

AAHP
AIDS Activist History Project

Interview Transcripts 2014.001 / 2014.007

Interviewee:	Darien Taylor – Part 1 / Part 2
Interviewers:	Alexis Shotwell & Gary Kinsman
Place:	Toronto, Ontario
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Part 1 – 7 February 2014

Persons present: Darien Taylor – DT
Alexis Shotwell – AS
Gary Kinsman – GK

[START OF TRANSCRIPT]

GK: In terms of getting going, the first question I wanted to ask was when do you first remember hearing about AIDS?

DT: So, I was talking about this with Eric last night and he was like, “Who the hell remembers when you first heard about AIDS?” but actually I do. Maybe it’s not the first time, but I have a memory of long, long ago hearing... thinking about HIV and about AIDS. I was doing some graduate work in Cornell in the States and that was where I first started to hear about HIV and AIDS. I remember that it was this gay guy with HIV or AIDS talking about the number of sexual encounters that he’d had. So, that was the first thing that I ever heard, and it was a huge number. And I remember doing the calculation of how much sex he would have had, and how many sexual encounters he would have had to have had daily since he was twenty, you know. “Ok, so he’s 33 now and let’s say he’s been sexually active since he was like, let’s say sixteen because, obviously, this guy’s a real slut.” [laughter] And sort of figuring out what that meant and just being like, “Whoa! That’s a lot of sex.” And it was really just a mathematical problem. That was the first thing that I thought about and then I remember. Because those days, and I guess really still now, we’re inundated with a bunch of post-modern theory about, you know, self and other and all that, and I had heard some description of AIDS being the body’s inability to distinguish self from non-self or something like that. Like, it’s kind of an allergen or a host response sort of description and I remember thinking, “Oh my god, this is very post-modern.” And those were my first thoughts about HIV.

GK: Ok. So, then you find yourself in Africa?

DT: Yup.

GK: And you discover that you’re HIV-positive, so do you want to tell us a little bit about that?

DT: Yeah.

AS: You were teaching there?

DT: Yeah. I was teaching in the rural areas in Zimbabwe. That was the time when I heard HIV in Africa was more about the Rift Valley. It was somehow this theory about the geography of the Rift Valley, which is in Uganda. You know, how the geographical description or theory about HIV and its prevalence in that particular area...

AS: Like, malaria being connected to mosquitoes being in a...

DT: ...certain area where... like, in low-lying valleys. I don't know exactly what it was and I certainly don't remember very clearly, but it was – HIV is in Africa but it's located in some mysterious geographic region in this rift valley, this part of Uganda in Africa. So, that was far away from Southern Africa and there was really no information in terms of our orientations at that time around HIV in Africa, or in Southern Africa in Zimbabwe.

AS: What year were you there?

DT: That was '85 or '86? Mid-80s. In fact, while I was there in Zimbabwe it was really a pivotal time because in the first years that I was there, there were articles in the media about how HIV wasn't in Zimbabwe, which was probably the first indication that there was the need to put out this disinformation. And by the time that I left, and I left knowing that I was HIV positive, I mean it was basically like, people were beginning to be aware that it was everywhere. But it wasn't really spoken it was more whispered in various places and after I left I stayed in touch with some of the other teachers. I was working in a Catholic mission school, a boarding school, and it really started to hit the school just after I left. People started to die and go to their cultural healers (n'angas) and get all sorts of really bad information about how to cure HIV and things like that. It would result in people dying earlier than they would have if they just let HIV happen. I was involved with a Zimbabwean writer who was kind of notorious. He was a bad boy. In Harare, I was seven hours away from Harare, which is the capital city. I'd quite often, probably about once a month, get on the bus, go to Harare and have a wild weekend – drink a lot, hang out with Dambudzo, and just paint the town red. And it was kind of glamorous because he was very... the sea kind of parted when Dambudzo walked by. He was this tiny, skinny, little man, which retrospectively I realize was HIV, but at the time he was just a tiny, skinny, little man like lots of guys in Zimbabwe were.

AS: And you were how old when you met him?

DT: I was probably about 27 or 28? Yeah.

AS: So, you were not a young, little... you were a 'real' person.

DT: Yeah, I was doing what I wanted to do. I mean retrospectively, of course, I wish I hadn't done it. For me, because my background is in literature too, being in Africa and... first of all, reading African literature, which is incredible. And because Zimbabwe had a lot of economic sanctions on it, it was hard to get literature other than African literature. So, I was just gobbling up African literature. I read so much African literature. And Dambudzo was really a star in Zimbabwe and had written a book that had... when he was at school... where do Rhodes Scholars go? Oxford? Cambridge?

AS: I think Cambridge, but I don't know why I think that.

DT: Anyway, he was a Rhodes Scholar from Zimbabwe and had gone to whatever university you go to when you're a Rhodes Scholar, and had written this book called... well, it's actually a novella called "The House of Hunger" that had received some commonwealth prize for literature or something. He was awarded a prize the same year as Neil Jordan who did "Mona Lisa," "The Crying Game" and all that. So, he was a co-celeb in Britain and in Zimbabwe when he returned and I just felt like, "I've arrived." Literature is at my door.

And because he was well known, after I'd stopped seeing him I found out that he had died because it was in the newspapers. If he had just been, you know... I wouldn't have known. Like, a boyfriend from the next village or something like that. Well, I might have known because word would have gotten to me, but actually I was travelling with a bunch of people and we were going to a campsite where we were going to camp for a couple of weeks on our holidays. We got out of the truck part way there in a town and I bought the newspaper and I saw it there. It just was like all of a sudden I realized what was going on. It was like, "ok." And by the time that he died there were little bits of information starting to happen around HIV in Zimbabwe. I was like, I know what's happening. Also, I had already at that point had a kind of unexplained... I had already had a seroconversion illness, but I didn't know what it was at the time. I had a really, really serious seroconversion illness. I was hospitalized for probably about a week. You know, just all the pieces just started to come together and then I spent about six months after he died basically trying to come up with some way of reassuring myself that – no, this was fine. I really knew that it wasn't and so I went in to Harare and tested. Because the thing was there was no privacy on the mission school. The doctors and the administrative people were all linked into the school system and there were no... like, I didn't have a telephone. If I wanted to make a phone call I basically had to use it off of the Headmaster's desk while they're sitting there. And the priests at the mission school had a telephone too and I went at one point to use the telephone in the priest's building and some 80 year old priest was rubbing himself up against me while I was trying to use the telephone, so it was just madness. Trying to find out whether you have HIV and having a priest rubbing himself against you; a Swiss priest. Yeah.

So, I went into Harare and I got a test, and the doctor... because, obviously, there wasn't point of care testing. The doctor said she would write me a letter. Also, your mail wasn't private. What would happen with our mail... like, all the teachers' mail at the school is that you get it dumped on a desk during our tea break. I remember seeing it there. If you've had those moments in your life where it's just like, everything hangs on this, and kind of goes icy cold. It's a slow motion kind of thing. Picked it up, went down to my little house in the teacher's compound and opened it and I was positive. But I timed it so that I didn't have a lot of time between the end of my contract at school and finding out I was positive. And I was thinking that I would stay if I found out I was negative because I really, really loved working in Zimbabwe. It was a very politically optimistic time in Zimbabwe after the war for independence, and the school that I was teaching at had become an A-level school and I was teaching A-level English. A lot of the students' ability to get into university in Zimbabwe depended on them having an A-level English credit. And it was very hard because English wasn't their first language and I was a very good English teacher. I was really able to help a lot of students get their A-level English `credits and go to university. It just seemed like there was this really remarkable transformation that was taking place at the time. I have a Zimbabwean friend now here in Canada and she says that when they were... she's from Harare, a Harare girl, and she said that they had a saying. Like, we talk about the sticks; they would

talk about the place that I was – “Oh, you’re from Jerera, you’re from Zaka.” You know, that’s where we were, so that sort of transformation was really happening at the socio-geographical.

AS: The people out there get their A-levels and go... yeah.

DT: And go to university in Zimbabwe, the University of Zimbabwe. They could buy their education by bartering corn or cattle and end up at the University of Zimbabwe. So yeah, it was pretty amazing.

AS: To be part of that.

DT: Yeah, for sure.

AS: Yeah.

GK: So, once you test positive, a short while after that you come back to Canada.

DT: Yeah.

GK: I think you were living in Hamilton then.

DT: Yeah.

GK: So, what was that like?

DT: Even though Hamilton’s just a short distance from Toronto there wasn’t really a lot going on. There was probably more going on than I knew about, but it was that I was just trying to figure out everything and I was balancing my fear and all that. I do remember going down to – it was called HANDS, the Hamilton AIDS Network for... I’m not exactly sure. Anyway, the Hamilton AIDS organization and I was just petrified to go in. Somebody who was at the desk said, “Would you like to sign in the guest book?” or something like that, and I was like, I think I did. I was just, “What are you asking me to do?” I was just so frightened and ashamed. Not knowing where to start, and it was hard to find where to start. Well, you know, there was no Internet first of all. So, it was like, a telephone book. You look up AIDS or HIV and there’s nothing there. So, I started by going to my family doctor, who wasn’t my doctor, it was my parent’s doctor, and he was completely... I guess, frightened, but uninformed. And the information that he gave me was really just, basically, his biases. But he did give the name of the doctor that was treating people with HIV. Then I, through that, managed to piece the little path together.

AS: In Hamilton?

DT: That doctor was in Hamilton. Yeah. I remember going to see the AIDS doctor in Hamilton – Stephan Landis. He was giving me information, and at one point he made a mistake and he said, “...and when you shave...” He was talking to me about razors because he’d just been telling men about shaving. It was like, “I shave my legs, is that what you’re talking about?” [laughter] He was

just so used to giving that information to gay men that he, in some way, hadn't quite taken... I don't know exactly what it is, but that kind of mistake was something that happened quite often. In the beginning it wasn't quite in their vocabulary yet to distinguish between men and women with HIV.

AS: Did any of them talk about that explicitly?

DT: No.

AS: Interesting.

DT: No, I think they were probably embarrassed. I saw Dr. Landis and Bill Siedelman, who ended up coming to Toronto and working with, I think, Sunnybrook. Actually, they ended being two great doctors. Yeah. They were great.

AS: And you didn't have to deal with the family doctor anymore.

DT: Yeah. That was ridiculous; you know, "Use Lysol on the toilet," and stuff like that.

GK: So, you became aware that there was probably more happening around AIDS in Toronto?

DT: Well, I had lived in Toronto already and I had known lots of gay guys before. I've always hung around with gay guys before HIV and, obviously, after. So, I know a lot of gay guys in Toronto. But, because I was HIV-positive, I had been slow to connect with people in Toronto because I didn't want to have to disclose my whole story. But I knew Bill Berinati. He was a chiropractor who was involved in Casey House and 127 Isabella housing for people with HIV and saw a lot of people with HIV in his chiropractic practice, so I got in touch with him.

GK: That was a good person to get in touch with.

DT: Yeah, because we had, to some degree, the same circle of friends before. He said, "Oh, well, talk to so-and-so, talk to so-and-so, talk to so-and-so..." and then I was in. It was like, "Ok, this is what we're all doing and this is what's going on. And here are the newsletters and..." The first thing that I got involved with was a healing circle on Carleton Street. Do you remember this? Glen Pelshea?

GK: The name I remember, but...

