

AAHP
AIDS Activist History Project

Interview Transcript 04
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Interviewee:	Gary Kinsman
Interviewers:	Alexis Shotwell
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Persons present: Alexis Shotwell – AS
Gary Kinsman – GK

[START OF TRANSCRIPT]

AS: So, the way we've been starting is to ask people to talk a little bit about how they got involved in activism before they were involved in AIDS activism, if you were involved in anything.

GK: Yeah. I was involved... I'm not going to go into any detail, but the first that I did was that I joined the revolutionary left – the Young Socialists – in the early '70s, and through that actually came in contact with people in the gay liberation movement. I came out shortly thereafter in the early '70s. So, I was involved in the Young Socialists, and then the Revolutionary Marxist Group (RMG), in terms of left groups.

AS: And you're in High School?

GK: I was in the Young Socialists when I was in high school. The Revolutionary Marxist Group would be a bit later, and then the Revolutionary Marxist Group was forced to fuse with another group called the League for Socialist Action, which produced the Revolutionary Workers League that we left on March 8, 1980, in terms of a number of the lesbian and gay people in it. I was involved in a lot of left activism, but also got increasingly involved in queer activism. So, I would've been involved in the Gay Alliance Toward Equality in Toronto, on its executive – the last executive possible that closed it down. Also, I was involved in the Gay Liberation Union, Gay Liberation Against the Right Everywhere, the Right to Privacy Committee, and then the Canadian Committee Against Customs Censorship. I mean I was involved in a lot of left activism and a lot of queer activism before AIDS even came on the scene. I think that gives you some sense of a background.

AS: I know we're not actually usually asking this, but I actually am curious. What do you think it was in you that made it be right away that you had a particular orientation toward collective liberation struggles?

GK: The only place I've ever talked about this before is in an interview I did with Deborah Brock, which is actually on *Radical Noise*, my website. But my sense of this in terms of having done some memory work about it is that I initially didn't really like school at all, but at some point I actually tried to do my best at it. In some ways, I was an awful student. I remember at Victoria Park Secondary School, I actually would try to put down other students, sort of constructing them as "stupid." I did really well at school, but it wasn't at all satisfying. So, that led me to sort of try to figure out what was going on. It was a very intellectual, cerebral radicalization that I was involved in; you know, reading Fidel Castro, Che Guevara, listening to Radio Havana Cuba. I did that for a long period of time before I ever did anything. The first political thing I think I ever did was, and I

have no idea why I did it... the War Measures Act gets declared in 1970 and the teacher at the front of the room – my home room teacher, I have no idea who it was – says, “What do those people in Quebec want?” And for some reason, I just put up my hand and got up and said something, probably based on Radio Havana Cuba. I don’t know what it was based on. So, that seemed to be the start of getting more actively involved and I went to a Pollution Probe event. I went from Don Mills, the suburb I was living in, down to Convocation Hall at the University of Toronto for a big mass meeting organized by the Emergency Committee for the Defense of Quebec Political Prisoners. It was quite a major event. I think it was Michel Chartrand, who was then the president of the CSN in Montreal, and Robert Lemieux. He was the lawyer for a lot of the FLQ (Front de liberation du Québec) people.

AS: He was my old roommate’s dad!

GK: But this was also an event that the – it wasn’t the Western Guard, it was the Edmund Burke Society that maced people, right. So, the whole thing stopped for a period of time and the Communist Party of Canada – Marxist Leninist and Red Morning – beat the shit out of them during that break period of time. Red Morning was similar to above ground supporters of the Weather Underground that never developed in “Canada,” but it was an attempt at revolutionary youth movement type stuff here. It was Rising Up Angry first and then it changed its name to Red Morning. And their theme was to serve the people and stop the pigs. They would organize free food where they would give you anti-Trotskyist talks, so as young Trotskyists we would go there and get the free food. I bought two publications at the Convocation Hall event. One was *Mass Line*, the publication of the Communist Party of Canada – Marxist Leninist. It was all about Hardial Bains, their fearless leader, and this wasn’t interesting. And then I bought a copy of the *Young Socialist* that had John Lennon and Yoko Ono on the cover, and this seemed really interesting. Later on I found out that this was actually their youth turn, which the leadership put an end to shortly thereafter. So, I joined the Young Socialists. I wrote and said I wanted to join and I got involved in it. I went from being very cerebrally, intellectually radicalized to becoming much more actively involved.

And that also was how I got put in touch with the gay liberation movement. I remember announcements being made about this upcoming demonstration in Ottawa in 1971, which is what became the “We Demand” demonstration. I consciously remember wearing really short shorts to go to a talk that Jearld Moldenhauer was giving at the Young Socialist / League for Socialist Action headquarters, which is now the Rivoli over here on Queen Street, and I did successfully attract Jearld’s attention. But that’s a whole other thing. I somehow made the transition and I mean I was initially involved in student organizing at my high school and high school student organizing more generally in the Young Socialists. I would say, maybe in ’72, maybe ’73, they were asking at a Young Socialists meeting, “We need to have a speaker at the Pride thing. Who’s going to do it?” And I put up my hand and became more publicly out. I had relationships with a number of the older men in the League for Socialist Action. Anyway, there’s a lot of stuff there. We don’t need to go into all of that, but it became not just an intellectual process. It became something that was very embodied. Even though I have lots of critiques of Leninist organizations, I think I learned a lot from being in the Young Socialists and the RMG – less so in the Revolutionary Workers League – that I was able to use in all sorts of different areas, including teaching but also in other areas of activism. It was, in that sense, a very useful experience. But mostly in the ’70s I would’ve been

involved in high school student stuff, only a little bit in terms of anti-Vietnam war stuff. I did help organize the Amchitka bomb demonstration. It was a nuclear test at Amchitka off Alaska in, I would say, '71. We organized a demonstration of about 10,000 high school students.

AS: Amazing.

GK: And I'm pretty sure that Toronto Gay Action was there and spoke. I think Paul McDonald from Toronto Gay Action spoke. It was actually getting involved in the revolutionary left that put me in touch with gay liberation, and created the context in which, I think, I could come out on some level. So, I had a lot of activist history.

AS: Yeah. Then, you got involved in the Right to Privacy Committee right away?

GK: Well, the Right to Privacy Committee actually was formed in the late '70s when the bath raids first started in Toronto, so I really didn't have much of a connection to it. I was having a relationship with Bruce Russell at that time, who had moved to Toronto from Vancouver and was also in the RMG. So, I remember him and the early days of the RWL when we were forced to merge. I remember he went to some of the formative events of the Right to Privacy Committee, but initially George Smith wasn't centrally involved in the Right to Privacy Committee. It really shifts and changes when there's the mass raids in February of 1981, when close to 300 men get arrested on that night. But I already was in touch with George Smith and Tim McCaskell. That day after hearing about it, I called their house and said what's happening? What can I do?

AS: They were already living in that collective house?

GK: They were in a collective house together.

AS: Who else lived in that house?

GK: I'm pretty sure Richard Fung did, who was Tim's partner. Someone named Ray Glendenning, very sweet, nice guy was living there. I mean it changed... David Mole lived there for a while. So, it was a series of people who lived there – a collective house. At that point in time, it would've been on Seaton Street, and I think it changes much later, but I'm only familiar with the Seaton Street collective house. So, I mean I knew to call there, and like, what's happening? Is there a demonstration? What can I do to help? So, I don't think I had any real involvement with the Right to Privacy Committee before that, but I was a marshal or, as I like to call it, marshmallow at that demonstration, and it was a pretty incredible event.

AS: People came out?

GK: Yeah. And it was following that that there was a sort of reboot of the Right to Privacy Committee and this huge public meeting at Jarvis Collegiate, and I was initially supposed to be the facilitator for the Public Action Committee, but I realized I couldn't do it. I just didn't have the skills. I mean even that night trying to facilitate, because I think we did the same thing as AIDS

ACTION NOW! (AAN!) would later do, which people broke into working groups. And that was a much larger meeting. This was like, 1,200-1,500 people.

AS: Amazing.

