

AAHP
AIDS Activist History Project

Interview Transcript 27
2014.028

Interviewee:	Sean Hosein
Interviewers:	Alexis Shotwell & Gary Kinsman
Collection:	Toronto, Ontario
Date:	November 15, 2014

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Persons present: Sean Hosein – SH
Alexis Shotwell – AS
Gary Kinsman – GK

[START OF TRANSCRIPT]

AS: It's November 15th, 2014 and we're talking to Sean Hosein.

GK: What we do at the beginning is to establish some common questions that we ask everyone. So, the first question we ask is do you remember when you first heard about AIDS and what you heard about it?

SH: It wasn't called AIDS in the very beginning because it was such a new syndrome. It was so shocking. The names kept changing every few months as more cases appeared and they were different from the first cases – different complications, different infections, and different people. It just confused everybody. So, I do remember it. It was 1982 in the winter and I was reading a *Toronto Star* article and it was a large *Toronto Star* article of at least one page, maybe two, and it was about "gay cancer." It was very striking because, well, who ever heard of anything called "gay cancer"? I mean homosexuality has been around for as long as we have and there was never, never anything called "gay cancer" and there wasn't even a straight counterpart, "straight cancer." So, it was quite an arresting headline because in those days you simply never saw anything about gay, straight, whatever – gay, or lesbian and bisexual. It was rare. So, it had these two arresting words in the headline that just pulled you in. And, at the time, I was still a teenager so it was fascinating to read this as my sexuality was evolving.

GK: Do you remember during that time period, what would you have been reading that would have given you information around AIDS or some ways of thinking about it?

SH: It started to appear – so we would say between 1980 and 1985. It would appear in *Newsweek* and *Time*, and then occasionally a few other papers would reprint articles that the *New York Times* had printed about 'gay cancer' and about the effect of what would later be called GRID, Gay Related Immune Deficiency, and then AIDS finally, in 1982, in the summer; it might have gotten the name AIDS after going through all these changes. And so, those magazines were the source. But I was also going to university at the time, I was bored and I would go to the university library and in the back of my mind was this 'gay cancer' thing and I would read the leading medical journals - *The Lancet*, the *New England Journal of Medicine*, and so on. And there you would see these reports of these cases of what we now call AIDS. And just as a postscript to that, I had suffered from severe allergies as a teenager. I had to educate myself about how to deal with this because I wasn't happy with the medical care I was receiving, so I had to teach myself immunology as a teenager. It took several years of being at the university library. It was like going to medical school at night, but I had all this knowledge of immunology, because that's what allergies are. And

the several years later this new epidemic came, which was... The 'I' in AIDS is about the immune system – so it was very easy to translate that knowledge into understanding this.

AS: I was going to ask you how did you come to even be like, “*The Lancet* is a thing that I could read”?

SH: Well, the descriptions in the first seven years of what we now call, the AIDS epidemic were just that – descriptions. They had no idea what they were dealing with—the complexity of the syndrome that would later be called AIDS. Parts of the immune system for them were new. It would be, “A patient came in with these symptoms; we did these tests; we looked under the microscope; and the patient invariably died as his/her body was overwhelmed by these strange germs.” And so there were many theories in the first three years of what might have caused AIDS, but fortunately a junior scientist working in the basement of the Pasteur Institute, Françoise Barré-Sinoussi, isolated HIV in 1983 and that then focused things much more, because before then there were just all these crazy theories.

AS: This is not a question, but I was at a party and I was talking to a guy who does blood tests, he’s a lab technician. And he was telling me this story about the machine that was built to count t-cells.

SH: FACS scan, fluorescent antibody cells sorter, flow cytometers. Yeah.

AS: He said that the guy... I just feel that you might know the...

SH: Rosenberg.

AS: ...who discovered that printed a book that said, “Here’s how to make your own.”

SH: I didn’t know that part, but there were two scientists a man and a woman; Leonard and Leonore? Herzenberg, yeah – did it. Before this, you had to look into the microscope and count t-cells, right. It’s very time consuming to do this manually; you could make mistakes... And it’s annoying. I mean, I’ve been in labs and done the same thing. So, this machine – developed in the late 1980s – was wonderful because you could start to look at all kinds of cells, not just the ones targeted by HIV. And so you could begin to try to understand more about the immune system. So, it was interesting. I don’t know if he did make that book, but he did tell people how to make it and since then, these cell counting machines – flow cytometers is the scientific name for them – have proliferated; they’re a lot cheaper, and they’re a lot fancier and they are very useful.

AS: It seemed so true that there was this innovation that took off because it was a way to measure and then be able to do treatments for HIV, but then it’s got these applications in Leukemia and all these other places where you’d need to be able to know – if I tag this cell and I fluoresce it, this is what it tells me about what’s happening in relation to...

SH: Yes, it has applications for studying the immune system. It has applications for cancer, for anything that affects the immune system. And the immune system is the least understood system of the body. Maybe apart from the brain, but even then it's a toss-up. I mean, how does consciousness really work, you know?

AS: But listening to it I felt like I wanted John Greyson to make a film about the way that the HIV and AIDS activist movement was functioning like a flow spectrometer for the, you know... like, I could just picture a musical number. Anyway... [laughter]

SH: Well, John Greyson does have a movie that I remember. He was asking activists if they wanted to be you know a virus or a T-cell in this movie and stuff like that, and then some of them accused him of typecasting.

GK: That was *Zero Patience* (1993) and Michael Callen got to be HIV.

SH: Yeah. You know, but I think theatre like that is very important for educating people and entertaining them.

GK: So, coming back to the 1980s: So, you're really interested in AIDS; you're starting to do reading about it...

SH: And I should add one more thing. Sorry. Part of the thing was, I was also starting to grapple with my sexuality and this happened throughout the early 1980s. It was very annoying in retrospect. They never really explained to us how people could become infected. They always said "bodily fluids". Well, what does that mean? Is it tears, saliva, nasal secretions? Are those secretions infectious? And it was all about a reticence to talk about – talk very clearly and explicitly about anatomy and sex. And I think that's one of the good things that AIDS has had is that it's liberated talk about sex away from body fluids. Now, we saw a resurgence of this language with the Ebola crisis where I saw the phrase 'bodily fluids' and I thought the parallels between the early days of AIDS and Ebola are stunning – the panic, the fear, the hysteria, the lack of knowledge, the confusion. I mean it makes for great media, but also are all bodily fluids infectious? How exactly do people become infected with Ebola...? You know, these are things they are now wrestling with because they've never had the chance to study Ebola because it's been so lethal; people usually died out quickly... but what has happened in West Africa is awful.

GK: How did you get involved in *Rites* magazine?

SH: *Rites* was a driven and focused lesbian and gay – emphasis on the lesbian – gay political magazine. This was at a time when politics was being sucked out of regular gay magazines and you had *Rites* come up and say, "You know what? There are still important political questions here that we have to grapple with and we will have to grapple with for a long time. It's not all song and dance, people. I mean, we will have song and dance too, but there are still important unresolved issues." And it was extremely generous of the women in the movement – lesbians actually, or women who identified as lesbians – to allow me, somebody they didn't know, to come in to their

magazine, which was at least – we would joke about it; that is, the men in it would joke about the amount of content given to women’s issues and men’s issues – but a minimum of 70% at the time went to women’s issues. It was generous of them, extremely generous and kind, and it showed that these women realised that AIDS was a political issue. Because, yes, it’s not just about testing and so on – when the tests came out in 1985. But what was going to be done with that testing information? Because there was no cure and there was no effective treatment at the time, so what would be the point of testing, you know? And there was this awful talk of – because it was a deeply homophobic time. Again, unless you were living there, it’s hard for young people today or anyone to imagine. But it’s maybe similar to what would be the political environment in sub-Saharan Africa right now – I’m not sure, you know parts of Asia and so on – that gay people were extremely despised, and I think that’s being kind for the most part. So, there was talk about quarantine and it was all about protecting what was called the ‘general public’ (whatever that means) against these, what were perceived as nasty – in multiple layers of the word – “homosexuals.” They weren’t seen as people who were sick and deserved medical care.

And I might point out that Public Health and the government did very little in the first decade of the HIV epidemic to help people who were ill and who were dying. You know, when you had the Tylenol scare, when you had Legionnaire’s disease, when you had anything like that Public Health moves swiftly and rapidly to deal with that - Toxic Shock Syndrome even. But, for the first time you had people of a minority who were despised and who were dying and the official policy was official silence and official indifference. And I think gay people at that time felt abandoned. They are citizens just like everybody else and it caused a deep sense of alienation among people with HIV and people who were their friends, and gay people as well. It was a double whammy for them. The state was trying to deny people their civil rights and they were actively opposing measures to help people with this plague. And that official indifference made AIDS far worse than it would ever be. Its spread was what is described as exponential; it means extremely far and fast. Had they acted in a responsible way – authorities around the world – when this broke out, HIV would not have spread so far in Western Europe and Canada and other countries. But by the time they finally started to act it was too late. It was awful and you could see this happening again in West Africa with the Ebola epidemic in that region when there were just a few spots happening in the most affected countries and, again, the officials and governments did nothing because Ebola was affecting poor people in isolated areas.

I remember, because one of my duties is to track emerging infections that could become a threat to us, so I was keeping track and I was just angry that the governments in West Africa didn’t act, and they didn’t act because the elites weren’t affected and it was affecting poor people and they thought, “Oh well, it’ll burn itself out in the rural areas. It takes seven hours for us to get there on rickety roads” and the same mistakes that were made with HIV were made with Ebola. And now look at it. It may take many years, to bring Ebola under control. It’s not a threat to the whole planet as it is now, but it’s very bad for the three most affected West African countries. And now there are all these orphans, just like there are with AIDS; their societies were never strong before and now they are worse off. Anyways, I got off-track.

GK: No, that’s right on track.

AS: It seems like immediately people that you were engaged with and talking to and knew understood that this was a political issue that needed a different kind of response than only a medical response, or did that come later?

SH: Well, it came because I was very privileged to be in this house with these intellectuals and critical thinkers and also meeting people like Gary, Mary Louise, others outside of that house who had political consciousness. Society doesn't just run magically. Things in society are skewed towards the advantage of the point one percent (0.1%) of upper income earners. If you want to look at it economically, what's constituted the 0.1% has changed over time, but it's still that group in control. They control the corporations, and so on. And I just want to say a sidebar here – I remember back in the 1980s bringing to them a little summary of Noam Chomsky's work about politics and they were all... well, not laughing. That's too strong a word, but giggling and stuff like that.

GK: This is the people in the house?

SH: Yes.

GK: Can I just say it was Seaton Street?

SH: Yes.

GK: Okay.

AS: So, who lived in that house? Do you want to say who lived there?

SH: George Smith, who co-founded the Right to Privacy Committee. Was he involved with *The Body Politic*?

GK: No.