DT: Yeah. That was the big thing. It's interesting when you look back on these things, but that was what people were doing because there was nothing else to do. I think there was some AZT (azidothymidine), but a lot of suspicion and people were genuinely not doing AZT if they could avoid it.

AS: Yeah. And so what would happen in the healing circle?

DT: In a healing circle you would massage one another and there would be fifty people. Not all HIV-positive; a lot of friends, a lot of people in recovery, so it kind of had some AA connection. There'd be a check-in and so you'd go around fifty people, and, in the second part, you'd break into pairs and massage each other. And you got all the information from the check-ins and then there was a break and you kind of went off and followed up with whoever, and then you massage one another. That was what people were doing back then.

AS: And was that grounded in any particular healing tradition? Do you know where it came from?

DT: Louise Hay.

AS: Ok.

DT: Yeah.

GK: Yeah.

DT: Yeah. Louise Hay... AA? I guess. Because there were so many people from AA there.

AS: Like a collective?

DT: Yeah.

GK: Did that healing circle have something to do with the AIDS Committee of Toronto or was it independent of it?

DT: I think it was independent of it, actually. Yeah. Although, Glen did work with ACT, but I think it was independent.

GK: So, did you meet any other HIV-positive women through that? Or were they were all men.

DT: Yeah. At the break I'd always go up to the women who were there and try to find out if they were HIV. It took me a long time to meet another HIV-positive woman; like, a couple of years before I met another woman with HIV.

AS: Were the healing circles... like, was it nice? Was it a good space?

DT: Yeah. It was a good space. It was a good space for collecting information and there were a lot of great people there. There were a lot of people. You could just gravitate to whoever you liked right from the check in. So, there were a lot of people that were like, "By god, that person does go on." You know, as happens with check-ins. That's a perennial issue of check-ins, right? [laughter] But there were some really great people there. After a little while I got a bit sick of the guru aspect of it; you know, of the leaders. Glen was one, but there were others and they were a bit like, kind

of... [snaps fingers] There was a kind of sanctimoniousness and, “I don’t eat bread that has yeast.” That was really hard because there was no real effective drugs or remedies or whatever. People were just doing anything and everything. And I think a lot of people, you know... I mean I certainly did. I felt like – well, do it all.

You were saying was the healing circle a nice thing to do... the pressure that I think was a little bit a part of the AIDS movement, and probably A-type personalities meeting. It was, do it all, all the time. That wasn’t very happy because that was such a level of self-surveillance. They did that “managing your health” way of thinking about. There’s your body of desire that got you into trouble and there’s this body of rigid discipline that has to be exercised against that body that will cure you. Because you wanted to hang on to anything, right? So, it was like, spend all your money on vitamins; spend all your day taking vitamins; spend the other time reading about vitamins. I probably did that for about a year and then I just broke.

AS: Super individual, right? Like, you have to care for your own body and if you’re not doing it, you’re doing something wrong.

DT: Well, yeah. And in that you’re rating yourself amongst your peers. I had an eating disorder when I was younger and, to me, that space of AIDS self care really harkened back to anorexia. I recognized pretty quickly and I was like, “Oh, I just can’t. Actually, I can go down that road, so I won’t go down that road.”

GK: You’d been down that road. Yeah.

DT: But it was hard to say no because there were a lot of people who were really rigorous. That notion of this good disciplined PHA [people having /living with HIV/AIDS] was just... I mean it’s one of the kinds of archetypes of the AIDS movement, isn’t it?

AS: Yeah, totally.

GK: So, you became aware that there were things beyond the healing circle that you might want to get involved in?

DT: Uh-huh.

GK: I’m not quite sure in terms of whether I think you both get involved in a HIV-positive women’s group around AIDS Committee of Toronto, and at some point you get involved in AIDS ACTION NOW! I’m not sure which comes first.

DT: I think I was involved in AIDS ACTION NOW! first. I think so, yeah. But they were very close in time because, basically, I had to move to Toronto to do those things.

GK: Right.

DT: They were probably close in time. I was going from Hamilton to the healing circle and back, so I moved to Toronto. Yeah, probably about the same time.

GK: Do you have any idea when that might have been?

DT: '88, '89? Yeah. I actually don't know whether they were simultaneous, but anyway in about the same time. But they didn't really fit together that well. There was a lot of skepticism within the women's group about AIDS ACTION NOW! There was a lot of skepticism about activism, the tactics of demonstrations, and just being loud and being angry. Whereas the women's groups, and maybe some of the men's groups as well, were trying in a way to make you not angry, but "deal with your feelings, and be ok and accept." The contradiction there was difficult.

AS: Did the women's groups come out of the healing circle or was it another formation?

DT: No, the women's group came out of ACT.

AS: Ok.

DT: ACT was in touch with enough HIV-positive women that they could put together a support group and so they did that at Hassle Free Clinic.

AS: Ok. And were you in that very early iteration of it?

DT: Yeah, I was in the first group.

AS: How big was it?

DT: About a dozen.

AS: Oh, wow.

GK: And it was facilitated by some of the staff at ACT?

DT: It was Bonny Benedict, who I think was Hassle Free, and Theresa Dobko, who was ACT.

GK: Yeah, so it might very well have been a joint thing. Theresa was definitely with the AIDS Committee of Toronto.

DT: Yeah. So, they were lesbians and HIV-negative, and that didn't sit well with me after a while.

AS: Yeah. How did that happen? Was it because of their institutional...?

DT: Well, there were no HIV-positive women around. At that time there were also a lot of issues about HIV-positive people working in AIDS organizations at that time. Like, there was a real verbalized position that HIV-positive people couldn't separate their issues from the issues of their clients. And so they shouldn't be working in HIV organizations. Not everybody agreed, but that was a position that was held and spoken about.

AS: And accepted?

DT: Yeah. I mean people with HIV tended not to accept it, but I think that there probably weren't that many people with HIV working at the AIDS Committee of Toronto at that time. And lesbians were very present in the AIDS movement through their connection with gay men and through women's health and reproductive rights.

GK: And that's where Theresa actually started to do work before ACT.

DT: Yeah? So, they were leading the group, but after a while I did feel, and I was probably one of the people that felt the most strongly about it, that this is something that women with HIV could do for themselves and probably do for themselves better. That was when I wrote the article for *Healthsharing*. And I remember giving Theresa a draft of it to read and she really didn't like it. She said, "You sound angry and critical." I may have gone back and toned down some of the language a little bit.

AS: What were you saying in that article?

DT: Well, it was one of those articles that looked... I'm able to identify it very clearly now when I look back on it as an article that's about the identity of a person living with HIV, but that identity didn't really exist strongly then. It was just being created. And it says the things about people living with HIV and how people with HIV can contribute, and what a woman who finds out she's HIV-positive might want to do with her life. And it talked about the difference between prevention and treatment, which was not clear in people's minds.

AS: Right. Because people were holding this position that the people who needed to worry about AIDS are HIV-negative, right?

DT: Yeah, that the task was prevention. I guess in their mind they thought what I wanted was information about how not to transmit the virus, which was not the least bit interesting to me because I wasn't having sex. I could scarcely conceive of a time when I was ever going to want to have sex. I wanted to know what to do to live longer. That was radical then. That was not thought about and there were no answers, really.

GK: And that article in *Healthsharing*, it was the first thing in any major feminist publication in the Canadian context, that I'm aware of, that actually talked about AIDS and HIV from the vantage point of someone who was HIV-positive, so it was really an important article.

AS: And it's hard...

DT: A woman.

GK: Yeah.

DT: There were men talking about it, but women... yes, absolutely.

GK: Yeah, for sure. But I mean in feminist publications.

DT: Yeah. *Healthsharing* magazine was... it's important to remember that this is before the Internet. So, *Healthsharing* magazine was the Canadian magazine on women's health, which was an issue that women were really, really interested in. It went out and people did see it.

AS: And did someone there ask you to write it? Did they know?

DT: No.

AS: No. You thought of it and pitched it.

DT: Yeah.

AS: Yeah.

GK: That's great.

DT: Yeah. It's funny because I was thinking about some of these things in preparation for this interview and I was thinking – wow, I really was kind of fearless. I found out where *Healthsharing* magazine was and I went down and I pitched it to Amy Gottlieb on Skey Lane. I was fearless. But the thing was I thought I was going to die, so I thought it really didn't matter. There's been moments since then when I've lived that I thought, "Maybe I should have been a little more quiet and not attach my name and my picture and all that."

GK: So, you didn't stay involved in the ACT HIV-positive women's group for long then.

DT: No, I did probably stay for more than a year.

GK: Ok.

DT: But I stayed in touch. AIDS ACTION NOW! for me was really the backbone of all of this work. The women's stuff grew off of AIDS ACTION NOW! AIDS ACTION NOW! was the river. The women's articles, group, various activities, the book; they were offshoots of the force of AIDS ACTION NOW! Yeah.

GK: We're coming back to AIDS ACTION NOW! Did you get involved in any of the particular committees?

DT: I got involved right away. The first committee that I got involved with was the Media Committee. And so what I did was I went to a Media Committee meeting. I met Sean Hosein and George Smith there. There was an action that was happening around ddI [didanosine]...?

GK: Right.

DT: They just kind of swept me off my feet. It was great. They were like, “You can write?” and they just took my word for it. They didn’t know me at all, but it was like, “You can write? Off you go.” The AIDS Committee of Toronto and *Xtra* shared office space there on Young Street, and *Xtra* had a fax machine, I think. So, we went off there and we composed a press release about ddI and we faxed it off. There was a media list that was programmed into the fax machine. Sent it off and that was my introduction. What I realized in working with them was that the way that I wrote was the way they wanted somebody to write. It was adequate in their view because, it was difficult. George was at sociology at OISE [Ontario Institute for Studies in Education] and Sean was... I don’t know what. But, you know, I had a lot of anxiety about whether or not I was going to fit in and be ok, and I saw that I was. They gave me a lot of really good feedback too. They really made me feel like, “Welcome and let’s get to work.”

AS: Yeah. But you hadn’t written a press release before?

DT: No, I hadn’t ever written a press release before. So, we did that and pretty soon afterwards they handed a committee [the Media Committee] over to me. I would convene the meetings and we put out *AIDS Action News*.

AS: How many people were involved in it?

DT: Probably, about half a dozen.

AS: Wow.

DT: Yeah. There was Bernard Courte...

GK: Yes.

DT: Because AIDS ACTION NOW!, through Bernard Courte, had really incredible bilingual capacity. We used to have a joke about when we’d finished off the Steering Committee meetings we’d say, “Don’t leave any paper around because Bernard would take it and have it translated.” [laughter] But he translated everything; and Pierre Tanguay, who was with CBC, also a Quebecois guy. Who else was in the Media Committee? Ross Fletcher?

GK: Uh-huh.

DT: Those are the people... Marie-Louise Adams might have been?

GK: Yeah.

DT: I know with Marie-Louise Adams and Helen Humphreys at OISE we did an early pamphlet around women and HIV. And then I brought in another woman from the women’s group who, I

think, sort of came in and out of the Media Committee and did some pieces around women and HIV.

AS: Uh-huh. Did people mostly get involved because they already had those skills and capacities, because you said some people at the CBC did...

DT: Yeah.

AS: And was it that how things worked? That people would come into AIDS ACTION NOW! ...

DT: There was also David Adkins .

GK: Yes.

DT: Yeah. And Irving... can't remember his last name. Yeah, these were all very, you know...

AS: Savvy?

