# AAHP AIDS Activist History Project

## **Interview Transcript** 2014.002

**Interviewee:** Brent Southin

**Interviewers:** Alexis Shotwell & Gary Kinsman

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Persons present: Brent Southin - BS

> Alexis Shotwell - AS Gary Kinsman – GK

#### [START OF TRANSCRIPT]

GK: What we've been starting off with is if people were involved in other forms of activism or organizing before AIDS activism. And I'm pretty sure that you were involved in other things before AIDS ACTION NOW!

BS: Yeah. Not a lot before. I mean it was only a few years after I came out, right. But certainly in Ottawa, with the Gays of Ottawa, and it was called Gays of Ottawa then. Then it changed names many times after that. When I first came out in 1983, early '83, I was there and I ran the youth group for a while. So, that was part of it. And they had a Political Action Committee, so I found myself on that as well. And they used to sometimes get bomb threats, right, so not so much then. More in the '70s, before I was there. But, yeah, no actual bombs fortunately while I was there. They did have some fire bombings before I was there. And so that's really where I learned a lot about the history of the movement and Stonewall and all that stuff was through there, right. And I came to Toronto in '85. I went to a number of demos and things, and youth groups here. That was the main activist stuff that I did. Yeah, and then, of course, AIDS ACTION NOW! I was there from the first big meeting and all the stuff connecting with that, and during lots of other things like, the Simon Nkoli Anti-Apartheid Committee. And I defended the abortion clinics for years as well.

GK: Yes. I remember that.

AS: And all that was after...

BS: Well, the abortion clinics might have been slightly before. I can't remember exactly when it started but it could've been before.

GK: I think it might've been slightly before.

BS: Maybe it was before, yeah.

**GK**: But it continued.

BS: Yeah, and it continued mostly into the early '90s. There weren't too many 'Operation Rescue' things after that.

GK: So, do you have memory of when you first heard about AIDS?

BS: The first time I went to the Gay and Lesbian Centre in Ottawa actually, there was a meeting about the 'new disease' – a good way to come out, right? Fortunately, there was one guy who staved to talk with me after that. It wasn't all bad. Because I had actually just shown up and they had about 50 people there and they were talking about this disease in San Francisco. But there was only one case in Ottawa, so don't worry about it. That was the basic thing at the time. So, it was right away. But I heard vaguely on the news because I used to run Mac's Milk - I was the manager. And so, two or three times they had a call button and I got to the Centre before I actually went in. And then I would get called away by the store, so I finally got in and then they were talking about AIDS.

AS: And it was a meeting specifically about "We need to talk about this"?

BS: Yeah.

**GK:** And that was your first meeting?

BS: About AIDS, yeah. And that was actually the first meeting when they started the AIDS Committee of Ottawa as well, which was not long after that meeting. That was what they decided out of that meeting. ACT was just starting and they needed something similar.

GK: So, you knew about community-based AIDS groups because of what was going on there, but any AIDS activism beyond that?

BS: And then, yeah, I just picked up - what was that paper in New York, the gay paper?

**GK:** At that time? *The New York Native*?

BS: I picked up anything I could see – *The Body Politic*? Which was funny to me, where I was living in Sandy Hill, there was a convenience store that had *Body Politic*, and I found out later two gay guys owned the convenience store. I think this is strange. Sandy Hill is not particularly a gay area, but anyway. So, I used to pick that up quite a bit. I learned quite a bit what was going on through that, too.

**GK: Right.** 

BS: I read people like Tim McCaskell and others. I didn't meet Tim until AIDS ACTION NOW! actually, but I'd read lots of things from him.

GK: For sure. So, you came to the meeting at Jarvis Collegiate, the founding meeting of AIDS ACTION NOW! That's in February of '88.

BS: Right.

**GK:** Can you tell us anything about that meeting?

BS: Well, I certainly had seen lots go around and heard all the talking, so, you know, in the meeting, everyone's stories about what was going on in the hospitals and other things certainly made me very angry. And I said, "I gotta do something more than just crying about it." That wasn't going to help. So, yeah, I think that certainly made me want to do whatever possible. I think the way they set it up, too – because they had all the different committees meet right away, instead of just dissipating all that anger. I mean I've been to other meetings and there's lots of anger, and then nobody does anything, right. So, I thought that was very good. And then the activist committee, the public action committee, of course, was the one that I went to most. So, that's where I went, and we had to scream and vell. I didn't like the Prime Minister at the time anyways and so it certainly gave me more reason not to like what was happening.

GK: Right. I was at the first public action committee too at Jarvis Collegiate. So, you got involved in the public action committee as your major...

BS: Yeah. That was the main committee in which I was involved.

GK: Can you say anything about how it was organized?

AS: Can I ask a question before that, actually? So, you might not know this. Do you know why the "Thor" figure was used on these early flyers? The hammer? "Too damn slow."

BS: Yeah. I don't know. I think they met with the artist people and they came up with that. So, that was before...

AS: That was before you...

GK: If you first came to the meeting, you wouldn't know the answer to that question. And I was at a few meetings and I had no idea.

BS: A lot of the symbols came from the group. I used to meet with a group of artists who would come up with great stuff. So, it was good though. Then, we came up with several issues to start on right away, so I think that was what got it going. I mean there was a good group. It wasn't really overly organized at first. I mean people came with lots of ideas and we took everyone's idea and tried to do everything. I think we realized that in a short time we couldn't do everything. And there were so many issues and everything was extremely connected between racism and sexism and homophobia. And of course, with the media, homophobia was the focus and it was primarily gay men, certainly in Canada, that were affected at the time. So, that had to be the first big fight, obviously, because that's certainly why in Canada they weren't doing anything. They didn't care about gay people, right. So, I think that's where the focus, and I think that if you look at the constitution that said it's a group that focuses on the gay community at that time. And really all the other issues were big issues and certainly affected it, but how do you solve the world's problems when people were dying right now was a big issue. And I think that was helpful. I think, when you're looking at that retreat [at Hart House Farm], that's what came out really plain, especially with Doug Wilson, right, when people were saying, "Well, we can't do this unless we have representation of every group and all this stuff." It's like, we don't have time. I mean those are all

the things and no one disagreed that we should try and include people, but you can't wait until everyone's included and then get everyone's opinion.

GK: So, the Public Action Committee, which you were quite involved in, I was involved in for a while too. Maybe you could tell us a little bit more about how AIDS ACTION NOW! was organized, because it had a steering committee and there were the various different working groups.

BS: Right. Yeah. I can't remember all the working groups, but there was a Treatment and Access Group, and then I think maybe an Activist Committee [the public action committee], and I think, what else was there, a Newsletter Committee, because we had a newsletter at that time. Those were the main ones I remember. I'm sure there were others. And the name of committees changed every year pretty much, right. If somebody got an interest then they'd get other people and start a committee. And then the Treatment and Access Group was always around, for at least until later. It shrunk in later years and there was only one steering committee and that did everything. The activist committee was there for a long time, but after a few years myself and others were feeling that because the steering committee would usually override the Activist Committee's ideas anyway, we felt like they might as well discuss things at the steering committees and make the decision. So, you have everyone's input instead of coming up with all these plans and then bringing it to the steering committee and then they say, "no." Or they change them. I mean that was the issue. Why have two meetings when, especially really other than the first year or two, the number of people actually doing the planning was small, right? And originally the steering committee meetings would be at someone's house and they'd go on for like, 6 hours. And then someone suggested why don't we use the 519, so it would restrict the time you could speak.

## GK: Right, because it had closing times.

BS: Yeah, and then they'd kick you out. [laughter] Well, I think the decisions become bad after that many hours because everyone's exhausted and you've talked about many issues.

AS: It's just the people who can still talk at the end who get to make the decisions.

GK: At the beginning the steering committee, did it have representatives from the various committees as well as other people on it?

BS: That's my recollection. There was. Yeah. Later, it got more formal where it had to be a certain percentage of people with HIV and other things, but at first it was just one representative of a committee, and then, and I think that was mostly it and then two or three from the original planning committee, I think.

GK: That makes sense. So, one of the first areas of activism that the Public Action Committee would have been involved in was the aerosolized pentamidine issue and that first major march in March.

