS movement. The AIDS movement and all these committees. I felt I never had any time for friends and family and they all took a back seat to AIDS. I thought, "You know what? I want to spend some time trying to redress that imbalance." Anyway, after that, I got involved in a few things. You know, not that much. I think, in a way, I just felt like, "Okay. I've done my time"? I still would get the odd call from time to time, from people asking me if I wanted to do something. And if it seemed interesting, then I would get involved.

GK: Right.

MA: Like, for example. Martin Schechter, from the Canadian Trials Network. He asked me if I would be the Canadian representative – Canadian community representative – on a multi-national trial that they were doing, the optima trial. I was on that for about seven years.

AS: Wow.

MA: From 2001 to 2007. And so… It was quite interesting. It was a trial comparing people on three to four drugs compared to, like, Mega-HAART. Because, at that time, that was an issue of "Is Mega-HAART better" than the standard HAART – or highly active antiretroviral therapy.

GK: Right.

MA: So, anyways, so it was a study, it wasn't a drug company study, it was run by three governments. Or funded by three governments. It was Canada, the US, and the UK.

AS: So interesting. I didn't know that about it.

MA: Yes. So that was interesting. And it involved traveling to London and to New York occasionally, and meeting with new interesting people. I think there was somebody else from the Canadian Trials Network involved in it, too, whom I knew, besides Martin. I did some things like that. I also got involved in work on HIV and the brain, neurocognitive issues. That's starting around 2007, 2008. I don't know if you want me to talk about that.

GK: I think that Alexis would *definitely* like you to talk about that.

AS: I would love to hear about that.

MA: Oh. Well. That began as a, really as a personal issue, because for years I'd noticed that HIV was affecting my brain. I guess when I got full-blown AIDS, I noticed it. That, it was affecting my handwriting, and maybe my memory a little bit. But, and I did speak to my GP, Donna Keystone, about it. She sent me to see Shea Rourke, who was doing research at the Wellesley at the time. So I went to see him, for testing, and the first time I went, he said, "Oh, your testing normal" but he said, when people are high functioning, sometimes the tests aren't sensitive enough to notice a difference. They hadn't tested me before.

AS: They didn't have a baseline.

MA: Yes. So. I continued to be followed by him. Of course, Sean Rourke, at the time, had no funding to do these tests, because it's not covered by OHIP or anything.

GK: Right.

MA: But, he was looking longitudinally at people with HIV and he still continues to do that. Anyway, when I'd meet with him, I'd say, "Is there anything that can be *done* to, do you have any intervention, anything that could help people, rather than just *follow* them—

AS: Right.

MA: Is there anything that I can do to preserve my brain function, or to improve it? You know, like you hear people talk about bridge and crossword puzzles and things like that." And he said "Well, really the evidence wasn't very good for those things." He said "Well, all I can tell you is that whatever helps the *heart* may help the brain." I guess blood flow and so on. So that got me interested in learning about what I could do for my heart and my brain, in terms of nutrition and exercise and so on. Also, I had been diagnosed with high cholesterol. I got quite interested in that. I didn't want to go on drugs, so I tried to control it with diet. Around 2005 to '7, I was noticing problems with word recall. It began with things like I couldn't remember the names of actors or the name of a movie, or things like that, that tend to happen to people. It started to get worse. I was having problems with, first complex words, then more basic words, like things like, even a word like "toaster" or "hanger" or things like that. It got to the point where I didn't want to go to meetings anymore because I was embarrassed. I would go to say something at a meeting, went to open my mouth, and the words… just wouldn't come out right. That's maybe not the right word. I would be searching for the right words.

GK: Right.

MA: So, anyway, I happened to see a television programme on TVO's "Agenda" with a guest, Norman Doidge, who wrote the book *The Brain That Changes Itself.*

AS: Yes.

MA: So he was speaking about a program called the "brain fitness program." A computer program, which was available through researchers in California, predominantly. It was *very* expensive. I actually ordered it for my dad and myself, because my dad had had a stroke. He'd had a stroke, maybe the year before that affected his memory. It's five hundred dollars for this thing, which seemed like a lot of money. It was, like, disks that you put on your computer. Anyway. My dad— it's a program that takes about two months to do? You do it an hour a day, five days a week, forty sessions. It had been shown, in some early trials in the US, to improve speed of processing and memory, could turn back the clock by about ten years.

AS: Wow.

MA: It was tested in people mainly in, like, a retirement home. So anyway, my dad and I both did it at the same time. We each did it every day. After about ten days, we started to notice a change. We both noticed independently that our handwriting improved, and that our memories started to improve. Anyway, I told Sean Rourke about it, and he was interested by the fact that I said that it improved fine motor control, too. As a matter of fact, I didn't even realize that my fine motor control *had* been affected? But it was only in hindsight that I realized that I had been having problems with things like putting a key in the door or dropping things and so on. Anyway. So then I told my friend, Greg Robinson, about it because he was having terrible problems with his brain function—

GK: Right.

MA: With his memory, and fine motor control. All sorts of manifestations. He had also been tested, I believe, by Sean Rourke. Anyway, he got tested by Sean before he did the program, and immediately afterwards. He had been at the point of almost dementia level on three out of nine tests and parameters, and afterwards he tested normal on all of them, and he tested above-average on three out of nine. So it just made a remarkable difference. So when he gave him the results, Sean apparently asked him if he'd cheated somehow.

AS: [laughing]

MA: Sean said he had *never* seen such improvement in results before. I kind of nagged Sean for a while, and then he agreed to do a trial. So he did a pilot study. First, he wrote up the results with Greg. Then he did a pilot study on the Brain Fitness Program on people with HIV. They are doing a larger study, now.

AS: That's amazing.

MA: They found definite improvement in people with HIV.

GK: That's great.

MA: So, actually I'm kind of glad. I feel like "Ahhh," you know. Because of my prodding and suggestions that this kind of got off the ground.

AS: Because you had a lot of engagement with, like, the physicians group and with various, like, treatment… did that, I mean that all just arose through engaging with HIV and AIDS. Right? You'd been a lawyer, without a medical orientation or background before?

MA: Yes, I guess when I was in university, and I was trying, I mean I did a degree in Classics and German. And I was trying to decide what to do afterwards, because I knew you couldn't get a job doing Classics unless I taught or something. But, so I was seriously considering law, but I was also considering medicine. Because I had an interest in it, and, I mean, I hadn't done any science since high school, but I still did consider going, applying to McMaster, to do medicine.

AS: Right.

MA: But I decided that, especially because of my interest in student government, that my personality was more geared to law and committee meetings and things like that. I thought law would be a better fit for me. Sometimes I wish I had gone into medicine. As I said in my earlier interview, just like some people with HIV, of course I was interested in the treatments and so on. But then it was really going on the Steering Committee of the Canadian HIV Trials Network that threw me in at the deep end. I suddenly got involved. I met all these researchers on the Steering Committee, and I attended the CAHR meetings and met more researchers, and they were all so welcoming and friendly. Well, for the most part. Not everybody. But for the most part. It was very valuable for me. I made a lot of connections and, as I explained before, for example meeting Bill Cameron and him taking me aside and saying "Don't take Saquinavir when it first comes out. Wait 'til the study results come out." I really believe that saved my life. I kind of got the impression, from my dealings with some of these doctors, that they seemed to think of me almost like an equal, because they knew I was a lawyer. They seemed to feel more comfortable with me. For example, the doctors at the Primary Care Physicians' Group. As I said, I met Doctor Logue – Ken Logue – at the Steering Committee meeting in Montreal, in May of '93.