DT: Yeah.

GK: Yeah. David Adkins goes on to make films.

DT: Uh-huh.

GK: And Patrick was involved too.

DT: Was Patrick? Yeah? Ok.

GK: At least, early on when you were involved he was there.

DT: Ok.

GK: He remembers meeting you in that context. So, you first of all get involved in the Media Committee, and then you become the coordinator of the Media Committee it sounds like. Are you?

DT: I'm not on the Steering Committee at that point. And then the next year I joined the Steering Committee. But I was going to all the Steering Committee meetings; I just wasn't a member of the Steering Committee at that point.

AS: So, the media committee put out *AIDS Action News*. If an action was happening... well, just talk a little about that.

DT: Yeah. I'm remembering that it did *AIDS Action News*. I guess it did the media around actions; although, to be honest I don't have strong memories of that. I'm thinking it must have also done

things like pamphlets and stickers and the handout bills for events. Like, Pride and the International Women's Day and things like that.

AS: One of the things I'm really curious about is organization.

GK: Right. How did it work?

DT: We met at OISE usually. I think partly because Bernard worked at OISE, George worked at OISE. There was a meeting space in the cafeteria. And you could go back and use the technology upstairs. Almost all of these things that I'm telling you we did were the first time I had used a fax machine. I remember the first, when we did the pamphlet on women and HIV with Marie-Louise and Helen Humphreys. That was the first time I'd ever seen anybody ever use – what was the early... Pagemaker? Yeah. That was the first time I'd ever seen text get turned. A lot of it was this engagement with really, really new technology and people who knew how to produce a newsletter online or on a computer. It wasn't online. It was on a computer. It is interesting the way a lot of changes that happened in AIDS organizing were accompanied by or facilitated by technology; all the new technologies that were happening at that time. So, we met at OISE and – what else can I say about that? We'd get the copies of the newsletter we had. We had a bunch of young people. One of them I remember was Ann van Burek. She might have even been on the Media Committee. Because she was a friend of Pierre Tanguay's and her son had to do some community service for high-school, or something like that, and so he would ride around on his bike and... there was so much by hand, right?

AS: Yeah.

DT: It was like, you're taking these newsletters and you're dropping them off here, and you're dropping them off here, and you're dropping them off here. Things really moved around the city, and around the country. I remember a friend of mine who was living in Victoria had a copy of *AIDS Action News* and read my name in it and got in touch with me. Through Brent Southin in the AIDS ACTION NOW! office; "I wanna get in touch with Darien Taylor." In spite of the fact that we didn't have a lot of current communication technology there was a lot of connection that was happening.

AS: And did the Media Committee have a budget? Like, how did the money for producing flyers and stuff...?

DT: I have no idea. I think AIDS ACTION NOW! had a budget. I know it had a budget, but you know what I think it was? It was centralized through Brent Southin as the office keeper. Does that make sense?

GK: Part of it is that I leave Toronto in 1990, and I think you're largely describing a period after that.

DT: I think it must have happened that way.

GK: I'm not even aware that AIDS ACTION NOW! had an office, so if you could actually tell us about that.

DT: What happened was at that time CATIE was also getting started - the Treatment Information Exchange. So, it was the tie project and it had an office on College Street, at College and Palmerston in the offices that aren't there any longer. Women's Press was in there; David Bray, who was a traditional Chinese medicine practitioner who saw a lot of people with HIV; Egale had offices there; Voices of Positive Women had its first office there. I think, ACAS [Asian Community AIDS Service] possibly. No, that doesn't make sense because ACAS started off as GAAP (Gay Asian AIDS Project). But anyway, different AIDS organizations across the street at the Euclid. There was a theatre, a film theatre that John Greyson did a lot of programming around AIDS. There was DEC (Development Education Centre), which was a publishing house that published a lot of political and cultural texts. So, that little area around College Street was kind of a little hub. There was also a printing company in there. Like, a designer printing company called Blackbird that did a lot of the printing for us and for other organizations there. Yeah. So, AIDS ACTION NOW! had an office; I think, basically an answering machine and Brent would go in. Brent Southin would go in sort out the mail and various things. And it was located in CATIE or in the TIE project. So, the TIE project became the location. Yeah, because before AIDS ACTION NOW! didn't have a location. That's why you're in OISE; it didn't have a location. But then it started to have a location at the TIE project on College Street and meetings started to be held there.

GK: That makes a lot of sense.

DT: Yeah.

GK: That's a missing piece of the puzzle.

DT: That makes sense. Yeah.

GK: It would be late 1990. So, you're involved in the Media Committee and you become the coordinator of the Media Committee. You were mentioning you were going to Steering Committee meetings...

DT: Yeah.

GK: What was your sense of how AIDS ACTION NOW! more generally was organized at that point in time in terms of the Steering Committee? How were decisions made about what AIDS ACTION NOW! was going to do?

DT: Yeah. Well, they were made at those meetings. Pretty much. And within the committees that met outside of the Steering Committee. So, there were the Media Committee meetings. There was a provincial committee, and that was Bob Gardner and Linda Gardner and Glen Brown and probably, Tim McCaskell at that time. Although, within a couple of years there was also a federal committee - what did we call it though? It was Federal treatment. I can't remember the exact name of it, and Tim used to go to that. But there was a provincial committee that the Gardners and

Glen Brown and probably, Susan Kasurak and others went to. And the provincial committee was very, very powerful. That was basically composed of the individuals on the Steering Committee that really has a good sense of how to shape the political agenda. They had a lot of power and knowledge and ability to work, skills that they had got from the Right to Privacy committee. They were academics from within the government, from working within women's health and reproductive rights. What was it? Ontario Coalition of...

GK: OCAC - the Ontario Coalition for Abortion Clinics.

DT: OCAC. Yeah.

GK: Yeah, which both Linda and Bob were involved with.

DT: And Brent Southin had been very involved in that. Chris Bearchell, who wasn't really part of the ongoing AIDS ACTION NOW!, but she was very present. Maggie's and the people who through Maggie's often connected for periods of time with AIDS ACTION NOW! I had a sense of the provincial committee, in a sense, steering the Steering Committee. In the beginning I was gazing on. I was kind of awestruck and star struck in an odd way. I was just like, "Oh my god, these people; they're so..." I wasn't very politicized, but these were people who've come through the Marxist study group. They totally know what they were doing. And so I was just watching, learning. I can remember the first meeting I chaired after I joined the Steering Committee. Oh my god, I didn't even know how to chair a meeting. I didn't know the relationship between an agenda and what took place at a meeting. I was so green, I thought a meeting just happened organically. It took me a few meetings to realize that there was a connection between an agenda and, you know... It was Robert's Rules of Order more or less with more consensus and less voting and that. But I knew none of that. It was all just... I was a sponge and I just totally took it in and I got it, but it took a while because I really felt a little bit out of place and kind of "less than." And so it was hard to do things like chair a meeting where you have to say, "OK. You shut up, and let's hear from you," and take a list and stop people who you totally admire from talking. Even to realize that to have the ability to see people that you're in total admiration of as sometimes being people that are also talking too much or off topic, or just riding their particular hobby horse of a topic and that sort of thing. So, that took me a while. I was really kind of googley-eyed. I got it eventually. Also, being a woman... I remember Bernard Courte saying, he was being very nice, he said, "I guess women chair meetings differently than men." [laughter]

AS: But were there many women on the Steering Committee though, when you came into it?

DT: Yeah, there were.

AS: There were?

DT: Yeah, but people really allowed me to come forward because they recognized that I had HIV. And so, I think, there was a really good understanding. It was also a huge bone of contention. There were people with HIV and people who didn't have HIV in AIDS ACTION NOW! But I think everybody kind of agreed that, "Ok, Darien is the one that is going to become the co-chair because

she has HIV, not because she's got the same abilities as someone like, Linda Gardner or Marie-Louise Adams" or something like that. They had way more analysis and ability in that sense. And it was hard, you know. I knew that I was way over my head most of the time. Often I would go home and just... [sigh] It was a bit embarrassing really because it was hard to control a lot of stuff that was going on. And a lot of the discussions that were going on between individuals who had years and years of organizing underneath them; and it was organizing that I was not part of. It was very hard to read that. I would end up feeling responsible for something that retrospectively I realize had nothing to do with me. It was about Glen and Sean, and George and Glen, and George and Tim; you know, the communal house over on...

GK: Seaton Street.

DT: Seaton Street. And then they were on Brunswick or something. They were in the Annex as well. Like, George and Sean and Tim and Richard and – was Gerald Hannon even living there?

GK: I don't think so.

DT: I don't know. Anyway, all these kind of gay politicians were all living together, and just living and breathing all these tensions and bringing them into meetings.

AS: Also, very powerful personalities. Right?

DT: Absolutely. Yeah, so that was intense.

GK: In terms of you being an HIV-positive woman, were you the main person who was involved in AIDS ACTION NOW! throughout that period?

DT: As an HIV-positive woman? Yeah, there were no other HIV-positive women there, until Maggie Atkinson came along and that was a lot later. Maggie Atkinson came on in the mid-90s. And Maggie had been in the women's group with me, so that was really nice the way she... she also moved over from the Hassle Free/ACT women's group into AIDS ACTION NOW! I have to say for Maggie, she took it on when it was... like, when I was doing AIDS ACTION NOW! work everybody wanted to be doing AIDS ACTION NOW! work. When Maggie was doing AIDS ACTION NOW! work it was after the drugs had come out and people were drifting away. That was really hard. When Maggie was doing the work when it didn't have all the urgency and the energy that's born of crisis and catastrophe.

AS: Yeah. And who was your co-chair when you were co-chair?

DT: Glen first and then James Thatcher.

AS: Ok.

GK: Do you want to tell us more about being a co-chair of AIDS ACTION NOW!? What that was about or what you remember doing during those periods?

DT: At the time that I was co-chair I was also the chair of the committee that worked on federal treatment issues. That used to meet in the Voices of Positive Women offices on College Street in the building that I was describing. That was Tim, Kalpesh Oza; Ken Blott, who was, as Tim once called him at a meeting... Tim was almost always able to keep his temper, but at one meeting he called Ken Blot a “sociopath,” and he was. He was. He was just there to rattle everybody’s chains. Who else went? Those are the ones that I can remember off-hand, but there were a number of other people that were in the Federal committee – chairing meetings, getting the agenda together. By that time I was living, breathing, and sleeping AIDS ACTION NOW!, and I was doing Voices of Positive Women work at the same time. But it all kind of worked together and I didn’t really distinguish. I didn’t put a lot of boundaries between the work. It was all happening at the same time.

AS: I’m curious. I want to hear about so many different things. One of the things I want to hear about is why the Federal committee came into being? How that happened? But I also really want to hear about Voices of Positive Women.

DT: Yeah. I think there was just a realization that we needed to be covering both the provincial and Queen’s Park issues, but then bigger issues like that EDRP [Emergency Drug Release Program] that we were talking about earlier on. There were a lot of issues that were more the domain of the federal government - the organization of research programs like, the Emergency Drug Release Program. We talked a lot about catastrophic rights for people with HIV at the time, clinical trials – those were the issues for those who were in the Federal treatment domain. We published a book on what to do if you want to get involved in a clinical trial and giving people information about how they could tell whether they were getting the placebo or not. This was how to break the code on clinical trials and things like that – what were some of the other issues that were happening then?

AS: There would have been things about getting...

DT: Drug release. Yeah, of course.