BS: We brought the coffins to the hospital.

## GK: Yeah. Can you tell us anything about that?

BS: Well, yeah. As I remember, the trial had been done in France, I believe, already and they knew that people would die if they gave that direct amount into people. They were going to do a study because they had to prove it here, for some unknown reason. They did that many times with different drugs. If it's not going to work on people with HIV in France, it's not going work on people with HIV here, right. Why waste your time and money? How can you find the ethical thing of killing people that you know it's going to kill, so they decided to bring the coffins to, I think, which hospital was it? The Toronto General?

## GK: TGH, Yeah.

BS: Yeah. That was TGH. And actually, my friend Danny brought the wood right from his basement. He said, "I got extra wood." He had just made up his basement into a room and he said, "We got all this extra wood, why don't we make coffins?" So, we made the coffins and brought them.

## AS: So, they were actually wood coffins.

BS: Yeah. They were actually wood. Real wood. Yeah. We went all out.

#### **GK: They were heavy.**

BS: They were very heavy, yes.

## GK: So, that was Danny... what was his last name?

BS: Ogilvie was his name. He died in '95, though.

#### AS: And he was involved?

BS: He was at that time, yeah. For two or three years, he stayed involved.

## AS: And the coffins were one for each person that would die during the study.

BS: Yeah, in the trial. The estimate of...

#### GK: I think there were three maybe, or four.

BS: Three or four, yeah. And there were the number with it because in trial what happened in France was this many died, so we guessed that it would likely happen here. Yes. I don't remember the result. I think they stopped the trial, didn't they? Do you remember? Or did they change?

#### GK: I think by the fall, AIDS ACTION NOW! actually had a campaign to stop the trial.

BS: Yeah.

GK: I think the march was two-fold. Maybe you can tell me more about this. My memory of the march was that it was actually to get access to aerosolized pentamidine for anyone who wanted it, but then was in protest at the restrictions of this particular clinical trial.

BS: Right. That makes sense. And then, of course, they went later to the Parliament Hill for the pentamidine and other things to protest for the EDRP.

**GK: The Emergency Drug Release Program.** 

BS: Right.

GK: Do you have any other memories of that first demonstration? There was the big community meeting, and then there was that was the next major event in AIDS ACTION NOW!

BS: Yeah. It was definitely the first, but other than marching there and stuff and I don't have any specific memories, no. So, I have more memories of after the CAS [Canadian AIDS Society] conference when we burned the effigy of Jake Epp, of course. I was surprised when the CAS people came out. That was CAS. Yeah. The turnout was, it was not a lot of work to get people out because we had the conference. So, it caused quite the stink when they held up the effigy of our friend there. [laughter]

GK: Do you remember the organizing for that event? We did a whole bunch of different things.

BS: What I remember, mostly it was around the preparation of who burns it and how we could make sure people don't get hurt. I wasn't in the conference, so other people in the conference were working the crowd to get them out and even the researchers, right. So, yeah, and which they got some of them to come out. That was basically what I remember from it.

AS: Do you remember who had the idea to do the effigy?

BS: Not sure. Was that Greg Pavelich? It might've been.

GK: Well, Greg was holding it when it got burnt.

BS: Yeah.

GK: I can't tell you whose idea it was. It was Michael Smith and Kenn Quayle who made the effigy, I'm pretty sure.

BS: That's right, yeah. So, I think it may have been because Greg always liked that. He wanted to do an effigy burning, so I'm thinking it might've been him.

## **GK:** Greg couldn't have a demonstration without an effigy burning. [laughter]

BS: That's what he wanted, but we didn't do very many of those over the years. It gets a bit tired. It won't get coverage either, right. So, if we wanted to get coverage - that's why we came up with many other ideas - die-ins and other ideas.

## AS: So, it would have come to the Public Action Committee to like, "we're going to do an effigy" and would there have been a decision?

BS: I think it wasn't as formal then. Yeah. I think earlier on, it was more the idea was come out and go do it.

AS: Go do it.

BS: Right. And became much more formalized later.

## AS: So, it didn't have to go through some process through the steering committee.

BS: No. They were obviously there. The idea would've come and the steering committee would talk - often they'd meet the same night at first, right, so that they'd... someone would go upstairs and they'd be at the other meeting.

## GK: My sense is that the effigy must have been approved by the steering committee.

BS: Yeah. I'm sure it was, but, again, remember we used to have the meeting and people would just run upstairs and say, "this is our idea," right in the middle of the steering committee after they'd talked about treatment and other things. And then that was it. So, it was much quicker than waiting for another week.

GK: Do you remember if you had participated in the die-in at that conference? At the very beginning, there was a CAS conference followed by this Canadian conference on AIDS, so the CAS people all stayed for it, but it was sponsored by the Public Health Association and other groups. So, at the very beginning there was a die-in. I was involved in doing stuff inside with Greg, and unfurling an "Epp = Death" banner.

BS: I probably was, but I don't remember for sure. And we did several die-ins.

#### GK: It would have been one of the first die-ins.

BS: Yeah. I'm pretty sure, because I was there and because of the whole thing... I can't tell you that I'm 100 percent sure.

GK: And do you remember any of the discussions in AIDS ACTION NOW! about how effective the burning of the effigy was? I mean we didn't really know this beforehand, but we heard things later.

BS: Yeah, it was definitely effective. I mean it caused "why is this happening" meetings all through Ottawa. We heard from people we knew who worked in Parliament. So yeah, and not too long after that there was the National AIDS strategy, right. So, I think, it was absolutely effective. And I think it was pretty good. I mean people were dying and the government was doing nothing. One thing, I had met with CAS and they were basically saying, "We can wait until everyone dies and just do prevention." So, I think the callousness of that, and I think at the time too, people were more affected by ideas for demonstrations than now. I think it was the time to do that. People thought the movement was strong. There were a number of things that were strong and people were still looking for some social change. Mulroney was the Prime Minister, so obviously there was! [laughter] I think that's why those types of things had an effect and because you could get away with it easier. There's a lot more security around now. Yeah. We're talking about the International AIDS conference in Montreal. Those types of things you'd never be able to do now.

GK: Do you remember any of the other things we would've done in '88? There was the thing on Parliament Hill that you described. You didn't go there, did you?

BS: No. I wasn't at that. And what else did we do?

GK: I think that might have been when the GG7 was there and AIDS ACTION NOW! participated in the demonstration against it, maybe in June. I'm not sure. I may have got the year wrong.

BS: Yeah. It could be.

**GK:** But then the things that I remember and...

BS: No. It helps because there are things that I remember, but I'm not always sure which years.

GK: So, there was some sort of consensus conference in Scarborough at some hotel that we did an action outside and I'm pretty sure you were there. Do you remember? And I think that was when AIDS ACTION NOW! produced that flyer that I had out last night: "There can be no consensus without people living AIDS," or something like that.

BS: Right.

**GK:** Do you remember that one at all?

BS: Not at all. No. Sorry. [laughter]

GK: I'm pretty sure you were there.

BS: Probably.

## GK: And the other thing that I remember was going to London, Ontario.

BS: Yeah. Those times I couldn't, because of work. So, a lot of the ones outside of town, I couldn't get to. I could move work around a bit, but I couldn't just take days off. [laughter] So, no, I wasn't probably like... yeah, it was the same. I never went to the AIDS conference in Vancouver either, which was much later. I'm sure you can get that from other people. I'm not sure if that's in your time frame though. I'm trying to remember. That was in '96, I think. I mean I remember a lot of stuff later in the '90s around Trillium, of course, because that was one of my big issues from day one. They kept saying, "Let's get all these drugs," and I kept saying, "But they cost tens of thousands of dollars, so even if you get them available through the EDRP, it's only a handful of people who can get them." Some of the people who were fighting hardest for it, who had money, they had houses, but I mean ten thousand dollars, if you're alive for a few years then everything's gone, right. Then, that can't work, right, saying, "Let's get all these drugs for people." I mean, that was a step but it was not enough. That was a hard one to get people's head around, that that was a priority, I thought, for some reason. I mean most people weren't thinking they'd live a long time anyways, I think, so they thought maybe I can afford right now and just save them.