SH: The Right to Privacy Committee that protected gay men from one of the largest civil rights violations in Canadian history at the time, where the Attorney General had unleashed the police on gay men in bathhouses and so on. So, he founded that. He went on to found AIDS ACTION NOW! (AAN!), and later CATIE (Canadian AIDS Treatment Exchange) as we get to your struggle. So, they had all come from the left and had this perspective of... I think one of the things of being gay at that time was that it gave you a sense of being an outsider. And when you look at history, you look at, "Okay. Who's controlling society and to what effect?" Whether it was stealing land from Aboriginal people in Canada, whether it was making a certain category of people less privileged or to have no privileges or rights, such as slaves, women in the pre-modern era, and so on. The same analytic that you can use there you can also use on gay people to help them. The feminist movement is really important because in the 1970s women's health became more of an issue and reproductive health and reproductive rights became more important. And that was one of the wonderful things about *Rites* magazine and about the early AIDS movement is that the women who were involved in

the struggle for reproductive rights also had experience with the medical healthcare system and they brought that knowledge to us, showing that medical knowledge could be democratized – that it was not the purview of the doctors, the heads of departments in hospitals, or even a family doctor; it can be for everybody. And you can take charge of your body for yourself to paraphrase a popular women’s health book at the time.

That was another advantage of being in *Rites*, is that they had a political consciousness. And people came, like I said, from all parts of the left. So that analytic allowed them to also bring in history to show how... I keep going back and forth between gay liberation and AIDS liberation, but Gary’s work and writings, as other people’s “The Fruit Machine,” and so on showed the political underpinnings of the regulation of desire and the regulation of what are called, or were called, “homosexuals” and stuff like that. It just seemed a little ridiculous. Not the writing, but that the state would try to control desire. So, we had come from a history of understanding how the 0.1% would try and do things to their advantage, whether it was stealing land or whatever. So, coming from that standpoint was also an activist standpoint that, you know, if women could fight back so could we. If black people could fight back so could we. Thus this analytic could be used to empower gay people. And also Gary’s work was very important... I remember him writing about and also taking me to a film festival where I could see things about issues such as these... Gay people had been fighting back for a long time – the films about the Mattachine Society and stories about, you know they were demonstrating outside the White House for decades before we ever thought of rising up. So, there was also a culture of that. I think the fight back by gay men against the powerful Attorney General, the Chief of Police, hundreds of police, the court system even, was an astonishing thing – that these ordinary people could get lawyers on their side, the courts on their side, and successfully push back against the agents of the state was an incredible victory. It was wonderful. And that then, subconsciously and later consciously, caused people to realise, “Well, if we can do that, we can do other things.” And the crisis at that time was AIDS, which was met by official indifference – people were dying, people were getting sick. And doctors didn’t know what to do. Few if any resources were offered to help understand this devastating syndrome. AIDS was so new. So, I felt I had to help, and part of that meant taking the medical information that was coming around then about what doctors were trying as emerging promising therapies that weren’t yet approved, but at least they were trying something – France and England and the United States and so on, Italy – and bring it to people here to let them know that there are things being done and we should be trying these here too to help our HIV-positive friends. So, *Rites* acted as a vehicle for that and it was really wonderful.

AS: So, you started off writing... You said columns about films and reviews and then switched into doing more. How did you think about that work? Was it like translating or just sharing...?

SH: I believe nowadays that it’s called ‘knowledge translation,’ where you take highly complex stuff and bring it down to the level of the average person. And George Smith was really good in helping me do that, because he went over my first piece and edited it very well. He said, “No, ordinary people don’t speak like that” because when you try to become a person – to help other people to engage in knowledge translation – you in effect unconsciously become... you can become the agent of the state as well. And George would say, “No, this is stuff that the ruling apparatus

would use, but you're trying to do activist oriented work and you should not use their language because then you become caught up in their way of thinking, their paradigms, and so on." And he would gently try and steer me away from that. And it took some time for me to absorb that, but it made perfect sense and it was very helpful because if we had followed the dominant paradigm in medicine at the time, we would have encouraged in the mid- to late-80s the near-poisoning of people. And then we began to see, medicine was not a monolithic thing, as it is for trade and the media, but it is rather filled with tension about what is the best treatment for any condition, whether it's cholesterol-lowering or certain forms of cancer or some other health condition. . There are deep divisions in some areas of medicine. Some of these are papered over, but they're there and it's fascinating to read about. And so, anyway it was AIDS that allowed us to pry open the black box of medicine and research to get competing ideas out about the immune system, how it might work, how it might not work, and what people could do with it. Some of this is encapsulated in the movie *Dallas Buyers' Club* (2013). You can see that there.

AS: So, just because the syndrome was in formation, right – was it easier to see the fissures between different approaches or different ways of saying, “This is what it is”?

SH: Yes, because there was no standard of care. I mean, yes, the doctors would get the person to take a physical, nurses or technicians would take some blood for tests, and, you know, the doctors would scratch their head at the results saying, “Well, I don't know what to do now? I have no idea, this hasn't happened before.” And so, one doctor would say, “Well, I'm going to try this approach – boosting the immune system.” Another would say, “I'm going to try this approach.” It was interesting to see these sides of academia go at each other because at the time they had as much right to saying, “Let's try this.” We learned so much about research, about how research is done, or should be done, shouldn't be done. It was wonderful. It was a very exciting time and we weren't aware of how important this was, at the time we were doing it, because we were so busy moving from crisis to crisis – whether it was dealing with, “Okay, what's our next step as an organizational level” or “So-and-so is sick and we've got to go to the hospital and support him or her,” you know, to “Oh, we need to do a demonstration because the Minister's coming and we should get media attention.” And you know they teach media analysis now and things like that, but I learned very early on how to do a press conference and we were very lucky as AIDS activists that we had friends in the media who came and taught us media analysis on the fly. And told us how to write a press release to get impact because you want to get impact in the media; or, called at the time ‘column inches’. You wanted to get on TV to make your cause available; how to speak clearly to the media. It was fascinating. And it's really helped me in my presswork because I do have to do media relations from time to time and interviews. Sorry, your question was?

AS: Just about how, coming to see the ways that medicine was done and translating that.

SH: Yeah. So, for instance, I can give you a piece about cancer. So, there was this editorial in a journal of clinical oncology in January 1991, and it was titled, “What would you do if this were your wife, mother, sister, self?” And you found that radiologists would say, “Well, the best therapy would be radiation therapy.” Then you talked to chemotherapists – “The best therapy would be chemo for this.” And for the surgeons - “Surgery, that must be first.” So, there are these tensions

and they ebb and flow and I think as more certainty comes out from all those clinical trials that can disperse some of the uncertainty, but always on the cutting edge of medicine there will be uncertainty just because so little is known. And so, that uncertainty haunted HIV care for a long time – over a decade, I would say. It's only gradually, in the last decade, settling down.

AS: So interesting.

GK: One form this took for you was the column that... If I remember right, the first column was probably called "Treatment Update, but I may be wrong, that you published in *Rites*, but that became the format through which you did a lot of work. I was just wondering if you could tell us a bit about that, because it evolves through *Rites* and into *AIDS Action News*, and into TIE and CATIE too.

SH: I think we called it "Treatment AIDS" or something like that. We didn't realise this, but it generally took a long time after infection with HIV for somebody to come down with AIDS. Now, it takes about ten years for that to happen in high-income countries, Western countries. It can be a bit faster in Sub-Saharan Africa because there are many co-infections – malaria, and so on – and the strain of the virus is maybe a bit more vicious there, malnutrition is an issue, and there may also be genetic factors, but in the West, about ten years. So, we didn't know that at the time. We thought you got this virus and you got AIDS like that. [snaps fingers] So, that is why the word AIDS was used so much in the early days.

GK: So, you think the first one was called...

SH: It had "AIDS" in the headline and we didn't know it would become a regular column because the first one just never is like that. It was about understanding the immune system and what HIV did and all these problems it caused and da-da-da-da. To show people it was a really complex problem, even in 1985 – or sorry, it was '86 – it was extremely complex and there wasn't going to be a simple solution to this infection and epidemic. But it also... you know, I was educating myself and my friends. So, it became a story about that; and then, you know, it was maybe a quarter of a page, maybe half a page; and then, over time I got three-quarters of the page; and then, a whole page. Again, *Rites* and the women in charge of that magazine were extremely generous to me. And I think, part of it's out of the sheer concern. My own involvement in this arose because I also wondered, "Well, maybe I could get this, even though I've never had HIV." And it was out of concern for other people – who may have been like me – that I got involved in this and stayed involved for a long, long time. So, *Rites* very generously allowed that and then over the years it started to grow. And then we called it... I think we called it "AIDS Update" for a long time.

Then, George Smith and Tim McCaskell were talking in 1987 about a group that had formed in the United States called ACT UP and it got tremendous attention in the media and so on, and it was very electrifying to them. They are both HIV-positive and, you know, they would say how it was the Coalition to Unleash Power (ACT UP), right, and it was just a really empowering thing for them. But also, ACT UP was not just bringing HIV-positive people together; it was bringing HIV-positive people and their HIV-negative allies together to do incredible things – media analysis, to get publicity, demonstrations... And, you know, the demonstrations were sophisticated. They

weren't just going out with placards, they would be like this: "Okay, what are our key messages? How big is the font and everything? Who is the media contact person? Our press release can only have a maximum of three bullet points and less would be better." They also had artists and the art that they had was wonderful. It was so full of energy, but it was also educational. It worked, you know. And you had this great intersection of all these talented people in the middle of a crisis. That was a wonderful coming together of humanity that stands as something that should be taught to people – that people can come together from diverse backgrounds and do wonderful things in the face of oppression - wonderful, hopeful and successful things. We changed the world.

So, that news about ACT UP inspired people here. And at first I was a bit sceptical, so I did not go to the very first meeting of AIDS ACTION NOW! I thought, "You know what, I've seen things come and go. I'm a bit sceptical. Let's see what happens. I'll wait a few months." But Tim and George bravely organized the first meeting of AIDS ACTION NOW! at Jarvis Collegiate and they had so many people come up and join and there was so much energy and excitement about it that the organization took off. And then I thought, "You know, I'll wait a few months and see if it's going" because there are so many needs in society for so much activism. I'd seen things come and go – not done by Tim and George, but look at the mess society is in now. So, I was sceptical if this new initiative would last. George Smith, anything he touches turns into a wonderful organization that does something successful. He and Tim McCaskell, along with many other people; many of whom are not with us today, some are in the photo you showed me and some of the names that you mention there. So, after six months I started to go to meetings.

GK: Six months period was up. [laughter]

SH: Six months period was up – "Okay, you've passed your probation. You're functioning and you're coming up with good ideas, right?" I had a really high threshold for things; I still do. It's not enough to be functioning, but you've got to do something. And George Smith came up with the phrase that was echoed to me at the late Bob Gardner's memorial, and that is "documents and demonstrations." It's not just good enough to have a demonstration for rage or anger that you're feeling, but you've got to ask what is your demonstration going to accomplish? How is it going to help us move forward? Yes, you demonstrate because you're angry. That's fine. But what are your aims for the demonstration? Is it to get media attention? Is it to educate key stakeholders? Is it to do something else? Is it..." You know, da-da-da. And so we always had to have a policy document to go with our demonstration. Now, that policy document might just be a page with key issues, but our demonstrations became eventually guided by our policy documents so they worked together. I believe he called it D & D – documents and demonstrations.

GK: I heard of documents and demonstrations, I don't remember D&D.

SH: And George Smith would chortle when he said that.

AS: And he was the dungeon master.

