

AAHP  
**AIDS Activist History Project**

**Interview Transcripts 13**  
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<b>Interviewee:</b>	Eric M. Smith – Part 1 / Part 2
<b>Interviewers:</b>	Alexis Shotwell & Gary Kinsman
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Part 1 - July 10, 2014

Persons present: Eric M. Smith – ES  
Alexis Shotwell – AS  
Gary Kinsman – GK

[START OF TRANSCRIPT]

**GK: The first two questions we ask just as establishment questions, we ask everyone these. The first question is when did you first hear about AIDS?**

ES: When did I first hear about AIDS? I heard about AIDS very early on. I was one of those people who considered myself very lucky when Ted Turner invented CNN. I'm a news person so, 24 hours of news was great for me. So, obviously, they were bringing the issue as soon as it happened. I mean, certainly the words weren't used at the time, AIDS and HIV, but the issue was there so I was aware of it very early on.

**GK: Great. When did you first hear about AIDS activism?**

ES: That was somewhat later, probably a couple of years later, and that was of course more where people were doing anti-establishment kind of things. It wasn't people who were sitting there and saying, "Could you please help us?" but people who were protesting, some of the marches in San Francisco. As far as in Canada, the first ones I was aware of were in Toronto and Vancouver. The Nova Scotia one, the first Nova Scotia group that was set up, we really didn't have a public profile. They did have a bit of printed literature that they were handing out at the gay bar. Other than that, there was no public image in Nova Scotia.

**AS: Which bar was it then? Was it before Rumours?**

ES: That was Rumours 2.

**GK: On...**

**AS: Gottingen?**

ES: No. I'm sorry. The first one, Rumours 1, was...

**AS: Granville.**

ES: Granville Street, yeah.

**GK: In this context obviously at some point, I think it's in '87 or is it '86? You discover that you're HIV positive.**

ES: In '86 I tested positive, yes.

**GK: So, how did that take place?**

ES: I was going in for day surgery and the surgeon, because I told him I was gay, sent my blood to Halifax to have it tested. He didn't tell me that it was being tested. I wasn't aware of it until I got a call from him on a Friday evening telling me that he had sent the blood to Halifax. He said, "You have AIDS. Don't have sex with anybody. Do you have any questions?" And, of course, I couldn't think of any questions right then. So, I said, "No." And that was the end of the conversation. Luckily my youngest sister came over about twenty minutes later and she felt there was something wrong, and I just sort of blurted out what he said. Naturally, she was upset and I realized very quickly that it wasn't a matter of just an issue for me. It was something that concerned a lot of other people. And that sort of helped ground me right away.

**GK: So, there's about a year between that time and when it becomes a public issue.**

ES: Right, I tested positive in August of '86. The first time, or the original public announcement... It wasn't actually a public announcement, it was one of my doctor's secretaries leaked word to the community. That was in May of '87. So, for the month of June '87 I taught and the parents were aware that I had HIV. And for that month there were no issues. There was only one call to the school, but that was from a mother who wanted to know what to tell her son because he was afraid I was going to die. It wasn't a health issue, you know, a concern of contact or anything, and other than that there was no problem.

**AS: The person, the doctor's assistant who leaked this, was the same doctor who had sent your blood without your consent or knowledge or was it a different one?**

ES: No. I was in day surgery, so the surgeon sent the blood. Yeah. My doctor's secretary, her reasoning was, she told her daughter because she had a granddaughter starting school in September. So, I mean, even if you follow that logic, it does break down because her granddaughter would be going to a school about six or eight miles from where I was teaching. So, you know, there was obviously more to it than simply a health care concern.

**AS: No, I mean it's just this like, incredible medical malpractice... I mean, just like unreal. Wow.**

ES: Well I mean, one of the things I was surprised at was how much legal advice I got from people who don't really know much about the legal system. You know, all kinds of people were suggesting that I should sue and, when you get right down to the bottom, at that time I couldn't sue her. I would have to sue the doctor because his practice was in his house. It wasn't like a clinic with several doctors. And so by the time lawyers explained it, you weren't even sure what the question was anymore. And from my point of view, it wasn't fair to sue the doctor. It wasn't his fault.

**AS: Because she had done this.**

ES: It's actually when he wasn't even in the country when this happened. He had been in Britain for a few months. So, yeah, I mean her reasoning was interesting.

**GK: So, this was your primary care physician's office and the assistant leaked it?**

ES: Yes.

**GK: Okay. And that was on Cape Sable Island?**

ES: It was in Barrington Passage. Actually, right at the head of the causeway that joins the two. He was very good in that he said right at the beginning, he said, "I'll be honest with you. I'm willing to treat you, but I don't know a lot about AIDS because I didn't think it would hit here for another ten years." So, I mean, he was honest right up front. And he also did say that if I did sue he would say on the stand that it had come from his office. So, I mean, he was always very upfront.

**GK: That's good. In terms of actual care stuff, what did you do in that early period?**

ES: There wasn't a whole lot. His concern was that I have access to as much information as possible, and he knew he wasn't really prepared to do it. So, he did two things. First of all, he set up an appointment with the HIV clinic in Halifax. So, right from the beginning, I was seen and had a file with the doctors there, really great doctors. The other thing was, he set me up with the Public Health Officer for our region who was based in Yarmouth. So, Doctor Sweet came down to talk to me, and one of the first things he said was, "I just can't believe this is happening." The poor guy had been working in Vancouver General Hospital and he was really burnt out with AIDS. So, he thought by taking this nice quiet public health job in Yarmouth he'd get away from it, and the first thing to confront him is me. Now, I mean, he's a great guy. And obviously he had lots of information because of his previous work. But I thought, you know, this is just so ironic that it is the first thing that happened to him. So, I got lots of information right from the beginning because my concern was, obviously, I'm putting the students at risk. Also, my sisters all having their kids. So, for me, there was a concern and that was why I think it was important for me to talk to people like Doctor Sweet and the people at the HIV clinic.

**GK: Right. So, during that summer, the information that you're HIV positive starts to get used by people in the local community and around the school board. Maybe you could just walk us through some of that.**

ES: I think to be fair upfront, for a lot of parents there was a concern. And I think that's understandable in a rural area where they obviously haven't been paying much attention to AIDS so, for a lot of them there is a concern. The problem came with some of the leaders of the concerned parents group. These people had been involved in a previous fight with the school board. There were two schools on the island, the school board wanted to combine the two. The concerned parents took them to court and lost at the end of June. And so, my case was something else they could go after the school board with. That's where I think some of the leaders, why they got involved; it wasn't so much a health care issue. Because, I mean, some of the leaders of the concerned parents group had some background in health, one of them, his wife is a public health

nurse. Some of the others had done work in nursing, so it wasn't that they didn't know or didn't have access to the facts. For them, it was a political thing to go after the school board with. And you saw that that would play out later on when elections came up and they were running for various offices because they saw it as a springboard. The thing played out over the summer, partly because I think the school board members were talking amongst themselves; they weren't talking with the public. So, the public was getting frustrated that they weren't hearing anything from the school board one way or the other.

The other thing, which I think, obviously in hindsight, was a mistake is that myself and Public Health didn't try to set up information sessions for parents. Instead, we let their side set the parameters of what they thought was safe. So, that's why it kept building over the summer. The school board tried various things. You know, they asked if I would see Doctor Schlech at the HIV Clinic and let him do a complete check-up and then issue a report that they could make public to the parents. There was sort of a lack of communication with all groups involved. So much so that when they actually decided to take me out of the classroom, I had no idea that they were debating, that they were thinking about that. I was actually in Doctor Schlech's office when they called because the superintendent somehow tracked me down in his office, and talked to me on the phone there saying they were taking me out of the classroom. The other thing was several days later, when they decided to make it public and they issued a press release. Again, I didn't know anything about that until about an hour later I got a call from a *Globe and Mail* reporter who somehow tracked me down. That's another interesting side into the whole thing is how reporters can find you. It's amazing. So yeah, even on basic stuff, there wasn't a great deal of communication. But that's basically what the school decided is they would take me out of the classroom. The union was somewhat involved, but not particularly on my side.

**AS: The union felt like, "Go ahead. Take...?"**

ES: Well I mean, when the school board decided to take me out of the classroom, you get the lawyers from the school board and the lawyers from the union meeting. So, I'm sitting out in the lobby.

**AS: You weren't in the meeting?**

ES: No. I wasn't allowed in the meeting. I had no idea what was even being offered. I didn't know until they had...

**AS: Decided it?**

ES: Yeah. And the chairman of the school board was sitting in the lobby and of course, we were talking back and forth. I had known her for a long time, because she had been involved with the local Liberal Party association same as I had. And we were talking and we probably both said too much, because we...

**AS: Knew each other.**

ES: And I said, “You know, the union’s lawyer is telling me if I go to court, I will lose.” And she said, “That’s strange because our school board lawyer is telling us if we go to court, we will lose,” that I would be put back in the classroom. So, you know. If you’re getting advice that suits the other side from your lawyers, you don’t know really what’s going on. Anyway, they did reach a solution, which was a \$200,000 settlement over five years; they figured salary and benefits. And, of course, back then you figured certainly in five years time I would be dead, so. The hitch was the school board didn’t have 200,000 dollars. So, they asked the province and the province said no. So, that of course...

**AS: Nullified the...**

ES: ...fell through.

**GK: It all collapsed.**

ES: Yeah.

**AS: But how did you feel about being taken out of the classroom?**

ES: Well, I mean, for me that was actually more scary than dealing with the HIV bit because I knew when I was three I wanted to be a schoolteacher. And in my mind, I couldn’t think of anything else I could do. Well, I mean at one time, I wanted to be Prime Minister until I was about twelve and I realized, “God, you must be a fool.” But yeah, I mean I’m not the kind that can tinker around mechanically or I’m not good at carpentry. I mean, even basic things, working restaurants, coffee shops, that kind of stuff is out because with migraines, the smells trigger the migraines. So, for me it was, “Okay, what happens if I can’t teach?” That was my fear because... I mean, this is before I started getting into AIDS politics and knew other people with HIV. My concern was, “Okay. If you don’t have a job, what are you going to do?” You’re going to sit home and I already knew at that age that sitting home talking to myself was not a good thing. I’m just not very entertained by myself. From my point of view, the union didn’t follow even it’s own policies. There’s a rule where the school board has to let you know, I think at the end of April what assignment you will have in September. My assignment, I would be teaching Grade 6 in this new amalgamated group. So, I said to the union, I said, “Okay, I have this. This is what I’m supposed to be doing.”

**AS: It’s a contract.**

ES: Yeah. Well, the union said, “No, we can’t. We’re not going to look at this issue.” And it got worse when the school board decided, they were planning to set up a resource centre. The county is rather large and schools are small, so some of the large equipment is too expensive. So, if they had one resource centre for the whole county and their solution was to put me in charge. Well, as I said, mechanical stuff doesn’t work for me. If I change a light bulb, I expect applause. I mean, that’s to be completely honest. So, I could’ve taken the job. They could’ve fired me in six months for cause, simply because I couldn’t do the job. And so the union said, “We recommend that you take this job” and I said, “I’m not going to take it because I can’t do it.” Well, if I didn’t take it then they wouldn’t be able to support me because it would be insubordination. I was refusing to do the work

that the superintendent was telling me to do. So, I went back and I said, “But I have a letter from the superintendent from April saying I was to be teaching Grade Six.” “Well, no, that’s not the issue.” And I said, “Well.” So, it was very clear. In hindsight, I don’t know why I didn’t tell the union just to frig off at the beginning, because when the thing first blew up the first time I met with them, and again, when I get to the union office, CBC was camped outside waiting for me.

**AS: How did they know?**

ES: I don’t know. Anyway, so I said, “No, I’d better talk to the union.” So, I go in and they say, “Well, meet the president” and I shake hands with the president. She introduces me to the vice-president, shake hands, talk about what a nice day it is. And then I go in to talk to the person who’s in charge of my file and his response, “Well, we don’t really want to make an issue of this because we don’t think it’s going to affect any other teacher because there are probably only ten gay teachers in the province.” Now, at that time there were 11,000 teachers, and I’m thinking, “This is a guy from the union representing teachers and that’s as much knowledge as he has.” Anyway, when I leave, they say, “Okay, don’t talk to the reporters. We’ll handle the press.” But I made it clear that I wanted to fight. So, when I leave I don’t talk to the press. I get up the next morning. The front page of the *Chronicle Herald* - “Smith gives up his fight for his teaching job” and it quotes the vice-president who I didn’t talk to about my case at all. So, it became clear to me right from the beginning that I wasn’t going to get very far with the union. And actually, four years later when I did make the settlement, even though the documents were signed at the union office, the negotiations were carried out, there was a new superintendent. He would come down on Friday and talk with the Minister of Education and other government people, and I would go to his hotel room on Saturday and we would talk. And that’s how it was decided. The union wasn’t involved.

**AS: No support from them around it.**

ES: No. So, I mean they appeared to get some of the credit because everything was done from their office, but no.

**GK: So, that fall a solution is found after you reject a bunch of these options, as a temporary solution.**

ES: Yeah. I made it clear to the school board that I’m not taking the job. So, the thing is sort of just hanging in the balance until the 2<sup>nd</sup> of October when the school board publicly announces they’re giving me my job back, and I have to say if I were one of the concerned parents I would’ve been totally pissed off too because it looked like they had been playing politics. Because funding for schools is based on how many students are enrolled on September the 30<sup>th</sup>. So, up until September 30<sup>th</sup> they were telling parents, “We’re not going to let him have the job.” So, they were sending the kids to school. Two days later, they say, “Well, we’re going to bring him back.” If the parents were to pull the kids out then, it wouldn’t have mattered because they would’ve got funding or the full year. It looked like they were playing politics. So, it’s quite easy to see why the parents were upset. No matter whether you agreed with what they thought about my case. I mean the school board looked like they had been playing games. That only lasted for about a week because things got really tense. They were making plans... What they decided, there were to have been two grade six

classes with thirty students each and they decided, “Okay, we’ll have three with twenty students each.” And if they would have said, “Let’s ask for parents who will volunteer to send the kids to Eric’s class” that would have solved them a large part of the problem. They would have got the twenty kids. Instead they drew names out of the hat, so you ended with a lot of kids in there whose parents were not pleased. So, they were making arrangements, they had the police involved about how... Because, I mean, for some parents it was having their kids in my class; for other parents it was for me being in school, period. So, the police were involved about how we were going to get people safely in and out and everything, And I didn’t realize this until after the police were involved, but. So on Friday, I think the second Friday of October, I get a phone call from the union saying that the government was going to set up a provincial task force on AIDS and would I be willing to serve on it. So, at that particular point it seemed the obvious thing to do. There was just too much turmoil and based on what he said were the guidelines that they were looking at for the task force, it seemed a positive thing to do. And one of the things was, there were several things they were rolling out but, I would be developing AIDS policies and AIDS education. So, those were two things that I was interested in in the beginning. So, I said that I would do it. And I would serve on that.