## GK: Do you want to tell us more about that campaign, and how AIDS ACTION NOW! gets involved in this campaign for this Trillium Drug support?

BS: Well, we came up with the plan. I think Mark Freamo and I and his partner went to meet pretty early on with the NDP when they first got elected. We said people can't afford these type of things. And we had already tried to make the campaign with seniors' groups and women's groups since it shouldn't just be for AIDS. And they kept offering us that. "Oh, we'll give more AIDS drugs," and we're saying, "Well, if people need drugs, they need drugs," and I don't think that sold well either. Yeah, early on we came up with a plan and then tried to meet with them and then had many, many discussions and we were told that there was a recession and we can't do it now and wait till later. So, always, the same lines that you get. There were many other steps in that, many letters and Bob Gardner wrote whole briefs but we'd meet, we'd meet again. The NDP was having a conference with Bob Rae in Hamilton. That might've been later, like '92 or so, and Greg said, "Let's organize a demo with the Hamilton group," which we did, but they didn't show up. So, there are three of us -Greg, me and one other. So, I said, "Well, lets go in," and I had a pass. But if they stopped you at the door because you don't have a pass, you were stopped! So, in the end, I got in. They stopped Greg. Many people had to stop Greg. He was pretty angry. [laughter] Because he didn't have a pass, and it was like, "Okay, he's really friendly."

So, I interrupt Bob Rae's speech and then he met with us – Greg and myself, with Ruth Greer, who was the health minister at the time. And they again said, "Oh no, we can only do it later maybe." And then we said, "Well, on World AIDS Day we're going to burn you in effigy if you don't do it by then." This was like, in November. The day before World AIDS Day, they announced Trillium, the drug plan. People who worked in his office said that was why. They had no intention of doing it.

## AS: They just didn't want to be burned.

BS: Well, and the election. We kept saying, the election is not very long away. I knew that they had no chance of winning, but we weren't going to tell him that. [laughter] And we knew that likely with the next government, we would never get it, so it was our last chance. We were getting closer to the end and, you know, he had already talked about these new budgets with all these cuts, right. So, how are we going to get something in? I think again, thinking of the effigy from before, that we didn't actually do that one but it was good, because we got what we wanted.

## GK: Without having to do an actual effigy burning.

BS: Yeah. And still, at 211 information services, it's one of the most common calls, people calling around drug access. So, that's from the Trillium benefit. A very tiny percentage are actually people with HIV who use it. That was our line too – you don't really have a health care system if you can be diagnosed but not treated.

## **GK: Right.**

BS: So, it would be pretty meaningless to say, "Yes, this drug will work, but where's your thousand dollars," right?

#### **GK**: Exactly how did it work when it got set up?

BS: Well, it's still similar and there have now been a couple of changes, but basically if you're lowincome, \$350.00 you had to spend of your own and then it was covered. And after that it was like, 3% in income – the higher your income went. And now you can do the deductible over the whole year instead of having to pay it all first. So, that's one thing they made, I don't remember when they made that change. I think it was shortly after the Liberals got elected, when they made that extension, because that was a big problem for a lot of people to come up with that money.

## AS: \$350 a month, yeah.

BS: I mean if you're on assistance it's the same drug formulary. So, you can get a different drug coverage. It is for people who continue to work. I think, it's around 60,000 people that use it at the moment, so yeah. That's pretty good.

#### AS: And so was that just completely easy, no problem, to go in and talk to Bob Rae?

#### GK: And interrupt him and...

BS: Well, interrupt him, people weren't very happy because I was an NDP member at the time in the riding association of St. George, St. David, or whatever the riding was called at the time. I mean the people in the riding were fine with it, the other members of our riding association. But some others from other parts, especially the Northern people were angry about me interrupting a speech. I thought - people were dying, I'm not going to care about the speeches. It's meaningless to me. [laughter] But he was fine and he wasn't mad. He said, it was an innovative way to get to speak to me, he said. And it was smart of them because, you know, it got them good press; he met with the activists. And, you know, Ruth knew what it was about. He didn't really know. She explained everything to him – that the drugs cost thousands of dollars. And, I think, she pretty much supported it. I think she had probably gone to him, just the way she talked as if she's, you know -"I brought you this brief," and "I brought you this and that." So, obviously, she had talked about it many times with him. I mean it's understandable, but it wouldn't click right away for him because it's only one issue of many.

## GK: So, the way it would work is... was there just a specific list of possible drugs?

BS: Yeah, there's a drug formula, the same formulary as for OW [Ontario Works] and ODSP [Ontario Disability Support Program], but they also had, I can't remember, a rapid thing for HIV drugs because they kept changing all the time. That's one of the things they put in, so that it could be approved quicker. And, of course, you still have, it's called Section 8, which basically allows, if there's no drugs that work on the formula, a doctor can put a form in to ask for the drug to be covered. And now they have a turnaround of 48 hours, which at first they didn't, but now it's 48hour turnaround to say yes or no. And if they look, more often than not, they say yes, but a lot of people don't know about that. And that's one I tell people a lot now on 211. "They said it's not covered" and I say, "Talk to your doctor. They need to fill it out, because if nothing's working you have to try it."

#### AS: Yeah.

GK: For sure. So, to come back to the earlier years of AIDS ACTION NOW! One of the big things that happens the next year in '89 is this conference, as you were already mentioning, in Montreal. Can you tell us anything about how that got planned and organized for?

BS: Yeah. We organized with the New York and the Montreal groups and people coming because they knew lots of people were coming, so what can we do? Lots of different issues like, public health issue was a big one for New York and for us around anonymous testing. So, certainly demos were planned around that, and it was a lot of fighting around which, because this are whose priorities? A lot of the New York ones want everything about the New York Medical Office for Health and all that, whereas in Canada... there are certainly similarities – other countries are doing the same stupid things, right, but that's really, most of the demos had to focus on that. We just had these days to do different demos – so, one was on international issues and one was the anonymous testing and then, treatment issues and those were the three main ones. There probably were others.

And then, the plan on the day we marched in was, of course, we were just going to march around and then people said, I don't remember who, I think, some of the New Yorkers said, "Why don't we just walk in?" Because it seemed empty, and we kept expecting somebody to come trying to stop us. But we went right onto the stage. So, that was good! We delayed the opening and had a banner saying, "Mulroney = Death."

GK: I think it was something like "Mulroney You Have Left Us to Die."

BS: And then we opened the conference, Tim opened the conference to people. And then eventually, we allowed Mulroney to come out and then the people, we had me and someone, I can't remember who else, held up the banner - "Mulroney = Death" - the whole time he was speaking. Yeah. So, that was good. That's probably the final straw before the AIDS strategy he decided to make.

GK: Do you remember, we had this AIDS activist centre. I can't remember what street it was on in Montreal.

BS: Right. I think was it at the "Y" or something?

GK: No. It was some... we rented some space on, maybe on Park Avenue, or off it. Do you remember? We had computers and all sorts of stuff; we had FAX machines, all sorts of stuff. Do you remember any of the sorts of things that went down there? So, you had to kind of coexist in the same space - ACT-UP New York, AIDS ACTION NOW! people, and the Reaction SIDA people.

BS: I remember there's lots of conflict. [laughter] But I don't remember all the specifics. I mean the base that I was talking before, what's the priority? What issues can we focus on? There are a thousand issues, because everyone wanted to do a demo on this, wanted to do a demo on that. They heard about this person not being driven to the hospital. Well, I mean that's one of the issues. that people are still being discriminated against, which certainly showed up in many of the briefs and stuff people did and flyers. So, there are many issues and we had to make sure. We really wanted Reaction SIDA to be the lead, because it's their town, but some of the New Yorkers were a bit aggressive I found. And they thought it should be all about what they wanted. I think we did a good job. I'm not sure who brought them down, but bringing that down to do some great demos, surprisingly. You would think in these meetings, there's no way these people are going to get along and we'd probably all have separate demos, all over the place, and then nothing would've got attention, right.

AS: And were the demos organized like, everyone working together on each one?

BS: The three major ones at least that we talked about that everyone worked on. I think people also did some of their own actions, but I can't remember what they were.