GK: At Jarvis Collegiate. And the Public Action Committee then was hundreds of people. And I mean it stayed being hundreds of people for a number of months. I just didn't have the skills or the capacity, which is why Tim actually took over facilitating the Public Action Committee. I didn't know enough about how to deal with contradictory positions of how to make decisions in that type of huge context.

AS: Yeah, so many.

GK: But, I stayed really involved in the Public Action Committee. I mean I was also involved in Gay Liberation Against the Right Everywhere [GLARE]. And I guess in terms of my activism, something that's important is, I never was inspired or really wanted to get involved in human rights organizing in a major way. The RMG queer people, myself included, RMG gays and lesbians, whatever we called ourselves, had I thought a pretty ultra-left critique of human rights strategies. But in a certain sense there's something to it that, since it wasn't really dealing with substantive everyday material questions. It was dealing with abstract sort of formal rights. So, I never was really very involved in any of the sexual orientation protection stuff and the human rights code. So, for me, like, being involved in organizing against the right wing or when the bath raids happened or the campaign against custom censorship, which interestingly enough. I mean, I think in some ways – George and I even had discussions about this – we did not want to be involved in very central ways in the campaign around sexual orientation protection in Ontario. Not that we opposed it, but it wasn't what we wanted to do. So, I was involved with George in the Right to Privacy Committee, but I mean I was not centrally involved in the Right to Privacy Committee. Gay Liberation Against the Right Everywhere was much more central to what I was doing then. But both George and I were involved in the Canadian Committee Against Customs Censorship or CCACC, which was largely formed to defend Glad Day Bookshop from attack. And we did work around that. That was probably some of the activism before AIDS comes up. In terms of AIDS, you know, I remember the *Toronto Star* headlines that say, "Gay Plague Arrives in Canada" in the early '80s. And I remember some of the first meetings that were organized to form the AIDS Committee of Toronto (ACT), and Michael Lynch speaking at them, and some of the doctors speaking at them, and I was one of the first three employees of the AIDS Committee of Toronto.

AS: Who were the other two?

GK: Sarah Yates-Howarth was a woman who was hired, who knew some of the gay men who were involved, who was a writer, politically not necessarily on the same wavelength as other people. Karsten Krossman was the other person, and we were the first three employees, hired for six months. It was a make work project and, I've said this before, but maybe I'll say it here, the first office was above Kentucky Fried Chicken near the corner of Church and Wellesley. And given the board members would come in with all this Kentucky Fried Chicken and the place just reeked of the smell of it. We always would joke that we were secretly conducting a study on the relationship

between consumption of Kentucky Fried Chicken and the acquisition of AIDS. There are a number of things that happened in the AIDS Committee of Toronto, but I'm only really an employee for those six months. And, I mean, there's a number of things I could say about that. I'm just not sure.

AS: Well, let's focus on the AIDS ACTION NOW! piece and then we can come back and see how much time we have.

GK: So, I was really familiar with AIDS from that point on, and it was interwoven with the fabric of my life. There was no way you could actually live in Toronto as a gay man during that period of time, and especially with the activist networks that had come out of the Right to Privacy Committee, without having some knowledge about AIDS and about kind of responding to it. And I was also involved in *Pink Ink* initially, which gets transformed into *Rites*, so part of what we were doing was obviously writing about AIDS and HIV.

AS: And raising other people's awareness, and...

GK: Yeah, and raising other people's awareness of it. And having articles on the politics of AIDS and things like that. I can't remember when but, at some point, Sean Hosein starts to write the early incarnations of "Treatment Update" as a column in *Rites* magazine. And, this is later on, but George Smith starts to write a column called "Diary of an AIDS Activist," but I think that's really closer to the formation of AIDS ACTION NOW! So, I was very familiar with AIDS in lots of ways, and aware of what's going on in the States, with the AIDS Coalition to Unleash Power being formed, and with the PWA (People with HIV/AIDS) Coalition in Vancouver and what it was doing. So, all of that was something I knew about.

AS: And so when was ACT formed?

GK: 1983.

AS: Okay.

GK: So, it was formed a little while before we were hired, which I think would've been the fall of '83.

AS: And pretty substantially before AIDS ACTION NOW! starts.

GK: Oh yeah. It's a pretty institutionalized AIDS service organization by then. I mean initially the language that was used was "Community-based AIDS group," but by the time AIDS ACTION NOW! is formed, I think, that the type of rhetoric of AIDS service organizations is starting to be used. It comes from the government and then gets taken up by the groups who are getting funded by various government agencies. So, by that time ACT is really institutionalized. When there were just the first three employees, we're setting up an office, you know; the library I'm starting to set up; I call each week to the Laboratory Centres for Disease Control to get the number of people who are designated as being infected, the number of people who died. I'm in charge of setting up some of the first liaisons with the Haitian community. Those are the types of things I was doing. All the

staff met with a lawyer, John Higgins I believe it was, around how ACT should get incorporated, whether it should have a charitable arm or whether it should only have one level of incorporation where it's all a charitable organization, which is what was eventually decided, against our recommendation.

AS: And that produces then a limiting in what the advocacy possibility is.

GK: Yeah. So, even though initially people say there's no way we're going to let this get in the way of us doing advocacy or supporting activist groups, within a year it's being used to say we can't support the Ontario Coalition for Abortion Clinics, because that's "political" and we don't want to put our charitable status in question.

AS: So, how did you hear about AIDS ACTION NOW! starting?

GK: I was invited to some of the first meetings that led up to AIDS ACTION NOW! being formed. I can't exactly tell you whose people's houses they were at, but I have a general sense of who was at some of these meetings. I think there were probably two or three before the big public meeting at Jarvis Collegiate which is in early February in '88, so the meetings happen in late '87. There would've been some primary care physicians involved. The name that most sticks out to me is Michael Hulton, who did stay involved in AIDS ACTION NOW! at least for a while, but there were other primary care physicians who were people – sometimes gay, sometimes not. Phillip Berger would've been another one, but I think he was less involved in the formation of AIDS ACTION NOW!, but a network of primary care physicians who were really troubled by what was going on with the people that they were trying to do work for. So, that was one component of what comes together in terms of AIDS ACTION NOW! I don't think that component stays so solidly involved, but those primary care physicians were there at the very beginning. And I think some of the events might've actually been held at some of their houses. And then there were gay men who were HIV positive, including Michael Lynch, and George Smith. I'm not sure when George discovers that he's HIV positive. Tim would've known he was HIV positive at that point in time. And there were certainly other people as well. And then there were a smaller number, at that point in time, of HIV negative gay activists. I think I was invited probably by George. I know I was at the meeting where the name of the organization was discussed, and George proposed AIDS ACTION NOW! as a slogan, all in caps with an exclamation mark. So, it was not just simply a name; it was actually what we were demanding. And that was certainly there. And certainly one of the inspirations for bringing all these people together was what was going on in the States – ACT UP (AIDS Coalition to Unleash Power) groups were starting to be formed, and that was certainly knowledge that Michael Lynch and other people brought to the group. Michael Lynch had a lot of contacts with New York City.

AS: And he would go to Fire Island.

GK: Yeah. But he was also going to New York City and had a certain knowledge of what was going on – that people were using various different drugs and treatments, and they were using the stuff and it was letting their lives be extended and their quality of life to get better. And there was a real feeling that this simply was just being denied to people in Canada, right. It was sort of that contradiction between knowing that people could survive and live longer, but it being denied to

people here that I think was sort of the central contradiction that led to the emergence of AIDS ACTION NOW! There were preparatory meetings – a number of them – that led up to the public meeting at Jarvis Collegiate, which was not as big as the Right to Privacy Committee meetings. Certainly, I think there were about 300 people at that first meeting, and as you described in another interview, the sort of “Thor”-type image and “Too Damn Slow,” was the slogan that was used. And I have no idea where that particular image came from... it was by Gram Campbell. I mean there were layers of people that had graphic design skills and art skills who were in and around AIDS ACTION NOW! And I think usually we would just let people go off and do it, and there might have been some direction provided.

AS: Like, “put an image of Thor on that flyer.”