GK: And that would be the steering committee of the Clinical Trials network?

MA: Yes. I can't remember if it was before or after the Berlin AIDS Conference in '93. I went to that. There was a group of Canadians who were hanging around together. Canadian doctors and some of the people from Hassle Free Clinic were there, too. I met some of the doctors there. And then, as I said, Doctor Logue suggested, "Hey, we haven't had anybody since James Thatcher come to our meetings. Why don't you come?" You know. And so I did. I think they were monthly meetings? Usually on a Friday afternoon from three to five. They would have kind of news updates and then they would have, quite often have a speaker for an hour, on the latest AIDS information. I think their funding came through the AIDS Bureau.

AS: And then, would you bring stuff back from the physicians group to AIDS ACTION NOW! or would you mostly—

MA: Yes. Yes, yes. I acted as a liaison between sort of. I found some of my minutes and agendas from those meetings of the primary care group. They might want an update on what was happening at CAHR or what was happening on insurance issues or compassionate access to a drug? So I would speak to those issues, and then if they wanted help with something, or you know, they were going to, I don't know, we were going to work together on an issue, then I would take that back to AIDS ACTION NOW!. So, yes.

AS: It was really both ways.

MA: Basically, I worked as kind of like a liaison. Yes. And my doctor was there, Donna Keystone, so we used to sit together at the meetings and kind of gossip. We used to joke about the fact that you could tell, at the meeting, who was gay and who was straight, because all the gay men were so good looking. [laughing]

Oh, I was just going to say that, to follow up on the trials, the cognitive stuff. Sean Rourke knew I was interested, so he asked me if I would be involved in some committees he was running. One was Neurocognitive Issues and Aging, so I was co-chair with him on that committee.

AS: Cool.

MA: I've continued to be involved in those things. I'm kind of nominally involved in providing some input on trials that, or in funding that he's trying to get, and so on. So I'm still involved in that.

GK: That's great. Just to go back, because we haven't had people really talk to us much about the clinical trials network, or – I mean, we've talked to Philip earlier today, about the primary care physicians group – or CAHR, or any of those groups. Could you maybe just tell us a little bit more about what they were like and what they did?

MA: Sure. Well, actually, I was involved with them a little bit, pretty much right from the beginning. So, I mean other people could, from the research community, could tell you more about it—

GK: Okay.

MA: From the *community* community, I'm probably one of the few who's around, because in '92, I attended the CAHR second Annual Conference, in Vancouver, and met a bunch of researchers at that. In a way, some of my treatment activism kind of got initiated then, because, there was some, as I said in the first interview, there were some things that irritated me about the presentations that were given, the tone about women, and so on, so then I started to write and get involved with that. The following year, I guess I was told that subsequent to the, subsequent to our Canadian HIV Trials Network meeting in Montreal, in '93, that the CAHR conference follows immediately after that. I somehow got some extra funding and stayed on for the CAHR conference, and that was pretty exciting. It was relatively small. I mean, I can't remember exactly how many people were there. Maybe a hundred? Two hundred at the most? It was kind of in an auditorium. A fairly small auditorium, small group of people. And Kalpesh and I were there. Kalpesh Oza.

GK: Right.

MA: I was learning a lot from Kalpesh and from Sean Hosein. I think the night before I was going to Montreal, we met at Kalpesh's, the three of us. As a matter of fact, he lived on the next block north of here.

AS: Oh, wow.

MA: He lived in a house and he rented, it was right through the laneway, right behind here. He had Sean and me over for dinner. I think he cooked a wonderful curry for dinner. And it was like… AIDS Research 101 For Maggie.

All: [laughing]

MA: They were telling me what I need to know and, what to focus on, and so on. And so Kalpesh was preparing me for being at the CTN meeting.

GK: Right.

MA: And, anyway, there was a reception at the, I think it was in the museum in Montreal, for researchers. It was organized by Cate Hankins, who was organizing the CAHR conference that year. I think she was president. Afterwards, a whole group of people went to some, a gay disco or night club, including Martin Schechter and Cate Hankins and a bunch of researchers. And everybody was out there dancing on the floor, Kalpesh dancing up a storm, it was a lot of fun.

GK: I'm sure.

MA: It was good, because I felt like it, it was because of experiences like that created more of a friendliness with the researchers. Like, some of my friends from AIDS ACTION NOW! or other groups, like Ron Rosenes, for example? They hadn't been so involved with researchers directly, and they, I think they felt more suspicious of them.

AS: Mmhm.

MA: Whereas I had had so many positive interactions with them, more or less, that I had a much friendlier relationship with them. Anyway. So, at that first meeting, I remember Kalpesh kind of being his usual sort of… shit disturber self.

GK: [laughing]

MA: He used to take me aback sometimes because he could just jump up and shout and say, "We're all fucking dying right now, and you've got to do something!" [laughing] It wasn't really my style, but it was definitely effective!

AS: [laughing]

MA: Actually, what was interesting was he and I actually joined CAHR that year, because they were kind of open to everybody becoming members. After that, it got shut down, and I think you had to be a researcher to become a member. But the two of us joined. It was definitely a smallish organization and group, and I believe Kalpesh and I were there to the bitter end, when they would have the meeting at the end of the Executive and elections of the new president and vice president and so on of the group. Treasurer and so-forth. I think that, in a way, that's when you kind of see what's really going on in the organization, is if you're willing to stick it out to when those meetings happen.

GK: Right.

MA: The Annual General Meeting of the organization.

GK: So you were also the community rep, I guess, on the primary care physicians group in Toronto? James had been there before, then there was a gap, and then you replaced him?

MA: Yes.

GK: What was your role there? How did you participate in that?

MA: It was kind of a closed meeting. I was there as the AIDS ACTION NOW! representative. They didn't have any other representatives from any other organizations. That was it. James had kind of wormed his way in there, or something. I don't know how. But, actually, James was a patient of Dr. Logue's, I believe. . So James had held that role before, and he had been Chair of AIDS ACTION NOW!. So there were the co-chairs of the Primary Care Physicians' Group, and they had an agenda for every meeting. I think there were certain standing issues that would come up, or they might want a report from the CAHR conference. I was quite often the only person who'd been at a particular meeting or something, so they would ask me to say a few things about it. So that's basically how it worked. I was welcome at the committee meetings. Except I remember they had one closed meeting on Euthanasia, and that was just doctors only for that.

AS: Huh.

GK: And, of course, that would have been really interesting to have been at.

AS: Totally!

All: [laughing]

MA: Yes.

GK: Right.

MA: So, yes. I attended that organization for a number of years. I can't remember when exactly it petered out. I guess Phil probably told you more about that.

GK: I remember it was around 1998, I think.

AS: Yes.