**GK: Can I just step back for a moment? Did you ever actually teach in the classroom during that period?**

ES: No.

**GK: So, you accept being on the AIDS taskforce. That lasts for about a year, right?**

ES: Yeah. So, from October ’87 to, the report was issued in October ’88. In the spring of ’88, I indicated to the school board that I wanted to come back when the task force was over. The task force was a really positive experience. And in reading back through some of the press coverage of the reports, you know there’s lots of praise for how well thought out the recommendations were, how they weren’t stand alone, they were all intertwined; and the important ones that the government didn’t accept, the media were extremely critical of the government. Although to be fair, the media by and large were critical of the government from the get go. And to go back, when the story first hit the news, because like I say, people were talking about it in the community in May. It didn’t hit the newspapers, the media, until August. So, it was sort of kept within the county. Which, when you consider rural areas, is amazing because, I mean I don’t want to stereotype, but you think the next-door neighbour’s a gossip and all that. But yeah, it didn’t hit the media until August. When it first hit the media, the Premier, John Buchanan was vacationing in Scotland. He came home several days later and, of course, he was nabbed at the airport. And his words were, you know, every teacher who has AIDS should be publicly identified. So right from the get go, you had most of the media realizing that the government wasn’t up to speed on the issues involved. I mean, the Department of Health was saying the right stuff, very quietly saying the right stuff, but they were saying the right stuff. The rest of the government seemed to not be aware that there was even a policy on AIDS in the Department of Health. To be fair, the leader of the Liberals also, Vince McLean, said something to the effect that teachers who pose a risk to students shouldn’t be in the classroom. And I think, today when most people do remember talking about it, tend to

remember John Buchanan's comments, but they forget to remember that the Liberal leader didn't seem to be on side either. So yeah, the media all along were fairly critical of the government.

**GK: Do you want to describe just a little bit more what it was like being on the task force, what type of work the task force did?**

ES: Well, it was interesting. When it was first set up there were eleven members and then it expanded. Eventually, we were twenty-one members.

**AS: That's huge.**

ES: I, in some ways, thought that was going to be a problem. There were ten people from the government departments; two from each of five departments – Health, Education, Social Services, Justice. I forget what the fourth was ... But they all had some connection, would be interested in the AIDS file. And of course, for me that set alarm bells ringing. And just to go back, I had been involved in politics since I was twelve. So, I knew how, if governments wanted to do things quickly, how they could arrange to do it quickly or how if they didn't want to do it quickly, how they could make a bottleneck. And I thought, "Okay, ten people from government departments. That tells you where it's going to go." I was wrong. These people were great. And I have to say I also had some misconceptions. A couple of the ladies were older, sort of I thought my grandmother, your blue rinse type. And I think, "How are we going to talk about anal sex with my grandmother in the room?" And in two weeks time, they're making me blush. [laughter] So, I mean it worked out well on that.

**AS: How interesting.**

ES: There were only a couple of issues where there was any real opposition in views, and that was always dealt with as just different ways to look at the issue. There were never any personal friction with any of the members in the task force. Besides the government people, there were people from the Medical Society, from the Nurses' Association, from the Home and School Association, from the Dental Association, Teachers' Union, from, at that time, the AIDS group in the city was MACAIDS [Metro Area Committee on AIDS]. They had representatives on it; they were put on later. When it first started, I was the token AIDS person and gay person. But yeah, it worked really well. There were three working groups: one dealing with education; one dealing with the legal issues; and one on the socioeconomic issues. And so they would get together and come up with ideas that would then go to that whole group. The only two issues where there was really a major disagreement were on anonymous testing. The people from the Department of Health were from epidemiology, so that was an issue for them. The other issue was whether sexual orientation should be included in the Human Rights Act. There were, I believe, three of the government people who were opposed to that. One, I'm pretty sure, was opposed to it because he didn't think there should be protection. The other two were opposed to it because they didn't think it fell within the mandate of the task force. And in fact that's what the Minister said when he rejected that proposal was it didn't fall under the Department of Health. But then again, the issues that were legal in nature and education in nature didn't fall under his department either, but they were accepted so,

his reasoning wasn't there. But those were the two issues where there was any disagreement and, as I say, it was friendly disagreement. It wasn't confrontational.

We did public hearings in various communities, I think there were 14, which I think they were really good in that they gave both sides a chance to express their views. There were a few where I was somewhat uncomfortable and these were the, I don't want to stereotype, but the right wing Christian groups who were talking about, you know, "We could solve this whole crisis if people would come to Jesus and..." And that's like, "Okay, but that doesn't solve anybody's problem. You can moralize all you want." The only one I missed was the one that was actually held in Clark's Harbour. I had planned to go but the chairman received several calls that there were concerns about security. I still wanted to go when he sensibly pointed out that I wasn't the only one. You there were other people from the Commission who were going to be there that could very well be targeted. So, I stayed away from that. That was an interesting one simply because... Well, some of the clips that were made, and somewhere all of these meetings are videotaped. I'm not sure if they're in the public archives or where they are. But I mean some of the scenarios the parents were coming up with to try and rationalize why they didn't want me in the classroom. I mean, the one that always sticks in my mind, and this guy would have been my second or third cousin, and he's standing up there, "What if Eric uses the bathroom, has an accident on the toilet seat and doesn't wipe it up before he goes out?" Well, one of the people from the Department of Health says, "Well, most people aim for the hole" but of course, the parents who were against me didn't appreciate that kind of humour. But I mean you can answer it on so many simple levels. First of all, there's a separate washroom for staff, so that's not an issue for the kids. The end of the story was, "What if a kid with a cut on his backside comes and sits down in the mess?" Well, first of all, again, why would an adult making a mess on a toilet seat not clean it up? Secondly, I think most kids would look at a mess on a toilet seat and say, "I'm not going to sit there."

**AS: With my cut bum.** [laughter]

ES: Yeah. So, this is one of the ongoing issues even to this day with the people down home is that I made the community look bad. And I'm saying, "No, no, no." And I say "Listen to the story we were told that was broadcast across Canada. I'm not the one making you look bad." And I mean, the Commissioners that were there you know said they found it hard not to laugh. And I mean, there were these odd moments that on a certain level they're not funny, but you have to laugh at them because it just shows if people want to prove the point they can carry it to a really bizarre extreme. But yeah, I mean the travelling around was basically a positive experience. And I think overall the thing that I take away from the whole thing, the thing that I feel really good about is, and these are rough dates, in November of '87 we commissioned a polling group to, you know these annoying things, they call you at home and there were a whole bunch of questions, but the main ones were - Should people with HIV, should gays be allowed in the classroom? And roughly when we did it in November, the results were about only 25 percent of people said they should be. When we did it six months later, the numbers were almost the opposite. Almost 75 percent were saying there was not a problem with it. And I think it was because of what the task force did, and I'm not good at blowing my own horn, but I think part of it was what I was doing with the public. When I was being public. Because I think no matter how hard parents down home wanted to paint me as an evil person, I don't think I come across as very threatening. I try to keep my cool. Now, I mean, if you're a politician or a religious person who's saying something, I can tear a strip off you

like you wouldn't believe. Again, this goes back I think to being involved with politics since I was twelve years old, several things you learn. First of all, always be honest. If you look like you're hesitating people are going to suspect what it is you're saying. The other thing is if you want to get a point across you don't do it by going on the attack and accusing other people of stuff. I mean, we only have to see that today with our present Prime Minister, but I mean Harper's this 'attack everybody' just turns people off. And even what he's saying is correct, a lot of people don't listen to it simply because of the way he presents it. And that I think comes from my being involved with politics early. I mean watching politicians make these mistakes, and think by shouting the loudest they're getting the most support when they clearly weren't. So, I think the way I presented myself had some role to play in it.

**GK: So, in terms of the recommendations coming out of the task force, the government accepted a lot of them, but it rejected some of them.**

ES: There were 47 recommendations. One of the recommendations was to set up a permanent advisory commission on AIDS that would advise the Department of Health, four were referred to this body. And basically, those were ones that called for guidelines or something, but one of them which we thought was particularly important had to do with the province funding AIDS groups, and of course that was passed on to this new advisory board to come up with some format for doing this. The three that were not accepted were in my mind, for people who were affected, were probably the most important ones - anonymous testing, and including sexual orientation and protection for people with HIV in the Human Rights Act. When they had the press conference, Doctor McKay who was the chair of the task force and the Minister of Health were sitting up front. I was sitting somewhat back in the crowd, although I might as well have sat in the front row because there were like two cameras pointing up front and half a dozen pointing at me. And Andy McKay is one of these, he can talk; I mean, you could have your leg amputated and he could talk you into it being the best thing that ever happened to you. [laughter] He went on to be a federal court judge, which is great. He had been president at Dal at one time. The Health Minister sounded okay. Then, of course, when he said which ones weren't being followed. The sexual orientation and protection for people with HIV weren't going to be included in the Human Rights Act because that was the current policy of the government and they didn't see that there was any issue with it. The other thing was anonymous testing. They weren't going to do that because of the confidentiality rules in the province and there was no issue with people's confidentiality being breached. At which point I get up and stormed out because it was either that or I was going to say something out loud. So I thought, "Okay, I will get up and walk out." Our office, this task force office, was just across the street from the Legislature, and I realized when I got to our building all the cameras except one had followed me. And I mean, that was basically the headline - "Smith slams AIDS stance." Because yeah ... to sit there and listen to him saying, "We don't need to put these things in place because there've not been any cases that have required it." It makes me think, "Okay, what have I been going through over the last year? I don't do drugs, but did somebody slip me something or what?" Yeah, it was just really bizarre to hear him say that.

**AS: But those things still were not followed?**

ES: No. The changes to the Human Rights Act were eventually made. The important one that was referred to the Advisory Commission, the funding for provincial AIDS groups, I don't think anything ever came of that. I don't think any funds were ever released. They were still depending on federal funding.

**GK: And the Human Rights changes don't happen until much later.**

ES: That's almost three years later. We did eventually get anonymous testing in Halifax and I think maybe Cape Breton has it now. The way it works though is they don't keep a file, a list of your names, but obviously if you go to a doctor with an HIV related problem then it shows up.

**AS: Because it's treatment, not testing.**

ES: Yeah.

**GK: And that's the same in Ontario now and everywhere else.**

ES: But there is no longer any master list apparently kept in the Department of Health, which was the issue. And I mean in reading back some of the news clippings at the time, that was the general feeling. I mean there were some people with AIDS who were responding to the Minister's statement, but there are people who, sort of the general population, were also talking and saying, "Okay, you don't bring in anonymous testing. You keep putting people's names on the list. If people don't have confidence in that list, all you're doing is preventing people from getting tested. They're not going to get tested." A lot of the general public could see that. The Minister could not. And, so yeah, again it was one of those things. There was a poll done, and I'm not sure exactly who did it, but this was a couple of months afterwards, and I believe it was something like 65 percent of the respondents didn't believe that if they tested positive their names would remain confidential, which sort of shoots down the Minister's theory. I mean when you got two-thirds of the population who, from just my case and two or three other musings in public, had reached that conclusion, it says, "Okay, the government's not listening at all." So, eventually they did bring in anonymous testing. I believe that waited until the next government. I think it was the Liberal government under John Savage, who had been mayor of Dartmouth earlier and was one of those who was always supportive of the AIDS groups. And being a family doctor anyway, he knew his stuff on AIDS.

**GK: The one thing I wanted to come back to around the task force was, I think you mentioned in an interview we did last summer that at one of the last public meetings, maybe it was in Halifax, that there was someone who was living with AIDS who actually spoke out at it.**

ES: Yeah. We had done... the fourteen. The first one was in Dartmouth and we sort of went around the province and we ended up back in Halifax. And the way these things work, people who wanted to do a presentation would write in, so there's a list of people who are going to, and then at the end if there's time, anybody from the audience who wants to can stand up. And this is where we were at the very end, the people who came prepared to present did. At the very end Andy McKay says,

“Is there anyone who has anything they want to add?” And this guy stands up and says, “My name is Kevin.” He said, “I’ve followed what’s been going on. I’ve watched,” and he said, “And all you’re hearing is nobody else with HIV has stood up.” He said, “So far, the only face is Eric.” And I’m sort of listening but I’m sort of thinking, “Okay, what’s going on here? Because I know his name’s not Kevin.” And of course, it dawns on me eventually, “Okay, I know why he’s saying that.” And he added a dimension that wasn’t up there with my story. Because in my case, for some people, the fact that I was gay was the problem and the AIDS thing didn’t matter. The gay thing was it. Kevin had been married and had two kids, which added another whole dimension. Even though he’s divorced, he still was getting lots of support from his family. And I think, even some of the commissioners I think were really moved by that, because even though they had been studying this for a long time. You know, it was not just these poor unfortunate single people who were involved. This guy’s got two kids who are going to have to deal with the fact that his father’s going to die in a couple of years. So a couple of months later ‘Kevin,’ who’s Bruce Davidson, is very much public. He’s one of the leading founders of the Person’s with AIDS Coalition, and with such family support from his sons that Bruce and his partner, Dale, actually did public speaking in the high schools in the Valley where his kids were still going to school. And again, I think for the kids that they were talking to, they were getting that, certainly extra. I mean, I could go in and tell my story and most of the kids were moved by it, but I didn’t have kids their age. So, there was a sort of distance for them, but this was totally different. Now, I mean the task force itself were certainly aware that a lot more people were infected. And I have to say, this was at the time the first half of 1988, the Persons with AIDS Coalition wasn’t formally set up but we were meeting around, sitting on kitchen floors. Of course, since we weren’t an organization we had no way of getting funding. The task force was really good at commissioning guests to do papers, which they would pay for. Not a whole lot, but enough to get us going. And one of the things that the task force wanted to look at was were there other cases where confidentiality had been breached? And the members that formed the coalition came up with about ten cases that at least raised issues. A couple of them weren’t technically where confidentiality was breached, but people who were refused service in hospitals once their status was known. I mean there were situations where one person who had donated blood was tested and found positive. The Red Cross couldn’t track him down, so they called Rumours and asked them if they would put a notice on the bulletin board asking him to contact the Red Cross.