GK: No one explicitly said, it's Thor. And then there was the meeting, which I think was pretty incredible.

AS: Can you talk a little bit about it?

GK: Well, there were speakers. There were testimonial speakers of people living with AIDS and HIV and some of their experiences. I think some of the primary care physicians would've spoken at it. There were some emerging demands, especially around aerosolized pentamidine, because at that point in time the number one opportunistic infection people were dying from was pneumocystis carinii pneumonia. And there was a sense that if people actually used as a prophylactic aerosolized pentamidine, pentamidine in an aerosolized form, that it would actually prevent the development of pneumocystis carinii pneumonia. And this was what people were actually dying from. So, this was a central issue in the initial emergence of AIDS ACTION NOW! And then just a general sense that there was no real treatment delivery. The drugs and treatments that could extend people's lives just weren't getting into their bodies, and this was quite central to what AIDS ACTION NOW! was about. And I think also in the beginning there was the focus on treatment information. There needed to just be more information around treatment so that people could make decisions – both primary care physicians and people living with AIDS and HIV.

I do have to point out that a number of those people living with AIDS and HIV who were involved in AIDS ACTION NOW! early on were probably more educated about this than their primary care physicians. They were quite articulate and quite able to talk about various drugs and treatments. They would have self-taught themselves to be able to understand some of this. All that leads up to AIDS ACTION NOW! being formed. So, there were a series of demands, maybe three, that were adopted – one was around aerosolized pentamidine; one was around more information... I'm not sure what the other one was around. We hadn't yet formulated catastrophic rights... We didn't use that language yet. And we certainly were not at that point talking about AIDS and HIV becoming a chronic manageable condition – that comes a bit later. But there were certainly three demands, and a major area of focus initially was aerosolized pentamidine, which leads up to the first action. The method of the meeting was I think to have a large group of people together to hear these people talking, to have some sort of discussion about the various areas of work. So, at that first meeting, I know there was a Public Action Committee meeting. That's the Committee that came out of there that met that night that probably had a meeting of like thirty-plus people. Not everyone went to the working groups afterwards. There was, I think, a finance

committee, certainly a media committee at that point in time. I suspect there was some sort of Treatment Group. There certainly was later on, whether it was actually one of those groups at that point in time, I don't know. But it was a fairly dynamic meeting. Now, in terms of how things were organized. I mean clearly there was some sort of committee that organized the meeting, which I think has something to do with the steering committee emerging after that, but I am pretty clear that the various committees had representatives that they also put on this committee at least in an initial way. I don't know if there were actually common meetings of AIDS ACTION NOW! after that. I mean there certainly came to be annual general meetings and things like that. I don't think that the first of those was held until the next fall. I think that basically the organization was a steering committee and these subcommittees that met fairly regularly and had some input into the steering committee. It became a steering committee sort of driven organization. But initially there were a fair number of people in these working groups and subcommittees. So, I think there was a fair amount of dynamism, because I think in the first period there were probably 25-30 people regularly at Public Action Committee meetings. So, it had a sort of a life of its own. I mean a lot of suggestions, a lot of plans for activism came out of that and they would go to the steering committee. I know at some points there was some tension between the Steering Committee and the Public Action Committee, because there were a lot of suggestions and ideas coming out of the Public Action Committee, some of which were being pursued, some of which weren't. And there would also be requests from the steering committee – we really think you should organize an action around this, right.

AS: Was it easy to get on to the steering committee, if someone wanted to join the steering committee?

GK: I know I was... I might've been on the steering committee for two different reasons. I was part of that group that existed before the big meeting, and it was probably partly also that I represented the Public Action Committee. Brent was often there. Greg Pavelich was often there from the Public Action Committee. There were at least three or four people associated with the Public Action Committee at that point in time. And Tim was involved sometimes in the Public Action Committee and sometimes not during that period in time. But the first thing that we were asked to do was around aerosolized pentamidine. So, the first major action is a demonstration of about 500 people that gathered at the 519 Church Street Community Centre, and it sort of had two areas of focus: one was just to get aerosolized pentamidine released to people, because it wasn't; and then there was this clinical trial going on. I don't know if its only site was Toronto General Hospital, but that was one of the sites. And it was based on a proposal and the language was "clinical end points" and they knew that, you know, people would die as a result of the placebo controlled – a double-blind placebo controlled method of this particular trial. So, this is one of the reasons why Danny Ogilvie volunteered. I think he must've had some assistance to produce these five – three to four probably – wooden coffins that we carried with us on this demonstration. The demonstration went from the 519, and maybe I should just back up for a moment. We were not clear at all who was going to come to this event. I think there were actually debates about whether we should just make it mostly a rally or like a short march, or whether we should actually go all the way to Toronto General, and in the end we decided to go all the way to Toronto General. We had some speakers at the 519 and then we went, I'm not even sure whose office it was, we went to a MP's office I believe, a Tory MP. And Michael Lynch gave a pretty fiery speech there and then the

march continued on to the Toronto General Hospital where it sort of became a candlelight vigil. I know us going to Toronto General Hospital was really controversial. There were some gay medical professionals who thought this was a really bad idea.

AS: And why was that?

GK: That we were actually interfering with research, that in a certain sense. Yeah, we could demand drugs and treatments, but to actually interfere with research that was going on was to interfere with people's careers and work and it was to take the struggle to a different level. And I think some of the people involved in the AIDS Committee of Toronto would've been pretty standoffish of this, because they were getting state funding and this was certainly not something they wanted to be directly associated with. On the other hand, there were, I would say, close to 500 people on this march. And it was from our vantage point actually quite successful and showed to us that there was a base of support for engaging in these types of activities.

AS: So, and was Toronto General one of the main places that people who had HIV and AIDS were being treated?

GK: I would say it certainly seemed to be from what I remember. It seemed to me a lot of stuff revolved around there, but I mean it spread out, I mean to other hospitals dealing with these questions at that point in time.

AS: I don't know that we need to get into this but just, I think that Eric in his interview talked a little bit about George's formulation about the difference between being treated and being a research subject.

GK: Yes.

AS: And do you think that that distinction started to be formulated in the context of that action? I mean, or was that part of the...

GK: No, I think it mostly comes later in terms of trying to make sense out of that. I think one of the really neat things about George's work, research, or if you want to talk about it as theorizing, was it always was related to the questions that were posed by the activism that we were involved in. So, I think it's that. But others, clinical trials coming up like the Ribavirin one, which I think is the next fall, where George starts to make this really clear distinction and shares this as a way of understanding things with other people in AIDS ACTION NOW! about the social relations of research and the social relations of treatment and how these are actually not the same and they're conflated together in these research trials, right, and that we needed to really distinguish these. It was fine if you wanted to be involved in research – to go and be involved in a double-blind placebo controlled trial – but if you're actually interested in getting treatment, this is not what you should be doing. So, this was an argument for having compassionate arms or open arms where everyone as part of this trial would get access to the treatment, right, so that everyone in this instance would have gotten aerosolized pentamidine, which was of course a direct violation of what was being said. We actually were contesting and challenging the way that type of pharmaceutical-based

scientific research was going forward, and began to actually challenge some of the science around how this should be done. And George certainly, was focusing on what was being thrown up for us about the situations we were facing. I mean the other thing about George at this point in time is that he is quite critical of the speculation and ideologies that people produce. Like, why is it taking so long to get drugs? Well, some people would say, “Well, it’s simply homophobia,” or it’s AIDS-phobia, or it’s just bureaucratic red tape, right. And none of these worked for George because it didn’t actually describe how this was socially organized. He was always interested in getting us to think about how this was socially organized, how it was socially put together, so that it wasn’t simply about the homophobia of pharmaceutical corporations or doctors. It wasn’t simply about AIDS-phobia either. It wasn’t even really about bureaucratic red tape, because what became visible fairly clear, fairly early on was that this treatment infrastructure just didn’t exist for anybody, right. There was nothing that actually allowed for people in catastrophic situations to actually get access to drugs and treatments. It just wasn’t how it was organized. So, in a certain sense that was all about a private contractual relationship between a doctor and a hospital and a pharmaceutical company, but it had nothing to do with what health care was in the Canadian context. It was just a complete area of absence and gap, right. In a certain sense, what George thought AIDS ACTION NOW! should be about was – we need to put that in place. We need to get that organized so that drugs and treatments could actually get into people’s bodies in terms of the social relations of treatment, not simply the social relations of research. So, that became a really profound way of orienting what AIDS ACTION NOW! was doing, especially in this early period.