GK: There were lots of things around sex worker rights, and a couple of other things.

BS: Right.

GK: And there was a specific event... well, the international issues was the Montreal Manifesto.

BS: Right. The Montreal Manifesto, yeah, which kind of tied everything together. So, really, all the issues did get covered in that because we worked on that for many months before, and were sending it back and forth. Not like now, you just email people. There wasn't such a thing. Even

finding each other, we had to pick corners, right, and where are you going to meet, and at all our demos we had the phone tree, remember?

## GK: Yeah. Oh yeah, we made phone calls then.

BS: And we had like, 500 or 600 members at one point. So yeah, we'd each take a...

## GK: Can you tell us more about that?

BS: Yeah. Well, we had all the members and they asked for numbers for anyone that would give it. And we also mailed lots of stuff at the time. If there was an action coming up then we would phone around and then tell people there's an action. A lot of people had answering machines by then, so at least we could do that. We didn't have to keep calling back a thousand times. But then, we'd do that and so we had a team that would do that, and part of the problem though, sometimes people wouldn't do it, right. And it's hard to know. They wouldn't want to admit it. But some people admitted, so I'd often take extra. I remember that, saying if you can't do it, don't have time; don't say you're going to do it. We also, of course, would poster all the streets around and get threatened by police sometimes and other things, because apparently there was a bylaw that you're not supposed to poster. They don't seem to enforce it very much anymore, but in those days they did.

So, I'm amazed how people found each other. I mean now with Facebook it's easy, but people saving they're going and they don't, right. We had that demo against the Russian anti-gay law the other night. Only about 100 of us, and on the website 389 people said they'd be coming. [laughter] So, it gives a lot of false hopes. I mean that was interesting. People now, one guy at an AIDS ACTION NOW! demo a couple of years ago, said, "How did you organize these if you didn't have cell phones to talk to each other?" It could be a problem if someone, sometimes you get confused about whether you're going to meet or whatever, so you probably lost people, right. People would go to the wrong spot. Or we had to change suddenly, because there's some, die-in or something. We were going to put the costumes on the statues at Queen's Park one time, and we had to go earlier than we planned so, how do you get a hold of people for four in the morning before the security got there and everything, right? We had to change spots because someone thought the Queen's Park security was at the restaurant or whatever. So, if someone came late, couldn't stay. [laughter]

## AS: What was that? I haven't heard about that one.

BS: Well, there were many demos. One of the demos we did was a two-part thing. In the morning, we got together and decorated all the statues on Queen's Park around different drugs and how much they cost and, you know, that they were not available and stuff. And we went into the legislature and also threw fake money down on the legislature.

## GK: Oh. I was at the fake money.

BS: You were at that one?

AS: Sorry. So, the costumes for the statues, they would represent the drugs that were...

BS: Yeah. They were different drugs and then there's a big sign that said this many people would die if they can't get the drug: if they can't afford to pay for it.

## AS: Cool. And that came out of the Public Action Committee?

BS: Yeah. At that point, it was mostly Susan, Lori, me, and Greg there. Not too many in the Public Action Committee by that point.

## AS: Getting up at 3:00 in the morning to go dress the statues.

BS: Yeah. And then it was the same day, later, this was a two-part thing, also a banner. They unfurled a banner, which Lori put under her shirt and they didn't catch that going in security.

## AS: I don't want to offend anyone. Are you, pregnant 'mam? [laughter]

BS: Well it was winter, so a big jacket and everything.

[...]

GK: There are pictures of that action.

AS: Oh, okay.

GK: I'm not sure that's the event I was at. It was actually when I was back from Nova Scotia at some point because I remember that Kim and Charlene came with me, who were also from Nova Scotia. Then we threw... it was AIDS money or something like that.

BS: Yeah. It must've been the same one. I don't think we did it more than once.

#### **GK:** It might've been some other event.

BS: Maybe. I think was the same time. But maybe you just didn't see the banner.

## AS: You might've been on the side of... and the AIDS money was like...

BS: Yeah. It was the same thing we really did at Pride the following year. We threw fake money at the crowd. We had 'Bob Rae on the float and then we had Vanna White doing the Wheel of Fortune, or whatever I don't know that show [Wheel of Fortune]. We had numbers, letters for the different issues, while we're...

#### AS: As the float went along in the Pride Parade.

BS: Yeah. Because it went around Queen's Park that year. It was after the failure of that Bill around same-sex rights.

GK: Bill 167.

BS: Bill 167, right. So, they decided to surround... go around Queen's Park and watch Maria the Cleaner - because she was the only one there on a Sunday probably. [laughter] But that was, what's her name in the lesbian community. That's her line. We march around Oueen's Park so that the cleaner can see us! That was her line.

AS: So, back to Montreal.

GK: Is there anything else you remember? I mean that was a very planned and really major AIDS ACTION NOW! thing.

BS: Yeah, it was certainly probably one of the biggest ones, when you're considering the numbers of people, between participants that were there that joined us, the people from Montreal and New York. And I don't know how many of us went from Toronto, around 20 or so, I think.

GK: I don't think it was that many for the whole week.

BS: Because, again, that's a hard thing to do – this whole week, right.

**GK:** We wrote an evaluation for the Public Action Committee of going to the Montreal conference. I haven't read it recently, but I did remember glancing at it, and our names are both on it. Do you have any memories of that?

BS: No.

GK: One point was about the relatively small numbers of people from AIDS ACTION NOW! who were there, and that we couldn't actually do everything we wanted to.

BS: Right.

GK: So, there was some slight criticism of the ACT-UP people just wanting to do their own thing. And there were other things too.

BS: I'm sure, and I don't remember what was on it.

GK: And I think that report was discussed at the steering committee as well.

BS: Yeah. Well, for me at the time too, that was the priority, and it should be everyone's priority. I mean reality now once you're older you think, of course, a lot of people. They couldn't get away from work for the week. [laughter] Probably lots more would've wanted to come, but that was... I don't even remember where I was working at the time or why I was able to get away.

GK: You were definitely there.

BS: Yeah, I know I was there. [laughter]

#### AS: And the Montreal Manifesto, were you...

BS: That was produced before, so it was all the issues around HIV-AIDS from racism to access to drugs to whatever issue; this is what we demand of different governments around the world, right. I think that was even sent to some people in Europe, but I can't remember.

GK: It was translated in French.

BS: It was translated into French, of course.

GK: It was between ACT-UP New York and AIDS ACTION NOW!

BS: Yeah.

AS: Do you remember who came up with the idea to start formulating that in the lead up to Montreal?

BS: No.

AS: I mean that's just why we started talking about the difficulty in getting... so, you're physically mailing the thing.

BS: Well, no. We would've had to mail drafts to each other.

GK: Well, not only that. I mean it was Chuck Grochmal and Herb Spiers - Chuck for AIDS ACTION NOW! and Herb for ACT UP [AIDS Coalition to Unleash Power] - who were the main coordinators of that.

BS: Well, there were computers then.

GK: Oh yeah. But Herb actually came to Toronto. Herb was in Toronto and talked to people.

BS: Yeah. He was quite often. That's right.

#### **GK**: At that point.

BS: Yeah. They must've met that way. Those two when they were together... even though they could type it up on the computer, no email. So, I don't know what then.

AS: They could have faxed things.

BS: Yeah, there was a fax then, barely. [laughter] They were horrible too. I remember the fax when I worked at home care, the paper would come out all curled up and you had to match the reports because the second page wouldn't have the person's name on it, right. So, you're going: whose report on which patient is this? And I often had to get people to fax it back right, and input the name on both sheets, because then three or four notes on a person and they'd all come in a ball because they send like, 40 – one nurse would send 40 reports up through the fax because they worked out of their cars, so they had FAXes at home or whatever. I don't know where they sent them from. It wasn't a very easy way to do it.

GK: So, one of the next things that AIDS ACTION NOW! does, starting that summer after the conference, is organizing around ddI.

BS: Yeah. ddI. Right.

GK: And our illustrious arrests.

BS: Yes.