SH: I would just say D & D. [laughter] And then I saw, "Wow. You guys – Tim and George and others – are doing all this stuff, but you also need to know there's a lot of work going on therapies

and we need to be able to articulate issues related to treatment.” So, I had my research skills... Again, it’s hard to imagine for somebody in the era of wireless internet, tablets, and mobile phones, and text messages, but you actually had to physically go in the library and you had to open physically something and look at it, assess it and photocopy it. I don’t know if people know what that technology is now, but it was very important because that’s how you got a copy of the article. Now there’s easier access to the cloud computing, billions of processing units of power, and I can bring any number of articles together, cloud it, and link it, and voila you have something there. We didn’t have that in the 80s. George was very into technology. He suffered from what he described as “Technolust.” And so, in 1985 he had his own computer, which was a very advanced and expensive thing then. And so, I was later building my own database of important articles and stuff up until the 90s and then a friend, who was a physicist told me, “Oh no, you don’t have to do that anymore. You can stop now because we have something in the lab we call Medline. You can just go to your home computer and do it. And it was wonderful. Anyway, I had to go to the library day after day. I could spend the whole day – sometimes evenings – photocopying, chase something, because there was no internet to chase these things down. So, you had to physically go deep in the bowels of the library to journals that had been bound into book form and photocopy those and chase a reference there that would lead to another... It was a lot of work.

The other thing was AIDS ACTION NOW! attracted in those days some very bright minds – people like Chuck Grochmal for instance. He used to work in the oil fields of Alberta, but migrated to Toronto. And he had found out about something called the American Foundation for AIDS Research (amfAR), which we hadn’t heard of. And he says, “Oh yeah, they have a treatment directory. It’s a book that comes out every quarter and it’s like a treatment bible and it tells you all the drugs that are being tested. Mostly in the United States, but also elsewhere” and he had one copy. And we went, “Whoa, this is great!” And so, that was one of our inspirations. Also, a guy in San Francisco, John S. James, produced a newsletter called “AIDS Treatment News.” And again, you can see the naming – the nomenclature – because, again, we didn’t realise that AIDS was the end point of a long ten, sometimes twelve, or fourteen year course of infection. It just wasn’t known at the time in the 1980s. All of these stimulated me. George made a joke once saying, “We’ve got your newsletter, Treatment Update, we’ve got amfAR, John S. James’,” something maybe from England or France, and I said, “Yes, I’m trying to make the best newsletter with the best information” and he goes, “Well, it’s nice that there’s competition out there. Competition is good” – you know, at once mimicking and mocking what is supposed to happen in capitalist society. He was very critical of how society was organized. And, yes, I would come home every night with a stack of photocopied articles from the library, come home to dinner and George and Tim would say, “So, what did you find?” And I could only tell them the good news because there was a lot of bad news in those days. And despite all my hard work of only giving them good news, they found out the bad news. I don’t know how! Because they never went to the library, so how did they find out the bad news? You know I actually kept files hidden from them because the news from some studies in those early days was so dreadful.

So, in AIDS ACTION NOW! we produced a lot and... I was very lucky. I came and I got my newsletter and people at the university – some of whom are in that picture – had access to is now commonly called a laser printer. Now, back then in the 80s that technology was expensive and precious and rare. But when you had something printed on a laser printer it looked *so good*. And they would take my text, copy-edit it for me, and publish it on this laser printer and I would go,

“Wow, that’s incredible. It’s real. It’s not just the ravings of me.” But also, this team of people developed. Bernard Courte is in the picture Gary showed us and he worked at the Ontario Institute for Studies in Education (OISE) which is now part of the U of T (University of Toronto). And he and other volunteers would book time on their big super computer and fancy laser printer and run it through there and publish the newsletter secretly as volunteers at the University. They would also very importantly translate it into French and this is one of things about AIDS ACTION NOW! – unlike many of the other activist groups that popped up and have now gone across the country – is that we always saw ourselves as a national organization; always saw ourselves dealing with Ottawa; and always saw ourselves as, well, bilingual. At least we tried to become like that. Certainly, that ethos was carried into the TIE (Treatment Information Exchange) project and CATIE and it took root, and today... Well, anyway... So, we called it “Treatment Update” and it was published, parts of it were published in *Xtra!* as well. And then, it became so big that *Rites* really couldn’t handle it anymore, so it had to be published on its own. And you know AIDS ACTION NOW! helped with that. I remember being on the steering committee of AIDS ACTION NOW! for a few years and being the secretary for a long time – and this also happened at CATIE in the early days – when it was all run on volunteer effort, other people translated as volunteers and so on. And I had to get money to send out the mail in an operation we called “Lick and Stuff” where you licked the envelope, stuffed it with the newsletter, and put a stamp on it. And we had this ceramic wheel that was based in a tray of water and you’d turn it and you’d take a stamp, rub it on the wheel, stick it on the envelope, and so on. You know, these are things today that people just don’t know about unless you worked in the ‘60s, ‘70s, or ‘80s in a small community-based organization. But yeah, we worked in a collective effort to do it. We would also do the same at *Rites* magazine, I would say. You know people, particularly the women, in *Rites* magazine were very supportive and for that I am very grateful.

And I think one of the major things that AIDS ACTION NOW! did that got it on the international stage was when the fifth International AIDS Conference came to Montreal in 1989. And we had been planning that for months because, as they say, “the whole world would be watching.” Tim in particular, and George, but Tim McCaskell was planning these demonstrations, what they would do and they were trying to coordinate it with the Americans. And it was very difficult because of secrecy. The American activists were not as forthcoming as they should have been. So, we were never quite sure what they were doing. There were so many of them; it was incredible. Like, this whole contingent came up from New York and they did do good things. You know they got the world’s attention. They tried to shame the agents of the government that were doing nothing, or who were lying to us, because there was an extremely right wing administration in power in the United States at the time whose president didn’t say “AIDS” for, what was it? The first seven years of the epidemic? But eventually a group of AIDS activists took to the stage at the conference. We were a bit outflanked by the Americans and, of course, the big media focused on the Americans ... their equivalent of the Minister of Health, the American Secretary of Health, or Undersecretaries of Health, and so on, who were there. And so, we were eclipsed by two things – that, and the Tiananmen Square crackdown that happened in China at the same time. And every day we would rush from the conference to see the next day’s newspaper or news on the TV because we were holding demonstrations, handing out press releases and all kinds of things. And then the Tiananmen Square crackdown just took over the news cycle and so, we didn’t get as much media as we needed, as we should have. It was a learning experience...

GK: So, just in terms of AIDS ACTION NOW!, you get involved in the continuation of doing treatment information and communication work, and you're also on the steering committee, do you remember anything else about your involvement in AIDS ACTION NOW! during that time period?

SH: Yes. So AIDS ACTION NOW! had many committees, right? There was a fundraising committee, an action committee, a this committee, a that committee ... I can't remember them all – a legal committee, prison committee – because AIDS in prison in those days was quite horrific and perhaps still can be. And there were so many committees that it required a lot of coordination. At meetings, we were trying to be very democratic and let everyone have a say but, as the people in Zuccotti Park found out a few years ago, that can lead to enormously long meetings where you get side-tracked because the burden of problems out there is enormous and it's not easy to solve. And I find people on the Left are very good with analyses, are incisive, very smart; people on the Right are better at process. I don't know why that is; it just irks me. But on the Left we will err on the side of democracy and give everyone a voice and so this sometimes led to extremely long meetings, sometimes unproductive meetings. But, you know, you were practicing democracy as you went along. Better we did that than have other bad things happen. So, sometimes we realised that we were so busy struggling with everyday issues, as I mentioned, crises, that we needed time to strategize and to get everybody's ideas together and made into a coherent whole. So we had several retreats – one of which was the Hart House retreat. It was a house the university owned somewhere north of Toronto on some farm land, and we spent a long weekend there, which is both fun and energizing, where we thrashed out major issues. You will see this happen again and again since that time. I can't talk about it before then because I wasn't around before then, but there are issues of the day that have a lot of energy that attract all kinds of people. In the 1980s and early 90s it was HIV – because not only were we enriched by people from the media, people from the sciences, people from the arts and so on, but politically it brought out a lot of people who wanted to show solidarity with gay people, wanted to show solidarity with people with AIDS, but also found that this was a locus of energy and they were drawn to it. So, you would see a lot of anarchists drawn to it. And the anarchists would remind us that there are many struggles and AIDS, is just one. And you know it was a struggle trying to find unity and purpose when you're being constantly reminded of the many problems that go on and engage democratically and so on.

Well, several times we had to refocus and find unity and purpose, and so on. You know, Professor Eric Mykhalovskiy (CATIE's first employee) would tease me about management and stuff; he'd call it almost an irrelevance, but revolutions don't happen overnight. They are managed, and you have to manage them or they get off course and so the right management is very important. And management can be used so that it becomes a tool of oppression, but my sense is that it is necessary to just keep things flowing along. Not over-involvement in day-to-day issues. But, you know, you've got a plan, let's move on and not get side tracked and so on. And that's what I mean by management. I use the term loosely.

AS: So, can you characterise what, in your experience working with AIDS ACTION NOW! was like?

SH: Like I said, revolutions need to be organized; a movement needs to be organized. It doesn't have to be around one person, but we need to have unity of purpose. You have to balance unity of purpose with listening to voices of reasonable criticism and constructive criticism and so on. And like I said, the energy here was in HIV, but other groups would like to capture that energy and use it for their own causes. And, you know, that's a reasonable thing. You have a cause, nobody's paying you attention and you see this – AIDS – happening here and getting media attention. And, I worry that we were too hard on the anarchists and some of their colleagues and, in fact, we cast some of them out because they were too much of a distraction for us... And looking back on it, I think that was a mistake. But they really needed to be understood and to be managed and their ideas incorporated. And I think it was hard for many people to manage them, particularly as many of our HIV-positive colleagues were getting sick and, in some cases, dying and so on. We had Steering Committee members who became very ill and died throughout. So, you're so busy struggling that you don't notice the loss; you don't notice the emotional toll of the losses until much, much later, when it becomes cumulative. I mean, I was so sick of funerals and being at people's bedsides that it was extremely hard for me to go to a funeral in the 1990s; after 1995-96, it was next to impossible. Only now can I understand that these feelings are what would probably be called post-traumatic stress disorder because I had seen so many people die and been at their bedsides, been at vigils. You know, talking to them when they were unconscious because psychologists and brain scientists say, "Well, they can actually hear you. They can't act on it, but they can hear you." So many deaths had occurred including that of my partner, George Smith. So, it was a very difficult time. But to get back to this, we had purged the anarchists and, I think, in the process lost some good politics and lost some energy that we exchanged for an extremely rigid clarity of purpose. I'm not so sure it was a good trade-off looking back. It might have been a mistake.

But, you know, I wasn't in charge. I might have been on the Steering Committee and passively let it happen by not doing anything, but I too was frustrated with the anarchists and their constant derailment of things. I didn't have the political experience that has accumulated over decades since. This *was* my political experience. I mean it was through *Rites* that I was also involved in gay liberation. Like, I remember demonstrations, with Gary and other people, at the Ontario Legislature, trying to get them to pass human rights protections for gay people. I remember in an election campaign in the mid-80s when Ian Scott (the Attorney General) was in the closet, of trying to work with politicians we could trust who on the down low would say to us, "Yes, we're in favour of gay rights and we'll help you pass this." It was a lot of work. And so I also cut my political teeth on gay rights. It was very exciting to be a young person, to have all these senior people around you like Gary who was much, much smarter and very brilliant and others, I might add, take you on and let you do things and give you the freedom to do all these things. I am in enormous debt to the women of *Rites* magazine, Mary Louise Adams and many women whose names I can't recall. Heather... Ramsey, wonderful Heather Ramsey; so many young women and so on, but also many men in the AIDS community, many who have died, who gave me the opportunity and chance to really shine. I'm just enormously lucky to have had these mentors with their really interesting politics, critical thinking and insight.