This also relates to what Eric was saying but up until that point in time, basically, what was going on around AIDS was, well, at first it was just make-work project funding, but eventually it becomes health funding, and it becomes palliative care. Public health – is the major orientation – which is, you know, I always say that, what you always have to ask about public health is, which public and whose health? Because it really was about defending the so-called ‘general population’ from infection, right. In that sense, people living with AIDS and HIV and the communities of people associated with them were the problem for public health. I mean all of the stuff around contact tracing, mandatory reporting, possible quarantine measures, all of that was mobilized by what public health is actually about, right. And George was very perceptive around that, in terms of understanding that we could not look at AIDS from that vantage point. To look at it from that vantage point was to not take up the standpoints of people living with AIDS and HIV, and that had to be fundamentally what we were doing in terms of AIDS activism and AIDS ACTION NOW! So, that was also something that was really quite profound here. We were doing something outside the framework of public health, outside the framework of palliative care, and outside the framework of state-funded AIDS service organizations too. There was this area that was not being addressed and this is what AIDS ACTION NOW! had to really focus on as a major part of its activity.

AS: And so AIDS ACTION NOW! did in that moment, take a really definite stance to not try to get state funding, to not become a charitable organization, or a non-profit?

GK: That was quite strong in the early period. I mean obviously it gets more complicated later on, but at this point in time, no, we were a political activist organization. We were not interested in being an AIDS service organization or getting that type of funding, because we’d seen what it had already done to other groups. Now, different people in AIDS ACTION NOW! would’ve had different understandings of this. Sometimes, it was simply put forward as a division of labour between the

AIDS Committee of Toronto or the PWA Foundation, which are going to do the basic educational work and support work and connect people up with social services and we're going to focus on the treatment stuff, but sometimes it was also put forward as a more critical analysis of those groups too. So, those two positions co-existed within AIDS ACTION NOW! and certainly it led me to see more of the ways in which the AIDS service organizations had gotten transformed from these community-based AIDS groups that wanted to do more, into these much more professionalized board-of-directors staff driven types of organizations that, you know, reproduced a particular form of organization that was in some ways quite similar to how state forms of organization are put together. And to see that happening, it made a lot more sense of what was going on for me and what had actually been going on in my experiences with the AIDS Committee of Toronto, which again I learned a lot from, but I could even see in that six months a lot of stuff that I didn't want to be involved with over the long term, right. So, you know, I got out of there after the six months. I mean I maintained some connections with ACT after that. The major issue AAN! organized around initially was pentamidine and that also led us to organize the Pentamidine Project and I wasn't directly involved in this. People would go to Buffalo and get aerosolized pentamidine and would bring it back. And there were primary care physicians who would actually administer it to people in Toronto. That was one whole area, and I wasn't at all involved in that.

AS: Do you know who was?

GK: I can't really say. I do know that that was something we were doing. That's something we obviously need to uncover more about. I mean getting aerosolized pentamidine into people's bodies and preventing pneumocystis carinii pneumonia was a really important initial contribution that AIDS ACTION NOW! undertook. And it doesn't mean that everyone who needed it was getting it, but it was a form of direct action. We were actually getting a treatment in that was not sanctioned at all in the Canadian context outside of the clinical trial that was going on.

AS: And maybe we could just talk about the action on Parliament Hill, where people are taking the drugs that are not currently or weren't then legal.

GK: Yeah. As a follow-up activity to this, an event was organized that (I'm sure I wasn't there) on Parliament Hill, where Michael Lynch and a number of other people whose names I'm not going to remember right now basically took different treatments that were prohibited in Canada or not sanctioned for people to use in Canada right in front of the clock tower of Parliament Hill, with that as the backdrop. It was a media event, consciously a media event. I think it was tied into visiting the federal AIDS Centre, which might have been the Laboratory Centre for Disease Control, which had some sort of AIDS Centre arm that was developing at that point, and so people also went and visited there on the same day that this was organized. A number of people went down from Toronto, both to provide support work as well as to be part of the event itself. Michael Lynch I think was quite central to the organizing of that.

AS: But you weren't involved?

GK: No. I was certainly aware of it. I was certainly quite clear on how it fit into this strategy. It was both a direct action thing, because people were doing things that were technically against the

rules, but also it was designed to have a media impact too. Like, people living with AIDS and HIV were right here in front of you taking these drugs and treatments that could possibly extend their lives. In many cases we knew it would extend their lives, right, especially the treatments dealing with opportunistic infections. In a certain sense, that's what the first area of organizing was around, you know, not anti-virals, nothing to do with HIV; it was actually, if we can actually stop – and this also came out of the States and out of ACT UP – if we can stop people from dying from these opportunistic infections, that's what people are dying from. They don't actually die from HIV itself; they die from the way in which their immune systems get destroyed and they become susceptible to these opportunistic infections. That was one of the first things we really organized around in a profound way, and that was certainly followed up with the event on Parliament Hill.

The next major thing I remember after that mobilization in March around aerosolized pentamidine and the initiation of the Pentamidine Project was this conference that was organized in mid-May. And there was a Canadian AIDS Society conference which was bringing together of all of what were now the AIDS service organizations. That happened for a couple of days and then following that there was a broader conference, I think, organized by the Canadian Public Health Association, with some state funding, and some of the Ministry of Health officials from the federal level spoke, not Jake Epp, the Health Minister. So, it had some really official character to it, and I think it was understood as being one of the first Canadian conferences on AIDS. There were certainly other things prior to this that took place. The Canadian AIDS Society was one of the co-sponsors of it. So, we had a fair amount of discussion, both on the steering committee and in the Public Action Committee, about what to do, and it was Public Action Committee that would've organized most of this. And we came up with a whole series of things. I think during the Canadian AIDS Society conference, we had some sort of workshop, but I also think we had a media conference. What we were interested in was trying to tap into the frustrations and criticisms that people in the Canadian AIDS Society were increasingly having with the slow pace of response from the federal government and from Jake Epp, the Health Minister. We were trying to tap into that to see what we could do. To facilitate that, on the opening of the official conference, not the Canadian AIDS Society conference, we did a combined outside-inside operation. I think 30 to 40 people did a die in outside the hotel where the conference was taking place, which I think was quite effective. Meanwhile Greg Pavelich, myself, and I think someone else, we smuggled a banner in. I think Greg hid it under his coat and we had... I don't know how we had press credentials, but I think we did. And as the delegate of the Minister of Health starts to speak, we just unfurled this "Epp = Death" banner at the very front of the conference. I think that met with mixed responses. I mean some people were very pleased that we did this. And what I saw happening, because some of us attended some of this Canadian AIDS conference, was that I think that this actually empowered or opened up more space for people from the Canadian AIDS Society groups to be more vociferous about their opposition to the government. It sort of crystallized some of that opposition and gave people a space in which they could go further, so this actually worked remarkably well. The next day, when we had the demonstration, we had no idea who was going to come.