**AS: With his name?**

ES: Yeah, his name – “A Message for [this person’s name]: Would you call the Red Cross?” And it’s like, “Okay, the notice doesn’t say anything, but anybody who’s been following the news, especially in a gay bar will be able to very quickly figure out what’s going on.” So, the task force were certainly aware that there were other people who were having issues with confidentiality and with having problems getting some services provided. And they were actually fairly clear that they didn’t need to meet these people. They were willing to have their story brought to them without forcing the people to come and be somewhat public, which again I think was a great thing for the task force to do.

**GK: I wanted to ask you one question around the media coverage of you and an expression they often used, which was ‘an admitted homosexual’ and how you sort of responded to that or how you felt about that.**

ES: “Admitted homosexual.” Well, I had two problems with it. First of all, it’s the “admitted.” I was never asked, “Are you gay?” The question was, “How were you infected?” And of course, you say, “Okay. I’m gay. I had sex with another guy who was infected.” And there’s just something about it that. You know, “admitted drug dealer,” “admitted murderer...” It’s like, okay, there’s something negative coming after “admitted.” You’ve done something really wrong. The problem was, it wasn’t the reporters who were writing it. It was the editors who were doing it. I want to give the reporters credit. I found the reporters great. They knew the issues. They were willing to listen. They would ask you about language. So, it was the editors back in the newsroom who were doing this. From what I understand, they thought it helped my case because, by saying that I admitted I was gay, they thought they were making me look like I was being upfront, as opposed to giving people the impression they had to dig for the information; that I had been *afraid* to make information public. So, that was there reasoning. It was sort of going at it backhanded which... Anyway, it was just sort of ringing in your ears. But I also have trouble with the word “homosexual.” That just gets on my last wick. It’s basically been used since it was invented as a way to demonize us as a mental health issue. The other thing, and this is something personal to me, there used to be a history series done in Britain, I think in the ‘70s, about the Second World War. It was one of the first times that there was actually any mention of the fact that gays were sent to concentration camps. The problem was the announcer, the narrator, had this really bad habit of referring to it as “homossexuals,” and it was like, I could feel my skin crawl. It was like, there’s something really dirty... At first, I thought, “Okay, it’s a stutter.” But if you listen carefully, it was the only time he made that “s” drag out. I don’t like the word. I mean that’s in the workshops I do now. I say at the beginning, you know, I refer to myself as “queer” and I explain why I don’t like homosexual. And of course the other term, and I mean you still see it today occasionally, but it was certainly used then was “victim.” And that was one of the very first things, to get said so I was writing to the editor quite a bit, but that was one of the very first things. One of the very first articles that they wrote referred to me as an “AIDS victim” and as an “AIDS sufferer.” So, I wrote pointing out that they were wrong on two counts; that I was not a victim and that being HIV positive, so I trying to explain AIDS is sort of the end-process and I don’t know if it ever sunk in, but. I think what it amounted to was it was a trade-off. Basically the coverage we were getting was really positive. The media were saying, “There’s not really an issue here. There’s no health, there’s no safety issue. This is just discrimination from people who are not informed.” And so, after a while, you tended to let those little things not bother you. And I mean my case was the first time that the *Chronicle Herald* had ever done an editorial that was bothering with the gay community. I think they ended up doing three or four over the years. So, yeah, it was a trade off. And again, probably to the average person listening they don’t pick up on the “victims” word. So, as long as what they’re presenting is, the medical stuff is fact and they’re not trying to paint people in a negative light, I think you have to make a little bit of trade off ... Oh, this was my letter about using “AIDS victim.”

**AS: Do you want to say what you said?**

ES: Oh, they had done an article on me. This was sort of towards the middle of the Task Force, May of '88, and they had asked if I wanted to go back to school and I said, "Yes, I wanted to go back in September." So, the article said - "AIDS Victim wants to Teach Again." And I said, "To begin with, I take exception to the repeated reference to my disease. The report gives the impression that I have AIDS. At this point in time that is not true. I have tested positive for antibodies to HIV. However, I have no symptoms of AIDS. AIDS is the final stage of HIV infection when the body's immune system has been seriously impaired. I must also complain about being referred to as an AIDS victim. People with AIDS and those who are HIV positive are not victims of AIDS. If we are victims, then we are victims of societal stigmatization imposed against those associated with AIDS as well as those perceived as homosexual. Many people see homophobia as being more dangerous than AIDS." And actually that was where the reporter called and was a bit upset and wanted to make clear that it wasn't the reporter's words, it was the editors.

**GK: Okay, so the task force is over... You were seconded to the Task Force from the Board of Education. So, now...**

**AS: And the Task Force took... That was a year?**

ES: Yeah.

**AS: Okay.**

**GK: So, now you're in a situation where you could go back to the classroom. What happens then?**

ES: Well, because the issue came up fairly early on about whether I want to go back to the classroom back in, it came about in May of '88, parents again had time to organize. I think though the government was already looking at, at least, a short-term solution. One of the recommendations from the task force was to develop an AIDS curriculum. The education department developed an AIDS education curriculum that would be part of the health program. And again, these things, from my history in politics, the people who were pulling the strings don't want you to know that they're trying to pull strings. So, they talked to Andy McKay, the chairman of the Task Force, who comes to me and says, "Okay, they are accepting the recommendation on the AIDS curriculum. They want to know if you will consider going back to the classroom, take a secondment to the Department of Education to develop this AIDS curriculum. It was one of those things that I saw both sides of. The negative for me was being in the Department of Education. I'm not a sitting-at-the-desk-and-writing-a-report person. For me, education means being down on the floor working with the kids. That's what I think education is. I'm not trying to slag off the Department of Education, because that can be an important role, but that's not my kind of role. The flipside obviously was that I could bring a whole lot to developing an AIDS curriculum that, if it were going through the regular channels, god knows how many years it would take. I mean, in the back of my mind I realized that probably what I would come up with would be certainly trimmed down, because I'm sure my views would be overly liberal. So, I was aware that would certainly be an issue. So, I did. I accepted this three-year secondment to the Department of Education. And of course, like a lot of things in life, you know you have these little voices in the

back of your mind saying, “You know you’re setting yourself up.” And so I did. I mean, there were a couple of weeks where I just sort of took off before I went to the Department of Education after the Task Force finished; first of all, because I hadn’t taken any time off during the year of the Task Force. Also, because, as I think I made clear, I was obviously disappointed in the way the government handled some of the recommendations, so I took a couple of weeks off by myself. Also, at this time, my partner was having more health issues as well. So, when I go to the Department, at first I think, “Okay, they’re being probably nice.” They just moved into a new building and they have a resource centre with samples of textbooks from all over North America. And I said, “Well, you probably need some downtime. Will you set this up?” And I thought, “Well, that’s great you know. I’m in this room by myself. I can talk to myself. That’s fine, you know. This will take maybe a weekend.” So that was fine. Again, it gave me some more time to be impressed. Well, then I got shunted to another office in the Department of Education. There were some computer games they wanted me to analyze and see which grade levels I thought they would be appropriate for. And when we’re talking about computer programs back then, we’re talking about Commodore 64s.

**AS: Yeah. It was like ping pong games.**

ES: We got the first two computers in the last two years I taught and that’s what they were. I mean when I tell young people about that, and I use the word computer, they sort of shake their head. But it was you know computers. And again, it’s like, “This is...” So, it became more and more apparent that they had no intention of letting me near an AIDS curriculum. Which I’m sure that I complained about loudly to several people in the AIDS community because I suddenly got asked one day if I would like to be loaned to MACAIDS, the Metro Area Committee on AIDS, to be their education officer. Apparently someone, I think it was Leslie Barnes, I don’t know if she was chair or; she was on the Board of Directors anyway. And I had been talking to her and complaining. I get along really well with Leslie because she was one of the people at MACAIDS who saw a need for us setting a Persons with AIDS Coalition, where with a lot of the people at MACAIDS there was confrontation. She was much more approachable. Anyway, she got in touch with the Department of Education and it was a great solution for them because obviously if I was working with MACAIDS, then there wouldn’t be any pressure for them to work on an AIDS curriculum. So, I agreed to do that. It was better than working at the Department, but again it wasn’t my cup of tea. As I say, I had been involved with the early meetings of the Persons With AIDS Coalition. When we did formalize it and incorporate it and all that kind of stuff that was done I think in about August of ’88. I was on the Task Force. We figured it was probably a good idea if I wasn’t on the Board of Directors. So, the six original board of directors, they opened the organization.

**GK: Do you remember who those six were?**

ES: Peter Wood, Bruce Davidson, Dale Oxford, Fred Wells, Frank Morton, and John Balzer. By December, John decided that wasn’t his kind of work. He resigned and by that time the Task Force was over, so I took his place. Working with MACAIDS, for me it was too institutional. It was more like a bureaucratic government office. I mean doing education stuff, and I was out a couple of times to Stepping Stone, that’s a sex workers group. And going to schools, that kind of stuff was great. But the atmosphere in their office, I just found sort of suffocating. And I don’t know if it was

because of my exposure to the Persons With AIDS Coalition or what, but the Persons With AIDS Coalition... I mean, people talking about sex all the time. Obviously at MACAIDS you were talking about it somewhat because of AIDS, but that was the only time sex seemed appropriate to talk about was if you were talking about something professional about AIDS. Where at the Coalition, someone was always telling an off-colour joke or, you know, what gay men are like when they get together. So yeah, the atmosphere at MACAIDS was not right for me. Plus, I mean obviously the fact that a lot of the people at MACAIDS didn't think very kindly of the Persons With AIDS Coalition also made it doubly difficult. You were sort of wearing two hats. As it happened, my partner developed pneumonia and I took two weeks off to look after him. So, MACAIDS goes to the Department of Education and says Eric's taking two weeks off because he's getting his teacher's salary, how do we claim those days? And the response basically was, we don't care how much time he takes off as long as he's not in the news, which told me, "Great, I basically have two-and-a-half years to do what I want." So, I sort of said to MACAIDS, "You know, I'm not comfortable here anymore, so I'm not coming in." So, I spent the next two and a half years full time at the Coalition. And it was right: the department didn't care. You know, they had no way of knowing. I was certainly putting more hours in there than if I had been teaching full time. But yeah, so I spent most of that three years at the Persons With AIDS Coalition.

**AS: I'm sure that wasn't their plan initially.** [laughter]

ES: No, their plan wasn't that I would be at the AIDS coalition. Their plan was keeping me quiet, so I wasn't in the news upsetting parents. And they got that.

**AS: That worked.**

**GK: And you weren't in the classroom either.**

ES: Yeah.

**AS: Yeah. Then instead you were able to produce lots more trouble and...**

ES: I mean it sounds strange when you say, late '80s early '90s, working in an AIDS organization was probably the best time of my life. I mean that sounds odd, because those were crisis days and people were sick and dying all the time. I mean as far as positive, rewarding feelings you were accomplishing a lot of stuff that in a regular job you weren't doing. You know, sitting up all night with someone who wanted to die at home. You know, you only met the person three times, but in that space of three nights you become best of friends and here you are wiping their backside. And a lot of people think, "Okay, how is that exciting or rewarding?" It is. You're accomplishing something. And it is... It was wonderful.

**GK: So, maybe just before coming back to the PWA Coalition and getting into what that entailed, how does this sort of story of you and the School Board and the Ministry of Education, how does it end?**

ES: Okay. So, my loan to the Department was from '88 to '91, so in September of '91 I would've been applying for the job back in... So of course, the beginning of '91, the press is starting to ask and I said, "Yes, I would like the job back." And this time it gets really, and I guess if I was one of the concerned parents I would understand, they're probably getting tired of this coming up. So, they take it a step further and they decide to set up their own independent school. They have some retired teachers who would volunteer to provide their time free, to do the teaching for free. So, that's what I was faced with. If I go back a lot of the kids are going to be pulled out. Well, I mean there are a couple of problems. First of all, there are obviously problems in the public school system. That's no secret. I don't think the solution is putting kids in an independent Christian school. And so that was, for me, the major thing that was sitting on my shoulders. If I go back, I'm, through no fault of their own, dumping the kids in this situation. I have a minor sleeping disorder, this was certainly making it worse. The migraines were getting worse simply because of this. And also, part of the question which wasn't really on my shoulders but I would've felt responsible for was if these kids were not in school on that magic day, September the 30<sup>th</sup>, then there would be no funding for them. So, even if I could force my way back in, the number of teachers that would've taught those students would end up losing jobs as well. So, I mean that was also sitting on my shoulders. And as I said earlier, the negotiations that took place were with this new superintendent Dr. Oss. for the school board who would come down every Friday. And I have to say he was one of probably the nicest people I've ever met. His attitude was he had to solve the problem in a way that would keep the kids in school but his solution wasn't simply to throw me under the bus. It was what kind of a deal can we make where both groups are going to feel like we accomplished something. And the solution was, and this goes back to the recommendations, the government, this was still the Conservative government, they had a different leader at the time, Donny Cameron, again through the back channels through Doctor Ross, said that if I would resign and go on disability pension they would make the changes to the Human Rights Act.