AS: So, the stuff that was happening on the provincial level that, at a certain point, people realized the province just couldn’t do those things.

DT: The province couldn’t and doesn’t do it. The province doesn’t do it. You can talk to Evelyn Gigantes all you want. She doesn’t have any ability to influence the release of drugs and things like that. So, that was more what we were working on and we did a lot of publications. We would do these annual or semi-annual... what we did was created substitutes for people’s doctors. If you got these symptoms then you’ve got this disease, and you need this drug, and make sure that you ask your doctor about it. Because they don’t necessarily know and people didn’t know, and we spent a lot... and it was to the point where we could encompass the drugs, the opportunistic infections, in something that was probably about three double-sided pages or something like that. So, that was also something that we did quite a bit of.

AS: Who would coordinate getting that out to people in other provinces? Was there an official mechanism?

DT: No. Even though it was about issues happening at the federal level and hopefully the actions that we took or the advocacy that we did would affect the entire country, there wasn't a really good mechanism for getting that out nationally.

AS: Although, clearly people were getting it.

DT: People did get it.

AS: They were getting *AIDS Action News*, and it was just informal...

DT: Yeah. It was pretty amazing. There was a lot of that coming out the United States. And a lot of what we were doing was looking at what ACT-UP was doing and treatment bulletins like, BETA and GMHC, and finding out what was available in Canada or what the drug was called in Canada. That sort of thing, so a lot of it was a translation of what was happening in the United States. There were some errors that we made. I think, retrospectively we made too much of clinical trials because I think that was more of an American phenomenon and we didn't quite realize that it wasn't going to be as important in Canada until all the work was done.

GK: That was partly, probably, because one of the first things AIDS ACTION NOW! came up against was the Pentamidine trial. One of the first things we organized was around that. So, there was that and the Ribavirin trials; there are a couple of things like that and, I think, lead people in that direction when the clinical trials in general didn't really pan out.

AS: But it set that tendency.

GK: A lot of the initial work around distinguishing treatment from research was done, which was really important work, but I think you're right.

DT: Yeah, and the notion of altruism and...

GK: Do you remember anything else during that time period when you were co-chair? You were working with Glen; then, you were working with James. Do you remember things that you might have been working on during those periods of time? [...] If nothing comes to mind we can just move on.

DT: Yeah. Let's just move on.

GK: So, the other train of conversation is Voices of Positive Women, and maybe we can come back to AIDS ACTION NOW! after that. How did Voices of Positive Women get going?

DT: In the ACT Hassle Free Women's Group I met a woman who had gone to Britain and seen what was happening with women organizing around HIV there. They had an organization called

Positively Women. Positively Women in the UK was... a lot of the women who started organizing it were women who had been drug users and often drug sellers. They had a kind of high-level distribution of drugs, so they had an interesting street savvy that we didn't have. They knew how to get the word out because of how they knew how to distribute drugs. They had done a series of brochures that she brought back and showed to the women's group that were, for me and for her too, just spot-on. This is what HIV-positive women want to know about; it was sex and reproduction, healthy living. There were three of them.

AS: Were they one-page flyers?

DT: Yeah, three two-fold. They had the graphics that appealed to women. One of the things that always used to bother me about the pamphlets around prevention and the pamphlets around treatment was that the prevention pamphlets looked expensive and glossy and sexy and fun. And the treatment brochures always looked... they were kind of a granola paper, a bit newsprinty. You could really see the values. The graphics on these brochures were fun, and from that we basically decided we're doing something. We need to do something and we had no idea what to do. It was interesting because it gets back to that point that I made earlier. I can criticize other people and say they didn't know what we wanted, but we also didn't know what we wanted. In sitting together with this woman and trying to decide what we were going to do.

We wanted to do something that was arts-based and international because both she and I had lived overseas. She'd lived in China and I'd lived in Zimbabwe. We sat for days and we couldn't figure out what it was that an HIV-positive woman would want to do with a small Canada Council Explorations grant. That was what we were going to go for. What would we say? What we'd do? It didn't even actually come to us and we didn't know how to write a grant, and we had George Smith come over to her place. I remember she made this nice Japanese soup and George just told us, this is how you do it. So, we got our idea and it was an anthology of women living with HIV. Now, this is in a time when we knew a dozen HIV-positive women in Toronto. We wanted to do an international anthology of HIV-positive women. There were no AIDS organizations for women at that time and we didn't know a single other HIV-positive woman in any other place in the world. So, we did it. We just did it. They tell you to do it; you carve it into small pieces. We did a call for submissions and we got a whole bunch, thousands, of addresses of women's health organizations and women's organizations and anything that... we were always copying down addresses from the back of conference proceedings and stuff like that.

AS: You would send paper mail?

DT: Yeah. And, in one way or another, we got it translated into about eight different languages. I remember we got a reply back from somebody in New Zealand saying, "We really like the look of your stuff, but it's in Hungarian." We had a little PO box over at the Parkdale post office and it just started coming in.

AS: And you got the grant for it?

DT: Yeah. I think it was \$1000, not huge. We ran this out of the Voices of Positive Women's office. We just did it. Basically \$1000 covered the postage. And we got Second Story Press, which was the

spin off from Women's Press around identity politics and they published it. We took that to Heather Ramsay, who is... actually, continues to be a friend of mine, but she was a dyke who was working in the government at the time and working on AIDS. So, we took her the stories that we had, and the pictures that we had, and the photographs and all that, and we showed it to her and we said, "Can you fund this?" She said no because it's international. And she was working with the AIDS Community Action Program [ACAP], the regional delivery of the federal monies. She said, "But I could fund an organization," so we applied and got money from ACAP. Then, we got money from the Ministry and were able to rent an office and finished the book there.

AS: And this was under the umbrella of Voices of Positive Women?

DT: We basically finished the book there and then started Voices of Positive Women. It was open. The office was open and we were doing some Voices work, but we were really... what was on the wall was a bunch of file folders that we were putting the different chapters in. Trying to organize the order of the contributions to this book. We got contributions from all over the world. It just made us realize that women, like everybody, wanted to communicate. All the women that we'd communicated with didn't know another HIV-positive woman, so we started to realize that was something that we could do locally, and we were off. That was a time... like, it's interesting because at that time it looked like the epidemic was going to be very different, then, it ended up being amongst women. People like Maggie Atkinson, a lawyer, a well educated, mother's a local politician, she's a lawyer, she's working at the law firm where Alan Cornwall, who was involved in AIDS ACTION NOW! was also working... they both announced their HIV status in the same week at this law firm. Like, you could imagine the law firm must have thought, "Oh my god, who else?" So, we were meeting a lot of middle class, white gals, actually. Probably a function of who we were; I think it was also who began to get tested at that time too. The epidemic did shift and become much more... and the organization, much more an organization that was working with mostly African women. At that time it was a lot of middle class, white women that were coming out to the meetings that were older women.

AS: And then...

DT: We published brochures. We did similar brochures to the ones that we saw from the UK. Trying to give information on what to do to stay healthy and stuff like, eat well, stay out of the sun, really basic stuff. The interesting thing though, the one about... we called it Positive Sexuality. It was a really interesting brochure because we did everything we were supposed to do in terms of, we received the funding and you were supposed to show drafts of your work to the funders and they would read it and make sure it was ok. In fact, we showed it to lots of people, basically, so they could have input. We showed it to Margaret Shaw at Hassle Free, and probably Theresa Dobko and lots of people read this brochure and certainly the funders did too. The funders were the city of Toronto actually. In it we put... because this is what we heard from women that they were afraid to disclose their HIV status to potential partners because of violence and loss of confidentiality.

So, we didn't know what we were doing. We didn't realize how big this was going to blow up, but we put, "As long as you're using condoms you don't need to disclose your HIV status to partners." And that was an attitude that was out there and, I think, we weren't closely aligned to

what the official line was. And clearly, nobody was because everybody read that brochure and in draft form there was no problems. The funders read it, they signed off on it, we published it and it just blew up, which is interesting when you think about the panel tonight – about criminalization and HIV. And we got a letter from the Medical Officer of Health, who was Perry Kendall. We got calls from our funders saying they were going to cut off our funding, blah-blah-blah. We were supposed to retract the brochure, which we didn't do. The next time we published them we changed that line, but we did continue to put them out. There was a lot of discussion within Voices of Positive Women about whether or not we would change the line. A lot of people were very adamant that this was how it goes. It became a discussion in the community that was really interesting because, I remember there were people at the Toronto PWA [People with AIDS] Foundation who said that they disagree with us, the women at Voices of Positive Women, because the partner of an HIV-positive woman didn't have the same heightened degree of suspicion, or whatever, as a gay man would with a sexual partner. So, that actually women should disclose. Yeah, it was interesting.

GK: Double standard, yeah.

DT: And it began to create an interesting discussion also about power dynamics in gay relationships too. That was interesting because, I think, again, people just weren't really thinking about it.

GK: Do you have any idea around when that would have occurred?

DT: About '91.

GK: That would have been '91, the dispute about that?

DT: About the brochure? Yeah, about '91; '90 or '91.

GK: That's interesting.

AS: Also, it's one of these things that I just have been thinking about a lot as we talk to people, and I'll continue to be, about this moment when people are trying to understand their behaviours and activities in terms of really unknowable medical, physical things; at these points at which that's really in formation. That's so interesting to me, how people, in order to articulate practices and treatments... also, thinking about what activities are you doing sexually. The assumption that everyone when they're having sex that a man and a woman are having sex and there's going to be intercourse, and that condoms are going to be involved. So much gets packed in there.

DT: Oh yeah. I mean your metaphor of stuff getting packed in there, it's really true because what I think happened to a lot of us too was we began to understand our sexuality and our sexual practices in a way that we were being told we had sex, rather than in the way we were actually having sex. I remember even at the women's group there was a discussion that we were having about sex and transmission or something, and I remember Theresa said something like, "Well,

that's because you women have a penetration," or "there's penetration when you have sex," or something like that. It was this interesting moment around a judgment about it, but also kind of limited – she said, "YOU have..."

AS: Speaking as an HIV-negative dyke?

DT: Yeah. So, it's true and we did... I mean, we were thinking about so much. We were trying to think about so many things. Sometimes there were these weird kind of lapses where it's like – well, men are talking about condoms, so women should be talking about condoms; the US is talking about clinical trials, so we needed to talk about clinical trials. And you didn't have enough time to take a step back. And it was all this new language that was being created, especially as a woman. What we had to do quite often was to take language that gay men were using, that was in and of itself quite new and...

AS: Like, information.

DT: Well, and also it was new and it was confrontational in a certain way. It was hot as in *tsss* and confrontational. And then, have to make that for women, right. It was difficult. You'd be hearing all these templates from gay men writing about it and then you'd have to think, and it would get really confusing, "Ok, but that's about a penis and an anus, and where's the condom?" It was very confusing because it was known that women were less able to transmit HIV and there were various thoughts about why that was. Everything was very unstable at the time.

GK: We're going to have to leave aside some of the questions for Part 2 of the interview, but it seems to me that things that might flow out of what you just been talking about that might be really useful is to talk a bit more about. You started to hint at the history and shift and trajectory of Voices of Positive Women. And then, to come back to that point that you were making about the time Maggie got involved in AIDS ACTION NOW! when other people were sort of falling away from it. I think it would be really useful to sum up this part of the interview and talk about that. We can come back and deal with some of the other stuff at a later point. Does that sound cool? Ok. So, maybe just a little bit more about Voices of Positive Women and what happened to it and how its composition changed.