## GK: But do you remember anything about that?

BS: Well, yeah I do. I remember the woman, what's her name? She was out for quite a while before we did the action. Her son was needing ddl [Didanosine]...

GK: I'm not sure; maybe it was before, maybe it was after.

BS: Yeah. Well, our plan, of course, was to demand the release – they refused to release it under the EDRP – of ddI. That seemed like the new big drug that was going to be helpful. And so we sent them briefs, we lobbied them, other people – I didn't meet with them – I think somebody even met with them at one point in there. I don't remember.

#### **GK**: That was Eva by the way.

BS: Eva, that's her name! Yeah, there you go. Our minds together will come up with it. [laughter] So, we decided to... we were going to have a sit-in. We did a little bit of training, but not much. We probably could've used more because I'd never done that kind of direct action. So, we decided that we were going to go into their office, which was in the Bay Street district there. And, of course, they had heard, so they had locked the door. And so we were in front of their office, we sat down and chanted, "release ddI now!," and "AIDS ACTION NOW!" But often we couldn't come up with good rhymes with a lot of these issues. We'd often chant "AIDS ACTION NOW!" a lot and people would get... you could tell when people were marching around because they would get, [slowly] "AIDS Action Now." [laughter] Anyways, then the police came to take us away and they just drove us around the corner in the end and gave us trespassing tickets.

AS: Was that the first time that people had been arrested in an AIDS ACTION NOW! demo?

BS: Yeah. I think so. I don't think there were any other arrests. Because most of the time they didn't really even care when we did die-ins over the years on the street. Because we never stayed for hours, right. So, we were always... once the media was gone, we were gone too. Like, what's the point now?

#### AS: Yeah.

BS: So, I think it was the only time period, other than Susan getting arrested because they thought she hit, when there was a crowd around Mulroney... well, she hit the cop because the cop grabbed her arm and she went like this [moving his elbow back and up], right.

**GK: Sue who?** 

BS: Susan Kasurak.

GK: Oh, okay.

BS: That was a demo when Mulroney... I think it was in the election year or something.

GK: Later, did someone chain themselves to something in the legislature?

BS: That was actually the Minister of Health's office, but I don't think they arrested anyone.

GK: Okay.

BS: I wasn't actually there because I was working. So, when James Thatcher went in and did a bit with the radio they went in and, I think, a few people chained themselves to the Minister of Health's – Frances Lankin at the time – desk or chairs or whatever, to try to get Trillium.

#### AS: Oh, that was in the Trillium campaign?

BS: Yeah. It was part of that campaign and James, just before he died, also did a video, right. James Thatcher.

## GK: So, we might've been the only seven people arrested in the entire history of AIDS **ACTION NOW!**

BS: Yeah. I mean there are lots of things now that people have been arrested for. Well, look at the G20 here, right, for doing nothing except sitting and singing in Spadina avenue. I actually walked by there just before they all got arrested.

AS: It's amazing that you could chain yourself to the desk of the Health Minister and not get arrested.

BS: Well, it was the NDP, so they liked to think of themselves as friends. I mean really there was almost no security in Queen's Park in those days or in the Ministry of Health or whatever. Like, they'd ask you to please check your bag when you went to the legislature. And then once Harris came in was when that all changed.

GK: Do you remember who the seven of us were who got arrested? There's one person's name I don't know.

BS: Greg, me, you... was Patrick there?

GK: Yeah. Patrick.

BS: Patrick was there.

GK: Steven Maynard, who was the one who gave a little training on CD.

BS: Yes, that's right. He's the one that did the training.

**GK: Russell Armstrong.** 

BS: Russell, was he?

GK: And he wouldn't go limp and do civil disobedience.

BS: Oh, Russell. Yes. I was surprised he came.

GK: But there was someone else. It was a person living with AIDS, a larger guy, maybe Brian something?

BS: Oh, probably Brian because he was really involved with Eva after... Brian, taught at George Brown. And he was still alive, at least a couple of years ago.

**GK: Really?** 

BS: Yeah.

GK: Well, we should try and interview him.

BS: I don't know if he's still alive now, because I haven't seen him in a couple of years. I see him on Church Street.

GK: Yeah. So, that was the seven of us. And you ended up having to plead guilty to get rid of the charges, but Russell and I, they misfiled the charges against us.

BS: Yeah. But it was just some small fine or something.

## GK: And that was a discussion that the group had about whether it was worthwhile to...

BS: Yeah, whether it would be a benefit to fight it.

## GK: And I think by that point there'd been more release of ddl.

BS: Yeah. There was. It probably would've been more going further if they still hadn't done anything.

## GK: Right. But the ddI thing, that was a longer term thing. My memory is that Eva came later.

BS: She may have.

## GK: I know Greg did a lot of work with her as well.

BS: Yes. That's true. Halpert was her last name. Eva Halpert.

## GK: That's right. And she had high-level political connections.

BS: Yeah. She knew people in the government.

## **GK:** Do you remember any of that? Who she knew?

BS: No. I don't know who she knew. Later with Brian Farlinger, his father was Harris' right hand man. Why I think we still had Trillium at the end of Harris' regime is because of his father.

## GK: So, AIDS ACTION NOW! had a series of retreats throughout its history. Are you aware of that? I think the first one was the one at Hart House.

BS: Yes. That was the first one and that's the only one we really went out of town for. The rest we had here – were one-day things, as far as I recollect. I don't think we ever went out to another one. I remember, I said, "I'll drive" - well, I don't like driving - but I said, "I'll drive if you do directions," because I'm terrible with directions. And Glen says, "I never get lost." And we got lost. And we had to call for directions, and find a pay phone. [laughter]

## AS: And so what happened at that retreat? What was it like?

BS: Well, I think there was a lot of tension around how AIDS ACTION NOW! was organized at that point. Some people wanted it like ACT-UP where people came from the floor and made ideas and you went off with them and there wasn't really a lot of structure. And other people thought that wasn't very accountable to the group as a whole. And so and I think that's where we made the constitution.

#### AS: Oh, at that retreat?

BS: Yeah, where we started up the constitution. So, and then, we had lots of discussion, as I said, until Doug Wilson got really mad. He thought it was about everything and really we were getting nowhere. After he got mad as someone who was fairly ill at the time, then we focused on just how we were going to do it - try to have a steering committee with lots of representation of people affected, all that type of thing. And Tim led the workshops, because Tim, of course, that's what he did for a living. But I think we ended up getting some great ideas, and more focused. Some people decided to leave after that, of course, the ones that really didn't want any of that structure.

## AS: Have those people been to visit ACT-UP groups? Did they have an experience of that?

BS: I don't know if they'd been there, or if it was just from the news, or from their knowledge. Some may have been, I don't know.

## AS: Did you have an opinion about it?

BS: I thought we needed some ability to take other people's ideas, more than I thought the steering committee always did. I mean part of that, and sometimes I even got invited, but they would meet in pre-meetings – like, Linda, Bob, and a few others. And then how were we going to get it through the steering committee type-things. So, I thought it wasn't very helpful because it sort of said to the rest of the committee – even if you had all these ideas, you didn't have a say because it was already decided. And most times, I agreed with their approach; it wasn't that. It was just we should hear the other people before you decide how it's going to work. I think it got better because they stopped, at least to my knowledge; they stopped that. I think it's because they knew there'd be tension, so they were trying to get the best way to get around that tension. But sometimes you have to have disagreements and that's fine. I mean attacking and that I think that's part of what came out of that retreat is attacking people because they disagree with you doesn't get you anywhere either saying, "You're a fascist," or you're whatever, right. Then, that happened sometimes. And I mean, some people were clearly coming from anger and wanted something done and just wanted to go bang their heads against somebody and that's not really helpful: understandable but not helpful. It's like, even when OCAP [the Ontario Coalition Against Poverty] went to that demo where they threw the bricks or whatever. And I knew they planned something like that.

## GK: Are you talking about the Queen's Park riot?

BS: Yeah.

GK: Okay, in 2000.

BS: I had gone to other demos, but I decided not to go to that one because, clearly, I didn't think that, you know, they're going to get through no matter what.

GK: They didn't actually throw bricks there.