At the same time, the doctors were becoming increasingly concerned about the... Well, particularly the migraines, because my migraines. I've had a history since I was ten years old with migraines. At that time, I mean when I was teaching certainly three or four times a week or something was not unusual. But the thing was, if you had a good sleep you would wake up and it would be gone. What was happening now was that, even if I did have a good sleep, and I mean sometimes it would mean going to emergency for a Demerol shot, which would knock you out for eight hours, but you would wake up and within an hour the headache would be back as bad. So, there was some concern about that as well. Of course, I tried to tell myself that you can't make a decision based on that, but.

**AS: It's pretty compelling.**

ES: So, I mean that was the bottom line. If I went on disability pension, they would make the changes to the Human Rights Act. I also realized that by doing that, I could continue. As much as I wanted to be back in the classroom, I could also, by having that free time by being on disability pension, I would have the time to again devote to AIDS causes to doing the education; a different kind of education but I would still be doing education. And obviously the kind of AIDS education I was doing, was a lot different than what most people would be able to do. So, I mean that was another side to it. So, that was the solution.

**AS: I mean, this is just like kind of amazing that they were like, “If you do this, we’ll make this change for all of these...”**

ES: And I mean it’s interesting because, as I said, we had the press conference at the teachers’ union building and the president of the teachers union and somebody from the Department of Education, and so it’s all done. Two days later the Minister of Justice, or Attorney General, has a press conference saying that they were going to make changes to the Human Rights Act. Nobody picked up on the connection until six years, seven years ago in the Pride guide.

**GK: It was Chris who pointed it out.**

ES: Chris Aucoin. It was the 25<sup>th</sup> year or something, and he picked out certain highlights over the years. And he mentioned that date and he said something about, “Was there a coincidence in the two things?” It was like, how come...? And nobody in my family even knew that because, as much as I love my family, they’re rural and they’re all Smiths and we tend to talk a lot, so. [laughter]

**GK: So, was part of the deal that you also were not supposed to say that there was a linkage between what you were doing and the Human Rights changes? Was that just sort of implied?**

ES: No.

**GK: Okay.**

**AS: So interesting.**

ES: Yeah, it was. But again, I don’t remember Doctor Oss saying I couldn’t say it. But again I knew that he was getting this information from the Department. Instead of the Department coming to me directly and saying this, it was the way.... Because then if it fell through government officials could deny that there was ever an offer made. And, because I had been involved in politics I sort of knew, they’re making this offer this way because they want to be able to deny it if it falls through. So that, in my mind, meant that I was supposed to be quiet.

**AS: Yeah. It’s really incredible though because making that change acknowledges that you were profoundly wronged and that they want to, for whatever reason, self-interest or genuine justice, and they want to make sure that others are not wronged like that.**

ES: And I mean, some of perhaps the insight I lacked when the thing originally happened, and for sure on the Task Force, that sort of three or four years later I appreciated. When the thing first happened, in my own mind, it was all about me of course. And it was only during that four years while I was with the Task Force and the Department of Education that I met a lot of other people and the concerns they expressed about their fear of publicity. And I mean there was one article in the paper, I think it was the day after the Health Minister turned down the recommendations to include things in the Human Rights Act and anonymous testing, and it was another person with HIV who they didn’t name who said he would rather die than have his name be made public. And I

mean, in meeting people who a lot of them were saying, “You know, I think I’m HIV positive but I don’t dare be tested because I don’t know what will happen if my name becomes public.” And in a lot of cases, it wasn’t just a matter like major publicity like mine, but what happens if my family finds out? You know, that kind of thing. And that gave me a wider perspective. So, by getting those changes made, it wasn’t just saying, “I was right all along” but it’s, “Okay, there are other people who I’m going to do this for.”

**GK: And were you satisfied with the text of the changes?**

ES: Yeah. Although typically government, they couldn’t specifically say HIV and AIDS. They had something about, you can’t discriminate based on the fear or supposed fear that someone has a contagious disease or, you know, it doesn’t specifically mention the... And part of it, I understand the reasoning is they don’t want to mention a specific disease because then another disease might need to be mentioned and if you make it general...

**AS: It’s bigger.**

ES: Yeah. But it’s like okay, how many government lawyers drafted this line? And I had already been involved in getting some changes made. One of the first things, when my issue first blew up and I moved to Halifax to be on the Task Force, one of the first groups that asked me to speak to them were the group representing Nova Scotia Universities, the student unions. Royden Trainer was chairman of the Dal Student Union and he asked me to go to the meeting because he wanted Dal to implement policies, both on HIV and for homosexuals, and so I went to this meeting. It was sort of my first one and I was a nervous wreck. Talking to ten year olds is one thing, it’s my cup of tea. Talking to adults, oh word. And I remember to this day, telling them right from the start, “Okay, you’ll see me shaking. If you see me pass out it has nothing to do with the HIV bit. It’s just I’m terrified of this.” Anyway, so I sort of briefly explained my case, and you know, made some points about a sexually transmitted disease. You’re in the age group where that’s going to be a problem. So, by the end of the session they had passed resolutions. And I think within a year Dal had implemented policies you know protecting sexual orientation and people with HIV and AIDS. So, I had already had some success in helping get those things changed. I have to say Dal has over the years, I mean this is from me sort of being there everyday doing personal research, they just have some wonderful policies and I mean there are posters up all over the library now. And you know Dal, the allies group, they’re a bridge group for gay and lesbians, they’re getting people together to help them get their float ready for the new Pride Parade. They’re just great.

**GK: So, maybe we should move back to the PWA Coalition sort of to get back to that. So, you’ve already sort of talked a little bit about it, about people meeting. Like, clearly the MACAIDS you were describing wasn’t meeting people’s needs. So, this was one of the....**

ES: Well, basically the two groups took two opposing views or two different ways of dealing with people and neither group was right for everybody, which makes sense. MACAIDS – they did AIDS 101 education. They were very good at... I don’t want to oversimplify but it was sort of, “Come in and have a cup of tea. Tell us what your problems are. What’s making you feel down and can we hold your hand?” The Coalition was more, “Okay, you’ve tested positive. Let’s go through your

crisis. What questions...?” Everybody involved in the Coalition originally was HIV positive, so you’re talking to somebody who’s gone through it. Okay. After two or three weeks or depending on the person, once you’ve got over the crisis and you’re okay, it’s, “What can we help you do living with AIDS as opposed to how can we help you die with AIDS?” That was basically the philosophy. And again it sounds strange when you think of in those days AIDS and sickness and dying, but I mean, at times it was almost a carnival attitude. There might be someone off in the lounge who had just come in with a new diagnosis who was crying, somebody else in the next room telling jokes that, well I probably wouldn’t want my mother to hear but, it was just really vibrant. And that was basically the philosophy. I mean, that was what was worked out. The first meetings of the people involved in the Coalition, as I say met sort of on the floor in people’s apartments, and it stemmed from what was going on in my case.

**AS: Did you already know those people?**

ES: No.

**AS: No. How did you get together, like how did people connect?**

ES: I started talking to Peter at the bar.

**AS: And he knew who you were before because of all the attention.**

ES: Yeah. Yeah. Now, I knew Bruce but I didn’t know him; I knew who he was, which is why I was surprised when he showed up at the public meeting as Kevin. But it was through those two that I got invited to this. I think originally because they thought maybe because I was on the task force, I could get them some money from the government, which obviously they were really disappointed in. But that’s how I got involved. This would be March or April of ’88. And the meetings went on from there. And some of the first things were simply letting other groups and organizations know we were available. Like, telling the doctors at the clinic, going to family doctors that were had a lot of HIV patients. You know, if you’re dealing with somebody who’s newly diagnosed and they want to talk to somebody, we do that. Making ourselves available to school groups to go out to talk. So, a lot of the first stuff we did we weren’t actually an organized group.

**AS: But you were doing those things in order to address the misinformation and people not having any real contact with people living with HIV.**

ES: Of course, the one downside originally was that all of us were gay male. That was one of the downfalls, one of the negative things. And so there were some groups who were hesitant to... I mean we had a long struggle to set up any kind of contact with the Nova Scotia Hemophilia Society; again, because we were perceived as simply gay men, and also because a lot of us were not bureaucratic. You know, someone bureaucratic would say, “Well, what can we do for you?” Someone from our group would say, “So, what the hell can we do to help?” I mean, just the tone. And I’ve said before, a lot of the original group at the Coalition were not people who had been involved in bureaucracies or what you would call ‘professional’ jobs. It was myself and Frank, who were both teachers. The others – Dale was involved in textile manufacturing, I think. Peter had

been involved in theatre, I think he'd done some design work for Stratford Theatre and that kind of stuff.

Where MACAIDS, most of those people had been more 'professional' people. And so they would do what I call my 'teacher talk.' You know, I can do that professional talk, my 'teacher talk.' Most of the time I don't bother with that, depending on when the situation requires it. And that was again one of the things some of the organizations sort of took them aback that we were prepared to get our hands dirty instead of simply talk. And so for some groups, that put them off a bit. But over the months we eventually brought in some professionals, and this turned into our advisory board when we set up the Coalition... When the Coalition was set up, we purposely set it up as a Persons With AIDS Coalition. The only other one at the time was Vancouver. And, to be on the board, you had to be HIV positive. So, before we were incorporated, we started bringing people on board. There was particularly a lawyer to help us figure out what to do. But you know there were social workers, a doctor, a priest, a public health nurse... I'm trying to think who else. But they were all having input because as I say, most of us didn't know how to work our way through the system. So, those people were our advisory board when we did set up. Only there was a mother, Lynn Hayes, who always an interesting story. Her son Robert had died early, in '83 or so, but when he was a much younger he had moved to New York. He actually worked with Andy Warhol. So, she always had a really interesting story to tell.

**GK: Do you remember any of the names of the people on the advisory board?**

ES: Yes. Bob Petite was the Anglican Priest; Bob Fredrickson was the family doctor; Lynn Hayes was the mother; Vida Doucet was the public health nurse; Mary Petty and Brenda Richard were the social workers.

**GK: And there would've been Maureen Shebib too.**

ES: Maureen Shebib was the lawyer. Yes.

**AS: And so was it that everyone on the advisory board pretty much wasn't positive?**

ES: None of them were. And they had no problem with being on the advisory board. Obviously, they couldn't vote on anything, but they had no problem with that. Whenever an issue was being discussed, if it was from their field they could offer advice, but the decision was left up to us. And Lynn, thank god, the mother who didn't belong to a profession, was an accountant for some small company, so she helped Dale with the books. So, everything tied in really well. And I mean these were wonderful people. They were willing to offer their advice and if a motion was passed and we didn't go along with their advice, they had no problem accepting that. So yeah, they bought into our philosophy of helping people live as opposed to helping people die.

**GK: So, the group gets incorporated and you eventually apply for funding from the federal government.**

ES: Yeah. The issue of funding... Of course, the province at that point wasn't doing anything. The federal government at that time offered core funding of 150,000 dollars to one group in each

province, which of course was a problem for us because MACAIDS already had that. So, we could apply for project funding, but I mean, obviously project funding was good. The problem with an organization like the Coalition where everybody who was sort of in charge is infected is you need some stability. So, we'd really need the core funding because you get a situation where a lot of the board members are suddenly sick or die, you're in a mess if there's not something stable there. So the people at Health Promotion, the Halifax group, Halifax branch of Health Promotion in Canada Health, were wonderful. They convinced the federal government to give us core funding as well. So, from '88 until when the two groups were combined, two groups in Nova Scotia got core funding. We were the only province to do that.

**GK: These are groups with provincial mandates?**

ES: Yeah. And I mean that obviously helped because you knew that. And for the first year we didn't have any staff and it was fairly easy because, well I was on loan from the Department of Education so I could be there as much as I wanted to, which was all the time. The other board members were basically there all the time because they had all followed that advice. Well, some of them had already been sick, so they had quit their jobs. But also at the time, the advice for a lot of people was if you are HIV positive, you should quit your job to avoid stress. And one way to not isolate themselves was to get really into throwing themselves into the Coalition work. So, we were there all the time.

**AS: And where was there? Can you just talk about the space?**

ES: The first Coalition office was on Gottingen Street. Unfortunately, it was on the second floor and there was about, well it seemed like fifty, but it was probably closer to thirty fairly steep steps. The plus side was that it was right across from Rumours, Rumours 2. And that's why when I say we were in the office all the time, quite often we were there late at night simply because there would be people that would come up and talk at Rumours, and what they really wanted was a quiet space where they could talk about what they were going through, so they would just simply go across to the office. It was great in that there were several small offices. So, obviously Peter had one as chairman, and if anyone was working on a particular project and wanted some quiet space they could go into an office. There were several larger spaces. And actually there was one large space where four people had desks. So, depending on what you were doing at a particular time, there was a space to do it.

There was a lounge for people who wanted to come in and watch television and not talk to anybody. And I have to say, even before we had funding, there was a lot of support. There were always goodies in the fridge for people who wanted to nibble. And I think a few overdid it based on the amount of growth that occurred. Yeah, the office was a good space. When we eventually did hire staff, we decided, and I think we decided quite easily, that the first staff person we hired should be somebody who is *not* HIV positive simply because, I think it was the Toronto group just sort of when we were looking at starting to hire somebody, they had gone through a period where twelve or fourteen people had gotten sick at the same time. Anyway, it was a huge disruption because of the large number of people who were suddenly not available to help. And we sort of said, "Okay, this especially applies to us when we were all HIV positive. So, maybe we should have somebody here who can keep the ship afloat if we're not able to do all the stuff that should be

done.” So, we hired Robert Allen who had been involved with the Kingston AIDS project – a real dynamo, one of these piss and vinegar types. And for the first few years, I think it worked really well. We also hired, as office manager, JJ Lyon. JJ is sort of an institution in the gay community in Nova Scotia. Again, he’s one of these people who, as I said earlier about Doctor McKay, you can have your leg amputated, JJ will come in as soon as you wake up and convince you it’s the best day of your life. And he has this ability. And we saw it happen so often, people coming into the office for the first time and sort of when JJ says, “What can we do to help?” They don’t know, they’re just devastated. And JJ just gives them a hug and they feel like they’re suddenly are home and half of whatever weight was on their shoulder is just suddenly dissolved. So, I think that was probably our wisest move was when we hired JJ.