I tease Gary. When Gary was not at the *Rites* office the rest of us would have this conversation, "Oh we've got to edit it, but we can't because it's so good" and "He's calling it media analysis again." And again, I just want to say, *that* analysis is so rare these days. Maybe it's because

the overwhelming corporate ownership of news and there's a certain sameness to the news. Analysis is rare there because the ruling apparatus doesn't want to teach you – the 0.1% don't want you – to learn critical thinking because then you'd understand how society is run, who really benefits and then you'd rebel against it. People who have the ability to think critically are rare. It's very difficult to teach, but I think it's the status of outsiders in society that and I've always felt since I was a kid and many of my colleagues in the activist movement – whether it's in feminism, or women's health, or gay activism, and so on have felt – that outsider status gives us a certain distrust of official messages and allowed, maybe, a certain wariness. We were very willing to analyse what was in the Kool-Aid as they say; whereas people now, they're sceptical for different reasons, but they don't often have a critical analysis. And Gary showed us that this was an historical thing. It had repeated itself in history. It was so empowering and electrifying, but I digress...

AS: It also seems that George was such an influence in being able to understand...

SH: George was enormously influential and important. You know, back until the age of the Internet when a young man came of age and wanted to come out in the city – I can only talk about the city – he would often be taken out by an older man and introduced to people, shown the bars, the clubs, whatever, you know, "This is so-and-so." "You've got to meet so-and-so." And I've had a number of older men who were very nice to me that way. We weren't lovers or anything, but... Chester Myers introduced me... The late Dr. Chester Myers, he was a biophysicist who emphasized the importance of nutrition in the pre-HAART (highly active antiretroviral therapy), or the "cocktail" era, because people were wasting (losing weight loss despite their best efforts as HIV damages the intestinal tract) and he was a scientist. This was interesting to George and some early figures in the gay rights movement. You know, I would go out to dinner with Chester and his friends and think nothing of it, but now it's like an important piece of history. So, yes, and what has happened today is that mentorship is just not there as much as it would be for young gay people, because with the Internet you can just find things; you don't have to talk to people. It's not like a hidden away thing. The gay stuff is out there. So, I think young people today might miss out on that and that entrée to this world and I was very lucky to be there at that very particular time in gay and human history.

George Smith was very brilliant. He had done the work for two PhDs and was doing work for a third. You know, those kind of people aren't common. I know people with two PhDs and there are not a lot of them. He was very, very smart. His mother told me that she would observe him in the playground when he was younger, under the age of ten, and he would already be organizing other kids in the playground. It was quite funny for us to think about George's managerial skills back then. [laughter] So, who knows? Perhaps some of these traits are genetic? I have no idea. But he was a brilliant and very kind person. He mentored many people academically and in the activist movement, political movements and, gay movement as well. And he brought an analytic that... You know, it was like Prometheus bringing fire from the gods is what his work was like. His work was based on the work of academician Dr. Dorothy Smith – that research can be about action to help ordinary people both understand the mechanism of their oppression, but also how to achieve what they need to to liberate themselves and society. It was like fire from the gods, as the ancients would say. Yes, there's the apparatus of the state and all that, but that can be subverted and that

can be changed. It was remarkable; it was infectious if I can use that analogy. George Smith, as I said, everything that he touched turned into a wonderful thing, whether it was me, whether it was the Right to Privacy Committee, AIDS ACTION NOW! and then TIE and CATIE.

And so, as I said earlier, AIDS ACTION NOW! had all these committees – the prison committee, the law committee, the this committee, the that committee... you know, the treatment committee, stuff like that. I mean, it was this octopus that we on the steering committee found very draining because we had to assign people on the steering committee to go to manage these committees and their work, and so on. Because otherwise they would just go off on tangents and the next thing you know we'd be derailed, right? So, for instance, it was wonderful that the energy captured by AIDS ACTION NOW! and the brilliance of so many people led to an organization called PASAN, the Prisoner AIDS Support Action Network, that supports people in prison, or who have come out of prison now, who have HIV, and things like that, and AIDS. It's a wonderful organization. Another despised group are drug users and a lot of people in society have the belief that it's some kind of failure of character, when... I see it as an addiction. I'm very biologically oriented, so I see these neurons and synapses and brain chemicals working. But, in a way, the way we describe addiction now as a medical problem reminds me of the early days of homosexuality when the concept was invented, as they say, in the late 1800s. It moved away from being a moral problem to a medical problem that doctors, and later a specialty of doctors called psychiatrists, dealt with. And I don't know how people with addictions feel about it being medicalized, but it's certainly better than not getting the help that people need. And I would stress that addiction is there in many forms. It can be food addiction, drugs, exercise addiction, video game addiction, and so on. But, yes, PASAN worked with this group of people called drug users and, again, we talked about the drug use quietly then. I wasn't very much in PASAN because it wasn't my core interest. But you had to deal with people using drugs and, at that time, that was a difficult subject to deal with, particularly for legal reasons and so on. Then, there was the legal committee, which dealt with people who had legal problems. You know, it could be people being deported because they were here, not Canadian citizens, and found to be HIV-positive, here without papers, people put in prison because of all kinds of charges. And so, this formed the Legal Network. I forget if it was HALCO or the AIDS Legal Network that became the national... I think it was HALCO, the HIV-AIDS Ontario Legal something. The HIV and AIDS Legal Clinic of Ontario (HALCO).

AS: HIV-AIDS Legal Coalition...

SH: Then, there was the TIE committee, the Treatment Action Committee. You know, like I said, we had all these people come from other issues. Like, Linda and Bob Gardner, who were very active on women's reproductive rights issues and so on. We would beg them, "Oh please come to our demonstrations." Then afterward we would say "Thank you for coming." And we would never think of going to theirs because we were so busy. But what we didn't think about was they were so busy too. They were busy, you know, working with their clinics and protecting people, giving them access to healthcare and information. And then they asked us to go to a demonstration for them, and I went along with Alan Cornwall – the late Alan Cornwall who was a lawyer, who had HIV and he was one of the co-founders of CATIE, what became CATIE – and we went, and it was quite an eye-opener because they were trying to ensure that women had access to birth control and, safe abortions if they needed it. It was a very emotionally difficult demonstration. We weren't scared

physically, but the other side, which was largely at the time driven by religious extremists, were saying very disturbing things. It was an exhausting experience; whereas demonstrations in support of AIDS causes were a very energizing experience. So, it was kind of an interesting thing. I know several of the people who went to the abortion demonstration had to go and do what they called... I learned later was called, “retail therapy” after, but anyway.

So, yeah, Linda Gardner and myself and somebody else, I cannot remember, it might have been George Smith ... We got a grant from the Trillium Foundation, which recycles lottery money in Ontario and they allowed us to hire our first staff person because we realised this treatment thing was becoming really big, it’s taking up a lot of work. We hired the person who’s now known as Professor Eric Mykhalovskiy at York University. He was our first staff person, or coordinator of the agency. And as soon as we created TIE, I kind of began to move away from AIDS ACTION NOW! because this TIE committee was taking up more and more work – Treatment Information and Education. We realised right away, we have to change, we have to become a charity, we have to do this and that. That’s the TIE committee. And we really began to think very independently of AIDS ACTION NOW! I mean, we still coordinated a bit with them, but we began to see a future that would be very different, because the work of treatment education was huge and it was going to become very large. So, George and Alan one night coined the name CATIE – Community AIDS Treatment Information Exchange, C-A-T-I-E. And we incorporated and we had legally it backdated to when we founded the TIE committee. We just carried on with our work, so I moved away from AIDS ACTION NOW! I went to a few of their demonstrations, but I just didn’t have the time to be in two demanding organizations simultaneously.

GK: TIE starts out as a project of AIDS ACTION NOW!

SH: That is correct.

GK: And when it becomes CATIE it sort of becomes separate and independent from AIDS ACTION NOW! Were there any sorts of tensions or difficulties there?

SH: Yes. I think some people in AIDS ACTION NOW! were understandably hurt that we spent so much time with what became CATIE because they also needed our energy and analytic and so on. Like I said, managing a revolution isn’t easy. So, they were a bit hurt by that. I understand their feelings now. But, you know, the legal people in AAN! had to go off and do their own work, the prison people had to go off and do their own work. By then the numbers of people infected was huge. I just want to say as a sidebar, I remember going to conferences in 1989 to 1994 – International AIDS Conferences – and one year they said a hundred thousand people were infected with HIV. And then the next year they said five hundred thousand. I naively thought, “Okay, that’s as big as it’s going to get.” And then next year at the conference we were told a million people were going to go, and then the next year four million. You know, once you get up there... these numbers are very hard for most humans to comprehend including myself; it was just so vast. And then the next year I remember it being forty million people and that’s when I was devastated. And since then it has not been easy for me to go to an opening ceremony of an International AIDS Conference because I was so traumatized by these growing numbers. I just can’t do it. Usually friends – mostly doctors and scientists tend to drag me to those ceremonies these days. Still, I’ve become deeply

sceptical about the opening ceremonies. I know there's a need to energize people and lighten things up, but it's very hard for me to go back because so many people have died, so many people will die. And I saw the latest UN stats on a slide the other day and the total number of people who have been infected is getting up there. It's like, around eighty million or something, and perhaps one day we will eventually approach a hundred million, which is just an astonishing number of people. It's like three times the size of Canada will have been infected. And I think forty million people have died. And if you think each one of those people knew someone around him or her – his or her parents, their spouse, their children, their aunt, their uncle, their neighbours, their colleagues, their friends, their pets – it's like, a huge domino effect in every direction. So, HIV has had a horrific effect on the planet and on communities. I think, in some way, the gay communities in the West have been so devastated by AIDS; they have never really recovered from it. And it affects them to this day – gay male communities in particular.

But yes, to get back to what we were saying: These groups, like I said, there were so many people, the need was so huge, people were coming out of the HIV closet, that we realised, "Whoa." You know, when we started talking about AIDS ACTION NOW! in 1987 and then actually forming it several months later, I don't think we ever imagined the need would be so great. We knew it was there, but not this big. At first we thought, "Oh it's just a big city problem, a downtown Toronto problem." Then we started to meet people from the suburbs who were straight-identified with girlfriends who would come down to our meetings – Ric Hatt, for instance, and his girlfriend Dory. I forget, I can't say her last name but her first name was Dory. Ric Hatt was a truck driver, straight-identified, and he came down to our meetings and he sat on our steering committee. And she lovingly looked after him through his dying days. We had haemophiliacs and the spouses of haemophiliacs who were infected with contaminated clotting factors come to our meetings, and were touched by us. One of my work areas was as an ambassador to the haemophiliac community trying to energize them, because they were young guys my age and they were really open to having a gay guy there was no big deal for them, which was really astonishing for that era. Perhaps this change in attitude was a forerunner for what young people today experience around sexuality in the big city, at least in some cases. But it was wonderful and we formed these links with the haemophiliac community in the end that we still have today. And we helped. They wanted our activism to infuse their movement because so many haemophiliacs were self-oppressed because it's a male disease, mostly straight men. You know it makes them feel weak and they don't want to talk about it and they bottle their fear and anger inside themselves. And then you add Hepatitis C and HIV on top of that; it was quite a psychological burden for them to handle. Many just curled up and died from AIDS, but some and their wives and girlfriends, made links with us and some are living to this day because of those links.