I mean all of this was seen as a gamble. Like, were we really trying to do this? And trying to see if we could bring together the energy coming out of the Canadian AIDS Society groups and their frustration and anger, with AIDS ACTION NOW! and it worked remarkably well. So, we had about 300 people gathering at the front of the hotel and there were a couple of speakers. I can't tell you who spoke, and the issue was really focused on Jake Epp. I mean the Health Minister, the inaction of the federal government... everything around the conference was around this theme of

“Jake Epp = Death” and people were just literally dying because this was a Minister of Health who was not doing what he should be doing. And we were using “Action = Life” as the other major slogan – so, come out and we’re going to do something about this! The 300 people gathered outside the hotel and we marched down Queen Street and then we went down Bay and we came to Richmond Street, which is a one-way street. I mean people were into taking over the street. This was a large group of people you couldn’t really keep them on the sidewalk. I remember, I was one of the marshmallows – the marshals for the event – and Tim was another one. And I couldn’t find him, right, to actually ask if it was okay we’re going to go on the street here, because that’s certainly what people were already beginning to do and certainly what I felt should be done. There was enough energy here; there was enough people that this is what we should do. So, we did do that. We took over Richmond Street. I think there was a Tory Party office on Richmond that we also stopped outside of and had a little bit of a protest there. Certainly by the time we were getting closer to – I don’t even know what the cross street is we would go up. We just went up basically around the hotel. Certainly there were cops turning up and they were not happy that we were on the street and were – I can’t remember, I have some memory that were police on horseback who were here as well. But we then went up the other side of the hotel and towards Nathan Phillips Square. Now, at some point Jack Layton was riding by on his bike, who was an alderperson at that point in time in the City of Toronto and rode his bike a lot. And I can’t remember if it was the police on Richmond Street harassing us or whether it was that they didn’t want to let us go into Nathan Phillips Square, but he talked to them and somehow convinced them to just let us do our thing. So, we moved into the corner of Nathan Phillips Square and one thing we had planned was the whole focus was around Jake Epp. Michael Smith and Kenn Quayle, who were both participating in the Public Action Committee, had done an effigy of Jake Epp that I think we carried through the streets for the whole march, and then the idea was that it was going to be burned at the rally in Nathan Phillips Square afterwards. They’d also put a “KKKCanada” on it, which I know that there was some discussion of later on, that this was not authorized by AIDS ACTION NOW! to do this. But that’s very present in all of the media pictures. I think Greg Pavelich is holding the effigy. I’m pretty sure Michael Lynch and a couple of other people spoke at Nathan Phillips Square and then we burned the effigy. And, you know, sometimes you don’t know if your tactics are going to work or not, but I think this was one time when that was clearly the right thing to do at that moment and really crystallized the opposition to Jake Epp.

We heard about two or three weeks later that Jake Epp was actually called into Brian Mulroney’s office and was asked, “Why are people so pissed off with you, so angry with you that they’re burning you in the streets of Toronto?” It was remarkably effective and it actually helped to create the preconditions for Jake Epp to be moved out of being Health Minister and for Perrin Beatty to be brought in, and helped to produce, the conditions in which a new perspective was needed by the federal state, state agencies in relationship to AIDS, and to managing AIDS groups. So, this was the start of the period of “consultation” and “partnership” that would eventually lead up to the National AIDS Strategy, which is a different question, but I think this activism helped to create a situation in which things could no longer go on as they had been, otherwise this opposition from a lot of the Canadian AIDS society people would continue. There had to be something which would actually contain or re-manage things, and that was where the National AIDS Strategy project came from, which took a number of years to develop. And Perrin Beatty was the health minister during that period of time. That was a remarkably successful action and a remarkably successful tactic in burning Jake Epp in effigy.

AS: And do you think that it was significant in that opposition that... it sounds like people from the conference, people who were involved in ASOs (AIDS Service Organizations) joined that action.

GK: Yes.

AS: They were a really big part of it. They were partaking in this more radical call.

GK: But also it's important to understand that many of them were not doing it on behalf of their ASO organization. What was really interesting was, in many circumstances with the ASO groups, they would simply not come, right. If it had simply been AIDS ACTION NOW! people, we might've had a demonstration of around 100 people at that conference. So, we were really not sure what was going to happen. It was really quite amazing that so many of them from that conference came out and joined this event. And we leafleted. We made sure that everyone at the event knew about this and when it was happening. It was something that really worked out, but in some ways we were not really sure until it actually was happening that it was going to be as successful as it was. I think that was actually one of the most interesting, innovative things that AIDS ACTION NOW! did during that early period. And it had, certainly taken the streets without any permission – all of the direct action aspects to it. And the burning of the effigy was clearly quite a smart thing for us to have done. We had no idea if that was going to be useful or not.

AS: And so do you have anything to say about the Consensus conference?

GK: Yeah. In terms of my memory of what else we did in 1988 – and I'm sure there's a lot more – I remember that there was some sort of conference first of all in London, Ontario. I think that was first. And a number of us went in a car, I can't remember who, to that conference; some sort of conference on HIV with mostly medical professional types at it. Some of us – some AIDS ACTION NOW! people – may have been invited but we had some sort of small protest outside basically just calling for – people living with AIDS and HIV have to be on all these committees. Otherwise, it just isn't representing the groups of people that need to be represented. So, some of us went on a day trip to London, Ontario around that. And then there was a consensus conference, which I think was between medical professionals, ASOs, people living with AIDS and HIV, and I can't remember if the pharmaceutical corporations were involved in it or not. But we, a whole bunch of us, I would say 10 to 15 people, went out to a hotel in Scarborough near the Scarborough Town Centre, but north of the 401. And I think at that point in time we actually – we probably learned this from ACT UP – but we had little tombstones. So, we did a die-in that actually said, "Dying of denial of drugs" or whatever, right. And I think it was for that conference that we produced this flyer that was headlined, "There can be no consensus without the involvement of people living with AIDS and HIV." And we leafleted everyone. So, the idea was to have an impact on them and to create space for more people living AIDS and HIV to be directly involved in these proceedings. Now, often times George would want to be the person who would go in, because he would see going in and seeing what was happening as really crucial to the research that we were doing, so he wasn't necessarily always outside. He was more... he was actually in practice more on the document side than the demonstration side, even though it was also really clear, you could write the best documents in the

world, but without the agency or the force to bring them about or to get people to hear them or listen to them this was just not going to go anywhere. You always had to have really clear thought out documents. You couldn't just sort of arrive there and not really know what you wanted to do. You had to put a lot of thought into it. Those were the major things I remember for the rest of '88.

Through '88 it would've been those events happening and then there's I think AIDS Action Now! has its first Annual General Meeting that Fall. And I think the Public Action Committee was still a fairly thriving subcommittee of AIDS Action Now! throughout most of that period. And then I got a job at Acadia University for the winter of the beginning of '89, so I'm aware of what's going on and I try to establish some connections with the PWA Coalition while I'm in Nova Scotia then. I'm basically teaching at Acadia as my first major teaching gig, and I know that I had this discussion with George where he said, "You're really going to go and have a teaching position right now, when we're doing all this stuff?" On the other hand, he really wanted people to get teaching positions too, but I do sort of think he felt somewhat ambiguous about that. I mean I was actually away for a period of time. And then I arrived back in Toronto when the major thing that AIDS ACTION NOW! was doing is planning for the Montreal AIDS Conference in June in '89 and I probably would've come back late April – early May from Wolfville. So, I got really involved in that and the organizing for that. And the Public Action Committee was doing a lot of that work. And there was also some sort of work that was going on around the Montreal Manifesto – liaison work between ACT UP New York City and AIDS ACTION NOW! I'm not even sure when people started to do that work that they had an awareness that Réaction SIDA existed, because it was not involved in the work around the Montreal Manifesto. So, it was ACT UP New York and AIDS ACTION NOW! who were going to sort of do this activism in Montreal, even though neither of us was based in Montreal. There were some connections with some activists in Montreal, but eventually we'd become aware that Reaction SIDA existed, which was... even though it certainly was a group that was inspired by ACT UP type groups, but it brought together. I mean it had Anglophones, Francophones, men and women, but I think it had sort of a more anarchist coloration to it, at least in terms of how it presented itself. It was also really new. Like, these were mostly pretty young people who would have just started to organize around AIDS and politicize and radicalize around it. You had, you know, AIDS ACTION NOW!, ACT UP New York City, and Réaction SIDA coming together and trying to organize. We had an activist centre. I don't know what street it was on. It wasn't that close to where the conference was, but it became the media activist centre. It became a meeting place for that whole week. And given there were like, a hundred people at least who came from – it may have been more – New York City in terms of ACT UP; there were a lot of people around. And there were pretty tense meetings about what to do. And, you know, the energy of ACT UP from New York City was absolutely indispensable for the success of the activism that week. It wouldn't have happened without them. And I think there were like, 25 to 30 people from AIDS ACTION NOW!, and probably about 25 to 30 people in and around Réaction SIDA who were involved in stuff. But we did have this activist centre for a week and that was crucial, I think, to undertaking what we were able to do that week. But they were pretty tense meetings and I do think that many of – certainly not all – but many of the ACT UP people from New York City were pretty dismissive of Réaction SIDA in particular. I mean there was some level of respect for AIDS ACTION NOW!, but Réaction SIDA were these young people, they don't look like us, they look like sort of hippy anarchists. The ACT UP people – at least the gay men – had a look about them. But there were a lot of women who came up with ACT UP as well. I didn't meet a lot of people personally. I remember some people here and there, and they were not there the whole week. ACT

UP people – I don't know – it was about half way through the week. It was clear they'd just mostly gone right. And they did their own things. Like, they went to some commercial sports event, where they'd do their safe sex stuff, right. They did a whole bunch of stuff on their own, while they were there.