**GK: Did the office stay in the same place or did it move?**

ES: It moved. By the time it moved, my connection with them had been broken. But they have moved several times. They were for a while in the Lord Nelson Hotel on Spring Garden Road. Then, they were down closer to the waterfront, I think in the old post office building there. They were up on Barrington Street.

**GK: You’re not talking about the Nova Scotia AIDS Coalition?**

ES: This is the new one. Yes.

**GK: Okay.**

ES: Yeah. The Coalition... I think they were still at the Lord Nelson Hotel when the two groups merged.

**GK: Maybe what we should just do is if there are more immediate things you wanted to say about the PWA Coalition? What it did, what you did in relationship to it... But if there’s anything more about the PWA Coalition... You eventually do become Chair of the PWA Coalition when Peter goes to St. John’s.**

ES: Right. After several years Peter moved to St. John’s, Newfoundland to the AIDS group there. Bruce Davidson is interim chair of the board for us, but it’s not something he’s comfortable with. So, I take over the job for a while. After several months of work on several issues that came up for me, it showed the board was going in a direction which is not what it was originally planned for. By this time, there were quite a few new board members. Most of the old ones had either, besides myself and Peter, the other four had died. Part of the problem was the newer ones who came on, they wanted to help but they didn’t have the fire that the original group did because when we got involved sort of the whole scene was new as far as publicity around AIDS, so we had to do the fighting. And I think, like most rights issues, the people who start out know the really bad times and are full of this desire to fight and not let things slide by, that the people who come on later and have not had to go through that really difficult time don’t, and I’m, not sure if I’m making sense, but they don’t have the same perspective. I mean you obviously see it in the gay rights movement. I mean the people who were doing the protesting in the ‘70s and ‘80s, I think were much more

determined than most gays today. Most gays today say, “Oh, it’s great to take part in the Pride Parade” but that’s the extent of it. They don’t remember the history and a lot of them aren’t even concerned about the history. They roughly know something happened at Stonewall and they have some idea that some people had shock treatments to cure them, but you know. And that’s what we were seeing with the Coalition, a lot of the people were coming in. And I have to say, some of the people who were becoming involved, and for me this was the real issue, one of the main issues was that they were becoming involved because it was, “What can I get out of it by becoming involved?” not “How can I help by becoming involved? How can I help the Community?” but “What can I do for myself by becoming involved?” And that was not where I saw it going.

The other issue, and the one that caused me to resign from the board, was there had been negotiations going on to set up a National Persons with AIDS Coalition as opposed to the Canadian AIDS Society. And we’d had a couple of meetings, or at least one meeting, in Toronto with five representatives – one from BC, one from the Prairies, one from Ontario, one from Quebec, and one from the Atlantic provinces. And I was the representative from the Atlantic provinces. There was some uproar over that because Peter had originally been scheduled to go, but then some of the others decided maybe he shouldn’t because he was serving on the Canadian AIDS Society Board at the time. So, as chairman of the Halifax group I was asked to go and before going we had discussed it thoroughly at board meetings and the board had supported the idea of a National Persons With AIDS Coalition. So, I go to Toronto, we have these discussions and I say “Yes, we’re fully behind this.” So, this works out through the AIDS groups. And a while later, when they’re having a second meeting and they’re going to put a proposal forward on asking the feds for funding, the board is no longer sure they want to support it. So, I say, “Well, obviously, I can’t go to the meeting and say, I don’t support it, because I still do. And okay, maybe you can explain to me why we shouldn’t support it.” And basically I didn’t get it. There was nothing. Well, there were two things that happened. One was that a couple of board members, a couple of new people had come on, who again, because they didn’t remember, weren’t involved in the early days it wasn’t an issue for them. An AIDS group is an AIDS group, basically. The other issue, and maybe I should tread carefully here. Peter still had lots of friends in Halifax and there was some upset because he had been replaced on the committee, and Peter’s support had changed. He originally supported the idea, but when it was suggested that he shouldn’t be on the committee his support waned. And so some of the people in Halifax decided only Peter doesn’t think it’s a good idea anymore, so maybe we shouldn’t.

**AS: And he was working for the Canadian AIDS Society...**

ES: He was on the board.

**GK: But he was in St. John’s with the Newfoundland / Labrador AIDS group.**

ES: So, that was when I resigned as chairman of the board. That was primarily the reason was because of that. There was another issue and this is going to tie in later to ACT UP [AIDS Coalition to Unleash Power]. But some on the board were uneasy about my relationship with ACT UP. And this is where you can see the Coalition had moved away from its early roots. The Coalition did not want to be identified with ACT UP, which again, if you still had people like Peter and Bruce and Dale around they would’ve been there because they remember the days when the only way you

get government's attention was to scream. The Coalition by this time, and this is – when are we talking about – May '91, they are uneasy because I'm associated with ACT UP. And they're afraid that if people see me associated with ACT UP it will imply that the Coalition is associated with ACT UP. So, that was the other reason why I said, "Okay, I'm not going to give up my association with ACT UP, so the alternative is to resign." Those were the two reasons I quit as chair. And as it happened, within just a couple of months, I resigned from the Board of Directors. And, again, it had to do with what I was saying, the old spark wasn't there. The newer people who had come on was, "What can I do for myself?" And they didn't really have time for this attitude that we need to go after the government to get something. They didn't think that was any longer necessary.

I guess what I saw happening was it was going from a fighting group, a protest group, to it basically becoming a social club. You know, "I've got a couple of hours, lets go to the Coalition and have fun," that was it. There was no more of you know, "Some government official said something stupid, lets put out a press release." Now having said that Wilson tried. Wilson became president, or Chairman of the Board. And Wilson himself did, but the organization itself was basically Wilson. And that's why a lot of the old guard saw, there wasn't really a Persons with AIDS Coalition, there was a person – Wilson – who was doing stuff that we were doing, the screaming and stuff. But the organization itself was basically what MACAIDS was, a social centre. So yeah, that was sort of why I decided that's not what I wanted to do. I want to keep screaming when someone needs to scream. And I think, for myself, it worked out because now, when there is any local AIDS coverage, which is rare, the press usually come to me. And I know I've been told by several people how upset at the Coalition get when there's an article and they quote me and sort of in the last paragraph, "A spokesman for AIDS Nova Scotia says..." they get quite ticked off.

But again, that's why I keep saying the Coalition originally was so good was because it did all those things. It did the social bit; it did the caring and helping bit; but it did the screaming and protesting and that kind of stuff, which you have to do. And as a result, which is why I referred earlier to the recommendation of the Task Force that the province fund provincial AIDS organizations. Well, the reason nothing ever came of that is because when the recommendation passed the advisory commission, instead of giving them some time to come up with how it should be done, nothing happened. When nothing happened, in the old days, leaders said, "Okay, what's your progress?" If they'd said no progress, we would've been in the streets hollering and there would be press coverage. There would've been at least some pressure put on the government. Most of the people from sort of '92 on, their attitude was the best ways to achieve things is to sit down with the Department and talk. And in some cases that works, but we know from the early days that quite often it doesn't work and that's why you had to scream.

**AS: So that shift had already been happening before the merger.**

ES: Yeah. It wasn't as obvious to people outside because, as I say, Wilson was still there and Wilson... I'm just glad I was never on his bad side because Wilson could be an attack dog. I think he'd been in the military and, yeah, I wouldn't want an enemy like that. So, I mean, the general public would still see it as being somewhat vocal but people who had some idea of what was going on in the community realized that it was basically Wilson.

**GK: So, I think that's where we're going to pause for today and we'll do Part Two.**

[END OF TRANSCRIPT]

Part 2 - July 24, 2014

Persons present: Eric Smith – ES  
Alexis Shotwell – AS  
Gary Kinsman – GK

[START OF TRANSCRIPT]

**AS: It's July 24 and we're talking to Eric Smith.**

**GK: Obviously, it's hard to do a Part Two of an interview, but just to come back to some of the stuff that would've been happening before the PWA Coalition was at least fully formed. You remember probably the *Chronicle Herald* with that wonderful, horrific headline "AIDS fiend strikes again." I wonder if you could take us back to that moment and what your response and other people's response was to that.**

ES: It's interesting that the question comes up today, because I actually ran into his sister earlier this morning. I haven't seen her for about ten years. Just several days after that article was headlined in the paper, I was doing a workshop in a university in the evening, so it was sort of general public, and that was one of the questions that was asked. And I began by saying, "If you think I'm going to be saying negative things about Scott, you're going to be disappointed." And I also tore a strip off the *Chronicle Herald* for that headline. I also pointed out that most of the other media were treating it more fairly. I guess, it's always a question about how you treat an issue like that really fairly, but they were less inflammatory in their language. As it happened, Scotty's mother and sister were there ... I had never met them before. They came up afterwards and were quite pleased with what I had said. And it was reported actually, the *Herald* itself reported one of the questions asked at the workshop was about the headline and I said, "The coverage was better than expected, with the exception of the *Chronicle Herald* headline portraying Wentzell as an 'AIDS fiend.'" I think that was the reaction that was taken by most people in the AIDS community and a lot of people outside as well, because a lot of people realized that regardless of what they thought of Scotty there was a deeper issue in that his name had been on the provincial list and it had come from that list. So, once again it was showing people that there's a danger in being tested in Nova Scotia because your information may not stay private. I think a lot of people, again regardless of what they particularly thought of what Scotty did, took a much broader look at the thing and realized that the way it was being handled was probably not a good thing.

**GK: Maybe you could just tell us briefly what it was Scott had supposedly done and also what happened to him.**

ES: Okay. Scotty infected his girlfriend. The reason it became a public issue was the girl's aunt was actually the lady in charge of the list of people who were testing positive. So, when her niece tested

positive, she knew that she had been going with Scotty and she knew Scotty's name was on the list. I think the other problem a lot of people had was that the charges were pursued by the family. The girl herself did not want to ... The girl took, depending on your point of view, some say she was not mature enough to know what she was doing, others thought she was being quite mature in that she said, "Okay, if Scotty is infected he may not have a whole lot of years left. I want to be around him for what time is left." So, I mean that was basically the run-down.

**GK: And was he put in jail?**

ES: Yes. He was convicted and spent some time in jail. And he actually got out. I think he died three or four years later.

**AS: Did that have an effect on how people were thinking and talking about their own practices? So, you were talking about the ways that the people in the community accurately said, "Look, this is an issue about whether it's possible to get tested and have that be private."**

ES: Actually, what came out of it was a concerted effort by almost everybody working in the HIV field in Nova Scotia, to take the attitude of advising people not to get tested. I mean, you had certainly people who would've been affiliated with the Coalition, some of the people affiliated with MACAIDS, and some of the frontline doctors. I know Doctor Bob was saying, "Look, there's no medications available. So, it's not going to help you. What you do is you assume you're positive, practice safer sex or shooting drugs or whatever you're doing; do it safely and again not be tested, so your name won't go on the list." Of course, it backfired a little bit when medication did become available because then you had to reverse the argument saying, "Yes, there is some reason to be testing." But that was basically, Scotty's case on top of mine, that's what it led to was simply people were being told not to be tested unless they were actually sick with something that was mainly an indication of AIDS. Then that was a different story, but if you were simply concerned that you had done something, the advice was, "Okay, assume you're positive and practice safer behaviours, but protect yourself. Don't be tested and get your name on the list."

**AS: And, I don't know this about his case, because in your case you didn't go like, "I want to go get tested." It was that day surgery. Had he gone to get tested?**

ES: Yeah. He would've had to have been tested because, at that stage, when a test was ... when the blood was sent in, your name would've been put on it. So, he would've been tested and it would have been tested positive. And when you tested positive, the results came back to your doctor, but a copy of the results went to the Department of Health. So, your name got put on this master list. And that's where, obviously, the trouble came for him.

**GK: Right. So, we're moving back then to some of the questions relating to the PWA Coalition, which we largely talked about last time, but one of the things I've heard about is that initially, and even though later on another needle exchange gets set up, that the PWA Coalition did some work trying to make clean needles available to people.**

ES: Yeah. We did. It wasn't something that was really advertised. There were certain other groups that we told we were doing it. And a lot of the doctors knew we were doing it. We just didn't put a sign out front, simply because we were not sure how it would go over with the politicians. It wasn't just a fear that they would go after the needle part of it, but that they might in fact use it as an excuse to go after the whole operation. So, it was done. I don't remember exactly when it started, but it did become one of the ways that actually broke down the Coalition being seen as sort of all gay men because you actually got people coming in for other reasons and that started to break down some of the barriers.

**AS: People who were coming in to exchange needles, would they also like hang out and people would know each other?**

ES: Yeah. I mean, the first few times people would come in, again, it was, "Okay, these are gay men. What's going to happen?" So, they would sort of slide in, deposit the needles, get clean ones and there were, I don't know, 20 or 50 steps to get to our office. You know, they only hit two of them on the way down because they were in such a hurry to leave. But after being there several times, things loosened up for them and it got so they would hang around.

**AS: Yeah. And I mean, Anita described food and sociability and people getting friendly.**

ES: Well, I mean when you had JJ at your front desk, there's always sociability. I mean, it's just wonderful.

**GK: So, other things that we didn't talk about in terms of the PWA Coalition is, in the early '90s there's the initiation of some outreach projects. So, there's a Women and AIDS Outreach Project. Can you maybe tell us a little bit about that and how it came to be?**

ES: The Women and AIDS Outreach Project... Well, again, since when we first started, it was basically all gay men. I was in charge of Women and AIDS. Now, I don't have a problem with that. I was raised in a family with three sisters. My first social demonstration was in high school was against a policy that girls were not allowed to wear pants, even in the winter. And so we staged a two-day walkout to get that overturned. So, even before I was really aware of fighting for gay issues, I was involved in... And I've always considered myself a feminist. I know some people have a problem with it. You can't be a feminist if you're a man, but I don't agree with that anyway. So, I didn't have a problem talking about the issues. Also, in Grade 10, I took Home Ec. As far as we can tell, I was the first guy in Nova Scotia to take Home Ec. And the family living part, we were given magazine articles we had to take home and summarize and stand up next class and give a one-minute presentation, and of course, the one that I was given was on menstruation. So, for me, talking about issues involving women was not a problem.