DT: So, Voices of Positive Women really included a lot of women with HIV. There were hundreds of women with HIV that were in touch with it. Not necessarily in the office, but that were in touch with Voices of Positive Women over time and it was a provincial organization. Which it wasn't really necessarily that successful in terms of delivering its programs provincially, but I think provincially women did see Voices of Positive Women as their organization. We didn't poster; we did the brochures, we had a peer counseling hotline, newsletters, a lot of the regular things that AIDS service organizations and AIDS ACTION NOW! were doing. There was a lot of advocacy for women's needs that was happening there, and happening at AIDS ACTION NOW! at the same time like, the sharing of information – where do I want to go with this though?

Well, the thing about Voices of Positive Women was the steering committee was, in its constitution, the steering committee was made up of only HIV-positive women. That was in those early days it looked like it was going to be possible, and in the early days it was possible, but it

really exhausted itself very quickly. I think you see that in a lot of AIDS organizing as a whole; a lot of organizations that started out as organizations run by and for people living with HIV have stumbled on that. It's easy to see that would probably be even harder for amongst a smaller group of women. Whoa, it's hard to... I mean what basically happened was that at a certain point, and I think it was a little bit premature, I got very concerned with the idea of the organization needing to go off on its own and do its thing and blossom and prosper and flourish and all that. I stepped back from it and others did step in, but I think that very quickly I found myself alienated from the direction of the organization. And one of the things that I felt very early on was that the organization was really in dangerous waters by not allowing people, that we speak about as allies now, in to assist it. This idea that was really, really prevalent in AIDS organizing and AIDS service organizations in the early '90s of self-sufficiency and empowerment, and by and for, and all that. I really felt like it wasn't completely working and, I think, Voices of Positive Women never made that transition. I think it didn't make that transition because of ego and weakness. Certain organizational egos and a basic organizational weakness, it just kind of disintegrated slowly and painfully. Although, it's interesting, the end... like, when the government finally pulled the plug on Voices of Positive Women, which I think was actually a weird, spiteful move that... I don't know, this is any other way, shape, or form than I feel it. I think it goes back to the stuff about the pamphlets and disclosure. I think that people filed it away and it was like – one of these days...

AS: ...we're going to get them.

DT: Yeah. I do. Anyway, by the time the funders actually pulled the plug on Voices it was really unaccountable. It wasn't that it wasn't delivering services; it was accounting for them. It was an organization that continued to deliver services. They might have not been the ones that they had in their funding proposal, they might not have been able to account... they couldn't account for the money in the way that they should have. That was clear. That's not ok, but when they closed down the organization you should have seen the number of women, women with HIV who got on buses, who got in cars, and came to the wrap up ceremony. You couldn't look at that audience and say that this wasn't an organization that wasn't still, let's say, meaningful for these women; and diverse, hugely.

AS: Would you say the weakness, when you're talking about the weakness of the organization, was that the reliance on the government funding? Was it organizational?

DT: No, the weakness was the reliance on HIV-positive women that didn't have the skills to do everything and the inability to see that it wasn't to the organization's benefit to reach out to allies to do the accounting, to do the things... why should an HIV-positive woman have to keep track of the money for the organization?

AS: It's tiring.

DT: We might not, at that time, have somebody who knows how to do that or whatever. And the inability to bring in women that can advocate really strongly in different places for HIV-positive women... I think it could have continued if it had made that transition. I definitely see my role in this because I was so persuaded early on. That kind of rhetoric and way of organizing around

people with HIV that recognized our abilities and our power and, “We know what’s good for us. You can’t tell us what’s good for us,” that sort of thing. I really created... the work that I did in the formation of Voice of Positive Women was really around that kind of vision, but I also feel that I was early and spoke. I don’t think I was heard because there were other voices that were still really loud about, “No, we can do it ourselves.” I think I also saw the mistake that we were making and that I started out making earlier on too.

AS: There are things that are not mistakes when you do them, but later the situation changes and then you have to change with it, and the mistake is not to change. I think that definitely it’s important that intervention happens early. And that people living with HIV are the ones that are having the say. It’s just, the world changes. I don’t know if that makes you feel better about it.

DT: That makes me feel better. [laughter]

AS: I think it’s true.

GK: So, just around then, you described that at a later point the shift in the women who were coming to Voices of Positive Women.

DT: The demographics?

GK: Yeah. From white, middle-class women to a broader group of people, any more reflections on that?

DT: This was when I was playing the more peripheral role in the organization, but the organization really, really struggled. I think struggled legitimately. I think that it struggled to incorporate women of colour. It struggled to transition from a group of middle-class women whose experience was mostly downtown urban Toronto, or connected to downtown urban Toronto in some way, to bring in and include women who were refugees, immigrants, from Africa, the Caribbean, but the thing that I think never really got recognized was that that demographic... I mean Voices of Positive Women recognized it, but I don’t think funders and people looking at women with HIV recognized, that women with HIV experienced the most dramatic demographic shift of any of the groups servicing people with HIV in the country, in downtown Toronto. And that Voice of Positive Women should struggle with that is only natural. What I think happened was that the organization couldn’t articulate that struggle and make it really known so that the government funders could give them money to help out with that or send in consultants to work with them, or something like that. So, the organization couldn’t articulate it and the people around didn’t see it and didn’t say it to help the organization.

GK: One more topic, Darien – is that ok?

DT: Well, what were you going to...?

GK: It doesn't need to be long. You describe something that I think is really important and it would be nice to have it recorded in this point in time, you've already talked about it, which is when you were saying Maggie got involved. AIDS ACTION NOW! was a different type of body. People didn't want to be in it; you were drifting. If you wanted to say a couple of paragraphs on that I think it would be interesting to tie things up for today.

DT: Ok. The time when I was doing a lot of work with AIDS ACTION NOW! was a great time to be involved with AIDS ACTION NOW! I mean everybody understands; everybody is going to be watching this anyway or listening to it. *We* understand the weirdness of saying that it was a great time to be involved because it was a terrible time to be involved too. The greatness and the terribleness went hand in hand, but people still had the surge of endorphins or whatever that you needed to really respond to this crisis, the catastrophe, the death. People just pulled enormous resources out of themselves, and these are people who are sick and people who weren't sick. But the people who weren't were getting sick too. There's so much talk about PTSD amongst survivors of that time. Everybody was just for years could pull those kind of response and daily – just at it, at it, at it. And that was the time when I was involved with AIDS ACTION NOW! Being a woman, I wasn't like... I was in it a lot, but I wasn't it in as much as a lot of the guys who were in it. None of these people were my lovers, right. It is different. I have to acknowledge that. Also, there was a kind of vibrancy; it was very alive, and I don't think there's any contradiction in saying that you're so alive in times like that. It was great the way being involved in AIDS ACTION NOW! was absolutely my life. It was just everything that I did was around that. It's easy to look at say, "Well, that wasn't very healthy. It wasn't a very good work/life balance." It was at a time that didn't... the response that came out of that time, you don't measure it by the standards of peaceful day to day life that most of us now have; that I do, anyway. I just had so much support and so much friendship and so much involvement and thought. A lot of really great things were happening even while... and we were successful in so many things.

That was the other thing, I didn't think that that was going to happen in the beginning and the success came so quickly. It was like, you were working, you were working, you were working. I remember the Yokohama conference and Brian Farlinger and Tim McCaskell from AIDS ACTION NOW! went off to Yokohama, to the International AIDS Conference, and they came back and it was nothing. And I think that was when they were still having annual conferences. So, that was probably '95... '94, '95. They were like – nothing's happening. Around then you could kind of feel people getting really tired. We didn't have real success yet and you could feel people starting to get tired. I really wondered at that time if anything was going to happen in my lifetime. I always did up to that point. Then, it was like, people that had been well and I'd been working with were now sick. And then Vancouver hit and everything turned around with Protease inhibitors, they just came very, very quickly. And it was odd because it was almost as if we were caught off guard in a weird way. AIDS ACTION NOW! had always been meeting with pharmaceutical companies in a way that I that ended up disagreeing with sometimes. We were so hand in glove with government and pharmaceutical companies and research and development and all that. And then, all of a sudden, the answer was there and we hadn't really seen it coming somehow. It happened really, really quickly. I think that combination of people, people getting sick, people getting tired... the internal resources were just getting exhausted. And then it was like – ok, so you just have to leap over there and you'll be kind of on the other side. It was like, if you weren't sick... like for me, I wasn't sick and I knew that the Protease inhibitors were there for me. It was a moment when it was really

easy to just pull back. A lot of people did. I did certainly. I stopped going to Steering Committee as much; my job became much more separated from my life; a lot of people that I knew that were sick died in that period; I started making friends in a different way. In a way, that separated HIV and my personal life.

And so, when somebody like, Maggie and Brian Farlinger was... he was sick and co-chairing AIDS ACTION NOW! at that time. When they were leading the organization, that was hard because what they were basically looking at was – can this organization function anymore? What AIDS ACTION NOW! did was it closed into a mailing list, an online mailing list. That's hard. That's really, really, really hard to do that. And I don't even know about how difficult it was because I wasn't there. I mean I was still doing AIDS work, but it was in a very different way. I don't know; it's hard. That whole time was weird, but there was survivor's guilt obviously. But there was something more that you don't hear described as well, or you don't hear described in the kind of two-words that everybody.... "yeah, survivor's guilt." I was prepared to die. I wasn't sick, but I thought I was going to die. In every aspect of my life, I had basically... it was just negotiated for two years, so it you could close it down really quickly. Realizing that I wasn't going to have to close everything down actually seemed like it was hard work to actually open it all up again. It's like the closing out of the cottage at the end of the season. That's kind of how I existed for a long time. Just really, really minimal, so all you have to do is lock the door and off you go. And then to actually open the door, put the linen on the bed, the knickknacks in the window. It was like, "Holy shit, this is a lot of work." And I had to change a lot of things that I had done, and I think that was the experience that a lot of people had. Coming back to life, that was a piece of work too.

AS: Did you feel you did that with the people who had been involved?

DT: No. I don't know whether maybe some people did, or whether that was a thing that people went away and did by themselves, but that was very separate. One of the things that was really crucial at that time was I bought this house. It's funny because Simon, who's living with me now, was in the States then and he remembers me phoning and saying, "I've decided to..." Like I said, it was sixteen years ago. I got this house for the tiniest little down payment and was like, "I decided to use the \$8000 that I have and put a down payment on a house." It just seemed like the riskiest thing you could do at the time. Not because of real estate, isn't risky at all. And I was seeing a therapist at the time and he said, "That's why they call it *real* estate." It was like investing in a real future. It was becoming real again. It was like you're kind of ghosting out slowly in doing AIDS work and living with HIV, and it was like you had to become real again in a weird way. And for me, buying this house and the safety and security this house represents to me is all part and tied up in that time.

AS: Like, becoming embodied and rooted.

DT: Yeah, real. Back to the post-modern, right? [laughter]

AS: I saw this talk with a woman, Rachel Herzing, who's been really involved with Critical Resistance, which is a prison abolition organization in the US that's been around for ten years. And she resonated with stuff I've heard people say about organizing. She said, "You just lived and breathed it, and you didn't sleep and you didn't eat very well. And you could

get through because you had to, so it was really necessary.” And she said, “About 5 years in we realized that none of us were planning to live,” in a less literal way. She said, “As soon as we started saying what if we’re imagining that we’re doing this work and we’re going to live past it, that’s a totally different way of planning.” It’s a different way of organizing. But she said, “You lose something there. You don’t have the kind of visceral understanding that other people are willing to drive their lives into the ground for this.”