The major thing was, we'd actually done all this planning in AIDS ACTION NOW! about the opening demonstration, which was going to be a demonstration outside where the conference was being held focusing on Mulrone. We'd lined up speakers and all that sort of stuff. And clearly ACT UP knew that it was not going to just have this little outside rally. So, they all come in and they just march right into where the conference is being held. And there's no security, so people just go up the escalators, and we march into the area where the conference is going to shortly start and we just take over the podium, right. And it's amazing; it's absolutely amazing. People are carrying all the ACT UP slogans, and then there's all the stuff that John Greyson helped us make – "The World is Sick" with various different slogans – "of criminal medical negligence," "of profiteering," a whole bunch of things like that. We had all of those signs and some were in French as well as in English, and we took over the opening session. It was Tim McCaskell who unofficially opened the conference on behalf of people living with AIDS and HIV and criticized Brian Mulrone. There were a couple of other speakers and we basically prevented the conference from happening for, I would say, about two hours. And then eventually – and I don't know if there were some negotiations that went on. There may very well have been, but I'm just not aware of that and then most people, most people didn't leave. Most people just went into the audience. And I didn't know this until I looked at the pictures that Alex had sent, but we clearly had unfurled the "Mulrone, you've left us all to die" during that period of time when we were taking over the opening session, which I have no memory of actually doing that. We were... like, it was Patrick Barnholden, myself, Shawn Syms, and I think Greg Pavelich and Steven Maynard, who were assigned to unfurl this banner when Mulrone was speaking. But I guess we got... we have to unfurl the banner now because all this was happening. I don't know how we got it back from holding it up and then hid it until Brian Mulrone actually was talking, and then we did it again. And we had no idea what was going to happen, how long they were going to let us do it. I think that some security moved towards us but they made no actual efforts to try and get us to take it down. It was pretty effective, right. So, everyone was seeing "Mulrone, you've left us to die." So, he was speaking and then the AIDS activists in the audience all turned their backs to him; many of them pointing to their watches, like "time is running out." And then people booed him when he finished. So, that was quite an effective intervention in terms of following up what had happened in the opening session, opening up more space, and certainly really putting a lot of pressure on the federal government. I think also by taking over that opening session and having Tim and other people who were quite open and public about living with AIDS and HIV – it created a different context for the conference as a whole.

ACT UP also did disruptions. I think when the New York State, Commissioner of Health spoke – they disrupted him. There was a whole series – like, different groups were doing different actions. And ACT UP also had its Treatment Agenda for that year. The Treatment and Data Group, I think it was called, within ACT UP had a really important media conference where they said, "This is our research agenda; this is what should be happening." And they were very clear and decisive around that. So, there were various things that happened. And then, as Brent was saying earlier, we tried to organize things on different days. There was one that was an international issues, which I think was unfortunately later on in the week, which is where... I think we were handing

out the Montreal Manifesto all the time, but we focused on that and we had speakers from around the world, but by that point – we didn't notice when we planned it – most of the ACT UP people from New York City had gone, so it was a much smaller event than we hoped for. There was a day around anonymous testing. There was a day around treatment issues. I know the sex worker rights people – Tracy Tief and other people would've organized an event as well. We saw each day we would focus on a different issue and I think it was all really effective. By the end of the conference they actually added a new speaker onto the final plenary, which was a member of the Vancouver PWA Society. So, for the first time, a major speaker officially addressing the whole conference was a person living AIDS and HIV. I think at that point at that conference, it really altered the dynamics within those conferences at least somewhat so that it was then clear in practice you couldn't ignore people living with AIDS and HIV in terms of how these conferences were organized. And it was also effective for us in terms of putting more pressure on the Canadian state around a whole series of issues. So, I think it was a very effective intervention. On the other hand, there were only like, 25 to 30 members of AIDS ACTION NOW! who were there. And about the same number of people from Réaction SIDA that didn't last that much longer, and it's actually the emergence and in some ways I had this feeling, partly like the boyfriends and the other people who met people from ACT UP New York City, that they decided to form a Montreal ACT UP group after that. I don't know much about how it develops after that. So, it was a very successful form of activism, but I think that those of us from AIDS ACTION NOW! who were really centrally involved really felt tired out from this event, in that we could've accomplished so much more if more people had been there.

AS: It was a lot of work.

GK: Yeah. I think Brent Southin and I wrote up something for the Public Action Committee to try and sort of evaluate this action. And I think that went to the steering committee, so there was some discussion about that. It was also a major expenditure of effort and resources on the part of AIDS ACTION NOW! I think it sort of exhausted us a bit.

AS: Did AIDS ACTION NOW! send... Was there money to send people to that event?

GK: Yes, but I'm not sure because we also must've rented this space. I don't think we got it free. We were doing fund-raising activities, but I don't really know how that money was organized. I mean we know a little bit more now about how ACT UP New York City had money, but we certainly didn't have a huge bank account. We had a pretty small amount of funds that we operated off of. That's something I'm just not clear about, partly because I have an aversion to dealing with financial stuff, but also partly I just don't know. But clearly there was some money. I think we got money from ACT UP New York City to pay for some of the stuff, and for the activist centre, because that was a joint activist centre between ACT UP and AIDS Action Now! and Reaction SIDA, but I think they come into it very late in the day in terms of the planning for this. I mean it was quite an incredible experience, but I think there was also ways in which we got a lot more than AIDS ACTION NOW! could have got on its own largely because of the energy of ACT UP New York City, and to some extent Reaction SIDA as well. I think in terms of AIDS ACTION NOW! really being strengthened as a group out of it – I'm not sure that happened. That summer the major issue that AIDS ACTION NOW! is organizing around, which is a little bit different than what

it had been organizing around previously, in terms of getting treatments released, was actually about a drug called ddi (didanosine).

AS: So, did pentamidine – aerosolized pentamidine – become available after '88.

GK: That's my understanding. One of the things I missed out on is that that fall, the fall of '88...

AS: While you were away?

GK: No, I'm actually around.

AS: Oh.

GK: I go away in the Winter of '89. That fall, I don't actually know what happened in that clinical trial, but there were major challenges to it, but it continued. And we actually organized a campaign *against* the clinical trial, which is not what we were asking for at first. We were just raising concerns and asking for like a compassionate arm that everyone could be involved in and for compassionate release through the Emergency Drug Release Program of aerosolized pentamidine to people. But by that fall, we were taking a harder line, basically calling – "This trial should be over. It's not ethical. It's denying people access to what they need to have." And my understanding, my memory of that is that all of those things combined together led to more and more compassionate release of it, and also that we were bringing it across the border anyway. So, that's my sense of what happened around aerosolized pentamidine. Now, I'm not trying to say that it became available to everyone who wanted it. I don't think so, but I think there was more and more release of it and my memory is that they actually stopped that clinical trial. I'd actually need to have that verified from somewhere else, because I mean we were getting pretty sharp at being able to say this clinical trial is entirely unethical. They wanted to do it in Canada because they didn't want to do it in a place that they thought was already contaminated with people using all sorts of drugs and treatments, like in the States. That's why they wanted to have a 'clean' clinical trial in the Canadian context, so that they could actually say, "This was an effective drug" and it could be marketed around the world.