Where we saw a bigger need though was when some women who were infected started coming to the office. And I did give them the factual stuff, but that can only go so far. So, we applied to Health Canada for money for an outreach worker for women, and that went very well. But again, the women who came to our office were much quicker to sort of join in than the people coming to the needle exchange. I think a lot of women aren't really afraid of gays. They know no one's going to put pressure on them for anything so they're actually more comfortable. But that

was I think probably our biggest success, was in actually getting the Women and AIDS project underway.

**AS: Who did you hire? Like, how did that happen?**

**GK: We can recover that.**

ES: I can see her face, but I can't give you a name. No, I'm thinking of Andrea Currie, but I don't think she had that job.

**GK: Was it Jane Allen?**

ES: Yes.

**GK: I think they're like other things with the PWA Coalition, you had an advisory board that would've involved other women from the community.**

ES: Yeah. Jane.

**AS: And so she would've used one of the offices that was available and been there?**

ES: Yeah.

**AS: Cool.**

ES: And you know a good part of her work would've been no different from the rest of the work everybody else was doing. There just would've been a small section that would have a different focus. So, and Jane again was one of these, you know, I don't think it mattered. It wouldn't if it was a crew of anarchists or a group of Catholic Priests. You know, she could find a way to entertain them. So, yeah.

**AS: And were there particular things that that group worked on? Or was it mostly just being available so that when positive women came in...**

ES: Well, it was partly being available when positive women came in, but I think it was also more a need for sort of a group where they could actually sit and talk. While I say, they didn't have any problem with sitting with the gay men, I'm sure a lot of them at times thought that some of the off colour jokes went on for too long, you know. And there's, "Can we talk about what's going on with us without somebody making a joke about it?" So, there was that thing. It was a sort of support group type thing. Yeah, that worked really well.

**GK: Yeah, and we're going to try to talk to some of the other people who were involved in that. I will try and talk to Brenda Barnes who's in the Yukon. We might be able to talk to her and we'll also try to look up Jane Allen for sure. So, another outreach project was the Black**

**Outreach Project and I was wondering if you could tell us a bit about how that was put together.**

ES: The Black Outreach Project came about through a mistake we made. We were invited to one of the churches in Preston. Preston is a black community. Now, at that time there were several black people that we were aware of who were infected. There was only one who spent a lot of time in the office. So, of course, I get chosen to go to this church, which that's the part that scares me, is the church part. But we decided to take the guy of colour along with us, so he could speak about it. I think they thought it went alright. I was kind of disappointed right from the start because one of the first things this guy said was that he was infected through shooting drugs, and that's not what had happened, he was gay. That's how he was infected, but he couldn't go to his church in his home community and say that. And you could tell in the reactions from the congregation that, while they felt sorry for both of us, they felt more sorry for him because he got it through shooting drugs supposedly, than for me who was doing something un-Christian. So, when I went back to the office the next week, I said, "Okay, better do something about this. This isn't going to work. You can't send him again." Part of our profile is when we go out to talk we are completely honest, and if the first thing that comes out of somebody's mouth is a lie, and I mean, it worked for that particular time because at no point did he slip up. But it's very easy to slip up and... So, we went after project funding for the black community. And that worked really well. There was still a distance with people who came into the office to see the black outreach officer. They were less comfortable hanging around. So, as a rule, they didn't join in and they didn't really take part in activities put on by the Coalition. Again, and you still see it today, a fair amount of denial in the black community about gay men and it was very obvious then. But it actually pointed up to the fact that a black outreach officer was really necessary because these people were not going to get any of their questions answered or anything if it depended on them coming to sit down and talk to gay men.

**AS: Yeah. White gay men.**

ES: Yeah. Exactly.

**AS: But, just on the community outside, in the gay community, was there much racial mixing and interchange? Like, were black men coming to the bar?**

ES: Only a few. There was never a lot of integration. There are a few more now, but there still seems to be a big difference. It's still there.

**GK: Can you remember any of the people who would've been involved in that Black Outreach Project, either as people who were employed or perhaps on the advisory board?**

ES: Her last name is Bernard. I think, Kim...

**GK: Yes. Kim Bernard who was in "Four the Moment."**

ES: Yes. I'm pretty sure Kim was the outreach officer, but there are several Bernard sisters, so I won't say exactly. I may remember her from "Four the Moment" but I'm pretty sure she was, for a time at least, the black outreach officer. I think those are two of the extra-high points for the Coalition. And I think we did a lot of good. And again, this being completely honest when we talk to people, that kind of stuff helps get your message out. But I think we also realized that we couldn't be all things to all people, and there were ways to improve how we worked with other groups. So yeah, I think those were two of the high points.

**GK: Great. If there's no other questions around that, we're sort of going to move into ACT UP, if that's okay. So, you're involved in the PWA Coalition but there's also this ACT UP group that emerges. If you could tell us anything about how it emerges. Does it have any relationship to the PWA Coalition? What happens there?**

ES: I have been wracking my brain to try and figure out exactly how and when ACT UP formed and I, for the life of me, cannot. I just remember suddenly being involved with it. Well, part of the reason I was involved with it was simply with my background as being vocal. I mean, I can do the sit down with the Minister of Health or whoever and discuss issues, but in those early days in AIDS you didn't have six or eight years to let something work through the system. So, I was also quite comfortable doing the screaming in the street. So, that's why I got involved with ACT UP because, after two or three years, the Coalition was not doing that as much anymore. Actually, that's what led to my leaving the Board of Directors, was because of my involvement with ACT UP. In the back of my mind, there's some connection to that and the ongoing battle with the gay group at the bar over going topless. Now, I don't know if that issue helped spark setting up ACT UP, or if ACT UP was already sort of forming and took that on as another issue. And again, that particular issue goes back to some of my difficulty with the Coalition because the issue was, since men could take their tops off when they were dancing, could women take their tops off when they were dancing? And I supported the right of women to take their tops off. Some of the Coalition were uncomfortable with me saying that. Granted the issue wasn't that clear cut because the gay group owned the gay bar, and they were also concerned with, "Okay, if women are taking their tops off, is that going to bring in government regulators, inspectors, to see if we were actually breaking certain rules." So, having said I supported the women, I, on another level, can understand the management's hesitancy in going along with it. But yeah, that issue became tied in with ACT UP.

**GK: So maybe we'll come back to that. Do you have any memories of being at an ACT UP meeting or how it was organized in any way?**

ES: ACT UP meetings... well, they weren't really structured. In the back of my mind, I think it's maybe it's sort of a meeting of anarchists because there was no structure, but even just sort of the meeting itself. Dan and Michael lived on the top floor of the hostel, huge open space, and off in one corner was their bed. So, quite often there would only be four or five people and the meeting would take place on the bed. And yeah, I remember the issues we talked about, obviously the shirt/non-shirt issue. There were issues about getting some action out of the Advisory Committee on AIDS, because nobody seemed to know what they were doing, if they were doing anything. And it had sort of more of a social justice thing, rather small issues that were involved. What I think actually came to define our group was the major event that was undertaken that sort of turned

into a flop, depending on your point of view, and that was the protest at the gay bar. One of our concerns was, most of the blowback that ACT UP got came from within the gay community. And I mean, that was very obvious when we did try to have a demonstration at the gay bar. The gay community in Halifax had no time for people who might want to disrupt their social events with inconvenient medical facts or whatever you want to call it. I don't even know how to describe it. The gay community... I mean, obviously, most of them knew the fact about AIDS, but they just didn't want it interfering with their lives. They didn't want anybody to make an issue of it. And I found that myself when my case blew up. The support from the gay community itself was iffy to say the best. So, I think that was the major spark under ACT UP.

Now, I know Dan... I don't know if we had officers, but Dan was sort of the lead person and I know he quite often was doing public speaking about it. He actually had a show on the radio station, at Dalhousie University, and he would quite often talk about the issues as seen by a radical group, including some comments that... Well, the one I remember, I didn't hear the particular show, but I happened to go to the Dalhousie library one day and somebody said, "Why is your personal life being broadcast on the radio?" I said, "What are you talking about?" I mean, most of my life was public, but the private part I didn't think was. Well, Dan had mentioned on his radio show that he had been in bed with Eric Smith the night before, and what it was was one of our meetings on top of the bed. But suddenly people were... Well, there were two things. First of all, "Why is somebody talking about it on the radio?" And the other thing was, "Why is Eric Smith having sex?" That was the other thing. And actually that was the issue I found in the gay community was, when my thing first blew up, "Why are you coming to the gay bar?" I mean, they weren't afraid of being infected, but "Why are you coming to the bar? Nobody's going to want to have sex with you." It was that whole concept that if you're HIV positive, you sort of cut off your genitals and hang them in a bag somewhere and forget about it. That was sort of the focus of ACT UP, was more the social justice issues. The things we were looking at as far as dealing with the government were issues, and in a lot of cases these were issues that go beyond AIDS, things like increasing the amount of money available to people on social assistance, so they can actually buy decent food. If your immune system's down obviously Kraft Dinner's not going to sustain you very long. But again, that's something that that goes far beyond people with AIDS. They were those kind of issues that we were looking at.

**AS: That AIDS kind of brought out.**

ES: Yeah.

**GK: So, there's a number of events that ACT UP organized. I was going to ask you about some of them and then come back to what happened at Rumours, which obviously is quite key to what goes on. One of the first events, I think, that ACT UP organized was on December 1, 1990 with the march with, I think, it was Pedro the Donkey. Do you remember that at all?**

ES: Yeah. I remember it very definitely because we were walking down Barrington Street. I turned around very foolishly. It was not that large a demonstration. We didn't go through permits and also we were on the sidewalk, and I remember turning around to see how many people were coming behind and I backed smack into one of those big metal post boxes and nearly knocked

myself senseless. So, I remember it for that reason. And it's like okay, just to be in the spotlight again I guess. But I remember simply because there had been some suggestion... At the time, Premier Buchanan had resigned and been appointed to the Senate, and while the Conservatives were choosing a new leader, the interim premier was Premier Bacon. So, there had been some earlier discussion about maybe using a pig. And I don't remember how it ended up that we got the donkey.

**AS: Pigs are maybe just harder to lead.**

ES: Yeah. I suppose it is fairly easy to lead a donkey, but yeah pigs. Yeah, that makes sense. [laughter] But, at that one... I don't know if they officially co-sponsored it, but the Coalition itself was involved because it was December 1. We were looking at World AIDS Day. It was a global thing and it wasn't being overly radical, so the Coalition was on board with that.

**AS: And the Coalition would be worried about being overly-radical because of having government funding?**

ES: Well no, because the funding came from the feds. This was a provincial issue. It was just that they had gotten quite comfortable working with the system and it was, again, they had gotten to the point where they were willing to have meeting after meeting after meeting with government officials to try and get things done. I mean, they still did occasional protests. And part of it was the evolution of the board itself. Most of the original members by this time had either died or were in such poor health that they weren't involved anymore. So, the intense focus that drew the original people in, that was no longer there. The new people coming on board were much more willing to accept small tidbits that came from the government than what the original people were. And that's basically where the shift started to come in at the Coalition. There were some people who were actually say, "Okay, well, the Coalition's not much different than MACAIDS was." That's why I was starting to distance myself and was really glad to see ACT UP come on the scene.

**AS: It's funny though because the donkey protest, just when I think about, it seems like it would be kind of radical to be bringing a donkey through the street, and was it going to the legislature?**

ES: I don't think the Coalition knew that was going to be part of it. [laughter] I don't think they realized that that was going to happen. That's why it was a little bit more radical I think than what they would have expected. That was one of the times that we actually had a die-in. Although being in Halifax, most people who felt inconvenienced by it had no idea what it was, you know. And I remember weeks afterwards being interviewed, I don't even remember who it was, but "What's with lying in the street?" So, I explained what a die-in was. He understood what I was saying, but he wasn't quite sure what good it did if people didn't understand what actually we were doing. So, it's like, "Well, maybe if you guys come out and ask questions early on, maybe..." I think that was the one big thing that ACT UP did that the general public would've seen.

**AS: And that action, what was it calling for?**

ES: Actually, we were still calling for the government at that point to implement those recommendations on human rights issues and anonymous testing. Those were the main ones.

**AS: Because that just was not moving.**

ES: Yeah. Although it's strange because that was December 1990 and sort of Spring '91 they're settling my case by agreeing to the Human Rights changes. But there were other issues, the issues about increases in family assistance limits for food and for extra for people who need Ensure and those kinds of products. We were also trying to get them to do something about living arrangements. My case was one of the examples that we talked about in the ACT UP group in that my partner was on social assistance and at that point, I was still getting my teacher's salary. So, the thing was I could've supported both of us if the province would've picked up his medication, but the province said, "No, we can't do that. It would set a precedent." So, according to the regulations my partner, because he was on social benefits, was supposed to be living by himself. Now, luckily we had a very good social worker who would call the day before to say he was coming by, so I would simply not be there. But it was those issues as well that we were trying to get the government to do something about.

**AS: And if he had been living on his own, would he have been able to afford everything?**

ES: No. Well actually, I should say, by December '90 he had died. But the issue had come before that anyway. It was an issue that was facing several other people. And I shouldn't just say one social worker. As far as we can tell, there were several couples in the same situation. And all the ones I had spoken to had the same situation in that the social worker were aware the couples were living together and would simply call and say, "You know, I'm coming by at such and such a time."

**AS: And different social workers. It wasn't everyone...**

ES: No. It was different social workers.

**AS: So interesting. I wonder how that culture... Like, how that happened?**

ES: No. Halifax, on a lot of levels, can be seen as a provincial town. We have had remarkably good relationships with most people in the health care community who worked on a person-to-person level.

**AS: And then once you go up a level?**

ES: The higher you get, the less one-on-one contact the person has, the less likely they are to take those things into account. I'd say that's true for almost all of the health people within health care or whatever. From what I've seen, it's always been fairly good. I can't recall anybody who really had a bad experience.