So, yes, all these committees had to go off and do their own work and there were tensions and there were disagreements. But we also had to protect our charitable status, because we saw ourselves dealing with treatment related issues. AIDS ACTION NOW! still had an important role to play at the time. People at AIDS ACTION NOW! did many things. I don't know all of them, but one of the very important things that they did came to fruition around 1995 was what is now called the Trillium program. Because diseases like HIV, cancer, and Hepatitis C are catastrophic illnesses and you just get your legs kicked out from under you and you can't earn income to pay for these hideously expensive drugs. We finally pressured the government to set up these drug funding programs so that people can keep working, stay alive, pay their taxes... We had to show a return

on investment for the government rather than just the milk of human kindness, and they did that for HIV and they've extended it for Hepatitis and for cancer. They don't like to advertise it because it costs them a lot, but I think there are other health issues in society that get funded by the Trillium program. I just don't know the full breadth of it. But that was something that AIDS ACTION NOW! did. And people such as James Thatcher and possibly Brian Farlinger were instrumental in the genesis of the Trillium program.

AS: That was a several year campaign to try to get funding to pay for drugs – would CATIE have been involved in giving information about how much drugs cost or what recommended...?

SH: We probably did do that, I just don't recall at the time. You know, the other thing that comes out is that AIDS ends up being a disease of poverty because you don't have the energy to work, you don't have the energy to do the normal things that in this society bring you income. So, AIDS brought up, made visible, a lot of the bad things that were happening in late capitalism that weren't getting attention before. Like you know, in the early 1980s health authorities actually thought that syphilis was going to wane; infectious disease was... "Oh, it's a problem for far away countries. It's not here." They were so naïve and AIDS made visible all the fractures in a late capitalist society, from mental health issues, addiction, homelessness, inadequate housing – those are just a few – legal issues, prison issues. And so, our energy and enthusiasm kept people alive ... You know, I'm privileged to have been an activist in a very important part of history and privileged to have been with people like Gary and his colleagues. But also to have made some small difference in the world and to be able to do this kind of work now.

One of the things I wanted to tell you is that, yes, I started off about HIV treatment, but what helped me was my analysis. And I tease Gary about his analysis, but it's the analytic that made us as CATIE – AIDS ACTION NOW! and then as CATIE – stand out and stand above the others when it came to bio-medical information. Like, when I was a teenager with these allergies I had to figure out, "Well, which drugs are going to work for me? Which are too toxic? Which are this..." you know. And that general way of finding things out, which is intuitive and which... I've had people from companies and the government come and try to understand how my brain works because I have no idea. And this analytic I then put on HIV and the emerging research fields to figure out the drugs that were good, bad, and so on. And now our work... CATIE has been transformed into a national agency and we're funded at the national level, so everything we do is bilingual. And we also work in the languages of new Canadians as well. But also, we don't just deal with HIV and HIV treatment; we deal with prevention issues and we also deal with Hepatitis C virus. It's a big part of our work. Not just people with HIV who have Hepatitis C because they're shared roots of infection, but people who have what is called Hepatitis C mono-infection, Hepatitis C alone. We deal with sexually transmitted diseases – sexually transmitted infections rather, that's the new term – STI (sexually transmitted infection). I know. I missed the memo when it went from STD (sexually transmitted disease) to suddenly like, "STI." It's like, didn't someone send us the memo? Like, where was that? Also, TB (tuberculosis) to some extent. So, we deal with this cluster of diseases. And that's our new mandate. We've become an internationally recognized organization for our work and simplifying the research into more accessible stuff. We don't pretend to meet the needs of everybody; we can't. But we do work in collaboration with other

groups who are working with substance users, for instance, people with extremely low health literacy. We have a range of products for different people with different needs. And we work a lot with front line organizations, so it's very exciting. And we have people in Europe asking us for guidance and help as to what is again now commonly called 'knowledge translation' – taking that heavy medical and complex stuff into simple things that people can use. We've had people from breast cancer and prostate cancer groups come to our offices to learn about how we work and to try to use that as a template for their groups. It's kind of hard for the prostate survivors because they tend to be older, sometimes grumpy men who seem new to being health activists, but I'm hopeful for some of the breast cancer groups.

GK: I just wanted to step back for a moment. You were mentioning poverty, and we have talked to Eric about this – but given you were living with George during the period of time with the Hooking Up project research, if you could maybe share some insight into why that became important especially for George to do that type of research.

SH: The Hooking Up project was a project that involved interviewing people with HIV/AIDS to find out, how they hooked up to the services that they needed, medical and social services. And he did these interviews with people that made visible the enormity of work that was involved in looking after yourself. Like I remember looking at his day timer and within the month there were all these appointments where he had to go to these different doctors, often specialists. But you also had to educate the family doctor what was going on with the infectious disease specialist and then the dermatologist or the other specialist and so on, because we didn't have electronic records in those days and these specialists didn't talk to one another. So, it often fell on the patient to educate the different specialists. It was an enormous amount of work. You know, as I mentioned, AIDS is a disease of poverty. It robs you of the ability to do the work, even if you have the energy; if you have the energy then you're discriminated against because you're kicked out of your house, your job, your whatever. And the stories of people living with HIV and struggling with HIV before effective treatment came along were very important... You'd have to jog my memory about the Hooking Up project but I do know there were stories captured about how people looked after one another that was really touching. Some people were abandoned when their spouse found out that they had HIV; you know, a whole bunch of horror stories. And people ended up on the street, people ended up with severe neurocognitive problems, because, you know, an AIDS activist by the name of Darien Taylor, a really wonderful person, said to me a long, long time ago in 1989, I think. She said, "HIV makes any pre-existing problem worse," whether that's a psychosocial, a biological, or an economic-political problem. And she was older than me; she had a lot of experience. I remember that expression, it echoes with me today because that's so true. So, if you had a hard time earning a living before it became even worse after your diagnosis of HIV... If you have mental health issues, it became worse because HIV affects the brain directly. You know one of the things that people feared most in the pre-HAART era, before 1996, was something called AIDS dementia, which is an end-stage condition whereby you would literally lose your mind. And you could lose your personality; your behaviour could become erratic; you could lose your memory. It was a horrible and fearful condition. You'd have to wear diapers and so on as nerves and muscles malfunctioned. And this was something that was deeply feared by people with HIV because you didn't know who would get it or when. There was no rhyme or reason to it. Thankfully today, due

to the modern therapies that are much safer, that are all in one pill you can just take instead of a handful of pills, that condition (AIDS dementia) is rare in Canada. But it was a terrifying thing back then. So, I don't remember all of the things of the Hooking Up project off the top of my head. You'd have to job my memory.

AS: You remembered lots of things.

SH: You know I'd like to prize myself on my memory but it's... There's only room to hold so many pictures of drugs, viruses and stuff like that.

GK: I think one of the reasons that it's of interest to us is that it was also what George was doing ... you know, George helped to set up CATIE, then there's the Hooking Up project, and, of course, it ends having to be completed by Eric. Right?

SH: Because George was becoming ill and in retrospect – I now can understand this – he lost his ability to focus and concentrate as much. He was on an experimental drug that was very safe and it was quite remarkable. It preserved his higher intellectual functions. So, for instance, just a few days before he died he wrote a speech for me. He dictated it to me. I filled it out and then read it back to him. "Yeah, that's fine. You can give it," he said, just days before he died. But this drug preserved his higher cognitive functions and, for an intellectual, that was really important. He felt trapped in this body as it gradually weakened and so on, but he still had his marbles towards the end. It was incredible. And, you know, Eric was nagging George, "You've got to finish this, you've got to finish this" and George couldn't understand why he couldn't finish it in the last years, but I think it's because he became depressed. If a person has a terminal illness that is to be expected. I spoke to you earlier about it, how I would hide things from him and Tim. They would in turn hide things from me. [laughter] And so, George would hide the true state of his health from me as long as he could. Until I had to accompany him to visit the doctor's and then I began to see what was going on.

AS: And, of course, you would have understood what was going on.

SH: Yes, far more than I was consciously aware... He would feel that I would know where this was going. And I also did my utmost with the supplements and drugs that were available at the time to keep him alive and I think I did a decent job. For years I was racked with, guilt. I used to ask myself: "Did I do the right thing? If I'd done this instead of that, would it have made a difference?" I know now that it wouldn't, but that guilt was there after the first ten years after his death because he was important to many, many people who were doing what is now called anti-oppression work, I believe. Because it was not just in AIDS that he had influence, right, it was in many areas. George was also concerned about kids in schools and the homophobia that they faced. I think he worked with the Ministry of Education in British Columbia at one time. He was also a lecturer at Simon Fraser and UBC (University of British Columbia). And so, he did some work on that, on young people facing homophobia. To summarize his work, it was about giving people the ability to see how they were being oppressed and to use that information to subvert the agents and agencies of oppression. In that sense, George's work was extremely subversive.

GK: And that work on young people ends up getting published... Actually, Dorothy has to edit three different versions together as the “Ideology of Fag” after his death.

SH: I can tell you that when Dorothy and I met several years after George’s death, we just hugged each other and cried. We couldn’t say anything. What can you say? It was very hard for us, so I haven’t had much contact with her. But George had enormous admiration for her and vice versa.

GK: Yes. I don’t know if you remember but there was a gathering of the support team and a few other people, and Patrick and I were able to be there, which was really wonderful. I remember Dorothy talking and just saying, about her work, that she couldn’t disentangle what was hers and what was George’s, right? It was quite an interesting, moving moment.

SH: In some ways Dorothy brought the tablets down from the mountain, to use an analogy from two millennia ago. And then George translated that for people. But at the same time, she went back up the mountain with George and they reinterpreted the tablets and then came down together. So, I think that is how they worked collaboratively. George was always working collaboratively with people. It was very nice. But I escaped from a question you were asking. So, the Hooking Up project...

GK: You can always escape from questions.

SH: Well, the Hooking Up project was really interesting because George and I had this talk – and I was telling my new partner, James, about it – and we were watching this movie called *Angels in America* (2003) based on the play. And in it, the partner for one of the men who’s been diagnosed decides that he can’t handle what’s coming, you know, with AIDS and dying, and he abandons his partner. George said to me before he died, “You know, I’d totally understand. We’ve met many people who have done it (have left their partners) who can’t handle it.” And I must have been 27 or 28 years old at the time and I had no idea what was coming, in a sense. Despite that I said, “First of all, it would never occur to me to abandon you,” I said, “I’m here until the end of this. You’re going to be doing all kinds of things,” and I said, “Yes, that’s what we’re here for.” And we joked in sickness and in health because in those days, same-sex marriage was just simply not on our minds. It never occurred to us, because we were too busy in the everyday struggles of gay liberation and also, more importantly, HIV and so on. So, the same-sex marriage thing was really off the charts for us. There were more pressing everyday concerns and struggles. And then, after his death I had to move house, and I remember going to the post office and telling them, “These are the two people who will be moving” (meaning George and myself) – and I had all my documents, you know – we had a joint account, we had a joint lease, his birth certificate, his death certificate; you had to prove your relationship and that. And the very nice woman, a new Canadian, said to me, “Well, you’re family so we’re going to tick off the family box here.” And I was just incredibly taken aback and go, “Are you sure?” I asked, and she said, “Yes.” It was actually a very political act on her part, recognizing two gay men as a family even though one of them had just died. We were treated as a family by this new Canadian in the post office, who had immigrated from a country that

persecuted gay people. It was incredible - a forerunner to the struggles that would happen in the next decade around same-sex marriage.