MA: Actually, I do have a file on it over here. I don't know if I put it out… [rummaging] Oh, yes. Here it is. So… Let me just see… Yes. So this lists, like… Did Phil, I guess he had files on this?

GK: In his basement, somewhere.

AS: He has them somewhere.

MA: Oh. [laughing]

GK: Not, it was not like this.

AS: Yes, it was not like this.

MA: Yes. So this… Oh, actually there was one other rep, I can see here, and that's Miriam Bast. She, do you know her?

AS: No…

GK: The name sounds familiar.

MA: She was the clinical trials coordinator at Sunnybrook. She worked for Anita Rachlis and she was the Canadian Trials Network representative on this committee, too. On the Toronto Primary Care Group. This is the list of the member of the Toronto Primary Care Group. So, it's alphabetical. Here I am, "Maggie Atkinson, AIDS ACTION NOW! Rep."

GK: Okay. So that's, I didn't quite understand until just now that you were actually representing AIDS ACTION NOW! there. That's great.

MA: Oh, and actually here, it says there's a CATIE representative, too. So, I was wrong. I wasn't the only rep. But they didn't want a whole bunch of community people there. But, so for example, here's one agenda, and it has, so the agenda… they have, for example, OACHA report, OHTN report, HIIP update…

GK: Sorry, what was that last one?

MA: HIIP? H-I-I-P?

GK: Do you know what that is?

MA: Health Information and Privacy, I think. Something like that.

GK: Oh, okay.

MA: Yes. So, unfortunately, some of these are on old fax paper, so you can hardly read them. So, this is 1999.

GK: Okay. So it lasts longer than Philip I think suggested.

MA: Yes. And here, so for example, "New Business – Progress of the VaxGen AIDS trial; Norvir soft elastic capsule release via special access; Private labs asking for health cards when patients want HIV anonymous testing… Something about public health. Then: Reports – AIDS ACITON NOW!; CATIE; CTN; Casey House update; CRIT; oh, Abbot 378…" So, so those were the kind of things that—

AS: Were you involved with CRIT at all?

MA: Yes. A little bit. Well, actually, not much. I just remember attending one or two of their annual general meetings. I mean, I was nominally, I guess, a member. But… yes. I went to, I remember going to one of their annual general meetings with Brian Farlinger. And [laughing] we were the only people who showed up for the AGM apart from the, like, the organizational people themselves?

GK: Right.

MA: [laughing] So I guess, although they advertised, public annual general meeting, and it was, I guess we were on their mailing list, so we got invited. But nobody else came. So there we are, solemnly looking over their financial statements and so on.

AS: [laughing]

MA: But, I mean I knew the people there, like James Austin, so I knew a bit about what was going on there, but I wasn't particularly involved.

But you were asking me about CAHR. I just thought I'd follow up on that. So that year, the '93, that I attended, that was the third conference. And then, the following year, I mentioned earlier that Anita Rachlis had been asked, to organize the conference for 1994 in Toronto. She asked me to be on the organizing committee. So, actually, one of the things I'm pleased that I accomplished on the organizing committee was I got the committee's agreement that there should be free admission for people with HIV. You didn't have to prove you were

HIV-positive, you just, said you were and you would get free admission. I knew that was an issue in the States, with AIDS conferences. The whole issue of admission and it should, we should be able to attend these things for free.

GK: For sure.

MA: And so that was good. We even, eventually, got scholarships available for people to attend as well, that were funded by the drug companies.

AS: To come in.

MA: To, yes, to attend. Usually those conferences were actually money makers for CAHR. They would… I guess because they got a fair amount of money and funding from the drug companies. You know, to be sponsors. You know, Platinum Sponsor, Gold Sponsor, Bronze Sponsor. That they actually ended up making money on them. They didn't charge a lot for admission or anything, but…

GK: Right.

MA: So, I helped organize the 1994 conference and then, subsequently, that's when I got ill. I actually attended the following year's conference in Winnipeg and Brian Farlinger spoke at that. He'd been invited as a guest. I mean, he'd been invited as a speaker, and he was very ill at the time. He couldn't really eat at all, anymore. He was having to do tube feeding. You know, I think he could maybe have a like a little bit of soup or something but he couldn't really eat anything. But anyway, he came, his sister Pam told me before the, oh I think she drove him to the airport and then picked him up from the airport afterwards. Anyway, he came. I remember he spoke at this meeting and he lambasted the researchers for not doing enough. I helped organize that they would name a scholarship after him. I quickly organized this at the last minute, running around and talking to the people who were on the steering committee of, I think, CAHR. I also spoke to one of the drug reps I knew… Oh god, what's his name? From Burroughs Wellcome.[Russ Read]. Anyway. Slips my mind right at the moment. So I said to him, "Look. We'd like to create this scholarship in honour of Brian." He goes: "Oh, okay." He got permission and he gave thousands of dollars for this. It was kind of nice to be able to just, like, that was one thing I liked? Not having to go through eight months of bureaucracy to get something decided, you could just speak to all the relevant people quickly and get something done. Anyway. So it was kind of funny, here, he lambastes the organization and all these researchers in his speech, and then they thank him and [laughing] named an award after him.

GK: Well then he was quite successful.

MA: Yes. They named an award after Kalpesh, too.

AS: Really?

MA: Yes.

GK: I didn't know about that.

MA: Yes. In the early days. Well, I guess it was around the same time. After he died.

GK: Right.

MA: So, yes. So he spoke, but he was so weak afterwards. I don't know if I should talk about this, but… his sister told me that, when she picked him up at the airport, that he was so tired and weak he just cried. You know? He died not much longer after that. I think he died shortly after Pride Day that year.

GK: Yes. I think that's, that's my sense too. I was going to move into questions that actually relate to memories of people who've died – but I don't know if Alexis had another question…?

AS: No, that's fine.

GK: And this seems like a good segue into it.

MA: Yes.

GK: So. Part of why we do this is just because there's people we can't actually talk to—

MA: Yes.

GK: —but we'd like to preserve some memories of them. You already talked a fair bit, in the first interview, around James. So I'm not sure if you wanted to say anything more about him, but people like Alan, Brian – who we were just talking about – Kalpesh, maybe more recently, because you knew Bob Gardner quite well—

MA: Oh, yes.

GK: Bob as well. But whatever you want to say. And I, we also realize that sometimes it can be troubling to talk about people who've died. So.

MA: Yes. Yes. Well. Let's see. Well, Brian Farlinger, I already spoke about him before. I heard about him from Darien, before I met him. You know, this wonder guy who ran 10k races and had zero T-cells. He was a lawyer and he worked, I think, for the Bankers' Association. Actually, he had a combined, I think, LLB and, what is it, B.Comm or something? No, MBA.

GK: Right.

MA: Yes. So, very bright. I think he was Co-Chair, or Chair, of AIDS ACTION NOW!, and then, so he was the one who got me involved in coming to TAAR meetings. He could be a little bit dry, but he had a good sense of humour. But so hardworking. Just so dedicated, so hardworking and, he could barely see because of the CMV retinitis, and working on these documents on his Mac computer, I think it was a Mac. So, yes. Just very dedicated and hardworking, and driving, driving others. It's just a personal recollection, but I remember… I guess it was, maybe it was the Christmas before he died. I remember him having Darien and me over, and he was baking shortbread cookies, and had us over for shortbread cookies and tea. So it was very nice. And he also did things like had a very nice, big dinner party in his home, with all of us AIDS activists there. He lived over in Beaconsfield. Did you know Brian?