GK: I think we’re going to have to call it quits for today, but thanks. Thank you, Darien. This was wonderful and I’m not quite sure how to do this, but we’d obviously like to do a Part 2. I think probably the best thing would be for us to actually get a transcript made of the first part so you can bounce off that when we do the second.

AS: If you’re willing to. How did this feel? Do you want to give us any feedback about it?

DT: No, it’s ok. I feel ok. I don’t know where we’re going to go with the interview, but just along what we’ve been talking about. I have been doing so much work since I finally allowed myself to leave CATIE, which is in a sense the last vestige of this because it became an organization that, for me, wasn’t really about what I wanted to be doing. And plus, it was just way too much. I allowed myself to leave it and for the past... it will be two years in May that I’ve left CATIE, but for two years I’ve just been trying to get myself ok. I’m actually at a point where I can say that I’ve never felt so ok for so long, forever. So, it’s ok and, actually, it’s such a great time to do all this stuff too. It’s not just because ACT-UP is doing an oral history project, that’s happening because, for some reason, it’s a good time to do this. There’s a zeitgeist, or something like that. Do you feel that?

GK: Yeah, I’m not quite sure where that comes from. I think there’s a re-interest in this period of time and, looking back on some of this stuff, it’s much broader than the ACT-UP oral history archives.

DT: Yeah, but there is a... with the films...

AS: I’ve been noticing and enjoying people’s irritation at the way history is getting told and this feeling of, “That is not what happened.” Like a lot of the stuff around the Dallas Buyers’ Club, where people are like, “But what about all these other things? What about the social movement that made it possible?” And so that’s really great that there’s this space where people can question.

[END OF TRANSCRIPT]

Part 2 – 24 May 2014

Persons present: Darien Taylor – DT
Alexis Shotwell – AS
Gary Kinsman – GK

[START OF TRANSCRIPT]

AS: A lot of the themes that we were talking about in Part 1 of the interview felt like they came to a close.

DT: Yeah. When I read the transcript I was actually pleased with how it read. You know, because it sounded cogent.

GK: In terms of the conversation we had last time, one area that we didn't get to, even though we got into conversations surrounding it, was basically AIDS ACTION NOW! and women, especially treatment issues and concerns. Is there anything you could tell us about that in terms of when you got involved in AIDS ACTION NOW!?

DT: There were so many things percolating around at that time that it's difficult to know if it was specifically AIDS ACTION NOW!, but I think one of the main things that happened was that there was a Canadian edition of the "ACT-UP Women and AIDS" book. I don't know the exact title of it. Anyway, it was put out by the Women's Committee of ACT-UP and so DEC [Development Education Centre] published it. And, I think we talked about this the last time, we were asked to do an appendix that included women's organizations. What was happening in the ACT-UP Women's Caucus really, really influenced my understanding, and I think all the women and all the people, because I think that men were looking at it too – our understanding of women's issues around treatment. I think I also talked about this a little bit in the last interview, but I think, in some ways, it misled us. Because in that issue of *AIDS Action News* that you showed me, it's about clinical trials and that didn't end up being as fruitful an avenue for pushing treatment and research agendas here in Canada as it was in the United States. At that time there was a lot of talk about women's participation in clinical trials, the information that we had about women's reactions to a plethora of treatments because, of course, back then it was not antiretroviral treatment, it was treatment for all the different opportunistic infections. You know – should these treatments be the same for women?

There was an examination of treatments that was really, really minute at that time that we were engaged in. I mean basically the question that we were asking was, "Are these treatments, which are tested mostly, exclusively in men, appropriate for women?" And then there were also issues around women-specific infections and getting them included in the definition of AIDS, which was really being led in the United States. Issues around candidiasis and different kinds of reproductive impacts that HIV might have – frequency of pap smears and things like that; treatment for abnormal pap smears; more or less aggressive treatment; new treatments, that sort of thing. That was talked about a lot. What else was going on around treatment for women? Well, there was a lot of talk about testing, a lot of talk about testing. Because the women that we knew that were HIV-positive, almost everybody came forward with a story about testing that was either, "I was refused testing," or "My doctor made comments about the type of women who would test positive," so that sort of thing; the interface with physicians, and then disclosure, which I think we talked a lot about last time. So, those I think are really the main issues that were going on around women and research and treatment and women's issues in AIDS ACTION NOW! and beyond.

AS: Would those things mostly get talked about in the Treatment Information Exchange meetings or would those kinds of conversations be happening at the Steering Committee?

DT: Yeah, everywhere. I mean the places where those conversations were talked about the most, I think, were actually informal places, really, because there was a kind of bleed out from the Steering Committee meeting. A bunch of people would go out for drinks afterwards and, you know, as I said the last time, everybody was kind of hanging out together all the time. So, those sorts of discussions... my memory is more that they were what you talked about when you were sitting around and didn't have to hammer home an agenda, which was always hard at the meetings; to get the agenda completed, and to arrive at actual decisions about what to do, and to move on to the next item.

GK: Did the women who were involved in AIDS ACTION NOW! start to meet together in a caucus or committee?

DT: Yeah, there was a Women's Committee.

GK: Who would have been some of the people on that when you were around?

DT: There was Susan Kasurak, Linda Gardner, Karen Pearlston, Vanessa Payne, who was a lawyer, Susan's partner Claire Merrydew did a lot of the graphic work for us, Mary-Louise Adams, Helen Humphreys helped out. They moved early, so I'm not even sure if Mary-Louise was involved in the early Women's meetings, she might not have been.

GK: I think she leaves Toronto in '89 or '90.

DT: I'm probably forgetting a couple. Julia Barnett...

GK: What was the relationship between the Women's Committee and the Steering Committee or AIDS ACTION NOW!?

DT: We would report in at the Steering Committee meetings and have our meetings report in. There was a lot of interest in those days still in International Women's Day and the march and after... the tables at Ryerson. So, we would have tables at Ryerson where we would just distribute information; we'd have little stickers made up. I think we had t-shirts one year. We had copies of that *Healthsharing* article that we talked about that I wrote, on the table. We did that. I have a very vivid memory of one year at Ryerson and the t-shirts said, "Women Get AIDS..." no, it was one of those ones where the t-shirt read badly because of the way that it was laid out. So, it said, "Women. Get AIDS. Get Active." What it was meant to say was, "Women Get AIDS. Get Active," but it was like, "Women, get AIDS and then get active." [laughter]

GK: You don't happen to have this t-shirt, do you?

DT: It was not exactly a Freudian slip, but it was probably more or less what I was thinking – wouldn't it be great if more women got AIDS? That would really make them get active in the movement. [laughter]

GK: Do you have any memories of the Women's Committee making proposals to the Steering Committee, for instance?

DT: Well, more just for the events. Did we make any proposals around political actions that were women specific? We carried a Women's banner in one of the Pride marches. I think it was more like that; it was more about visibility, in my recollection. It was more about visibility for the issue than it was about specific concrete proposals around needing this type of, you know... women would get written into the policy, but more in kind of motherhood statements. Kind of like, "And women and children and people of colour..." but I don't remember that there was an issue that we really took on that was women specific that everybody got behind - man, woman, trans-person, child... I don't remember that, but could be that I'm just not remembering.

GK: At some point, and I can't remember when this is because I had read it from the newsletter, there was a die-in at Church and Wellesley that focused specifically on women and AIDS. Do you have any memory of that? I'd have to look it up again. It seemed that there were men involved in it. Clearly, it was an AIDS ACTION NOW! project.

DT: The thing that I can definitely say about AIDS ACTION NOW! is that they were really... I mean I think it was partly because I was there, but they were so open to that sort of stuff. And I think, because I was there and then, you know, latterly a few other positive women, they were just like, "Let's go. Let's go." So, if there was a die-in around women, yeah, I wouldn't be surprised at all and I wouldn't be surprised if men participated in it. It was a place where I really felt, and I didn't necessarily feel accepted as a woman with HIV, I felt accepted as... like, here was a place where the identity of people with HIV was really important and I was a person with AIDS equal to every other person with AIDS there. And that was a really important feeling and it's one of the things that I think, in a weird way...

Some of my more recent dissatisfaction with some of the things that have been happening, you know let's say at CATIE – I mean yes, let's say CATIE because that's where I was working – as prevention re-entered the way we think about AIDS as the package, that whole focus on 'integration' and all that, the gender divide got reinserted. The place that I see this now is in a lot of the discussions about, I think it's one of the discussions that's happening at ACT right now, is should ACT become a gay men's health organization. That really scares me because, as a minority in the group called 'people with AIDS,' I've always felt like I needed gay men to attach myself to because they're going to be the people that push the agenda as the majority, and as men, and as, you know, the whole description – white, middle-class, originally blah-blah-blah. And the idea that this is going to become a gay health centre, or a gay arena of concern that will be partly occupied by AIDS, but also other issues of gay men... it makes me worry about like – where's my old age home going to be? It's going to be an old age home with probably a lot of uninformed straight people and straight nurses and straight doctors going, "Eww." Yeah, so anyway; that was the beautiful utopia of AIDS ACTION NOW! for me at that time.

GK: I want to come back to the point that you raised last time, and you just re-raised it here, which is, looking back on it, a certain sense that AIDS ACTION NOW! put too much of their faith in clinical trials. If you just want to elaborate a little more about that.

DT: I think that clinical trials really were not a big part of access to treatment in Canada. They were more so in the United States. And I think because – I'll just speak about myself – I was just a sponge for information and a lot of the information was coming from the United States, rather than Canadian-created, I didn't suddenly make the distinctions between US and Canada. And I guess a lot of people along with me, kind of jumped on whatever was coming out of the States and replicated it for Canada without thinking, "Well, do we have a system for clinical trials?" And maybe we got tricked into thinking that we did have a system for clinical trials because there were a lot of... like, there was a Canada ACTG [AIDS Clinical Trial Group], and a CRIT [Community Research Initiative of Toronto]. The guy on the cover of that newsletter that you showed me was with CRIT, which was about trials. One of the earlier things that was really exciting at AIDS ACTION NOW! I remember when I first joined, was that CRIT was going to try to replicate the Kemron trial, which was this weird drug that had been shown in a country in Africa to improve outcomes for people with HIV. It wasn't a useful drug at all, but people were, you know, rushing around trying to understand anything that appeared to be useful and CRIT was going to run a Kemron trial. So, there was all this stuff around trials and drugs that who people seemed to be interested in that didn't really... and there was a lot of talk about finding out whether you were on a placebo or not, and how to bust clinical trials, or altruism and all that.

But I think it was very theoretical rather than actual Catastrophic Rights and stuff like that. It strikes me retrospectively that it was more about theory than what was actually happening on the ground. Maybe to a certain extent that's a criticism that can be made of AIDS ACTION NOW!, that there was a theoretical... I mean it was a lot of smart people and there was sometimes an interest in theory that was a little bit not quite in contact with what was on the ground sometimes. Retrospectively, I have lots of thoughts about AIDS ACTION NOW! I think that, for me, it mirrored the government too much. It was a bit too hand-in-glove with the government and, I guess for myself, I have never been that interested in government politics. For me, in a weird kind of way, I think I would have been more attracted and, in a sense, useful to an organization that was more anarchic. And I was always like, "Why are they asking the government's permission? Why are they informing the government that they're doing what they're doing?" I understand it, but it never really... I was kind of like, "Just hit the streets! We don't need to tell Frances Lankin that we're going!" So, there was that dance that AIDS ACTION NOW! did very intricately with the government that I didn't... first of all, I wasn't interested in; second of all, I wasn't able to really participate in that effectively.