So, the Hooking Up project unveiled the lives of HIV people and those lives were involved – like I said, whether they were being kicked out of home on the street, their jobs – what it meant to look after yourself, coordinate your own care. I mean could you imagine asking a cancer patient to do that? It would be horrendous. But that’s what almost every HIV-positive person in those days and/or their partner, their best friend, or their parents, spouse had to do for them. So, I remember another episode... George had, we’re not sure what happened, but perhaps a seizure. And so he ended up in the intensive care unit of the hospital and I got to spend a lot of time in the ICU. I had no idea how the ICUs (intensive care units) were run. But what I saw was day after day the doctors pulling the plug because the people in the ICU were – he was the only HIV-positive one there – they all were accident victims; people who had been shot many times or stabbed many times – terrible, hideous vehicular or workplace accidents and they were going to die. And the doctors were practicing what we now call euthanasia quite routinely because there was no way you could keep those persons alive and in a conscious state. And they would coax the family into this, get them ready, there’d be lots of crying and they’d gently. The family would go away and then the plug would be pulled. Sometimes they’d stay, but most often the family would go away. And I would watch as the doctors, and nurses, and technicians would come and unhook the people and take them away. And I saw this happening day after day. And so... I saw this actually happening on the first day I was there. Nobody noticed me because I was in the corner with the “AIDS victim”, but after that I decided I would spend as much time as I could in the hospital’s ICU because I was worried they’d pull the plug on George. And he was put into a state of unconsciousness but he came out of it after a day or two. The drugs were just to relax him and so on. And I said, “I gave orders to revive you. Was that the correct thing to do?” And he said, “Yes” even though he had given me firm instructions at home never to revive him. He had countermanded those instructions. That was interesting from a psychological point of view. He came out of the ICU and I was holding his hands for hours while he was sleeping, just guarding him from the doctors. I didn’t trust the ICU doctors because I had seen the doctors routinely giving the instructions for the plug to be pulled on so many other people. I remember the neurologist, he was the chief neurologist, coming in to see some of his patients with the Head of ICU and they saw me and they’d said, “Oh, that’s so lovely” and stuff like that. And, “You don’t have to worry. He’ll be out of here in a few days with you; we can send him home.” That was a kind of behaviour from the guardians of the ICU and the hospital that I didn’t expect and it was really... Maybe it was just them... because we had heard so many horror stories about what happened to people in the hospital, right? You know, you’d be kicked out or your spouse wouldn’t get granted access. They didn’t ask to see my ID or anything, they accepted the fact that I was his spouse and they treated me accordingly. It was really refreshing because we knew horror stories were happening everywhere. Those also happened in the Hooking Up report when George talked to people. But seeing those two movies I talked to you about brought back those scenes of guarding him in the hospital.

And I also remember a political memory and that is from the late 1980s of, somehow they found out that Roy Cohn, the lawyer who was very, very critical to the McCarthy hearings – the McCarthy witch hunt where right after the Second World War ended, the right-wing became very aggressive at rooting out any opposition to its agenda of the 0.1%. – Roy Cohn, he was a very important and deeply homophobic figure. He and J. Edgar Hoover, of all people were in the closet.

And at some time in the late 1980s it was announced that Roy Cohn had AIDS through the networks that Tim and George had. Tim was really good at having international networks. Tim could tell you what was happening in the gay world in London, in India, in Southern Africa, in South America. Like, Tim was a news service and, I think, he worked in international news at *The Body Politic*. It was quite a revelation for me (and probably other people) that Roy Cohn was both gay and dying of complications related to AIDS. I received quite the political education from Tim, George and their colleagues.

GK: He did exactly that.

SH: By then he had left *The Body Politic*, but he still had up-to-the-minute news from his correspondents around the world. And he knew that Roy Cohn... And it was really interesting to listen in on the conversations about it. They were at once disgusted that Roy Cohn had been so anti-gay all these years and had hurt so many gay people, and had been a part of their oppression and yet, he was now obviously HIV-positive, and obviously he had got HIV from having unprotected sex with another man, and that he was going to die from AIDS. And Roy Cohn used his political connections to get the emerging therapies for HIV ahead of everybody else. It didn't help him one bit; in those days such therapies were toxic. But I think at some level, they tried to feel sorry for him, but it was extremely difficult.

GK: Yes, I can understand that.

SH: You know, he (Roy Cohn) was responsible for people committing suicide? It's very hard to forgive the damage he did, he and his colleagues, to gay people around the world for decades.

GK: So, I think we've moved into the section of the discussion around remembering some of the people who've died. If there's more you wanted to say around George, but there are other people.

SH: I could go on. He was a brilliant, brilliant person as I've said. He cared about so many people, so many causes. You know, he cared about everybody. People like that don't come along every day. And, again, I was so privileged to be in his circle and to be his partner for all these years, and to be associated with all these people and his friends. I was just damned lucky.

AS: How did you meet?

SH: We met by chance, because I was at his house to see Tim. Tim was always taking an afternoon nap, so it was George's turn to make dinner. It was September 1984, and it was George's turn to make dinner and George was making a quick dinner because I think he had a class that evening or had to do something. And it was a tuna casserole, a curry tuna casserole. I said, "Oh curry, really? What are you making...?" "Oh, I'm putting this and that." And I broke down laughing because it was not curry. But then he called my bluff and I had to make the curry up for him. So, I said, "Next time, I'll make the curry," but this time he made it. After that I would help him make the curry for it. It was quite tasty!

But yes, there are other people. So, you mentioned Chuck Grochmal. And again, HIV brought people with different political views, most were on the left, on the left-of-centre but there were people who were not. And George was really good at bringing diverse people to a common purpose even though they might have a bit of right-wing views. In other words his thinking probably went along these lines: “Okay, so you’re a bit right-wing. You don’t have time to change who you are now. You’ll change into a progressive later, but right now you need to do this.” So, in that sense he was really good at bringing people together for a common purpose. You know, history might have been different had Rosa Luxembourgh had him or Martin Luther King or any of the other movements.

Chuck Grochmal was, I would say, at least right of centre and people didn’t always appreciate his sense of humour and some of the things he said. He was also a person who was easily irritated. I used to just ignore his outburst and try and work with him. George was able to get him to work, but in the end I think he was pushed out of AIDS ACTION NOW! and he died a lonely death. George and I were the only people on the Steering Committee who would still talk to him after he left. I would go spend hours with him in the evening sitting on his bed, reading him bedtime stories and stuff like that, holding his hand as he lay slowly dying. He would tell me his life history.”

AS: Chuck also understood some of the things you were working on?

SH: Oh yes. Chuck taught myself and other people some of the medical stuff because he had contacts in the United States.

AS: How’d he come to it?

SH: Well, I guess he’s dead and now I can say it. So, he was an oil worker but on his deathbed, you know, I held Chuck up as this icon, and he said, “Really, I’m just a drug dealer.” ... I had no idea of this until he died, he had no job and yet he could sometimes fly off to New York or other American cities on short notice. He was good-looking before he got really skinny. He was a very attractive man and he could fly off to New York and afford this because during the disco era people would party and he would sell drugs on the dance floor. I don’t quite know how or how much, but he made a decent amount of money as a drug pusher. You know, just pills. So, he told me this on his deathbed and I never told anybody until about ten years later. It was just so shocking. You would never say bad things about a person with HIV. Another anecdote is this: there was Ross Laycock. Ross Laycock was this biochemist from Alberta who had moved to Toronto, likely to escape the homophobia and HIV phobia. He was a very beautiful, handsome man and reserved, but quite smart and he came down with HIV and in particular, at that time, in the first decade of HIV among men who had sex with men, you’d come down with a cancer called Kaposi Sarcoma, or KS, and you’d begin to develop these splotches on your skin. And people at first – again the naiveté – we thought this was just an external condition. But each of those lesions on your skin mirrored some lesion that was inside your body on an organ or a major intersection of blood vessels, it was horrendous. Anyway, he I remember was very supportive of me and he found my work very interesting and I was shocked that this biochemist, this PhD biochemist, was lapping up the stuff I found about KS in the library and wrote about. At the time we didn’t know that he had KS under

his clothes. We had no idea, but he was always interested in KS. “Well, yeah. It’s part of AIDS. Whatever”, I thought at the time. And then, we didn’t see him for several months and then one day George and I were on the subway going to an AIDS ACTION NOW! Steering Committee meeting, and we got on the subway and there was Ross Laycock sitting and he was polka dotted, in that he had multiple lesions of KS (Kaposi’s sarcoma) on his body and he had a couple on his face – or a few on his face actually – and so we came and sandwiched him, and sat next to him on either side and talked to Ross like it was completely normal to do, and we may have dragged him to the Steering Committee that evening. [laughter] But he was an early member of AAN! Yes, but these are some of the things you do that you don’t realize are important at the time. For instance I heard from my Asian friends that during the outbreak of SARS (severe acute respiratory syndrome), the businesses and restaurants in Chinatown were suffering because nobody wanted to be around Asian people and there was, you know, stuff like that. So, I told my partner, James, about this and I said, “Well, let us go out for Asian – Chinese food, Thai food.” We went out of our way to go downtown and eat in Chinese restaurants to show solidarity with Asian people. And so the same thing George and I did about that time – was to show solidarity... why shouldn’t we sit next to someone with KS? You can’t get anything from them. The fears that some people had— It’s silly. But that was some of the discrimination that he faced. I don’t think people knew on the subway he had AIDS; they just knew he had something bad. He was scary to them. People were treating him like a leper.

GK: Really early on another person involved in AIDS ACTION NOW! – it may have actually been before you got connected with it – was David Marriage. Do you remember him at all?

SH: The name rings a bell.

GK: He would’ve had very, very clear KS lesions.

SH: I know the name. I don’t remember... I know another boy, young man, who died early was the guy who worked in Glad Day Bookstore, James.

GK: James McPhee

SH: Yeah. He was just wasting away. It was awful.

GK: So, there are other people we can ask...?

SH: Yes, please do.

GK: So, again, especially if you were involved in the first six months – I’m not sure you would’ve had direct connections with Michael Lynch in AIDS ACTION NOW!...

SH: I had... Well, he was very nice. I first heard about him from a student who took a course – this great girl who had no idea he was gay and said, “Well, first of all, the teacher is teaching English, and he wears these white-framed glasses. (Who ever heard of that?) And the class is so electrifying

and interesting!” Sure, sure, I said to myself... Anyway, I did meet him at a Steering Committee meeting and he was an important source of news from the U.S., because he was an American who fled... the forced enrolment into the army because of the Vietnam war. He had a network in major U.S. cities that would tell us what was happening there regarding HIV. Michael Lynch was a handsome professor at U of T and a very nice man and I don’t know how we met... maybe it was at a U of T function or through tennis or through AIDS ACTION NOW!, but he lived in a wonderful house near the downtown campus, and I can tell he was an intellectual because when I went to his house he had huge ceilings – so very high ceilings – and it was floor to ceiling books. And you know it was like a library, it was just wonderful. But we would play tennis from time to time and he was very nice. He was in AIDS ACTION NOW!, but he pulled back after some time, probably due to his own deteriorating health. And I also didn’t have as much contact with him because eventually, he didn’t have the energy to play tennis; though he never said that to me. Michael was again, one of those people who hid their decline well And my work – you know, that was once a volunteer thing; eventually it had to be done full time; it was just all-consuming. So, Michael Lynch was very smart and incisive. He taught us a bit about the media. He brought in news from an American context – from America – that was very important. And he also told us what was happening there within the AIDS movement. So, that was really useful. Also, he was in a centerfold in a magazine whose name I can no longer recall. In his prime he was quite the specimen. But he was just one person. I mean there was this book that makes him out to be the founder of the AIDS movement. So, it was not like that.