GK: I met him a couple of times, but it was largely, he was around largely the times when I wasn't living in Toronto.

MA: In '93 we did— AIDS ACTION NOW! had a national treatment activists meeting.

GK: Right.

MA: And a sizeable document came out of it with our recommendations. Have you see that?

GK: I think I've seen that.

MA: Yes.

GK: Was it explicitly an AIDS ACTION NOW! document, or was it… a broader document?

MA: Yes, I think it was a, it was an AIDS ACTION NOW! document. Yes.

GK: I've seen the AIDS ACTION NOW! document.

MA: It was fairly thick, I think. Anyway. I saw the other day, my name is on the front as one of the authors. When, really, Brian wrote it. I mean he just was so up on all the research compared to everybody else, it seemed to me.

GK: Right.

MA: He was just *so* knowledgeable. And all the basic science, which was pretty much beyond me. Anyway, so he pulled together this national meeting and kind of ran it and we had sessions on all these different treatment tracks and so on. And then he came up with this report, and with recommendations at the end. Then we took this report around, kind of like a dog-and-pony show, to different groups to present our stuff. For example, one of the groups we went to was the Canadian Trials Network had an Ontario satellite. Each province had their own satellite, or each group. I don't know if each of the Maritime provinces had a group, but Ontario did. Actually, Ontario had two satellites, I think, because of issues between Anita Rachlis and Bill Cameron, I think. Anyway. So there's the Ottawa satellite and the Toronto satellite. So we met with the group that got organized through Anita, because she was the head of the Toronto group. We presented our findings to them. Brian's idea was he wanted to get all these groups to sign on and endorse our recommendations. So he was very methodical and organized that way, and thinking things through with strategy. That document also became important later on, like when we were, when we were talking about our research goals for the future and, we sent it to various AIDS, like CAS – the Canadian AIDS Society – and so on. So it was an important document. … I think I've already talked about him.

GK: Yes.

MA: Alan Cornwall. As I explained, I knew him from the firm and became friends with him and his partner, Paul Meagher and would go to things at their house. You know, they had a lovely home and were just really very nice people. You know, really great people. Alan was another pretty driven person. I mean, it is hard work just being an associate lawyer in a downtown law firm. And then, on top of that, to be doing AIDS activism, plus he was a member of the Steering Committee of AIDS ACTION NOW! and he was involved in setting up the TIE project, and that became CATIE. Paul Meagher was involved in that, too, of course. And then, also, he and I helped establish HALCO. the HIV and AIDS Legal Clinic. That was quite a bit of work.

I must admit, over the years of getting involved and setting up organizations, I got heartily sick of things like looking at bylaws and organizational documents for… organizations such as Voices and HALCO and so on. I guess we were dedicated, driven, because I mean, we knew there was so much discrimination against people with HIV and what they were dealing with. I mean, for me, some of that was second hand. Because I hadn't, I mean, I'd hear about how, gay men would be turned back at the hospital and couldn't be with their partners, and things like this. I mean, Alan knew more about that. Anyway. So Alan, he was carrying on – kind of like I was, but more so – he was carrying on this double life at the firm, because he was kind of this very straight demeanor at the office, and as I said, it was so kind of homophobic and closeted. And it wasn't openly homophobic, but it's just nobody was openly gay. And when you've got a firm of six hundred people, that's a bit odd. So, anyway. So Alan, he decided to leave the firm shortly after I did and, in a way, I felt he'd waited too long. It was a shame, because his partner, Paul Meagher, died shortly after he left. Almost around the same time. It was a shame, because they didn't really get a chance to spend time together before Paul died. And then, subsequently, Alan got involved with, oh God, now his name escapes me. I just read it yesterday. Because I wrote an article about Alan for CATIE. He was executive director of the AIDS Committee of Toronto for a little while. He had a degree in social work. Oh, Charles Roy.

GK: Okay.

MA: Anyway. So his subsequent partner was Charles Roy. But Alan became quite ill in '95. Actually, it's interesting. In those days, AIDS was kind of like a roller coaster, you know? You could be very sick, and then you'd kind of recover a bit, but not to where you were before. But then you'd go down again. So you didn't necessarily expect to die just because you got sick. You thought, "Oh, okay, well, I'll probably recover, but…" You know. You knew it was kind of a downhill route. He certainly suffered that kind of thing, and then I remember being at his home. He had a Pride Day party at his home. But, he was in bed, on oxygen, and then he died the month later. He died in July of '95. That was a *really* bad month. Because he died and Brian Farlinger died that month and also, I think, Kalpesh died that month. So, but Alan had a lot of, kind of, *joie de vivre* and fun. He was very talented. He was a talented pianist and also he'd been a gymnast, I believe, at university. I saw pictures of him. He was so muscular and everything, in photographs from when he had been a gymnast. Also he spoke a couple of languages. Russian and French and some German. So, he was a very talented person. Anyway. He was close to his sister, who was a florist. I think maybe his father might have had a little issue with him being positive and everything. But, anyway, he had a very strong social life and personal life. Our lives became... I think, for many of us, our social lives became so wrapped up with HIV. I mean, most of my friends, in those days, were HIV positive or from the AIDS organizations. People like Bob and Linda Gardner became friends. I mean, in a way, going to meetings was a way of socializing.

AS: Mmhmm.

GK: Yes.

MA: Because we didn't socialize, I didn't socialize too much outside of that. Because most of your time seemed to be doing these things. So it was social, just going to an AIDS ACTION NOW! meeting, really. Or working on issues together, after meetings.

GK: Right.

MA: You know, working on a brief together, that kind of thing. And Alan and I did work on some briefs together. But anyway. I also wanted to mention Kalpesh Oza. Have other people talked about Kalpesh? Yes?

GK: Including, it's interesting, because he crosses over from Montreal to Toronto.

MA: Yes.

GK: So we've also got people talking about him who knew him from Montreal.