**AS: Right. It's really interesting how just having someone who does that calls the day before they come, even if there's a really unjust policy in place at the upper level, makes such a**

**huge difference. So, those were all parts of the things that people were calling for and the demonstration. And so, was the die-in at the beginning of the march?**

ES: It was more at the beginning because it was down South Park and Spring Garden Road down by the Lord Nelson. So, it would've been more at the start.

**AS: And did everyone lie down or was it some people?**

ES: No. Some of the people in the march itself didn't understand, didn't know what a die-in was. Actually, what I found when we did major events, quite often you had more outsiders taking part than people who were actually involved. And that was always one of the strengths of the Coalition in the early days was, having said that the gay community didn't particularly want to deal with these issues, you could always get a good response to these kinds of things. But yeah, the die-in... I guess I should've qualified that when I said a lot of the general public didn't understand, because some of the people involved didn't know what was going on.

**GK: It sounds like ACT UP might have some idea of what it was going to do on the march that not everyone necessarily understood.**

ES: Yeah.

**GK: Okay. So, when people did the die-in, were there people who outlined their bodies in chalk or was it just people lying down on the ground?**

ES: There were a couple of people with chalk. Again, I don't think that the Coalition was aware it was going to happen because there were only a couple of people with chalk and they were people who were associated with the ACT UP group.

**AS: I find that there's this major focus in a lot of the remembering of this time, that people remember ACT UP New York. Sometimes they'll remember ACT UP Philadelphia, Chicago, but there's not a lot of actual popular memory that there was ACT UP chapters this side of the border. So, I've been wondering whether there were tactics like that – doing a march with the donkey and having a die-in – was there connection between the ACT UP group here and other groups in Canada or in the States?**

ES: No, I think it was simply most of what we knew about other groups was what we got through the news or through information put out by the groups. We weren't around long enough to become big enough to really affiliate with anybody. I don't see us doing a demonstration in the Catholic Church. Even though I call ACT UP Halifax radical, I don't see them doing that.

**AS: Right, in this context.**

ES: First of all ACT UP New York had a whole lot more members, so you could get at least a handful of radicals to do something like that. With a group like Halifax, even the radicals, a lot were country folk who had grown up in the church and even though, I think, most of us were

disappointed. When you come out, you're always disappointed with what the church does. You know, you can see your grandmother sitting there and is that the way to get the message across? Then again, if we had existed for a long time and maybe got some more people on board, I don't know. But with the original people, there might have been a handful who would've done that, but I don't think most people would've done that.

**AS: But there wasn't particularly a direct line to some other...**

ES: No, I don't think.

**AS: Interesting. Thanks.**

**GK: So, there's nothing more about the march with the donkey? I take it the donkey was originally supposed to be a pig, was a play on the Premier's name. The donkey was suggesting the slow-movingness or obstinance of the government?**

ES: Yeah. Yeah.

**GK: That sounds really neat. You don't happen to have a picture of that.**

ES: No.

**GK: We're definitely trying to find a picture of the donkey. One other action we've heard of that ACT UP either did or was involved in was the presentation of some sort of cake to the Advisory Commission. Can you tell us a little bit about that?**

ES: Actually, I don't know a whole lot about that. I'm not sure who started that, because I know that the Coalition was involved quite heavily in that one, so I don't know if it was the Coalition's idea and ACT UP hooked onto it. I wasn't in the city that week, because that's something I would have definitely gone to, and I didn't. I'm not sure where it would've been, but I do know that there was heavy Coalition involvement because I think Wilson was the one that presented the cake. I suspect because he presented the cake that it was more the Coalition's idea and they got ACT UP to assist ... But, again, it was this idea of, "Okay, you've been here" I don't know if it was one or two years "and what have you accomplished?" And again, it's that radical part from the early days that says, "People are dying quickly; you can't work this through a bureaucratic system." I do remember there was some confusion in the press over it. They weren't really sure what to make of it. Other than that, I can't tell you very much. I'm just quite sure that it was more a Coalition thing.

**GK: Maybe we can move back to talking about what happened at Rumours? What was the plan for that particular night in terms of raising AIDS issues?**

ES: ACT UP had been having parties, again, in this big loft at the hostel and partly tied into with the shirtless issues because women were invited and anybody could go topless. And it was a dance party, but at the same time people were discussing. So, it was a mixture of like having a meeting with actually being at a dance. And the idea came through those and how even when people were

dancing, they were discussing AIDS issues or whatever was that, since a lot of the gay community didn't particularly want to hear the message, then maybe we should take the message directly to them. The plan was simply to takeover the stage for five minutes, get the music shut off and there were a couple of people who were going to speak and that was it. I mean, that doesn't sound particularly radical. It turned out to appear radical simply because the management ended up coming across as very conservative. We learned several things from it. First of all, my job was to get the DJ to turn the music off. Well, he didn't want to do that and I said, "Well, if you don't turn it off for me, somebody's going to make you turn it off." Now, the guy's like, 190 pounds. I was 120 pounds. After the event, when he relates the story to the manager, either he told her or she interpreted it to mean I was going to make him turn the music off. And it's like, "Yeah, right." Finally, he does shut the music off for a few seconds until the people on stage start talking and he finally understands what's going on. So, he turns the music back on. So, you got the music playing. You got somebody on stage with a bullhorn and the people on the floor are mostly booing and catcalling, which again sort of reinforces what I've said before about the attitude of the people at the bar. Once the people on the stage from ACT UP see that they're not accomplishing anything, they leave. Now, the bar had formerly been a theatre and at the back of the stage is a big full screen and somebody made a little nick at it on the way out, and that's where the trouble came from. Well, I mean there would've been trouble simply for the actions of the people involved, but that's where the major trouble came from. The group said, Yes, of course, we'll pay to have it repaired" - a couple of hundred bucks. Well, the management decided they had to have a whole new screen.

**AS: And the management was the gay group in town.**

ES: So, this is what basically led to the folding of ACT UP was simply because we were going to be presented with this bill of several thousand dollars, but there were several problems. First of all, I get called into the manager's office the next week. I just sort of cringe now when I think about it. And I've replayed it in my mind so much now I don't remember whether she said, "You've been a 'naughty boy' or 'you've been a bad boy.'" And I'm thinking, "Christ almighty, lady. I'm in my 30s. What are you talking about?" Of course, her version of the story was that I had threatened the DJ that if he didn't stop the music, I would force him to. And I said, "Well, look at me. Do you think I could force him to?" Anyway, the end result, I was barred from there for four weeks. The people on the stage were also barred for their activity and this is when the whole thing about the screen came in. There was somebody I think from the Valley who came down to actually look at it and that is where the couple of hundred dollars to repair it came from was this was a professional guy. But the manager said "No, that's not going to happen. We'll need a whole new screen." So yeah, I think we lost all the way around. I shouldn't say we lost. It just showed that there was no appetite in the community.

**GK: Was there any response to your being barred and the other people? Do you know who the other people were who were barred from that club at that point? I know some other people were because of the shirtlessness issue.**

ES: Well actually, maybe I'm confusing the two. I'm not sure that the ones on stage were barred or if they had been barred previously for shirtlessness. There was a follow-up. I didn't know this was going to happen, but the next weekend, since I'd been barred I obviously didn't go to the bar, some

of them had run off a pamphlet sort of saying, “How strange it is that Eric Smith is being banned from a gay bar,” but that was basically the end of the whole thing. The general response was, “I’m out here to have a good time. I’m not interested in anything else.”

**GK: You began to tell us a little bit about how that led to the demise of ACT UP here, but maybe you could tell us a little bit more about that? Or your memories of how did it fall apart.**

ES: I don’t remember that it so much fell apart as it was just sort of the realization, everybody said, “Well, what’s the point?” Part of it also, I think, Dan was moving away, and Dan had been sort of the focus of the whole thing. And nobody else stepped in to try to lead the group.

**AS: And he had the physical space where the parties happened and the meeting bed.**

**GK: The meeting bed.** [laughter]

ES: Yeah, I think a lot of people just sort of said, “Okay, what’s the point?” You know, when you’re going after government, or official government, you expect to bang your head against the wall. But when it’s the affected community and you’re basically getting the same reaction from the men, it’s like, “Who are we talking to but ourselves?”

**GK: Was there anything more you wanted to say about ACT UP? Anything that’s come up in the conversation you haven’t had a chance to say?**

ES: Not that I can think of.

**AS: I just have one more question about it. Were a lot of the people who were involved in ACT UP people who had that same path that you had of being involved with the PWA Coalition and then wanting to have a more radical space where people were...?**

ES: No. Actually, I don’t remember that anybody else involved in ACT UP had been involved in the Coalition. They may have been to some of Coalition events, but had not actually been involved in the Coalition. And I don’t recall any of the people who were active in ACT UP actually being infected. Their involvement came about totally different from the people who were involved in setting up the Coalition.

**AS: Do you remember if there was a formal decision? Like, “Okay, Dan’s moving away. Let’s dissolve this or let’s let this go” or was it more organic?**

ES: If there was a meeting where that was decided, I wasn’t there.

**AS: And then it wouldn’t have been that people who had been involved with ACT UP would have progressed into working with the Coalition or working with MACAIDS because they would’ve been...**

ES: No. Some of them still went to some of the Coalition activities, but I don't recall that any of them got involved with the Coalition. To a certain level, I think it would have been very difficult for them to become involved with the Coalition. We had felt that the Coalition had been bad-mouthing us anyway, sort of. Their attitude was that, by ACT UP being vocal, it was making it harder to achieve anything with government officials. So yeah, it would have been really difficult for ACT UP people to become involved with the Coalition.

**AS: That's also so interesting that they wouldn't have... Sometimes, when I've been involved in more institutionalized spaces, actually at some level, they're happy that there's a more radical group that can say and do things that they can't do that isn't tied to their funding guidelines or not being too political in order to continue being able to pay staff.**

ES: Well, that was the core reason for setting up the Coalition. The first year the Coalition had no funding and the problem was MACAIDS was not radical. And that was the whole concept of the Coalition, which is why, because I kept that philosophy, it was easy for me to work with ACT UP. But the newer ones that had come on the Coalition board were much more content to work through the system. I don't want to overstate, but to a certain point ACT UP was stealing some of the limelight. Because to go to people for anything on AIDS was the Coalition; suddenly, sometimes the press were going to ACT UP and the Coalition didn't seem to appreciate that there's some value in having a radical group.

**GK: The other aspect that I think's important perhaps to bring out a bit more, you've already sort of hinted at it, because ACT UP provided a context in which women could be shirtless, there seems to have been more women, probably HIV negative women, involved in ACT UP. I wonder if you just wanted to talk a bit about that in terms how it brought some groups of men and women together in a different way.**

ES: I think for me, that always sticks out as the major issue, I guess, probably because it went on longer than one time events. And I don't know that it actually did anything for the issue itself because the people that went to these parties were also the vocal ones at the meeting of the gay group in wanting the right to go shirtless. Men who were uncomfortable with women taking their tops off weren't coming to our parties, so they weren't experiencing something new and getting comfortable with it. While a lot of the people who came to the parties were comfortable with it, it wasn't reaching out to anybody else. I often thought at those parties, if the good parents of kids at Sable Island could see me at this party, what would they think of my qualifications to teach their kids?

**GK: So, there's not that many more questions. It's basically coming back to that first attempt at the AIDS strategy and then if there's anything more you wanted to say about people who've passed away. Those are basically the two crucial questions that remain.**

**AS: What about the PWA Network? Did we talk about that last time?**

**GK: We did talk about that, but the one thing you didn't mention, was Doug Wilson's involvement in that and I did want to come back to that. Maybe if you just mention your**

**connection with Doug Wilson through that because this can also be part of remembering Doug Wilson too.**

ES: Doug was, I think, vitally important in trying to organize a National Persons With AIDS Coalition. As I understand, he was the one who had put out the original call for representatives from each of the regions. And the meeting I was at, he was certainly the one who had done all the research. He knew all the ins and outs. I think he had a really good idea. It's unfortunate that it didn't get carried through. And on a personal level, it was great to meet him, meet Doug, because I knew of him before. Obviously, he had been in the news with gay rights issues for a long time, so it was great to meet him and his partner Peter. He was really the driving force behind the whole thing.

**AS: And why? What was his idea for it?**

ES: Basically, his idea was having a group of PWAs speaking and agitating for themselves. Again, it gets down to this cutting through the bullshit. And I don't want to be critical of CAS [the Canadian AIDS Society], but representing all the community-based groups in the country, they seemed much more willing to do that. They will sit down, "If we don't reach agreement, we'll meet again" and they would meet again. From Doug's point of view, working on the frontlines with people who are dying all the time and people who are sick and don't have the services they need, we don't have the time to do that.

**AS: Have another meeting later.**

ES: No. That's why I strongly supported the idea and I think why, when it was first talked about, the Coalition supported the idea. But of course, to make something like that work you do have to have funding and the feds were not going to have any part of that. Then again, it's also important to note that some of the people who were most against it were the very ones who a couple of years earlier were advocating that attitude of going after the government and not pussyfooting around. I think for some of them it was a matter of, they weren't being involved in the original planning of it and since they weren't being involved then they were going to try and castrate it right from the beginning.

**GK: My memory is that AIDS ACTION NOW! supported Doug in doing this initiative, but it was his initiative that AIDS ACTION NOW! supported. So, I don't know if there would've been other people who could've acted on it. And he was also getting sick by this time.**

ES: Yeah.

**GK: So, your memory is that the feds actually rejected the funding application?**

ES: I don't know if a proposal got put forward or if just in preliminary talks. They just said, "Don't even waste your time." Again, it's unfortunate because if the people in the Health Promotions office in Halifax would've been in charge, I think you might've found funding. They were the ones who managed to get full funding for the Coalition even though we weren't entitled to it. That's

what I was saying earlier about the response we've had in Halifax with the people who are working one on one, we've had great results. And I think you would've seen it. Fortunately, you would have seen a different reaction if these people had been in charge.