So, we had a major campaign and my sense is that we at least in some ways won that campaign, either they added a compassionate arm to it, which would've been one way of doing it, or else maybe the trial was stopped, I'm not sure. That's really a lot of what happened around aerosolized pentamidine. That was the first drug and the first treatment that AIDS ACTION NOW! was really organizing in a major way around. Obviously, there were all sorts of other things. We were doing, like we were starting to produce. It wasn't just Sean's "Treatment Update," it was pamphlets that would actually describe various types of treatments, like the one that has the people taking the drugs on Parliament Hill on the cover. So, getting more information out there, talking about the new drugs and treatments. Early on there were also lots of educational events that AIDS ACTION NOW! would organize. You might get one of the doctors from the States to come and talk about treatments. But there was a lot of self-education going on around – what were the drugs and treatments. I mean people learned a new language – opportunistic infections, you know, all of these things – people were learning a new vocabulary. By the next year there's actually much more of a sense that, AZT (azidothymidine) is the one drug that's being pushed,

right. And it has major toxic impacts on lots of people's bodies. So, people are starting to raise really serious objections, "I can't take AZT; it's like poison to me. I can't take it." There's an increasing emphasis, if you're convinced that you need to be taking something around the virus itself, and that just trying to rely on drugs to get rid of the opportunistic infections isn't good enough, and that increasingly people were feeling like, maybe we can put a stop to these opportunistic infections, but it's not actually making us any more healthy, right, in the long run. It's preventing us from dying and that's great, but there needs to be something more than that. So, by the next year people are starting to talk about, and people find out about more drugs at the conference in Montreal too. But people are starting to find out, there's this drug called ddi that Bristol-Myers owns and that for people who can't take AZT, it seems to actually have some similar characteristics in terms of how it can fight HIV and reduce viral loads, so there's people that are starting to get really seriously interested in taking this.

Now, I'm not quite sure why this becomes a major issue for AIDS ACTION NOW! I know there were people who were approaching us about it. We were aware that people were being denied it by Bristol-Myers. Bristol-Myers was not releasing it on compassionate grounds and even if the Emergency Drug Release Program said you should, the drug company was under no obligation to release it. I do know at some point Eva, who Brent was mentioning earlier today, her son Ivan was really ill and was completely unable to take AZT; it was just toxic to him. So, she was doing individual work and I can't remember if that precedes this or comes later. I think it happens later. Access to ddi becomes an important issue for us, and the enemy now is not the state; it's actually the pharmaceutical corporation itself. My memory was that the Emergency Drug Release Program was okay about people getting access to this, but Bristol-Myers would just say, "no." So, we decided that we have to do something about this, and again we decide on a tactic that combines a number of different things. First of all, there's a publically announced media conference held at Nathan Phillips Square where people talk about ddi and why it's really important. I'm pretty sure there were primary care physicians, other people speaking at it. I think Doug Wilson was involved in helping to organize that and probably George as well. But at the very same time that that's happening, there's seven of us who are supposed to go in and occupy the Bristol-Myers office. I think it was actually our sousing out the location that morning that actually led them to think that something might be happening. So, when we eventually do arrive there – like, this is all time coordinated, so we were supposed to arrive there at the exact same time the media conference is starting, so that they can actually announce at the media conference that this is in progress. So, the door is locked; we can't get in, so we decide we'll just blockade the entrance, right. So, there's seven of us and we just sort of sit down with linked arms in front of their doors and office, just over at Bay and Queen, and then what happens is they move – from the media conference, they move to a picket outside the office in support of what we're doing inside. There's Brent Southin, Steven Maynard, who's the one who gave us the limited type of CD training that we got, Patrick Barnholden and Greg Pavelich, Bruce – who's last name I'm forgetting but Brent has talked about him – and Russell Armstrong. Anyways, there's seven of us who get arrested... maybe I'm not thinking about myself.

AS: I think you counted yourself.

GK: Anyway, there's seven of us who are there and I can't remember how long it was that we had to wait for the cops to come to get us, but I do know, and I think Colman Jones probably had

something to do with this – Colman Jones was involved in AIDS ACTION NOW! but also had connections with the media. So, he would sometimes assist in trying to get the media various places. Anyway, the media arrived. I'm not sure... I think they arrived at the same time – around the same time that the cops arrived. And then of course the cops say, you've got to leave; if you don't leave we're going lay trespassing charges. And we say things to them like, "you're putting the profit of this corporation above the needs of people living with AIDS and HIV." So, there's a little bit of interaction that goes on. But eventually it's clear they're going to arrest us for trespassing.

AS: And was arrest one of the explicit aims of the action?

GK: I think we expected that to happen.

AS: It was a likely possibility.

GK: It was a very likely possibility. The one thing that I don't remember – I don't remember there being support people around at all for us. I mean, I'm sure there were but I just don't remember that. I don't remember a lawyer being on call or anything like that. I mean I know we got legal advice afterwards. We got legal advice from Bob Kellerman, who was with the Law Union of Ontario – a very progressive lawyer. We went and had a meeting for all of us who were charged with Bob after that. So, but it was our first attempt to do this type of stuff and the seven of us got arrested and basically, the plan was we were all supposed to go limp and that happened for most of us – I think for some of us less successful than others. I think Brent got a little bit hurt, because they carted us to the elevators and then took us down to the basement. That seemed to be their objective. And they did it to us individually, right. So, the others of us would still be there blockading and chanting while they would take people away. And I don't remember the order in which they did it. But I do remember that when it came to Russell, he was sort of like, "going limp's not what I'm going to do." He just walked with them, right. But we had collectively decided we would go limp, so we all would get carted down to the basement garage, I think, in the building because we were put in a paddy wagon. But basically, what they did is they'd give us trespass notices and told us we couldn't go back into the building. And I know they released us, I don't know if they just released us from the garage or they after drove us a little ways. I don't think they drove us away. They just released us from the garage and we marched back and we joined the picket line. And there was a huge round of applause and it was pretty inspiring that way. So, for me, it was my first experience of being arrested; it was also my first experience of being involved in a civil disobedience direct action event. For me, it was actually really useful and important and it clearly put certain types of concrete pressure on Bristol-Myers; it involved the cops; a whole set of other relationships took place. The media was there. The media covered at least part of the arrests. I'm not sure if they were actually there for the entire arrests, because it would've taken a while, because we were all taken – I'm pretty sure – individually. It wasn't like we were all carted off at the same time. I thought it was a pretty effective action.

And I know that it, in combination with other activities – and I'm not sure when Eva was sitting outside the office on her own in a chair for like long periods of time. All this stuff together, eventually it had some impact on Bristol-Myers in terms of creating more release possibilities for ddi. So, that was again another successful action. And we were also getting more successful in having the Emergency Drug Release Program (EDRP), which is, a federal state body that was

basically set up to determine if on compassionate grounds certain drugs and treatments that hadn't been properly tested in the Canadian context should be released to people. So, we were putting pressure on the EDRP all the time for compassionate release. I mean that was one strategy. The other was to have compassionate or open arms of the drug trials; that would actually be another way we would get access to the drugs and treatments. So, that was a major focus that summer – the summer of '89 – that we were involved in.

And the last major thing I was involved in before going to Newfoundland in the fall was, there was a retreat. So, I mean, I was involved in AIDS ACTION NOW! quite centrally from the time I came back, through the Montreal Conference, through the ddi action, and then there was a retreat organized at the Hart House Farm at the end of August, if my memory is right. And it was a fairly small retreat, but it was people from the steering committee at that point in time, and representatives of some of the various working groups. So, I don't think there were more than 15 or 16 people at this retreat, and it was a fairly major retreat because we were trying to figure out: Where is AIDS ACTION NOW! going? What are our outstanding issues and problems? Basically, you know, what is the future going to be for AIDS ACTION NOW!? I do remember that George Smith presented some of the analysis that was developing for him around treatment activism and treatment access politics and treatment information politics, and that was really quite useful for people. So, George would workshop his ideas. And sometimes they weren't always entirely accessible to people, but he would try to make them as accessible as possible. It was in some ways he would want this to become not simply just his take – just simply his analysis – but to allow this to be taken up by the group as a whole, as its types of perspectives. In a certain sense, doing the research was not to write papers, it was to be able to bring, at least in a preliminary way, the analysis back to the people in the group – to allow it to inform their activism. So, I remember George giving some really good presentations at this conference. We had food there. I think we cooked collectively. One morning we had oat bran. I think Patrick probably organized that, because I was going to go to Acadia. And because of going to Acadia, I had to have a medical, and I had high blood pressure, so oat bran was supposed to be the magic cure-all of it. So, we were all going to have oat bran. And Russell Armstrong snuck off to, I think, his church choir on the Sunday morning, because we were all supposed to be staying there.