MA: Yes. Yes, he was a, he was really one of a kind. He was vivacious and fun and kind and caring and intelligent. I mean, he was actually doing research at the lab of Mark Wainburg in McGill. So, as I said, he had been at the Canadian Trials Network, he was on the Scientific Advisory Committee. So when a clinical trial protocol was being reviewed by the Steering Committee, first it would be reviewed by the Scientific Advisory Committee. Kalpesh was the only community representative on that committee. So, actually, I think he might have partially been behind the Community Advisory Committee forming, because I remember him complaining that it was a huge burden for him to kind of represent the community by himself, on this committee. I think it was a bit daunting for him to, even though he had a science background, for him to have to review the protocols for running a clinical trial and to, provide all the input on it. So anyway, he was also on the Community Advisory Committee. But, as I said, he was the only community representative on the Scientific Advisory Committee. And it was a lot of work. I mean, these protocols we would get would be thick and, we'd have a bunch of them to review for either the in-person meetings of the, well first we, the way the meetings were set up? We would have the Community Advisory

Committee would meet and, I don't know how it worked with the Community Advisory Committee and the Scientific Advisory Committee. I guess the Community Advisory Committee met first, then the Scientific Advisory Committee, and then the Steering Committee would meet. So I would have to take the, I would have to take the input from the Community Advisory Committee to the Steering Committee. And to give them our report on what we thought about the particular protocol and any recommendations we would have for changing it. Demands we had for change before we felt we could approve it. So, actually, I have to say that the Steering Committee was always very good about taking our requests or demands or recommendations seriously. They'd listen to them and basically there was almost never any argument. They just would say "Oh, okay!" You know? "Yes. That's what we're going to say." You know? "That. We'll have to do that. We'll have to change that." So, yes. It wasn't, it never really was a contentious issue. You know, we really got very good support from the Trials Network. I'm sorry. I know I'm jumping around.

GK: This is great.

MA: But I only stayed at the Canadian Trials Network for four years, on the Steering Committee. That was, my term ended in '97. When I started, it was a four- year term. So I basically thought, "Okay, I've done my four-year term," and it was '97, and I was busy with getting the renewal, the National AIDS Strategy, and other things.

AS: Yes.

MA: I just thought "Okay, other people can kind of get involved." There were other people on the, the Community Advisory Committee, at that time, was doing okay. So I left in '97. I still had involvement with the CTN, as it was called, even though its initials are the Canadian HIV Trials Network, everybody called it the CTN. So I continued to have involvement with them over the years because they asked me to be on subsequent committees. Like, for example, another year, I was on the Associateship Adjudication Committee. Basically I reviewed applications for the associateships they had. They had scholarships that provided funding to residents who were interested in doing work in HIV. So I was on that committee one year. I was on the ethics committee another year. So. And I was on their, what's it called, like kind of their "future planning" committee at one time. Actually, that was in '94. So… Yes, it was '94. The year I got sick, I was on that committee. I was on a number of different things for them.

GK: Right. For sure.

MA: But, to get back to Kalpesh. Yes. It's, it's interesting. He was kind of… I think he was respected and really liked by the researchers, you know. I think that they understood that he would get up there and swear at a meeting and carry on and so on, but that it was important to do that. And I admired him for that, because it's not really my style, but it was great for him to evoke and show that anger, which was important to make people understand the importance of the issues.

GK: Right. For sure.

MA: So anyway. I'm not sure I have much more to say, other than that.

GK: Alright. It was really quite helpful.

MA: So, and as I said, after he died, I'm pretty sure that it was either the Canadian Trials Network, or CAHR, named some award that they had. I think it was in the, it might have been in the basic science track, I'm not sure. They had awards for, top abstract or something, or there were other awards, like for scholarships and so on. I can't remember, like I think one award was named after George Smith, and that was like the Socio-Epidemiology Award. The track. But they're not well-known anymore. It doesn't seem to be well, that information isn't out there. It's not disseminated. I remember talking to Mark Wainberg about it one time, and he, actually he mentioned it to me. He said, "You know, you and I were there, and we remember that these things happened, but it doesn't seem to have been captured." He said "These things should be registered somewhere." You know, that it's written down and people know about it. Probably in the minutes, somewhere, if it's there.

GK: Right.

MA: I remember when CAHR was doing a history. They hired someone to do a history of the organization. And I *leant* all my CAHR files to them, so, because I have a lot of the stuff from the beginning. Ann Silversides did it. Do you know her from the—

AS: Yes.

GK: I know her largely from the book that she did around Michael Lynch. But I did have, she was originally doing a much broader history of AIDS organizing. And it became narrowed down around Michael Lynch. So.

MA: I see.

GK: I was interviewed by her, and we've been in touch with her since then and got access to some of her materials.

MA: Oh, have you? So she, I leant her all my CAHR materials for that. Yes, actually it was a real loss when Mark Wainberg died. It was quite shocking. It was horrible, that he died of drowning like that, you know. And he was still running his lab at – what was the name of the hospital? – Our Lady of Mercy or something like that.

GK: Right.

MA: Yes. I mean, he still ran his AIDS lab. So he still would have had, I'm sure, years to contribute.

AS: Yes. Good work.

MA: And such a vital person.

GK: Yes.

MA: Really, an AIDS activist, himself, you know. He really became an AIDS activist. So. Anyway. I think I've covered the people you mentioned. Because there was more—

GK: The one other person is much later on, is Bob Gardner, just because—

MA: Oh, Bob Gardner.

GK: —You said you would have known him during that period of time and we haven't, because he's sort of, he died after we did a whole bunch of the Toronto interviews, we haven't actually got people talking so much about him. So.

MA: Yes. Well, I wasn't as close to him, at all, as, say, Tim McCaskell.

GK: Right.

MA: Did you talk to Tim at all about him? Or is it too late?

GK: We probably should go back to Tim and talk to him about that.

AS: We had been hoping to talk to Bob, but…

GK: We actually had him lined up and then he was too sick.

MA: Oh… Did you talk to Linda?

GK: We've tried.

MA: Oh. It's too early. It's too soon.

GK: I think, I think that's my sense of it.

MA: In a way, Bob and Linda were kind of like this pair for me, because I first met them at AIDS ACTION NOW! and they pretty much were always there together. Though Bob worked, I believe, at the Legislative Library.

GK: Yep.

MA: And so he was a great source of information for AIDS ACTION NOW! and he was an erudite, interesting person, but with, again, a great sense of humour. He and his wife, Linda, they just seemed tireless in supporting AIDS ACTION NOW!. The people, themselves, whether it was being on – not support groups, but you know what I mean, when somebody's dying. Care teams. You know, that kind of support? But also, and they were very good friends of Alan Cornwall and Paul Meagher So I know it was hard for them, when Alan and Paul died. First Paul, and then Alan. They were also friends with Charles Roy, too.

Who, again, also passed away. Charles is another person who was an activist and, very bright, went on and did his masters of social work, and the theme was about AIDS. And then headed up the, he was head of ACT for a while, and then I kind of fell out of touch with him, I guess, after Alan died. He subsequently died, himself. But to get back to Bob… He had this kind of professorial manner, in a way, when he'd be at AIDS ACTION NOW! meetings. He had a beard and almost had this kind of twinkle in his eye and just… He was a very thoughtful person, and I think maybe partially, like, he and Linda had been involved in activism before that, for years, I think, in the abortion, access to abortions, abortion clinics and so-on.

GK: Mmhm.

MA: And so he was a real modern man, with supporting women's issues and so on. Anyway, he would be very helpful with things like writing briefs. Even when he wasn't – I mean, he and Linda were members of the Steering Committee at certain times, but even later on, when he was no longer a member, and didn't come to meetings all the time, we could always count on both Bob and Linda to help out and to show up at demos at the drop of a hat, and so on. I do have some references, I think back in 1999 or 2000, of him working on a brief with Greg Robinson, together. Drafting something. So, yes. They were always willing to help. I knew them sort of, somewhat socially on the side of seeing them for dinner at Tim McCaskell's place.

GK: Right.