BS: No, no. They didn't actually throw bricks, but it's whatever they did. They decided they were going to get through no matter what, and I said, "Well, they've stopped you. They're going to beat you up. What are you going to do?" Then that becomes about that - being beat up. And I'm sure the cops went overboard. I wasn't there, so I didn't see them, but I've seen them do that many times. One time at an abortion rights demo, they said if you cross this line - they put a line of chalk - and they'd beat you up, right. So, I know police do that, but it's not and I definitely agree with most of OCAP's issues. It's just that sometimes you have to think, is this going to really move that issue forward? And I think especially there... those were immediate, but they were also long term issues around housing or whatever. But that was, "Hey, these people are going to be dead," and most of them within eighteen months, at that point, was the norm. I mean that stuff is happening now. so we have to say the drug release, being able to pay for them, better research – all those things had to happen right now. And then we can solve the rest of the world's problems after that. And people were, as I said, at the retreat... I remember saying to some people, who wanted all these other issues, "There are many groups, many activist groups that you can go to. You can be in more than one," and I was. I was involved with OCAC. I said you can be involved with other issues, but this one group can't really. And if you're going to try and get people to demos, you have to have some sort of focus of why they should come because most people aren't activists. And even most of the people involved in AIDS ACTION NOW! had never been activists before because it was their personal issue.

## AS: Right.

BS: For their friends or for themselves.

AS: Yeah.

GK: So, we're now moving into the 1990s more, and on those questions I'm actually much less clear. I'm really glad you've already talked to us about the Trillium drug funding struggle, which was a big one that AIDS ACTION NOW! was involved in. Were there any other things that you were involved in that earlier period in the 1990s?

BS: Yeah. I mean there were a lot of the things around the National AIDS Strategy because they were threatening to cancel it. So, that was back and forth many times. There was a number of demos around a whole bunch of different things it paid for. One was - we had the dingbat - I don't remember exactly what year he (David Dingwall) was Health Minister. Well, it would've been after '93. And so there was that. As soon as they came in of course they did massive cuts to federal government services. So, that was a big one – one of the big issues that kept coming back, because they renew it for a year and then threaten to cancel it. So, that one we did, the David Dingbat one, that was the one I remember the most because we had those artists again; we had all these displays and he was at a conference. We had the National AIDS Strategy ending this fall, and this funding will end. So, we had this plastic baseball bat and we knocked over the little, some of them were houses or whatever the little props were. So, that was that. And then we met him after, actually.

**GK: You brought the baseball bats.** 

BS: No. We didn't.

## **AS: They wouldn't let you.** [laughter]

BS: But he was banging on the table saying, "You're ruining my photo ops!" He did the same thing with the stamp. They had launched the AIDS stamp and we demonstrated at the AIDS stamp ceremony around the same issue – cancelling the National AIDS Strategy. So, we were going to have a red ribbon on the stamp – who cares, right? [laughter] So, we gave him his photo ops, yeah. And it was more honest. Most politicians wouldn't have said that directly. It was kind of honest that it was all about the photo op. Lives are at stake and these programs are at stake and all that type thing. So, those were big issues.

Certainly, treatment and research was calm, so the treatment action – TAG or whatever they called it – committee was very active right after that too. So, there's a number of different research projects, different research protocols, you know, especially around, I don't remember exactly the years because it went on for years, but around – how do you do a trial? And on placebos, we pushed the no placebo group at the end. You have people who want to take the drug and don't want to take the drug, or take one drug and another, to combine that. Eventually, they got a lot of them to change those projects, I think. So, those were often the issues. I don't remember what demos we did particularly around those. Because it did kind of wane after the first five years, right, once Trillium was got. There was lots happening, but not lots of demos, and it's usually reaction at that moment with – we're going to cancel another program, or... when was Schabas? I can't remember.

## GK: That's 1990. Do you remember anything about that?

BS: Oh, yes. Richard Schabas. He was going to quarantine HIV-positive people. I think he... already the NDP was in though, so it must've been '93 because they kept him.

## GK: It keeps coming up from him.

BS: Yeah. But I'm trying to remember when we did the big demo, which actually about 500 people came to.

## GK: Yeah. I think that's 1990, but we can...

BS: It might've been '90. Yeah. Anyway, probably in the first months because that was one of the shortest term demos. We went postering and then two days later had a bigger demo than these other ones that we spent weeks organizing. People were really pissed off; people were really scared about that; of course, quarantine camps and all the inferences of that. I mean, they did something similar in Cuba, but it wasn't in camps, particular for health care, they'd send them to this particular place. And people were very angry, and it was a very energetic march. And I think it never went anywhere because they never of course followed through, but he kept his job well into 1995-96.

AS: Wow.

BS: Yeah. Even after the government changed.

## AS: Wow. I didn't realize that he'd kept his job.

BS: Yeah, for a very long time. He was on the radio. A number of us called in when he was on the radio about that, too. "It's for their own safety," he was trying to say on the radio, right.

## GK: I think that might've been, along with the first demonstration, one of the largest AIDS **ACTION NOW! actions.**

BS: Yeah, by far. Most of our demos were at noon too, to try and get the actual... whether it was around trials or anything to get the company people there. And all of them were actually the majority of our people came from OCAC, but not actually people for – which always used to irk me that not more people would come from the gay community who were being so affected. But we were lucky that we had that connection because demos would've been really silly if we had 20 people, right.

## GK: Right. So, there are a couple of things that you mentioned that I wanted to just come back to. You mentioned the artist group a couple of times. Did you remember who would've been in that?

BS: Other than Andy Fabo, I don't remember anyone. I didn't often connect directly. Somebody else would bring the stuff.

## **GK:** There was this artist group that was around AIDS ACTION NOW!

BS: Yeah. And John Grevson, of course, did a lot of stuff. Yeah, but other than those two, I don't know who was involved in that. And we'd often come up with ideas in the activist committee, and then send it to them. So, I don't know who had the direct connection.

## GK: Did you ever work for AIDS ACTION NOW!?

BS: I did.

#### GK: Okay. Tell us more about that.

BS: Well, that came actually from Brian Farlinger, when he died because he left lots of money and he told his friends, so we ended up with like \$45,000 in the bank. And people were saying, "Oh, we're not getting this done." No one's answering the phone calls because people would be leaving lots of messages. So yeah, it was part-time like, 20 hours a week or whatever. I ended up doing the office stuff, and then I'd take minutes at the meetings and stuff. That was for a couple of years. I don't know how long exactly.

#### AS: Was there an office then?

BS: We had an office on College Street, near Bathurst.

## **GK:** It was the Treatment and Information Exchange.

BS: It was inside TIE, yeah. So, we just had one room; and files there, lots of files. And they ended up, after we stopped having an office in my apartment for many years until I gave some to the archives, and the rest I recycled. [laughter]

#### **GK: Recycled? No!**

BS: Well, because the archives said they already had a lot of it.

## GK: I know, and they would get rid of duplicates anyway.

BS: Yeah, and I didn't. And most people that I knew were involved, or you asked people if there was anything they needed. I mean mostly it was just newsletters, minutes, which we had copies of. It was actually not until 2009, when I moved in with my partner, that I got rid of lots of it because I didn't have a room to keep it in. So, get rid of it now.

## GK: What did you do in terms of the work? Was there an answering machine or something?

BS: Yeah. There was a phone machine. And then we'd have certain hours I was there like, three times a week, there for 3 or 4 hours. But mostly you'd get calls about safer sex really, which wasn't related to AIDS ACTION NOW! So, I'd tell what I knew because I knew quite a bit and then give them the committees, if they wanted further health information or whatever. So, there were calls and then I seemed to find things to do, but I don't remember what. Stuff people just used to do on their own. And I kept at it for quite a while. We weren't paying a lot, obviously, because the money has kept us for many years. And then what's her name that... she lives in Nova Scotia now, I forget her name. Anyways, she took it after. And then Alex McLean did it for a little while, after I went to do another job.

#### GK: So, in that sense, you were the financial coordinator for a period of time?

BS: Yeah. Well, I still officially have the books.