GK: The Ann Silversides book.

SH: Yeah. You know, I understand that to sell a book you have to make this person into a super-human character but he didn’t found AIDS activism, as I’ve told you; I was there from the beginning and I can tell you all the people involved. He was a very nice person, decent, smart and gave very good advice for Op-ed pieces for the newspapers and stinging criticism of anybody who attacked people with HIV, withering criticism but he was not a major part of the ecology of activism. Don’t get me wrong. Michael was an important source of advice and strategy to people, but he was not – as is unfortunately portrayed in the book, the source of or leader of AIDS activism in Canada. He wasn’t like that.

GK: So, we can talk about another Michael – Michael Smith if you remember.

SH: Michael Smith came to us from the anarchist movement and his story is really interesting. I don’t know if he was gay, to be honest; I know he had sex with men, but I don’t know if he was gay-identified. I think at one point he had sex with men for political reasons. Much as I – before I really understood what being gay was – I said I was gay for political reasons, before I really understood being gay and had sex with men. So, I didn’t understand but for political reasons I said I was gay, probably because that’s where I was going to end up but I was ahead of myself with that; I didn’t really understand what it meant politically, or rather what it meant to be gay, but what I did understand was that I would ally myself politically with this group with which I had some affinity. So, Michael Smith was an anarchist; he told me some really interesting stories. For instance, when he lived in Amsterdam with his partner – or friend at the time – they were so poor that they

couldn't afford drugs (heroin to inject) but because they were psychologically addicted, they would draw some blood out of themselves and then shoot it back up, which again –I really didn't understand addiction and substance use at the time, but which now – as I'm older I study substance abuse – I have a better understanding of. He would tell me this at his bedside when I was visiting him in the hospital; he had a terrible fungal infection. So, Michael Smith, I went to visit him and find out what he needed to do, so I went to the literature in the medical texts. Here's what the doctors say you need; here's the drugs they say you need; these are the schedules; so, he got it and he survived. However, one of the drugs given at the time was nicknamed "Amphoterrible", because of the terrible side effects on the kidneys. The real name is Amphotericin B, but we and even the nurses called it "Amphoterrible." So, he survived.

And before I forget, a really empowering thing that happened to me was with Tim McCaskell. It was around 1986; Tim came to me and said, "You know all this stuff about HIV that you're researching and stuff, well my doctor said that my platelets – these are some red cells in the blood that you need to help clot when there are cuts – are really low and if they fall much lower, I'll bleed to death. And they want to cut an organ called the spleen out, because the spleen is eating up the platelets. And you know, I had heard on the streets this is a bad thing to do, but I need to argue with the doctor. Can you help?" I said, "Sure". So, I went and I did the research in the library and the reference librarian saw me and she said, "Well, what are you doing?" So, I explained the situation. And she was very kind and she directed me to the right places that I wouldn't have noticed, one of my first forays in the reference part of the library. It turned out that I would later be counselling her. Her husband was a haemophiliac and had inadvertently infected her. She had no idea if she was infected at the time, but she did later become ill and she became one of the people who used our services a decade later, but I had no idea at the time, and I don't think she did either. Anyway, so I found out all this information, came back and told it to George who helped me condense and then go to Tim, "Here are your key points. Here are all the things you need." And he went and he convinced his family doctor – the family doctor referred him to a cancer specialist, and he got into a terrible fight with this the cancer specialist. But in the end Tim never got his spleen out and he's alive today. And had he had his spleen taken out, he probably would've died as most people with HIV who had their spleens removed did back then, but he didn't and he's alive. And the fact that Tim with my help could push back against the cancer doctor, who worked in the hospital – in the ivory tower of the hospital – it was just subconsciously empowering; I didn't realize how important this was until ten years later, but it really is one of the things, along with *Rites* that helped propel me forward, because it showed that if the cancer doctor can't read the same things that I was or didn't have the time or whatever, there was something wrong with the medical system and the way it educated people. I mean I wasn't making this stuff up; it was right there.

AS: Yeah, and they just weren't reading it.

SH: Yes.

AS: Or couldn't put it together in the same way.

SH: ...and this is where again you have those tensions within the cancer community about what is called expert opinion and evidence, and now more and more of the medical community is trying to move away from expert opinion because it's essentially anecdotal, to evidence-based courses of action, and what's pushing that is austerity, because we have to find the least costly and most effective way of dealing with the problem. Austerity's forcing this – the enforced austerity under which we live. So, other people...

GK: Doug Wilson.

SH: Doug Wilson was teased as the little animal that lives on the prairies... the “prairie dog” from the grain-producing areas of Canada and he became the head of the Human Rights Association in Saskatchewan, and I think he had some political incident where he might've lost his job or something because they found out he was gay and he had to fight. He became the head of it and then he came to Toronto and I remember going to my first meeting at *Rites* magazine, which was held in the carriage house of someone we fondly called the “Bitter Baker.” So, we were taking the streetcar from the Dundas Station along Dundas Street east and this blonde guy was on it and that turned out to be Doug Wilson. We both got off there and went into 428 – or was it 425? – and that was an interesting house because Dennis Findlay, the owner, had a lawyer as a tenant in the front of the house and then some other guy who was like a beauty consultant or department store window dresser – I don't know exactly what he did. So in going to *Rites* magazine, we would meet this strange closeted gay lawyer, this window dresser and myself and have these, looking back on it, very strange conversations... and the closeted gay lawyer would beg me to go to Glad Day Bookshop and buy him pornography because he could not go there for whatever reason as he was too repressed... but oddly, he knew exactly what magazines he wanted, right. And this is before the internet. So, I would go buy them for him. And then the window dresser was there and he was like a character out of a cartoon or novel, along with his big hair. He would go back to talking about all those movies with film stars like Lana Turner, Rock Hudson and Errol Flynn. It was a very strange atmosphere in the front of the Bitter Baker's house; perhaps like something out of a time capsule. They would drink wine, eat chocolate and apply hideously expensive moisturizers from Paris in the middle of the day and I would listen to them and their stories of a long dead past with my jaw open. Denis was not often part of those conversations, at least when I was there. This salon had the quality of a fairy tale.

AS: And why was he called the Bitter Baker?

SH: Well, I think people at *Rites* felt that he was somewhat, at times, bitter for them. Even though, I think at first he kept them in the front of the house... Yeah, and then he kicked them out and cast them into the back in the carriage house, because he needed to expand his kitchen. Denis was a great cook and his goods were in demand by major outlets.

GK: ...which was bigger.

SH: Which was bigger, but...

AS: Colder?

SH: Yes, but at least you didn't have the Bitter Baker constantly coming around and nagging you. But also Dennis kicked them out, so there was some bitterness about that.

GK: Sometimes he would share the baking stuff...

SH: He sometimes did share the baking and was delightful, but then when we were cast out into the coach house, the carriage house, he wasn't so sharing anymore.

GK: This convinces me that the oral history of *Rites* magazine needs to be done too, but we can't fully do that here.

SH: But the other thing too was I think *Rites* paid a minimal amount of rent. So, Dennis was another generous soul, right. He had a degree in marine biology, and here was a gay man you know hit by the Pink Ceiling and he formed his own bakery – Altitude Bakery – which some snide people at *Rites* nicknamed, *Attitude* Bakery. But Dennis was a very kind and generous soul. He later became an important volunteer at CATIE.

GK: Yeah, Dennis had also been involved in the Right to Privacy Committee.

SH: Yes. But Dennis was a very big influence, and I think I was invited to a Christmas party in 1984 at Seaton Street and there were all these hot older gentlemen there. Dennis was one and so was George Smith. And George – I think they had just come back from the television station in Hamilton to give an interview about gay rights and stuff like that – but you know George and Dennis were good at dealing with media. And they had come back fresh from the interview and were telling people at the party. You know one thing led to another and after that George and I became an item. But it easily could've happened that it would've been Dennis because they were sitting next to each other... but as luck would have it, I went with George.

AS: They were sitting next to each other.

SH: I got the intellectual.

GK: So, there's also some other people who died during that period.

SH: Oh before I forget, Michael Smith also, when his father came to visit him from England, insisted that I was the only person he wanted his father to meet. I don't know why? And so I got his father to tell the tales of Michael Smith, of how Michael – I think he had an upper class background – would play the piano and Michael was so embarrassed because he liked to portray himself as this grungy anarchist.

AS: Yeah.

SH: Yeah. And so he did that and he had a privileged upbringing against which he rebelled. But I don't know why he wanted me to meet with his father. His father was nice enough. But Michael was a very sweet and nice person – very bright too. Like this is the thing, right, when we lost the anarchists, when we drove them out of AIDS ACTION NOW!, we lost a lot of energy but also some very smart people, and we suffered because of that. I think AIDS ACTION NOW! could have been much bigger and stronger and the whole AIDS movement could've been bigger and stronger.

AS: It's also hard to know about, you know...

SH: This is only in retrospective. But like I said, George was good at working with people from all walks of life, from all different political points of view, and getting them to focus, but it was taking up more work, but he wasn't in favour of expelling the anarchists...though he found dealing with the complex issues that they raised and the impact it had on the organization (AAN!), draining at times.

GK: So, there are people who died during this period, but you would've... you largely would've been involved in CATIE as the primary reference after the early 1990s, right?

SH: Yes.

GK: So, you would not have actually probably met Brian Farlinger.

SH: I met him... yes, several times. We'd end up at the same meetings. He was a nice person, again from an upper class background. He flew to his last international AIDS conference, which was in Japan in 1994, hooked up to an IV pole on the plane.

AS: Wow.

GK: Did you know James Thatcher at all?

SH: Yes. A nice person but came from a very different part of the political spectrum, but brought down to earth by HIV. It's amazing what HIV did. I mean in those days someone's sexuality could level class boundaries and political boundaries between people. HIV did that.

AS: Right. So that people who had perhaps been very privileged realized, oh...

SH: They were telling them, you're going to die and die very quickly, and you know what? The rest of society and privileged friends don't care for you.

AS: Right, and the people that do care for you are...

SH: ...are around you right now. Yeah.

GK: So, there also have been people who have died later who were really involved in this time period and died of non HIV-related problems – Greg Pavelich would be one.

SH: Greg Pavelich was a wonderful, kind soul. His heart was in the right place. Although he was not the most focused person, he was also very committed. But in those days, there was an expression that – he didn't have HIV – but that was meant for HIV-positive people that went something like this, "Get fat. Don't die." So, we didn't actually care if somebody was fat because I mean when you're young you don't think about cardiovascular disease. Greg wasn't that old. He was older than me but I didn't see him as being you know really older, but he kept getting big and he died from complications of heart disease, you know and that was really hard on me because he was a sweet guy and nice to me. I don't think I went to his funeral. I just couldn't.

GK: Yeah, in 2003. Well, his funeral was actually in Sault Ste Marie. So, Patrick and I did go to it.

AS: Oh, you did?

GK: Yeah. And a seemingly gay Catholic priest presided. But aside from that it was not a good event to go to. But there was a memorial service here at the 519 Church Street Community Centre in Toronto. So, another person that's much more recent is Bob Gardner, who would've also been quite involved in ...