MA: I remember them being, I describe talking to them after James Thatcher's memorial, and feeling like, "Where are we going to come up with ideas, now that James is dead," not realizing that people like Bob and Linda were definitely sources of some of this valuable, some of these valuable ideas. But, actually, you made me think of somebody else: Glen Brown. That was a huge shock, when he died recently. Actually, to be honest, it was shocking not just for me, and not just Glen, but also first it was… Oh, God, now I can't think of her name. I think I've got to use that brain fitness program again.

ALL: [laughing]

MA: She ran the rehabilitation, oh God, I can just see her in my head. She ran the HIV and Rehab organization. I don't know if you know the one I mean. Oh…

GK: I don't think so.

MA: It's a Canadian… do you know it?

AS: No.

MA: The Canadian Rehabilitation, I think it's like Canadian— CWGHR! Canadian Working Group on HIV and Rehabilitation. And, oh, who ran that? She was friends with Darien. Maybe Darien might have mentioned her to you. It was Elisse Zack. Anyway. It's an important organization, CWGHR. [Now Realize Canada]

GK: Right.

MA: And Greg Robinson was involved in it.

GK: Right.

MA: But she was their executive director.

GK: We can find her. We can figure that out.

MA: Okay. But she was kind of on the periphery of AIDS ACTION NOW! and Voices and she wasn't positive, herself. She was friends with Darien. And, first, she was involved in, somehow or other she got some job working on HIV and… I think it was HIV and Hepatitis. [It was HIV and TB]This was in the early days, before they realized how important that was. And so she was working on that, and then she got involved in what was referred to as CWGHR and although it was called a "working group," it really became an organization. Actually, I spoke at one of their annual general meetings, which was really large. I think it was held at a hotel downtown. So it dealt with research on things like physiotherapy and occupational therapy for people with HIV. Anyway, an important organization. So she died a couple of years ago. And, unfortunately, I didn't hear about her death until after the funeral had already taken place. So it was, first of all it, somehow it's a shock to those of us who are HIV positive, when our negative friends die? It's like, it just, it shouldn't be happening.

GK: Right.

MA: So, first, she died. And then Bob died. It was like What??? I didn't know he had been that ill, and I would have offered to have been on a care team or something like that, if I had known. But… But anyway. So, yes. These were the people who were supportive of us and it just seemed so shocking that they should die before we do. Anyway, and then Glen. Have people talked to you about Glen?

GK: Yes. If you want to tell us about your memories of him, that would be great.

MA: Well… I remember meeting Glen early on, maybe at some party or something. Maybe at James Thatcher's place, that might be right. I remember being struck by how good looking he was. Of course I knew him through AIDS ACTION NOW!. He was an invaluable part of AIDS ACTION NOW! and through his, because he worked at, God, I don't know what he worked—I can't remember the organization.

GK: OCUFA [Ontario Confederation of University Faculty Associations].

MA: OCUFA. Right. So, through them, he had access to their fax machine and he had all these media lists, so he would just press a button when he needed to send a fax to all the media for AIDS ACTION NOW! but he seemed so knowledgeable about what to do. I remember he helped run a media workshop for, I think it was for Voices. To train us in how to do public speaking and so on. It was really very helpful. He just had this engaging, charming way about him, and could kind of lighten the atmosphere if things were tense at a meeting. He's another person who kind of faded off a bit, in terms of his involvement with AIDS ACTION NOW!. Well, also the thing is, is that he got involved with CATIE.

GK: Right. [laughing]

MA: That was a problem we had, actually, at AIDS ACTION NOW!, is that so many of our people were being kind of sucked into positions, working full time, in the AIDS movement, so the problem was they had no energy and time left over to be involved with AIDS ACTION NOW! anymore. I should have mentioned that earlier.

GK: Yes, but that's…

MA: It definitely seemed to happen that, like, Darien was working in the AIDS movement. Well, first of all, Darien was working with Voices. But, then later with CATIE, but everybody we seemed to know, they seemed to kind of get these jobs. They became, like, professional AIDS activists in a way.

GK: Yes.

AS: Yes.

MA: So, that did take away from AIDS ACTION NOW!.

AS: And then, as soon as they got those jobs, they were restricted, right? In what they could do politically.

MA: Yes. Yes. Yes. I mean, yes. We could sometimes try to work around those things, but… yes, that was an issue. That was one of the great things about AIDS ACTION NOW!, that we weren't beholden to anyone, because we didn't take funding from government or drug industry. So, for example, when David Dingwall threatened to make life difficult for us, I didn't… I don't think I mentioned the time around that meeting we had with him. That was, I believe he was in Toronto, at the 519, because he was showing off a new stamp from Canada Post. It had been done in honour of the International AIDS Conference in Vancouver that was coming up. And so they had that AIDS stamp, picture by Joe Average, I think it was. Anyway. So he was, there was a reception and a ceremony for that, the unveiling of the new stamp, at the 519. We had a demonstration outside. Actually, I thought it was quite cute. I don't know who came up with the slogan, but we had signs saying something like, "Lick AIDS not stamps!"

ALL: [laughing]

MA: I even dragged my poor father to the demonstration. He was, we were all out there with our signs, marching around. And, next thing I knew, I see my father. He's standing there, eating a croissant. I said, "Where did you get that?" He said, "Oh, I was in at the reception." I said, "You're not supposed to do that!"

AS: [laughing] Go to the reception…

MA: So, anyway, after we had demonstrated and so on, somehow or other, his people said that he would meet with us. So then we met with him back at CATIE's offices, and that's when he turned kind of ugly and, said "If you make life difficult for me, at the conference, I'm going to make life difficult for you." And so it was a bit scary, actually. The guy was just really kind of a bully and mean. I just thought it was totally inappropriate for him to threaten us like that.

AS: Yes!

MA: I'm trying to remember why I told you that… Yes, so we met with him at that time and, oh, I remember that it was very good that we weren't dependent on them for any funding.

GK: Right.

MA: You know? So, yes, he could threaten us. But what could he really do to us? Nothing. So that was good. Though it was funny, because when we would have some demonstrations, we would often have our friends – who were at organizations that took money from. For example, people like Louise Binder and Ron Rosenes, Tony Di Pede all these people, they would be, they were working for AIDS service organizations—

GK: Right.

MA: Or they were on the board, or something like that. So they didn't want to get their organizations into trouble, but they could come as members of AIDS ACTION NOW! well, they'd come to our demos and so on. To help out. So people were kind of wearing two different hats.

AS: Mmhm.

MA: But, so, AIDS ACTION NOW! was very good to be, we had that…

AS: Yes. You could do that.

MA: Organization to be able to do that. But yes, so… But about Glen. Yes, he was very, he was really an invaluable member of our, of the organization. And—

G: Yes, we were lucky we were able to interview him before—

MA: Oh, were you?

GK: Yes.

MA: Oh, good.

GK: Yes, it's a two-part interview, too, that we've put together as one. So.

MA: Yes. Yes, good.

GK: Yes, that was very helpful.

AS: Very important. Yes.

MA: Yes. Very important.