#### GK: You're the treasurer.

BS: I'm the treasurer. I guess I am. [laughter] We don't have a lot of things going on, so it's pretty easy. For a time too, after that; around '98, I think they decided whether we would keep it, or – are they going to close, are they going to keep going? And then we stopped meeting regularly. Then it was really until about 2006 with the AIDS Conference here in Toronto that they decided to relaunch the steering committee.

## GK: So, you stayed connected all along.

BS: All the way through, yeah, in some way or another. Even now, I go to some of the steering committees: I don't do that much. I do some of the books and stuff, but Alex and them, that's what young people do – most of the ideas, which is great. To me, it's silly to have this money just sitting there if you can use some ideas. And they've raised a little bit of money too, because there isn't much money left now. And it was my idea to close the office, and stop having the phone line so they wouldn't run out of money. So, it would've ended. Because we moved the office too – between the research initiative after CATIE, that building was torn down, we moved. So, it was there for a few years too, and they were actually charging quite a bit.

GK: Do you remember when that office would've got closed down?

BS: I'm trying to remember. It was probably around 2000.

GK: Oh, okay; that late.

BS: Maybe 2002, even.

AS: What was that like, the transition from more activity? Can you just talk about that part? I mean it's a little bit later than we're supposed to technically talk about, but it's really interesting.

BS: Yeah. Well, I mean the main thing is people weren't dying quickly once the new drugs came, right. So, how do you get people motivated? There were still issues obviously, and new ones come up all the time, but there were a number of times they tried committee meetings on a certain issue and 20 people would come. But it was good to have the name. I don't think the politicians knew because sometimes even writing a letter and putting "AIDS ACTION NOW! would have caused issues, right. Because they remember, "Oh, they bring the demos." So, I mean that brings me back a bit around politicians, around when the NDP actually got elected, of course, and we assumed the Liberals would get elected. And then all the demos were around the Liberals and we were all upset. Elinor Kaplan (Liberal Ontario Minister of Health) was mad at us because we were ruining their re-election possibilities. And I think James met with her after, and she was crying and saying, "It's your fault." I think we got a lot of media attention, but I don't think we caused them to lose power. [laughter] I don't think we had that much power. I'm sure we didn't.

GK: I think we're moving towards the end of the conversation. One of the things we wanted to ask you was about people who have died who were involved in AIDS ACTION NOW! So, any memories of the people that you remember who died during that period of time?

BS: Yeah, some of the early ones - David Marriage and Ross Laycock, who when we met with Perrin Beatty who was freaking out because he had Kaposi's sarcoma. I remember that.

GK: Okay. So, that's that picture - that was Ross Laycock.

BS: Yeah.

## AS: Do you want me to show you that picture?

## **GK**: It's alright.

BS: Anyways, that's Ross. And then, who else? Well, there's Chuck Grochmal, who I didn't particularly like, actually, but anyways, it was sad that he died. And who else died? Of course, James Thatcher.

## GK: You mentioned the video that he did before he died. Do you have any more memories of that? I mean we'll try and track it down.

BS: Well, I only saw it once, so obviously... I mean it was basically just talking about the affordability of drugs because he had some major issues. So, his face was all distorted by that point; I think that's why it had such an effect because... and he kind of said if I could afford such and such. But that wasn't true because he actually had quite a bit of money. He probably could've afforded that drug that might've still been around, right.

#### GK: That was in 1993 at some point

BS: Yeah. Right. Just before he died.

## AS: Were you friends with him? He was the co-chair then?

BS: [I wouldn't say friends] but friendly. Yeah. And then, of course, Brian Farlinger was later.

#### GK: Do you want to tell us a bit about him?

BS: Well, Brian came from a business background, so it was not certainly someone you expect to be an activist. But I guess he was seeing what happened when you get sick, and what can happen... and his mother was NDP. She had run for the NDP, even though his father was a longtime Tory. They weren't together anymore. So yeah, he came in from that perspective and all that we needed was to have the right information, because first he said he thought you just need the right information and someone would have to listen because it only makes sense to do these things, right. And clearly that wasn't the case. But one thing you could see from when he became co-chair was his background of being a boss because he was a little bossy. I told him, at that point I wasn't paid, so I was saying, "I'm not your employee." [laughter] And, of course, Kalpesh did quite a bit, especially around treatment and stuff.

#### **GK:** Can you tell us anything about Kalpesh?

BS: Well, he was quite brilliant around treatment issues. So, he was a big help in treatment action stuff, and around research because he did research for a living.

#### AS: What was his work?

BS: I don't remember exactly what he did, but I know he was a researcher. Not for a long time, because he was pretty young and got sick, and then he stopped working for the last two or three years.

#### GK: And he moved here from Montreal.

BS: Yeah. He originally was in Montreal. Well, after he came to Canada, he was in Montreal and then came here. He went back to Montreal for his last year because he had friends who were taking care of him.

#### AS: In Montreal.

BS: Yeah.

## GK: And there were lots of other people too.

BS: We actually did a list at one point. Maybe someone will have that.

#### GK: Yeah, we've got one.

BS: You've got the list, yeah.

## GK: Do you have any memories of Michael Smith?

BS: Oh, of course, Michael. Yes. He was fairly early on. He was a great guy, and his funeral was quite interesting too.

#### AS: Why was that?

BS: Oh well, because of many different things. He had the Christian minister, to the Radical Fairies, to the anarchists. So, there were many different symbols of the different things, right. And it was quite fun. They did a Fairy march or something, if I remember, right at the end.

#### AS: Where was it?

BS: It was at the funeral home on Sherbourne.

## AS: I was saying to Gary earlier that every time that anyone talks about Michael they say, they get this sort of, "Oh, he was such a lovely person." So, were there lots of people there?

BS: Oh yeah. It was hundreds of people there, yeah. Well, when we used to defend the abortion clinic, he was the one that knew all the words to "Every Sperm is Sacred;" he would start singing.

He actually brought us all the words, because most of us didn't know the words - to the antichoice people as they marched around. [laughter] So yeah, good memories. Yes, but he died right in '89, didn't he?

#### GK: No. It was later than that.

BS: '90 maybe? It wasn't long after we started.

GK: I would say '91, but I'm not sure. I was not living in Toronto then, but I did see him a number of months before he died.

BS: Maybe it was '91. It seemed like even in a 25-year period it was still early, but later than I thought then.

GK: And there were two other names I just mentioned if you wanted to say anything about them - Doug Wilson?

BS: Oh, of course, Doug. Yes, mentioned in the meeting there. Doug. Well, again, he was great because he had a long experience of activism too. He was in Saskatchewan in the '70s. Was he fired or something? Or a teacher or something? I can't remember.

## **GK:** His position was terminated.

BS: Terminated, yeah, for being gay. A very nice man, and when he got... he rarely got angry, so when he got angry that is when people would stop and say we have to think what we're doing. Any other names?

## **GK: Oh, it was George Smith.**

BS: Oh, George. I know George.

GK: There were lots of other people, but just to come back to David Marriage - can you say anything about David Marriage, because I remember him quite a bit.

BS: Yeah. Again, he wasn't involved very long either.

## GK: It was very early on.

BS: Very early he died. He was a wonderful guy. He planned his own memorial, so it was quite funny. It was in the backyard of his partner's. But I don't have a lot of memories other than he was very nice and was one of the better memorials. One of the positive things around HIV is that most people did memorials, not these religious services, and talked about, you know, all that happened and the positive parts of their life; and not just about the end part, which we did for Danny too, which I organized. So, we went through all the different things he did.

AS: Danny...?

BS: Danny Ogilvie was the one who helped build the coffins.

AS: Yeah.

GK: Yes. One thing around Danny I'll just mention was, I think at some point, we wanted to use those coffins again and he'd thrown them out. Do you remember that?

BS: Oh yeah, yeah. Danny was... it wouldn't last five minutes if it was in the way. He used to smoke, so he would repaint his place every six months because of all the smoke on the wall. I'd say, "Why don't vou stop smoking?" Or vou repaint. [laughter]

AS: That's a lot of smoke.

BS: So, [...] those coffins were gone probably two weeks later, not long.

GK: So, when we wanted to use them again they just were no longer around.

BS: Yeah.