GK: Just around that, do you feel that there was a current within AIDS ACTION NOW! of meeting more with the government? I'm thinking partially of what Glen Brown said at that forum on public health measures and the criminalization of HIV, where in retrospect he felt that AIDS ACTION NOW! wasted too much on these government committees studying what to do around people who were not obeying public health rules and stuff like that. I'm wondering if your feeling is that that got stronger in AIDS ACTION NOW! as time progressed; as it moved a little bit further away from the earlier activism that it was involved in?

DT: That was an interesting thing to hear Glen say, although I don't think he proposed an alternative really, which, of course, that would be an interesting thing to think about. AIDS ACTION NOW! always had this complexion that was very intellectual. And so by that nature it was attracted to academic discussions, political discussions, and an understanding of those kinds of systems that, at the time, I just thought, "Well, I better try to learn as much as I can."

I remember when Glen Brown was asking me if I wanted to co-chair I said, "Well, I don't understand anything about the government. Could you explain the government and its relationship to health and all that?" And he laughed and said, "You know, that's what everybody's asking about." In a way I really didn't understand it, and probably now I think I don't necessarily accept that's that only way to go, but I couldn't articulate it well. At that time, and I think as I drifted away from AIDS ACTION NOW!, it was probably really fundamentally about that kind of exclusive way of approaching things and talking. There were so many things that AIDS ACTION NOW! taught me, but it never taught me how to have those kinds of discussions, probably because I didn't value them and didn't want them as much as the people who were engaging in them. The thing with AIDS ACTION NOW!, there was definitely the whole political purity test that very few passed, and I don't know to what end. I'm not sure that it was to the end of anything better like, around HIV. I don't know if that whole political purity test was to the end of more treatments or faster or better research, or anything. I'm not really sure. I think it was a bit of an end in itself, really.

And I think one of the functions, looking back on it, that I played, and I kind of knew at the time that I played... I'm not basically a social convener, but in the situation of AIDS ACTION NOW! I think I brought in a traditionally female role in a weird kind of way. I brought in and made comfy a space for people who weren't going to contribute to the organization in a really engaged political, thoughtful way. They were there because they were people with HIV, some of them marginalized, poor, not straight. You know, the people that AIDS ACTION NOW! was representing had a place at the table in part because there were a few people, but I think I was really, really central in this – that I hung out with those people and explained to them what was going on, and told them what the acronyms were, and was nice to them in a way that somebody like Tim McCaskell wouldn't be. Like, I didn't meet Time McCaskell for a really long time in AIDS ACTION NOW! and I think it was just because Tim existed on another plane, and his didn't intersect with mine for a long time. Really, I don't mean that in a horrible, judgy way. And Tim's health was good and I hung out with a lot of people that were sick. I did a female, motherly, friendly... that kind of role.

AS: And did you know those people from earlier?

DT: No, I didn't know anybody from earlier. This was all... everybody was new to me. The people that I knew prior to getting HIV did not go into AIDS ACTION NOW! with me. I knew nobody at AIDS ACTION NOW!

AS: So, some of the people that were maybe more marginalised, or living in poverty, or didn't fit that...

DT: ...or were irritating in meetings.

AS: ...or who couldn't be good meeting subjects.

DT: Yes. They were totally irritating in meetings.

AS: Did they have a role in AIDS ACTION NOW!? Like, they were going to join the Public Action Committee or they were going to...?

DT: They went to lots of demos. It was great to have those people that would really get angry and they would have a little meltdown in a meeting. They would look bad; like, they looked unhealthy and they would be angry. And they would write letters and they would get obsessive. They would be marginalised in all of their, you know, glory. They would sit around and write letters detailing their day-to-day troubles and pain and all that, in a way that was really sincere and really kind of out there and really unacceptable. But looking back on it, that's what it's all about. Like, I couldn't; Tim couldn't. There were a number of people who couldn't and wouldn't ever write or do those kinds of things, and those people would.

AS: And that was the point, in a sense, right? Their lives. I can't remember the name of the person that... Eric...?

DT: Barry Way; Ric Hatt; Ric Hatt's girlfriend, Dorey. They were a weird bunch of people. I know Eric was talking about Barry Way and that Eric has the letter. Like, Dean Folkins, a gorgeous little 18-year old son of a Salvation Army Lieutenant, who... I mean he was beautiful; he was kind of like, a skinhead. There was an ARA meeting, an Anti-Racist Action meeting, where AIDS ACTION NOW! was going to lend solidarity and he got thrown out because he was wearing one of those parachute jackets and had Doc Martins and had his hair... they were saying, "Would somebody vouch for this young man?"

AS: His aesthetic is all wrong.

DT: Yeah, his aesthetic is all wrong for ARA. And Kalpesh Oza; these were the people that didn't... in a way, they didn't fit into the meetings, but they were the reason for the meetings. They were the reason for the organization and it was great that they were there, and they floated in and out and didn't stay. I remember I was trying to get some of the women from Voices of Positive Women to come out to meetings and they would fall asleep. Those meetings could be pretty dull. Probably, the only reason that I stayed awake was because I was chairing and I was petrified.

GK: It does keep you awake when you're chairing.

AS: That's a very bad subject for a meeting! Sleeping!

DT: Yeah.

GK: There are a number of different ways we could move now. We could actually move into memories of people who've died, and that's entirely up to you and what you want to talk about in terms of its emotional ramifications. That would mean people like, Kalpesh or

James Thatcher or other people. Or we could go through the history a bit more because we do know that, from the last conversation, you're basically moving away from AIDS ACTION NOW! in '95/'96 and getting involved in CATIE. I don't know if you want to talk a bit about that first or we can talk about specific individuals, whichever you want to do.

DT: We could do either. It doesn't matter.

GK: We should go through a little history first then. So, you already talked about the context in which you left, or starting drifting away from AIDS ACTION NOW! But then, you get involved in CATIE, which, in some ways, comes out of AIDS ACTION NOW! and becomes something quite different.

DT: Yeah, but I didn't get involved with CATIE for quite a long time since CATIE had to empty itself. In the end of my connection with AIDS ACTION NOW! I was just feeling unheard, I guess. But, I think, that a lot of that is my shit – just me. I increasingly felt like there was an unspoken central committee that existed that consisted of – and this was I think to some degree, a figment of my imagination in its intensity – Bob, Linda, Glen, Tim, that's probably more or less it, who had an understanding that was never made clear. They had an agreement that was based on where they came from rather than anything that was created at AIDS ACTION NOW!, so I never knew what it was exactly, but I knew I somehow couldn't ever get there. And I think I was so wowed by AIDS ACTION NOW! that I didn't understand my difference as a difference, I understood it as failing. I guess, either way, I probably would have wanted to withdraw. I turned it into a little bit of a, "They don't want me; they don't need me," or whatever; I think it was probably just a way to get out because AIDS ACTION NOW! It really could hold you in.

AS: It's like the things you have to do to get escape velocity.

DT: To what?

AS: To get escape velocity – to leave.

DT: Yes! Oh yeah. I mean AIDS ACTION NOW! saved my life. It saved my life. I really do think that. But at a certain point you do have to move on. And that was a really difficult time because it was like, all these people who had meant so much to me... I experienced a lot of guilt.

What else was happening then? The other thing was CATIE because CATIE was created by AIDS ACTION NOW! and it started to occupy a really big space within AIDS ACTION NOW! It's true, I did get involved with CATIE on the board, and the organizational politics of CATIE became, to me, really... and Tim stayed out of that, but Bob and Linda were incredibly involved in CATIE. Then, later Glen Brown as the Executive Director, and those organizational politics became really kind of toxic. Actually, it's funny I'm only sort of putting this together as I'm saying it, but I think that was more what was a wake up call to me around the people of AIDS ACTION NOW! than actually all the work that we'd been doing together within AIDS ACTION NOW! So, the CATIE work became – and I'm just remembering it's stuff like HR [Human Resources]. Like, the hiring of the Executive Directors at CATIE and being on the board was hideous. It was just hideous. Things were getting too thick, too incestuous. I think, for me, the final death knell was actually... I had started hanging

around with Craig McClure who's in that photo that we were looking at. He came to town. He got a job at CATIE. He was very, very charismatic; like, it's really no surprise to me that he ended up at the top of the AIDS world, but I mean it kind of repulses me at the same time. He was a very charismatic, very intelligent person. We started to hang out a lot together and I got pulled into his way of thinking. We were forming a little midnight chat session, talking a lot about AIDS together. And he was never very pro AIDS ACTION NOW! He had a critique, and I can't really remember what it was, but he went for the job of ED (Executive Director) at CATIE against Glen Brown. They were the two candidates for the ED job and I was on the board, and Bob and Linda were on the board. We were all just way, way, way too invested in that process. I should never have been involved in the hiring process; as, I think, a number of other people. I really don't think Bob and Linda probably should have been involved in it either. Glen got hired and Craig didn't and I was just like, "This is just all too much." I felt that Glen was being rewarded, in a sense, for all of his work at AIDS ACTION NOW! and I didn't like that. I withdrew from CATIE, and probably from AIDS ACTION NOW!, more or less around the same time because of those kinds of things.

I think prior to Glen's hiring the Executive Director had been Wayne Hellard and before that job he'd been an ED of one of the organizations in one of the Prairie provinces. I'm not sure where, but he was from the west. He was a horrible human being and very protected by the board. And I just had a big, big disagreement with that; he was a bully. You know, I'm better now; they have molded me into a nicer board member, but back in those days – and it was partly because of what I learned through AIDS ACTION NOW! – I would just call it, and it was very disruptive in the CATIE board meetings. I remember Wayne Hellard looking daggers at me and saying, "Are you saying I'm lying?" because I was.

AS: What did you say?

DT: I think I just kind of sat there. I don't know that I said yes, but it was like, "Well, you named it." I was saying that he was lying. He was saying – this is what happened; and I was saying – no, this is what happened. It was just like – I can't do this. I like people to get along. I wanted to be the social convener. I was like, "C'mon, it's great! The meetings are boring, but we'll go out for drinks after and I'll tell you what happened." [laughter] I mean I loved the ideals of CATIE and it was a great job later on for a long time, but I just wanted to get away from all that for a long time. Like, I remember when I was working at the AIDS Committee of Toronto or doing government contracts, and I knew I had another job or wanted to leave my existing job, or something like that, and Craig would say, "Well, go to CATIE," and I was like, "Never!" It took a long time to get rid of the emotions of all that.

GK: Maybe we can move back into thinking about people you knew in AIDS ACTION NOW! who are no longer around. So, we're interested in a bunch of people because part of what we want to try and do is remember people; and that's part of the project. People have died and their stories need to be part of what we're doing. There's a whole bunch of people we are interested in. Kalpesh Oza is one; James Thatcher's another; George, Brian Farlinger, a whole bunch of people. And some of the ones who are not usually thought of would be really useful for us to hear about in particular. Whatever you want to say, we're interested in hearing.