**AS: So interesting.**

**GK: The second time, I think, I met you... I met you earlier on, maybe you were doing a speech at Acadia or something, but probably the third time I met you was actually when we were organizing around the province finally trying to develop an AIDS strategy. And I was just wondering if you could share any sort of memories of that or ways in which you would have evaluated their highly inadequate AIDS strategy.**

ES: For me, when they come out with the strategy in the summer of '92... this is almost four years after the Task Force on AIDS had made its recommendations, and they had done basically no more than restate those recommendations. They had not said anything about the ones the government had turned down. There were several of the recommendations that needed some in-depth work to implement them, such as creating a sex-ed program for public schools. Some of that had been done, but that wasn't done by the Task Force or by the Commission, they had simply delegated it to people in the Department of Health. So, four years later from the Task Force basically nothing had changed. They had the Advisory Committee on AIDS. Some of the people on there were infected, I don't if they were called focus groups at that time, but there weren't stakeholders. From what I could tell, there was no outreach to stakeholders. Well, I shouldn't say that. They talked to maybe the top people at some of the AIDS groups, but by '92 most of the people at the tops of the AIDS groups were somewhat integrated into the provincial system, so they weren't going to stir anything up. So yeah, it was frustrating. Obviously, they could not force the government to make the changes to the Human Rights Act or implement anonymous testing, but they could do some simple things drawing studies from other places about the effectiveness of anonymous testing in getting people to be tested. Or what's happened in other provinces with including things in the Human Rights Act. But they didn't even do that kind of basic stuff. And, having said that, I should qualify it by saying, there were some 'apple pie' statements about, "There should be no discrimination in health care settings" and that kind of stuff. If you give me a week, I can come up with a whole lot of those things. They aren't going to effect policy, or make life any better for anybody.

**AS: Change funding priorities.**

ES: And I think, actually, you've hit the nail right there with the funding priorities, because that was one of the things. One of the recommendations, it was passed on to the Advisory Committee, was to look at the province funding AIDS groups, and after four years – nothing. You got nothing. And I think that was the one that was probably the biggest disappointment. It was disappointing, although eight or ten years later when they came out with a new strategy, early 2000s, it was just as frustrating. I think the only thing that had changed is that they claimed to have talked to some stakeholders in that they talked to some people who were HIV positive. Unfortunately, the HIV positive people they talked to were the ones who hung around at the Coalition office. Now, I don't mean to say that you don't take their views into account, but their views, what they're thinking, is

based on what they're hearing in the office. I was never able to identify one independent person who was contacted about things they were looking at. And again, the strategy was this very vague thing. It's we need to "improve" something or other. Okay, but now that you've been going for eight years, nine years, could you maybe suggest how you could improve this. So, both attempts were basically useless I think.

I think the bottom-line is that the Commission allows the government to cover its backside, because the government can say, "Okay. Look, we've got these people who are working on it." And that's basically what it's accomplished. I actually was on the Advisory Commission for a year and I remember being asked if I wanted to have my appointment renewed. And I was like, "Why? Why?" First of all, you meet one evening a month. Now, that's not going to accomplish anything in itself, but we were doing this endless, endless, endless thing. The year I was on they were discussing anonymous testing and I can remember there was a doctor on there from Dal Medical. And he kept saying, and I don't remember what it was now, but basically what it amounted to was having nominal testing but calling it anonymous testing. At the time I was still involved with the Coalition, and he said, "Will the Coalition accept this?" I said, no. "What if we do it this way?" "No, that's not anonymous testing." It went on and on and on, and it's like, "Why are we discussing this? If it's not going to be anonymous testing, don't try to call something else anonymous testing." And that's what it was the whole time. So, twelve meetings – that's quite enough. I can sit home and grumble to myself instead of coming here and getting migraines listening to these people. So, it wasn't a matter of, as I said before, looking at places where they were using anonymous testing and seeing if it encouraged people to be tested or whatnot. It was just a way of, "How can we seem like we're doing something without doing something?" Again, covering the government.

**AS: We hosted this little public history thing in Toronto that was looking at criminalization and resistance to criminalization. So, now one of the things that seems to be happening more is people trying to manage viral load and having doctors involved in saying, "This person is a problem because they're not taking their meds" or they're not. And I've just been reflecting on what it would look like. How things would be different if certain things had happened around things like anonymous testing, anonymous treatment? What kinds of things might be different now? And of course, a lot did happen. People did a lot.**

ES: And the press the next day... I mean, they obviously talked to me because I had been...

**GK: This is the media conference that, I think, you spoke at?**

ES: Yeah. The two statements I make, the thing that most discourages me about the strategy is how similar it sounds to a lot of the recommendations that were made to government four years ago and very little progress has been made. I think at this point the Commission should be saying exactly what the government should be doing, and it mentions anonymous testing. But also you got Wilson Hodder, who's chair of the Coalition, you have Gary Kinsman himself who comments here, and they also talk to the Black Outreach Worker, and the Women and AIDS Outreach Worker, and they point out that the document doesn't mention minorities at all.

**AS: And this is in what year?**

ES: '92. So, they're well on.

AS: Yeah.

**GK: As an aside, the one useful thing about that experience was in terms of organizing. I was involved with the Valley AIDS Concern Group then and was the person from there who was doing some of the work with this group. But there was actually for the first time, that I'm aware of, a meeting of people from all sorts of different groups across the province that would do work around AIDS and HIV concerns. And not just groups that did that kind of work, but groups that might do it as a small part of what they did. I think the Pictou County Women's Centre was involved, a whole bunch of different groups. So, that was actually important, but I don't know if anything came of that. I think it sort of fell apart or collapsed after this. After this, we did have meetings with government people trying to lobby them, and I think maybe even before it, but we've got to recover more of that history too. But that's where I remember... I'll just mention this one story. So, there was a meeting the Red Room in the Parliament Building and Tuma was the first person who spoke, and just reminded everyone there that this was the same room in which the Proclamation around the scalps and the value of the scalps of the Miq'maw people were done. I just thought that was quite amazing. That's all I wanted to say. [laughter]**

**AS: I just put the camera on you so that we could see. Also, your red shirt looks good with the call for Chretien to have an AIDS strategy. [referring to poster on the wall behind Gary]**

**GK: So, in terms of other questions. We've already, especially when we were at Anita's, talked about a number of people who were involved in the PWA Coalition who have passed away. Are there any other memories or comments you wanted to make about anyone who was involved, especially from that early group when you were most involved?**

ES: If you go back to the early group... I don't know how to say this, I wish most of them had still been around in '94-'95 when the government said, "Okay, we're going to cut funding and the two groups have to combine," because everybody, both groups, the boards, trotted off to someplace in the Valley to have a confab and myself and Peter Wood were invited. By this time, Peter was back from Newfoundland; his health had started to deteriorate ... And we were known as having big mouths sometimes and were not attached to either group, so. And of course, both Peter and I were against the two groups joining. Maybe not so much against the two groups joining as there not being some group that was specifically HIV, because we remembered the reason for setting up the first Coalition and we had seen the downslide it had taken, and we were worried that basically the voice of PWAs was going to become invisible again. Basically it was a waste of a weekend, because they had already obviously decided, unfortunately. And this is usually what happens. People with pull in the two organizations were more concerned about making sure they had jobs. Having said that, I understand the rationale for joining if half the funding is going to be cut then, obviously something's got to give. So, on a certain level, I understand it. But again, it's the losing of the HIV voice. When the two groups did join, the new board had to be 51 percent HIV. The issue of course was they didn't have to be publically identified, so you had no way of knowing in fact... Well, at

first I think we trusted them that they actually did have 51 percent, but there was no way you actually knew in fact if that was true.

**AS: Was there someone who would be like entrusted secretly with that knowledge?**

ES: The way it goes, before the end of a general meeting, they come up with a list a people. The people in the office, the fulltime staff members, would be aware if some people were HIV positive who weren't public. So, they could have approached them to be there. The thing is, since they weren't publically identified, you didn't know actually if there were nine out of sixteen or whatever. And it did become an issue later on, because after several years it became clear that half of them weren't HIV positive, and they didn't even pretend. The issue was we can't get HIV people. Okay, why don't you look at the organization to see why HIV people aren't becoming involved anymore? I mean, for some people hanging around the office is important to them. Most people no longer feel a desire to be involved because there's no chance for input. Again, I go back to my early experience, our board made all the decision. We decided what was going to happen. When we had staff, it was their job to carry it through. Over time, especially with this Coalition, with the group now, the staff go into meetings with recommendations, which the Board who, again, different from our day when the Board members were around the office all the time, they were only there for the monthly meeting. And so, they automatically approve what the staff say without taking into consideration, "What do the HIV people actually think about this?"

So, that's far removed from your question, but I wish those people from the original Coalition were still around because I think certainly we would have been able to set up at least an informal, vocal group of HIV people who could still do the public speaking thing. We obviously wouldn't be funded, so we wouldn't have office space and that kind of stuff but, I think we would have. The way I look at it is I simply look at what happens when infrequently now, but when there is an AIDS story, the press come to me and it pisses the Coalition off to no end, but the story will be full of quotes from me and the last paragraph will be from someone from the Coalition. And it's like, okay, if I were working at the Coalition that would tell me something, but they don't see that at all, that they should be trying to invite input from the affected community. That just doesn't seem to be there at all. To a certain point some of the policies are a bit strange. If you wanted to try and track down somebody you knew ten years ago, they won't even tell you if the person's still alive. I mean, I understand confidentiality rules, but they won't even tell you if the person's still alive. And I can't say for sure now, but I know at one point they wouldn't even introduce people in the office to each other.

**AS: Bizarre.**

ES: They were taking confidentiality that far.

**AS: That is the opposite of the way it sounds like it happened in the very early days of the Coalition. It was a place for connection.**

ES: So, I think if those people were around. You know, if you had Frank Morton, Fred Wells, Dale Oxford, Bruce Davidson, Peter Wood, and some of the other people who came on later, Raymond McDougall ... I think people like that who were vocal enough, while we probably wouldn't have a

formal organization, I think we could still draw on that background support that we got from the advisory committee. People who want to help, but know that the voices of people living with AIDS/HIV themselves have to speak and that's why... I don't remember that any of the advisory board was ever involved in the new group. There was this feeling that the new group isn't focused on HIV, it's a top-down organization. But yeah, if some of those people from the early days were still around, there would still be some sparks under some people's backsides. [laughter]

**GK: That's a good memory. Maybe just three more questions then. One is that you can answer if you want to, but I just wanted to ask you how your involvement with the PWA Coalition and ACT UP changed your life, or sustained your life.**

ES: These are things you can't quantify, and I don't want to overstate it, but I think it's part of what kept me alive. I'm basically an introvert, so when you suddenly get this big crisis attacking you and you feel like you don't have a whole lot of support. My family, people who knew me very well, thought that I would just crumble because they knew me enough to figure, "Okay, he's going to lock himself in a room and avoid everything and that will just be the end of him." So, I think they were really surprised when I didn't do that. The first year I had the Task Force, so that kept me busy, but then the Coalition keeps you busy in a much different way. The Task Force is a government-type thing so you get deadlines to meet and all that bullshit, and at the same time you were accomplishing something because when you're doing the media, if you would do it calmly and rationally, you do change people's attitudes. But the Coalition, you still had some deadlines, but a lot of it was more the touchy-feely – helping people who were going through a crisis; helping someone who wants to die at home; trying to get somebody on medication, to try to get them hooked up to a doctor or get them on medication. And I think that helped me certainly survive and helped me not lock myself in. And I have to say, having said I'm an introvert and basically a quiet person, you can get a hell of a lot of satisfaction out of screaming at politicians and religious people. By god, it's a wonderful form of therapy. There's a British comedy that I watch quite often and this older lady is out beating a rug, and a younger lady next door to her starts vacuuming her rug, and she says to her, "Isn't that a bit old-fashioned." And the old lady says, "Well, that's what we had to use. It's what we used before nervous breakdowns were invented." [laughter]

And I think there's something in that. Actually hollering at people. Again, not me doing interviews and stuff where you're trying to change the general public's opinion because you don't accomplish anything by screaming in there, but I think part of hollering at politicians is just to get them to recognize that you are saying something. If you talk quietly to them, they don't even notice or realize that you're in the room. I found something very therapeutic about it. So yeah, I think my involvement with the two organizations was really beneficial for myself. And I think the whole thing I went through, certainly in hindsight, and I know after I settled my case and had a year to calm down, some people think I'm strange for saying it, but I'm glad it happened in that hindsight does show me that it helped to change attitudes. Not only for the general public but for a whole lot of people who were infected or affected who had never talked about it to anybody. Now, I'm not particularly religious, but my dear grandmother who was a good devout Baptist, when I told her that I was infected one of the first things she said was, "God must've chosen you because he knew you would fight this through." And I think that's what it became. It was not, "Would I actually win my case?" And one of the things that I think really clued it into my own mind that there was value in what I was doing was, this must've been about January of '88, the Task Force had only been

going for about three months, and I was doing a workshop somewhere in the New Glasgow area. There were two teachers there from Cape Breton, just the other side of the causeway and they came up afterwards, and they said they thought they had a kid in their class who was infected. And what should they do? How should they approach it? And I realized right then, “Okay, as difficult as this battle is for me, what if the publicity thing was happening to the ten year old. How difficult would it be for him?” And that’s sort of what clued in for me that there’s value in doing this and it’s not about you, whether you get your job back. So yeah, in hindsight, I’m glad it happened. I get to educate in a different way and sometimes talking dirty is fun. In fact, most of the time talking dirty is fun.

**GK: That’s a really good line. So, the only I think the remaining question, because I think you’ve given us lots of people to talk to already, is just if there’s anything else that’s occurred to you as we’ve been talking that you haven’t had an opportunity to talk about?**

ES: I can’t think of anything. I still like to get together with the few old-timers who are still around, more to compare stories. And there are a couple of older guys who’ve been infected for a long time who are not public about it, and one of them, most of his family doesn’t even know. But it’s talking about how we see the same thing from a different angle. How I saw much differently being in the public eye and how they see it from being very quiet. So, you get that whole process. That whole timeline has been really interesting.

**GK: That’s great. Thank you so much for this.**

[END OF TRANSCRIPT]