But it was a fairly intense event. I don't remember everything that happened. I mean there's an agenda that we actually have in the files for what we're going to be looking at. I do remember that Jackie [Wilson] – and I'm not remembering Jackie's last name – from a group called, COMBAT. I can't remember what it stood for, but it was a fairly recent group that was organized. It was an attempt to organize in the Toronto Black community around AIDS and HIV questions, but not in a gay way at all, not coming out of the gay community – a different way of trying to organize. And Jackie was raising important questions about racism and racialization, but also about how to do AIDS work in communities of people that were not gay-identified at least – how to do that. It was also raising questions then not only about treatment access but about all of the sorts of issues related to AIDS and HIV. And I know that Renee du Plessis – at that point in time I think – and Karen Pearlston for sure were raising concerns about this focus on treatments was a little bit too narrow. I mean George's analysis was quite critical about public health, but we never went and directly challenged public health. It was sort of like, that was over there and we were doing stuff here. So, some sort of notion of broadening this out to include especially issues and areas of concern related to people of colour and to women. I mean that was raised, I think, in some important ways at this retreat and there was some major resistance to that. So, it was a little bit of

an impasse, and what would that mean in terms of organizing around AIDS ACTION NOW! There were a number of people there who would've been in a certain sense raising certain criticisms – it would've been Greg Pavelich, myself, Patrick, Jackie, Renee, and Karen at least. I mean it was a fairly significant portion of who...

AS: Of the people there...

GK: Yeah. It's a fairly significant proportion. And some people would've been, you know, into much more... it's just this narrow notion of treatment access. Also, a narrow notion of treatment access relating to people who were largely gay men, or at least around those types of circles and networks. So, that was a major source of tension that was not really resolved at the retreat at Hart House Farm. Now, I think there were some real differences of opinion but I don't actually remember it being that charged. I do know and I was away that fall, right. I was in Newfoundland, in St. Johns, but I do know that one of the things that came out of it. I think that Karen in particular, but also Renee and I think Greg, to some extent Patrick, Michael Smith – who was not at the Hart House farm retreat – thought that one of the problems was an organizational question. That AIDS ACTION NOW! was just not organized in a way that could mobilize and really draw upon people's energies. And that was one of the reasons why, even though it had so much successful activities, it really wasn't involving that many people at that point in time.

This was, I think, at that point in time the Public Action Committee was much smaller than it had been initially. It was no longer 25 or 30 people; it might be 5 or 6 people. So, I think that was happening to some of the other committees in AIDS ACTION NOW! too. The question was being raised – how can we get more people involved? How can we be a more dynamic group? And some people were quite inspired by ACT UP and some of them had gone to ACT UP New York City meetings, which were organized on an entirely different basis than how AIDS ACTION NOW! was organized. So, I think there was some sense that becoming more like that would be useful for AIDS ACTION NOW!. What ends up happening, insofar as I understand it... the central proposal coming from Renee and Karen was to make AIDS ACTION NOW! less of a steering committee driven organization. There should be more regular meetings of everyone who is involved in AIDS ACTION NOW! and those should actually be the decision-making meetings, right. And people could come with ideas and decisions could be made there. I think, at least Patrick and myself didn't think this was going to fly because it had been a steering committee based organization. And even though that wasn't what was initially articulated, I think increasingly the steering committee was seen as being where people living with AIDS and HIV – if they were a majority of the steering committee – would maintain their control over the organization. I mean there was something important about that – that this shouldn't become an organization that was actually no longer defined by the needs and concerns of people living with AIDS and HIV.

That led to this discussion in AIDS ACTION NOW! and there were maybe multiple meetings. There was at least one major meeting, either at the Church Street school or... I'm not sure where it took place, and I wasn't there, where this was debated and discussed. I wrote something for that, which I hope I can find somewhere. And insofar as I remember what I wrote, it was an attempt in a certain sense to bridge the divide by saying that if we were really going to think through what treatment access politics was about, it involved all of these other questions of social justice. They weren't separate distinct things. It wasn't like the needs and concerns of people of colour or women were somehow outside the framework of treatment access. So, an argument that, you

know, treatment access politics was social justice politics. In a certain sense, these weren't separate and distinct things. If you really wanted to deal with treatment access you had to deal with all of these questions. And I know that was read out at this meeting, but I was in St. John's then. My sense is that the people that proposed that there should be more of a focus on having more general meetings and these meetings having decision-making power – some of them drifted away and some of them stayed involved, but stayed involved in a way in which they longer raised these questions. I think Renee and Karen in particular would have been the people who disappeared from direct involvement in AIDS ACTION NOW! at that point in time. That's at least my memory of what that dispute and debate was about.

And then, for a number of years I'm in St John's. I'm back in summers and get involved in AIDS ACTION NOW! for different summers, and then once I'm in Nova Scotia I wouldn't have been coming back to Toronto in the summers. But I do know that one of those summers – and I think I had some contact with Glen Brown around this, so it's later on in AIDS ACTION NOW!'s history – I actually tried to write a document on the Emergency Drug Release Program and, in a much broader way, what we could actually do about it. I remember writing that and I don't think anything ever came of it. Yeah. So, I stayed connected to AIDS ACTION NOW! but was never actively involved again. I mean I would've gone to demonstrations and meetings when I was back in town. I remember going to the demonstration that was largely Queer Nation, but AIDS ACTION NOW! would've also supported it, when the Gulf War was declared, and there was a contingent that started on, I think at Church and Wellesley, that was maybe 150 people that marched to join the general anti-war demonstration. And there were certainly people from AIDS ACTION NOW! there. But that was, when I was on this Canadian AIDS Society panel – we were trying to write a pamphlet on homophobia, heterosexism and AIDS, and I was living in St John's then, but they flew me in here and I said I was going to skip part of this meeting because I was going to this demonstration. I mean I have to. So, I was involved in various activities at various points in time, but not centrally involved in AIDS ACTION NOW! after that.

I learned an incredible amount from being involved in AIDS ACTION NOW!, and in particular from George, even if we didn't always agree. George's position would've been – even though I think it changed later – I think his position at the time of the retreat and around then was that it was really absolutely crucial if treatment politics were going to be central that people living AIDS and HIV always had to have majority decision-making power, and the only way to secure that was on the steering committee, which I think I would disagree with. So, we had disagreements, but I learned an incredible amount from George about organizing. And this was also earlier in the Right to Privacy Committee, but also about how to do activist research. I think he was really quite incredible around that. Even if I had political disagreements about his particular position on a question at particular points in time, I certainly learned a lot from him. And Tim has always had amazing organizational skills. So, Michael Lynch was involved in getting AIDS ACTION NOW! going and then drifts away. I think he comes back on different occasions, but also gets sick pretty early on.

The other thing, I think, that maybe just needs to be painted into the picture is how many people died, right. I mean both members of AIDS ACTION NOW!, but just how many people died. I mean my memory is there were forty to forty-five people who I knew fairly well who died during that period of time. And some of the memorial services would be great but some of them were still organized by people's families, in which case it would just be lies about people's lives. So, that takes a sort of emotional toll on people. But I think AIDS ACTION NOW! for a while really rode this

energy of – we were actually making a difference. People were getting access to drugs and treatments. You know, this activism was really effective; it was making a change. It wasn't just symbolic; it was actually making a change and a difference in people's lives, and people were living longer as a result of what we did. And that was really important.

[END OF TRANSCRIPT]