DT: Well, you know, lots of crazy people. Like, Kalpesh was wild. Oh yeah, he was all of about 80 pounds soaking wet. He'd come with his scarves. Or he'd do his Montreal hippie look, which was really not an appealing look. And it all looked kind of great-slash-bad on him... you know, this tiny little frame. I think he had ADHD; it's the sort of thing that we would name right away now. Then, I think, it just wasn't part of our vocabulary, our diagnosing vocabulary. It was just so hard to chair those meetings because he would just be so off the wall. He knew a lot about research because before he came to Toronto he had been doing his MA or his PhD, or something, in Mark Wainberg's lab in Montreal, so he knew.

AS: He came to Toronto from Montreal?

DT: Yeah, and before that from Windsor, and before that from Gujarat in India. He was quite an amazing guy. He could speak French fairly well for having just been plopped down and acquired it. He was very sociable and he knew some of the Montreal people. He knew Chris Cockrill, who was involved in the Canadian AIDS Society; they had worked together. And Jose de Sousa, who's still an old school activist with no organization, in a sense, in Montreal. Yeah, he was delightful and funny, but just totally off topic. Very out, you know? I mean back in those days I was pretty gossipy and I hadn't quite acquired the boundaries. I never really did, but I have more than I did then, and he was even worse. He did this... there used to be an annual celebration of South Asian culture called Desh Pardesh. Do you know this story?

GK: No. I know about Desh Pardesh, but I don't know about this.

DT: So, Kalpesh decided that he was going to do a performance in Desh that year called – this was when everybody was rollerblading and he had a pair of rollerblades – “Rollerblades and Living with AIDS.” Basically, what he did was strap on a pair of rollerblades and he rollerbladed back and forth on stage and really just said whatever came into his mind about living with AIDS. I don't think he had a script or practiced it. He called out a lot of AIDS activists, especially HIV-negative ones, and questioned their motives. It was really pretty scandalous.

AS: Was it a manifestation of ongoing tension, or was it just a surprise? And had a lot of people come to Desh Pardesh specifically for Kalpesh's performance?

DT: I don't think we knew what it was going to be, but Kalpesh was a bit of a South Asian celebrity because he was like, the only South Asian guy with HIV that people knew. Devan Nambiar was the other one; Devan ended up working at CATIE. There were these organizations, but there were very few people with HIV associated with these organizations. And so people like myself as a woman and Kalpesh as a South Asian gay man, those people – us – we had this enormous... it was like a big microphone. And people in that little activist community knew Kalpesh and they wanted to come out and see him do “Rollerblades and Living with AIDS.” He was a South Asian activist cultural celebrity of sorts. It was a manifestation of ongoing petty, irrelevant tension. And so that's what it was – a manifestation of complete pettiness, and lack of boundaries.

AS: ...being performed on a stage with rollerblades.

DT: Being performed in front of an audience. And after that I calmed my relationship with Kalpesh because I thought this is just too inflammatory. I wasn't part of his care team because I had said something to him about, "You've gone too far." He didn't take kindly to it.

So, he started to get sick, and that's a sad thing. These people, like Kalpesh, who participated in AIDS ACTION NOW! and amassed all this treatment knowledge and disseminated all this treatment knowledge, when it came to his own care and treatment he was... I remember going up north with him to my parent's cottage and he could barely get out of bed. He and Brian Farlinger and I went up together, and Kalpesh was like this little tiny thing. He was just such a small, small man. He was just curled up the whole time and we said to him – because there were drugs that were available – we said, "Don't you think you should be going on drugs?" And he was like, "Oh well..." You know, and he didn't recognize that he was ill. Yeah, I think maybe he did eventually go on drugs, but it was too little, too late. He was cared for by a woman and her partner. After he died there was a memorial where everybody sat in a circle. That was what we often did, sat in a circle and shared reminiscences. And I knew that I just had to keep my mouth shut at that meeting because it was like, (whispers) "You weren't nice to Kalpesh... where were you?" and all that. Whatever. It was my bad and, in a sense, it's none of their business. Steve, who was Kalpesh's roommate at one point and was very involved in the South Asian community, a gay man, stood up and he talked about a funny picture of Kalpesh up at my cottage, and how he looked in the lake and something like that. And he didn't realize that he was doing anything that was breaking a taboo, but he'd mentioned my name and you could kind of feel this frisson go through the crowd. This woman said, "Well, yes. And there are people in the room who didn't support Kalpesh," and she just did this whole tirade that was directed at myself and Brian Farlinger. Those were the days where things seemed to be falling apart in a way. I'm telling you about my personal experience with my friends. Kalpesh and Brian Farlinger died in the same couple of months. Brian was there at Kalpesh's memorial and then Brian died a couple of months later. It was hard to be taking all this shit, and anger, and hatred even though, of course, those emotions were there.

AS: Right, along with all the other emotions that were happening. Do you remember what year that was that Brian and Kalpesh both died?

DT: It would have been '94 or '95.

GK: Do you want to talk about Brian Farlinger a bit more? He was obviously someone who was important.

DT: He came into AIDS ACTION NOW! through the Treatment Information Exchange. He had been doing letter writing on his own around treatment issues and had got involved in AIDS ACTION NOW! He was a banker, and looked like a banker, and came to meetings in his banker's outfit, and just didn't look like the AIDS ACTION NOW! gang. But he was dedicated and he was smart, and so I encouraged him to get more involved. And, again, that was a bit... he wasn't part of the golden circle because he was politically quite right-wing really, except on the issue of HIV. I mean his father was one of the CEOs of Hydro in the time when there were a lot of problems. The problems at Hydro, one existed over a numbers of CEOs, but his father was one of them, a friend of Mike Harris. Mike Harris attended Brian's funeral, which was good and bad. He was a lawyer for the Canadian Banker's Association. His right-wing credentials were... actually, his mother was

involved in the NDP and ran for the NDP, and was a representative for the NDP in Rosedale, or something like that. So, he was an interesting guy, but he didn't really fit into the AIDS ACTION NOW! that I knew when I came in. So, those changes were... and James Thatcher was another of those guys. Like, he was such an Upper Canada College... you know? Oh my God, and those are difficult strains to blend together. I mean James Thatcher would always wear monogrammed shirts with his initials, so it would be James – whatever the middle initial was – Thatcher. There'd be a little one on his immaculately pressed dry-cleaned shirts. And then, just to prove he was a really cool guy, underneath the monogram, he had a tattoo of the monogram. [laughter] So, these are the people that we're trying to bring together.

AS: These two, and Kalpesh.

DT: Yeah, and Barry Way; and Ric Hatt, who was a straight trucker who maybe had sex on the road, and was just like, a loud... he used to wear suspenders because his pants didn't fit him very well, because he was already getting skinny at that point. And his Iranian girlfriend Dorey Mohsenzadeh; I mean these were really different.

AS: How did they get involved?

DT: Because Ric had HIV.

AS: He just heard of AIDS ACTION NOW!?

DT: I think people with HIV really loved the idea of an organization that was speaking about their issues and was allowing them to speak about their issues. It was that weird thing about voice. But when you give people voices, they can say horrendous things. They roll around on roller-skates and deliver diatribes against their friends, or they curse and swear and say hideous stuff and get things politically mixed-up. That's what giving voice to people does along with all the other good stuff; or they lie. The number of people who were HIV-positive who passed through, somewhat through AIDS ACTION NOW! and through other organizations... it's very strange, you know. It's that attraction of voice and the microphone and the amplification is really attractive to a lot of people.

AS: Would a lot of these people be in the mix in Steering Committee meetings?

DT: Quite often, yeah. I mean they'd be leading them! James Thatcher, myself, Brian Farlinger...

AS: Would Ric Hatt lead a meeting?

DT: No, but he was regularly there week after week – it was biweekly, wasn't it?

AS: Time after time.

DT: Time after time. Yeah.

GK: So, you were co-chair with James.

DT: I was co-chair with James and with Glen.

GK: Were you co-chair when James died?

DT: No, I wasn't co-chair when James died. I was co-chair with him and then he died the following year. I think Brian Farlinger was the co-chair with him when he died. But I was co-chair with him when he was really, really sick.

GK: James did some pretty dramatic stuff towards the end. I was wondering if you might want to tell us about that.

DT: Well, I was actually away at that time. I was travelling and you were at my house.

GK: That's right.

DT: I was travelling in Northern Africa, in Egypt, at that time. At the end, James knew that he wasn't around for that long. I'm not sure that James didn't commit suicide, but anyway. James knew that the end was near and he videotaped a statement. Yeah, about how there was a need for more AIDS drugs covered on the drug formulary. He taped this and then he died soon afterwards.

AS: Where was that shown, that tape?

GK: I showed it in my classroom at Acadia.

DT: Did it get on the news?

GK: I think it actually got on the news. The limitation of drug funding was actually killing him.

AS: What was the formulary?

DT: The drugs that could be covered when you were on social assistance.

AS: We had this conversation with Brent Southin about winning what then became Trillium, and one of things that he talked about was someone offering AIDS ACTION NOW!, "Ok, we'll cover this for AIDS patients," and AIDS ACTION NOW! saying, "No, we need this to be for everyone who's living in poverty." Do you remember anything about that?

DT: I don't remember that specific discussion because it was the notion of Catastrophic Rights. I think AIDS ACTION NOW! early on understood that it had to extend beyond AIDS; that was always part of the politic.

AS: How did people come to that?

DT: Well, there was this book called *Catastrophic Rights* by John Dixon – it wasn't written specifically about AIDS, was it? – and that really informed people's understanding. And I think that people were really taking chapters from the book. I remember reading that book and that's not what I would normally be reading. I'd normally be reading literature. But yeah, he must have been on social assistance. And this was the guy who'd been very politically involved again, in capital 'L' Liberal politics, and who had friends in the political establishment, who ended up on social assistance in the end. You know, an Upper Canada College bright young thing. I'm forgetting what the actual tape was about because I wasn't there.

AS: I don't want to direct you, but I'm really interested in this because of what you were saying earlier about having a sense of being a person living with AIDS with other people living with AIDS, and having that be the... I just think it's really cool and amazing that people were still steadily able to extend solidarity beyond that to say, "This can't just be for people with HIV/AIDS. It has to be for everyone."

DT: Yeah, it is. It might also have something to do with the fact that AIDS ACTION NOW! had always sought, and was to some degree successful, in including people with haemophilia, particularly James Kreppner. He was really the person with haemophilia that came pretty steadily and kept in contact with AIDS ACTION NOW! And so, I think, a little bit of that understanding informed us too.

AS: Yeah, and when you were talking last time about Positive Voices – that there's this quality of global vision of what's happening to all those people.

DT: Yeah. And I think that the circle that I talked about, the golden circle, those were people that had a very, very informed global politically attuned beyond AIDS analysis.

AS: Did you ever work with Michael Lynch at all? Was he pulling back from AIDS ACTION NOW!?

DT: No. I wasn't in with Michael Lynch, but I came into contact with Michael Lynch because when I was working with Andrea on the book *Positive Women*, one of her professors was Michael Lynch. He would start his classes at the beginning of the year by saying, "I've got AIDS and blah-blah-blah," and he was very out about it, so she asked him if he could help us to make contacts. I think he knew Cindy Patton and a couple of other people that we thought might be helpful in terms of putting us in contact with other women with HIV. So, that was the Michael Lynch connection.

[END OF TRANSCRIPT – Part 2]