GK: I do remember that, yeah. So, in terms of what we've been talking about, is there anything else that's arisen for you; things we haven't talked about? Other memories of things that you think are important that we perhaps missed?

BS: Not that I can think of. I mean there's certainly lots of things we missed because there were many demos over the years, certainly around – we missed a lot of the Pride – many years of Pride.

#### GK: Yes. Tell us about that.

BS: Many years of Pride, we'd do die-ins. And surprisingly, we'd get thousands of people to participate, who would never come otherwise. I think also because we'd do it for like, two or three minutes. But we'd organize that often with the Pride Committee; often Greg was on the Pride Committee, fortunately. You know, just stop for five minutes and everyone just circle people with chalk, and the issue of the year. I don't know how many years we did that, but a few anyways, and so those were very good. And some demos there'd only be a hundred of us and we'd do a die-in at Wellesley and the surprising thing always is the police would just let us. Sometimes they weren't even there because we'd never tell the police. Unlike now, we never... most people asked for permits, they'd rarely do it, but we rarely, if ever, would ask for a permit. I don't think we ever did. What would you want a permit for? [laughter] And I think police should learn from that too. They usually let us do it, and I think others; it's the same, right. It probably caused less problems than trying to stop people. Those were good. I think that's part of the reason people thought we were so much larger than we really were, because of those things at Pride.

AS: But it would be like...

BS: They think all these people would really participate all the time and I think that helped, even when we'd write letters to the government because they'd seen these thousands of people die-in. And I think we also, if you look at AAN! as a whole, we were lucky we had a number of people who had worked in government that could write our briefs and stuff. So, we had a heads up, or that had worked with media, that type of thing, right. And originally, with media, we'd just say let anyone speak. But really, some people didn't know what to say and then they'd never get covered because they'd say too much. And I think we were very lucky that we had people that you could hear break it down to ninety seconds for what we can get of our message across. I guess he doesn't work for the government anymore, but Bob Gardner could certainly... his knowledge was more help than we could ever imagine because he gave a leg up before we ever started any brief.

## AS: Were there structures to train people in doing those things?

BS: Not a lot. That's one of the things we talked about many times at retreats, but we didn't do good mentoring. I think we were trying to get so much done, especially in the early years, but even later. It's like, I think that's in any group because you're trying to say – I already know what I'm doing and just because you know what you're doing doesn't mean you can teach either. So yeah, we didn't really do that because people usually came with that experience. And I think that's why we lost some people over the years who were interested, but didn't know where to fit in, especially if you came to the steering committee and they were talking about all this medical technical jargon, which eventually I could follow. But at first I couldn't. What were the different drugs and how do they react. But now, if I went back, because I haven't done much, they talk about some of them now and I'm not as on-the-ball. I know there's still the cocktail, and now you can get it almost in one pill and that's everything that they've changed the content of those many times over. And so the current content I wouldn't know, because I didn't pay attention the last few years, but we have CATIE [Canadian AIDS Treatment Information Exchange] now; we just call it CATIE. If someone needs to know, you tell them to call CATIE, which is fortunate and was actually an AIDS ACTON NOW! project as well. Nobody's talked about that. The government first sent off to different institutions a couple of times, and I think they spent lots of money and didn't come up with anything.

I think that's the big thing that any group could do, and maybe AIDS ACTION NOW! could do is, how you get new people involved? And I think that's part of what we did – newcomers groups and other things over the years – to try and educate people. But they didn't seem to last very long, because if you went into the activist group probably you could get a little more, because it was just about activist stuff, right. But anytime you went to the steering committee or treatment action group, if you're a beginner it was way beyond what anyone even with education in university around that issue, some people had trouble with it, let alone lots of other people. In spite of the image, gay men were not all middle class – a lot of them worked at retail and many other places that. Or me, I have a social work background, nothing to do with medicine. I mean some social workers work in hospitals, but that's not my background.

GK: You've also given us a whole bunch of names of people we should try to talk to.

BS: Yeah. They can give you better information. The one thing I'll say is that, yes we didn't do everything right, but I think AAN! had tremendous success. And I think we have to remember that, even around criminalization now. Well. ves. 25 years later. Maybe if we'd done it this way. something else would be different now. I don't think so, but, at the time, that was the right approach, I think.

## **GK:** And what was that approach?

BS: It was an approach around keeping in Public Health those "unwilling unable," whatever, to practice safer sex when they've been diagnosed, you know. So, that issue is still a big issue. The reality is that in the rare occasion where someone can't be educated, then public health can intervene. And I think, ideally, most people with education will practice safer sex. It was our idea at the time. Also, it was easier at the time because it was a death sentence, right. And now people, some people think, sometimes some of the people would think, "Well, if I get it, I just have to take a drug," or, "If I get it, I won't die for 20 years and I'll be old." If it was there and you could get it, you could die at 18 months with really no treatment – was a very different approach you could use, right. So, times were different and I think it's easy for people to say now, which I've heard at some meetings, "Oh, I think we made a mistake giving it to public health," and all this stuff, but it was either criminal justice, or saying in the last option go to criminal justice, which I think it's the last option to go to the criminal justice system. I think it's not a criminal thing in most cases. It's a guy going around... the rare cases where you know someone and trust them and you said you were negative, and you're in a relationship where it's an issue – where is that line? It's always going to be hard to draw. I think that's a last resort - to do as a criminal act. And I think this is becoming common, which is unfortunate. We're building all these new prisons; we have to have someone to put in them, right?

GK: So, I'm not sure there's anything else, unless there's more you wanted to say. That's really interesting you wanted to talk about how important AIDS ACTION NOW! was: if vou want to say anything more about that.

BS: Well, I think the reality was that, eventually, because there's enough numbers, drug companies would've done something, because it was just profitable. But I think you would've talked another 10 years before they would've come to the point where AIDS could be somewhat chronically managed. I mean in Canada now there's less than 200 people in a year die, right. At one point, we were at 2,500 – 3,000 some years. So, I think the reality is that was happening especially in the first few years. And people, and discrimination – it could've easily turned to be like Russia with gay people right now. Because, if we hadn't kept the sex positive, gay positive approach – back then we mostly talked about gay men – but if it hadn't kept that approach, I think the backlash could've been severe. You even had people like Elton John trying to go back into the closet during that time, right. I think that's where, not just AIDS ACTION NOW!, but the AIDS movement as a whole was successful, including ACT and others, but that this is an evil thing; it's a terrible disease that people can get, but that's been moved forward. Now, I'm certainly not saying, which I've heard a couple of times in Xtra, AIDS made us grow up. I think we were grown up long before that, or that, you know, it helped get us towards more gay rights. It may have pushed the bar because it forced people out, but eventually that would've happened anyway. That I certainly would have

loved to have seen – not watching people die. I think we could've found other ways to get people out of the closet and other things. I mean that AIDS is certainly not ever a positive thing that it happened, but I think we handled it as positively as possible in a crisis. If we had ten years to plan, we probably could do perfect planning, but overall.

AS: It's also interesting, I mean Amber Hollibaugh who is a U.S. activist who was involved in ACT-UP and she did a lot of labour organizing in California. She has this book called My Dangerous Desires. It's kind of a memoir of those years and she says, "I often reflect on what would've happened if AIDS had happened and there had not been this vibrant movement against repression." And so it's also just, in a way, it's interesting to think about if there hadn't been the resistance to the Bath House raids and all of those things. What would...

BS: I'm sure there would have been quarantine camps. There's no doubt in my mind, there would have been, yeah. I mean you go back to the '60s when people were using fake names, saying I'm a friend of Dorothy's, and all that stuff. There's no way, with people killing themselves after having been caught having washroom sex. Yeah. It absolutely would've been a horrendous time, if we hadn't had the early gay movement and feminist movement too, because a lot of our ideas came from them, both in the gay movement and in the AIDS movement; a lot of them. Yeah, if it hadn't happened, then I probably never would've come out of closet. Probably pretended and got married too, right, if you see people quarantined and all that stuff.

## GK: If you don't have more to say...

BS: No. I think that's good. [laughter] Thank you so much.

## GK: I think it's really great.

BS: Well, thanks for doing this. It's going to be interesting once you're done.

[END OF TRANSCRIPT]