GK: So I think we're moving into the last two questions, unless you have something else? So one is just, as we've been talking, or as you reflected on the first part of the interview, is there anything else that's come up that you wanted to talk about. Because, like, we've written up some questions and stuff, but it might have sparked other thoughts or memories for you.

MA: Nothing really springs to mind particularly. Oh, actually! Just various thoughts that spring to mind. One thing I was thinking about when I was reviewing the minutes from our early Voices meetings. At first, I was looking at the minutes, and I thought "Oh, wasn't I at that meeting?" And then I realized, "Oh, I was using a pseudonym back then." I don't show up in the minutes, because I, at that time, I used a pseudonym: Cathy.

AS: Right.

MA: Because I…

AS: You were still working at the firm.

MA: Yes. Actually, quite a few of the women in the minutes, it's not their real names. And so, yes, it was just… that's the way things were at the time. I mean, it's better now but, people who still work, I'm sure it's still somewhat of an issue. I was impressed when I looked at what we, we did accomplish a lot in just a couple of years, before I left. And, I mean, most of that's down to Darien, because she was the staff person and she was the one kind of doing all the heavy lifting.

GK: This does bring us back to, if you did want to talk about the plaque things. For Voices. Were you, at the time when they put up the plaque for Voices of Positive Women?

MA: I was at the second plaque unveiling, down on College Street. I think they did one on Isabella?

GK: That's the one I was at.

MA: Oh, were you? I only found out about that the day before the plaque unveiling on Isabella. It was, I felt that that was really poorly organized. I thought, "How could you not invite the first board" you know, the members of the first steering committee. We weren't invited. I don't even think thatAndrea Rudd got invited, you know? And she was one of the founders.

GK: I think, I think Darien— what I heard,

MA: Darien was invited.

GK: Invited, but was, someone was sick or something—

MA: Her brother died the day before, so she couldn't make it. And so the organization that was doing the plaque, I can't remember what their name—

GK: It's called, it's a play on "museum". It's like "Myseum"?

MA: Oh, is it? It, well…

GK: At least the one on Isabella. Maybe there was—

MA: Yeah… Well, it's some, yeah, it's got an odd name. But anyway. I think they're government funded—

GK: Yep.

MA: —to go around and do these projects. [It's the Department of Public Memory.] Anyway. They approached me, because I had, I think I wrote to them and said, you know, "Look. You did a really poor job of organizing this because there are people who weren't invited". So they decided to have another plaque unveiling on College Street, at the site of where the original office was, and Darien and I were there. But I think we were about the only people there.

GK: Oh, really.

MA: Yeah.

GK: Yeah. Because that one, I didn't hear about that —

MA: I mean, it wasn't well advertised. It was a nice ceremony, but it was very poorly attended.

GK: There were a fair number at the one, the previous one that I was at, and I heard about that a couple of days before, and went to it. And it's this "Myseum" of Toronto group, which is funded by some government body to do things like this, right?

MA: Yes. Yes.

GK: But there were about, I would say there were thirty or forty people there.

MA: Really?? That many?

GK: Because the Archives is so close, they brought out chairs and stuff for people.

MA: Oh.

GK: I went because no one else from the AIDS Activist History Project could go.

MA: Oh.

GK: But I have to say that, I mean there were a couple of people I knew there, but that was it, at that one.

MA: Well. It was, I found out because I was having lunch with Louise Binder the day before, and she said "Oh, are you going to that?" Like, "What?"

AS: Yes.

MA: So I'm sure there were people there. Like, I'm sure they didn't invite everybody who was involved in the—

GK: Yes.

MA: Well, like, for example, I think Andrea Rudd didn't know about it, and she was one of the founders of the organization. And I talked to Marlene Freise about it, she was the Vice-Chair for me – so she was acting Chair in '94 to '95 or something? - She didn't hear about it. You know, it's not that hard to get in touch with some of these people…

GK: No. There's some problems, obviously, in organizing it.

MA: Yes. Well, it seemed like nobody really took a systematic approach to inviting people. So. Something's— Well. I got invited to the, I think it was, I don't know, I think it was the tenth anniversary of HALCO, or something? Fifteenth anniversary. And so I tracked down Mark Freamo for that. So the two of us went to that. That was good. But anyway. No, nothing else really springs to mind.

GK: Okay.

MA: Maybe when I'm reviewing the notes of the next thing.

GK: We'll put the two of them together.

MA: Okay.

AS: And you can add things and take things out.

GK: You can always add things or subtract them, or whatever.

MA: Yes. Okay.

GK: And I, our last question always is: Suggestions on other people to talk to. Which is a bit more precarious than usual, because we're actually coming to the very end of the project—

MA: Coming to the end. Yes.

AS: Yes.

GK: But we're still interested in your suggestions on whom we might talk to that we might not have thought of.

MA: I'm not sure of who all you *have* talked to. Because, I mean, I'm getting a sense. I did look online last year when, but I haven't looked on it since.

GK: Right. And there will be some new things up now.

MA: Yes. Did you talk to Paul MacPhee?

GK and AS: No.

MA: Because he was Co-Chair for a couple of years. He was very involved in some of the campaigns we ran. Like the, well, for the renewal of the National AIDS Strategy, he was, he was very involved. And also he was very involved with the Trillium Drug Program. I described that a little bit, I think. Yes.

GK: Yes. And we've got other people who talked about the Trillium stuff.

MA: Oh, have you?

GK: But you talked more about the problems that happened after it was committed to, right?

MA: Yes. Yes. Well, Paul was our point person. With the Trillium drug program, for example. For fixing all the problems. I mean, he probably, I guess he probably had the man who was in charge of that program, Carl Marshall, I think he had his number on speed dial, you know?

ALL: [laughing]

MA: Like, he was always dealing with him. That was one problem that we had, I think, is that… It reminds me of something Tim McCaskell said once, and that was "We can tell people that we want to go to the moon. We don't have to figure out how to get there." But it seemed that, invariably, when we would say "Oh, we want something-or-other," then we would be involved in having to set it up, or whatever. You know? And, I mean, on the one hand, yes, we say we want to have input. But, on the other hand, it can be exhausting and exhaustive work to provide that input. Like, for example, once we got renewal of the National AIDS Strategy, then we had to provide input on what shape that should take in the future, and so on. There was so much work involved that was done by Greg Robinson, for example, and Louise Binder. Did you speak to Louise Binder?

GK: No. She's been on our list, but we have never got around to it.

MA: Actually, there's… I think she's speaking at something coming up. She's definitely somebody that you should speak to.

AS: Yes. Okay.

MA: And Paul… What about Greg Robinson?

GK: We haven't. See, part of it is that, because we have this arbitrary date of '96—

MA: Oh, sorry.

GK: —We haven't been looking—

MA: Oh, sorry, I didn't realize that.

GK: But, no, it's not— But it's not that we don't want to talk to people. But I think we tended to emphasize people who were involved earlier on.

MA: Oh, okay.

GK: So it's really been important to talk to *you*, as involved later, and I think you've led us to understand more of the significance of some of the stuff that happened later, so. If we do another Toronto round of interviews, we'll try to do some of these people.

AS: Yes. Well, because also Toronto's kind of unique because, in a lot of the other cities, the kind of fading that happened, or the kind of like people being like "Oh, that's done! There's nothing else to work on here"—

MA: Yes.

AS: —meant that the groups that existed just really did dissipate. And there was kind of only ASOs left? And so Toronto's unusual, that AIDS ACTION NOW! still exists and still does work—

MA: Yes.

AS: And that also all of these other organizations that kind of came out of it, right?

MA: Yes.

AS: So, that's something. And it's been complicated because we have wanted to really capture it, what it is about Toronto that made that be the case, without making the whole project just be about Toronto, you know?

MA: I mean, I think that Toronto is so, like – well, I hate to sound about our organization, but… I think that we were doing, even though we were just a little Toronto organization, we were doing national work.

AS: Exactly.

MA: You know, like we were, or international work. I mean, we were meeting with these international drug companies and negotiating compassionate access for the whole of Canada.

AS: Yes.

MA: You know, so we were doing work for everybody, you know? And so, I mean some people from out west, they can be quite negative about Toronto. Like, I don't know if you ever met Arn Schilder?

GK: Heard the name.

MA: Yes. Anyway. I remember him blasting me because I was from Toronto.

GK: But I'm quite familiar with that.

MA: That attitude?

AS: That attitude.

GK: Yes. But I'm also familiar with the attitude of how, you fall off the face of the earth if you move from Toronto to the East Coast. When I lived in St John's, it was like… "You've fallen off the face of the earth."

MA: [laughing]

GK: "You no-longer exist to us," right?

MA: Oh, really?

GK: So, I mean, but yes. No I understand entirely—

MA: Yes. Works both ways.

GK: Well, yes. But I understand entirely what you're talking about. It is very interesting to us, maybe you have some insight into this, that there was very— I

mean, obviously, there were networks in terms of the conferences you're talking about, that brought people together from across the country. But in terms of the more activist groups on the ground? There actually wasn't that much interaction between them, if you look at the groups in Halifax that we've been focusing, or Montreal. Or Vancouver for that matter. Right?

MA: Yes.

GK: I mean, there was some. But there was actually a lot less than you'd think.

MA: Yes, there—

GK: Right? So I think, in some ways, AIDS ACTION NOW! took on a whole bunch of different mandates, including the more federal one, which was there very early on, in terms of access to drugs, too, right? In the EDRP and all that stuff. But it was maintained around the renewal of a National AIDS Strategy, all those sorts of things. That those other groups actually focused on more localized situations.

MA: Yes. Yes, I'm not aware of any other, I mean maybe some of the Quebec groups might have, might have had some input. Like COQIDA orCPAVIH or something. But it seems to me that the, that there was nobody else really on the national level or the federal issues, the way we were, in terms of activism. And so I guess we worked with, like, CAS.

GK: Right.

AS: Yes.

MA: Or, yes. CAS. We were, in a way, almost like one of the national partners?

GK: Right.

MA: We'd set ourselves up that way, and nobody else seemed to be on the scene that way.

AS: Yes.

MA: Yes, I don't know why that happened the way it did. But it did.

GK: Well, there was one attempt, that I think Doug Wilson was involved in, earlier on, to set up a, it would have been a parallel structure to the Canadian AIDS Society, but would have been HIV Positive groups? So it would have been—

MA: Oh, yes. I remember vaguely about that.

GK: And I think the Canadian AIDS Society got very upset with it, and it got torpedoed? But that wasn't—

MA: Well, there was—

GK: That was actually an attempt to create—

AS: A national—

GK: —A cross-country thing. So, like Eric Smith in the PWA coalition in Nova Scotia was involved in that, and various people across the country. But, because it didn't come to fruition? I think that was one moment where some of that might have happened.

MA: Yes.

GK: But it didn't.

MA: There was, in a way, it's a little bit like the difference between ACT and PWA, here in Toronto. One's for people with HIV, and one's the organization. I mean, for example, at the OAN and also at CAS, there was the PWA Forum.

GK: Right.

MA: So that was kind of the outlet for that. I did attend some of those meetings. Both of the OAN and of the, of CAS. Which were good. I think part of it was a matter of funding. You know? That there wasn't funding available for a national PWA organization and that's probably one of the reasons it petered out. And, yes. No, I think part of it was funding. It was a big deal to have that CAS – not CAS. To have that National AIDS Activists meeting that was organized in, it was in Toronto, and I, somehow there was funding to bring, but we didn't get government funding or anything. I don't know where the money came from to help bring some people in from across the country for that meeting. [According to the report from that activist meeting held August 20 and 21, 1993, , "Confronting the HIV Research Crisis:Treatment Activists' perceptions of the Canadian AIDS Research Effort" funding for that meeting came from the James Thatcher Memorial Fund, the Canadian AIDS Society and the Canadian HIV Trials Network.

GK: Do you happen to have any information on who was at that meeting? From across the country? That would actually be something that we'd be quite interested in.

MA: I could try to find out.
[There were 33 community-based treatment activists from twenty organizations based in communities from Halifax to Victoria. They are as follows:

Russell Armstong
Maggie Atkinson
Linda Gardner
David Garmaise
Kalpesh Oza
Ron Parker

Claudia Brabazon
Doriano Dalvano
Emmanuel Clerk
William Davis
Lauro De Haan
Wayne Dennis II
Pierre Desmarais
Peter Donovan
Brian Farlinger
Bob Gardner
Gregg Gonsalves
Phillip Haines
Wayne Hellard
Wilson Hodder
Sean Hosein
Steve Johnson
Bill Leeming
Tim McCaskell
Doug McKay
Wayne Moore
Brent Patterson
Glen Pelshea
Edward Sandberg
Arn Schilder
Alex Solski
Robyn Sussel
Darien Taylor
Mark Whitehead
Bill Woodfine

GK: To see just what types of interactions were happening then.

MA: Yes. You know, it might have happened concurrent with the, with something like the CAS Therapies Committee. See, actually that's one of the things I was just thinking about. The CAS Therapies Committee was a little bit like a, it was a national treatment organization, in a way. And Brian Farlinger was Chair of that. He was responsible for really, maybe "responsible" is the wrong word. I gather he really pushed for the accessibility of that for Francophones. You know, he really insisted that it be, that the minutes and everything be translated, and he was bilingual himself, so. But he really insisted that it should be accessible for people who were Francophones. So I think there were people like Maude Loignon I think, was somebody was involved with that. I knew some of the people from across the country. Well, some of them from the Community Advisory Committee, because we also had national representation. Also, when I went to some conferences, sometimes there would be people from the other provinces there. People like Arn Schilder and a few people from Quebec I knew. So I knew some of the people from the CAS Therapies Committee and then also CTAC was also a national treatment advocacy organization.

AS: Right.

GK: Right.

MA: But… Anyway. So, yes. No, there's… it was a shame, in a way, but I think CTAC tried to do that. You know? And to build up the activists from the ground up, on the ground, across Canada. Because that was one of the things that I think they felt was missing. It was almost like a school for activists. Which Louise has been involved in trying to set up, in a way. Like, to train activists. Anyway. I think that's about all I can tell you.

GK: This has been great. Thank you so much for spending some more time with us.