SH: Bob Gardner was one of the great minds in AIDS ACTION NOW! around strategy, especially after CATIE was formed, George and I moved to what was initially called the TIE Project. We were calling it CATIE internally, even right after it formed. We just didn't tell outsiders of the name until we got the legal documentation accepted. We also picked that name because it was a woman's name, and we wanted to point out subtly some of the deficiencies in the activist movement, which is largely run by men – gay men – and didn't deal with women's issues. So that was the whole agenda of that.

GK: Anything else about Bob in terms of being involved in CATIE? Because he was also involved in AIDS ACTION NOW!

SH: Bob's wife...

GK: Linda.

SH: Linda was more involved, and then eventually Bob and Linda... Bob came on the board and was there for many years. And Bob and Linda made a wonderful contribution, but after 1999-2000, they were getting burnt out. It was time for them to move on. So, they were granted honorary life memberships on the CATIE board, but they had to move on.

GK: Are there any other people you can think of who would've been involved in AIDS ACTION NOW! or CATIE who died... You mentioned Alan Cornwall. I realize he wasn't connected with AIDS ACTION NOW!

SH: He was.

GK: Okay. Well then, tell us about Alan.

SH: He came to meetings of the Steering Committee. He attended some retreats and somewhere else. He was very important. He gave us a lot of advice for free about setting up CATIE. He ensured that after his death – he was on the CATIE board – and after his death, we would get free legal help for years from... the law company who hired him. But he also had to go on disability, early on because being a lawyer is very draining...

AS: Very stressful.

SH: Yeah, and so he was one of the co-founders of CATIE, and we worked very closely with him. Bob came on later after it was more established.

GK: Okay.

SH: Alan did research regarding the possibility of having buyer's clubs in Canada, because buyer's clubs – as you know from the movie, *Dallas Buyers' Club* (2013), you could set up these buyers' clubs in the U.S. to bring in drugs that looked promising but weren't approved in the U.S. for people with HIV and their doctors to use there. So, we were looking at trying the same thing here but he spent a lot of time researching it. Under Canadian law it would be illegal and they could shut it down. Prison is not a good place for HIV people, and we didn't want our HIV-positive colleagues imprisoned so we never set up a buyer's club, but we spent a lot of time researching it.

AS: But when AIDS ACTION NOW! was bringing in medicines – because there was this period maybe...

SH: Briefly.

AS: Yeah. Bringing in...

SH: The pentamidine project, right. So, those were nebulizers and they did that before... It wasn't a buyer's club like the one in New York City, San Francisco, or Dallas...

AS: ...where it would be a centralized operation...

SH: Yeah.

AS: Got it.

SH: It was not a Buyer's Club, because it was just one thing around the nebulizer. Pentamidine you could get.

GK: ...in Buffalo.

SH: Yeah. But the nebulizer, and to break it up into tiny droplets, and they brought in... Pentamidine was eventually approved by Health Canada.

GK: Oh yes.

SH: But yeah they would bring it in ahead of time. It was just this underground network that would also bring in stuff from Mexico, but it wasn't a formal Buyer's Club, and it didn't have the breadth of a Buyer's Club. It was more narrowly focused on the pentamidine issue, because there was this life-threatening pneumonia that affected HIV-positive people, and at the time pentamidine would save their lives. It's a really toxic drug and you know it would not be the drug of choice now to treat or prevent that type of AIDS-related pneumonia.

AS: Right, but then it was.

SH: But then it was all that they had. The other thing Alan and George decided was that, we can't set up a Buyer's Club but we can ally with researchers to set up clinical trials for promising compounds in which the community is particularly interested. And that was another useful thing that activists did. So, they did some of their own clinical trials – informal ones – in Toronto things like Saint John's Wort and its extract hypericin, which have anti-viral activity in the test tube, and you know we did an informal trial of it. Here's a brief explanation – viruses are coated with a fatty membrane and if you use a detergent like substance you can break it down and damage the virus. Based on this, the underground movement of activists shared a recipe that you would make in your blender – a mixture of eggs, certain fats, supplements and so on. It seemed to help delay the decline due to AIDS by a few months but later we found out that this occurred because the concoction in the blender was a great source of high-quality protein and fat. However, as an antiviral it was an utter failure. So many things worked well in the test tube but did not work in people, but we didn't know that at the time and did not know why. They did do a clinical trial of Chinese herbs that I think was very promising, and I was really mad at George when he stopped taking it, because it was safe; it was not toxic. It seemed to help peoples' quality of life and for a time, stabilize their immune system.

GK: So, is that the Community Research Initiative that you're describing?

SH: I think you know those were inspired by things that we did at the Community Research Initiative. It might have not involved the Community Research Initiative. It might've been independent, but the CRIT as it was called.

AS: What did the "T" stand for?

SH: Toronto – Community Research Initiative (CRI). So, there's CRI in New York or ACRIA (AIDS Community Research Initiative of America) as it's now called in New York. And they modelled... they have ones in San Francisco now and so on. So, I actually became the scientific director of that for a while. Yeah. You know, they did interesting things, like they did this trial of oral interferon, which at the time (early 1990s) was the hottest thing. It didn't work, as the Toronto study showed. They did many other trials that I can't remember them all, but that was spawned by the activism of some of the doctors who were willing to work with us, and our energy as well. People like Dennis Conway and Michael...

GK: Hulton.

SH: Hulton. Yeah.

GK: Can you tell us a bit about them? We were hoping to talk to them...

SH: So, Dennis Conway is still around. He is in private practice. He mostly has a counselling practice now. Michael Hulton went... I think he burnt out after a few years seeing so many patients die. He went to San Francisco and became an anaesthetist.

AS: Really?

SH: Yeah. And I don't know what he's doing now. I saw him a few years ago while he was visiting Toronto. Only now that you remind me, I realize that he is an important historical figure.

GK: Those are two people we definitely want to talk to.

SH: Right, but Dennis Conway is here. I've seen him at dinner meetings and so on. But they were gay doctors involved with the primary care doctors group in Toronto, a lot of whom had gay patients. Not all the doctors were gay; some were straight. But they had gay patients. It was no big deal. But then in the late 1970s and early 1980s their patients unexpectedly started getting these weird infections and fatigue and then became sicker, and that's when they got a lot of AIDS patients. So, they tried to do stuff about it. And, you know, there were fights with the hospitals, but they also ran clinical trials and...

GK: No, that's good. I mean we're very glad we got to that because we – aside from I think a couple of people mentioning CRIT here, we haven't really found out much more about it, and we do want to talk to the doctors who were involved. Would you have had anything to do with Philip Berger?

SH: Yes. Philip Berger was brilliant. He is a very nice man, very brilliant man. His wife is a lawyer. So, he's the perfect doctor in that he's absorbed a lot of her legal teaching. So, we could get ersatz legal advice from – quote-unquote “legal options” – that he would point us to. But he also knew how to use the media, and how to interact with the media. He knew politicians and key people in

the bureaucracy. And again that thing about press releases, never, never have more than three key points – preferably just one. He taught us the importance of sending out a press release late Sunday night, so it captures the Monday morning news crowd and stuff like that. He would give us wonderful advice. He would also help us with medical education issues. He taught me a lot of medicine. He's the head of family medicine now at Saint Michael's Hospital and he taught us a lot of things. He was our ally.

GK: He was Michael Smith's doctor.

SH: I'm just trying to think of anybody else, right. Brent Southin is still alive – a wonderful person. Glen Brown is still alive. You know, Glen was another person who worked – we all had daytime jobs in other areas and we would devote time to this cause. And it was Glen's employers who... We were very grateful to all people's employers that we could do this. And Glen was a source of unflagging energy for the activist movement for decades. It was amazing. And he did many amazing things. Darien Taylor... Have you talked to her?

AS: Yeah.

SH: Yeah. Darien Taylor was a really interesting person. Darien is important not only because of her activist struggles and her story and wisdom and influence, but because she co-founded Voices of Positive Women ... I bonded with her right away. You know that woman – she died from breast cancer... is it Kathy Acker? – who would do books that had titles such as "The Empire of the Senseless" and make fun of standard literary texts but distort them and reframe them and subvert them. Her books are fun. And I think we were walking along in the bookstore and we ran into each other there. We were both looking at the same book.

AS: The Kathy Acker book.

SH: Yeah. She is a really wonderful person and is still active and well liked. Another is Maggie Atkinson...

GK: Yeah, we haven't yet talked to...

SH: Okay.

GK: She comes a bit later on.

SH: Yeah, she comes later on. She's very important.

AS: She sort of sees AIDS ACTION NOW! through...

SH: Yeah, without Alan Cornwall and her and she's very important for that. And there were other people who have passed away like Kalpesh Oza, who was a scientist with two Masters of Science

degrees, and working on his PhD. And he took over my role in AIDS ACTION NOW! when I left, which was really good.

AS: What was he working his PhD on? Do you know?

SH: I forget, but I remember he would be working in laboratories with cells. He would be at meetings with us on a Sunday and then he'd have to go back and work on this experiment, because experiments take time, and then come back to the meeting.

People can turn, change and learn from their mistakes. Even the former Attorney General became a judge on the Ontario Court of Appeal to our shock in 2003, 04? I don't remember – he ruled in favour of same-sex marriage in a judgement that reverberated around the world. And this was the Attorney General that two decades earlier had unleashed the police on defenseless people.

GK: This was around the Bath Raids.

SH: Yeah. He had completely turned around. So, you know I think forgiveness is very important and dialogue is very important. I'm certainly not one for encouraging conflict and I think activism requires patience, and activism is something for the long term. Many people are too caught up in the immediacy of whatever they're doing to see this and appreciate this, but I can now. And I have given at least a quarter century of my life to fighting HIV and I can one day – not soon but one day eventually leave knowing that I've done something good and helped people's lives in some way. And that is a privilege that most people in the world don't have unless you're a doctor but our little band was able to do things that made a difference... You know, George said AIDS would actually help improve the human rights of gay people and I never understood that, and I still have a hard time understanding it, but now I can see bits and pieces of what he predicted, because George would say in one sentence what actually would need a book to be really explained, but he would just... what do they call it in the media? Use sound bites. He learned to do sound bites early on. He would almost mock the media because he understood how they work. So yeah, sound bites. He understood that. He understood even in 1993 and 94 – he died in late 1994 – but he knew in 1994 that the world was going to be in a bad place later; environmentally yes, but also economically and politically and socially he saw that very clearly then. He was very good at predicting the future. I remember a few months before he died he was looking at a political-economic TV show and I came in to the room and he said "Thank goodness I'm not going to be around 20 years from now – the world's going to be a disaster." He would repeat that from time to time whenever big, complex problems were the focus of the news. It was a really annoying habit of his because I intended to be around for the future!

GK: So, I mean I think that the last question then is as we've been talking, is there anything, any other topic or issue or experience that you haven't had an opportunity to talk about with us?

SH: I think one of the things that we cannot underscore enough is that the AIDS movement had allies in the bureaucracy, in the media, in the police, in the civil service, in pharmaceutical companies that were secret supporters. Some of them were gay but most were not; they were

straight people, mostly HIV-negative that did whatever they could to support us because they believed what we were doing was right and it's wonderful to have that kind of support. It enabled us to understand how Health Canada worked. We had no idea. We learnt how many systems worked, from bureaucracies to companies. And one of the amazing things that we were able to achieve – in George's vision for the future – was that we would liberalize the regime under which medicines for emergency use were legally brought into this country. For instance, you know, we would go to the government after Chuck Grochmal brought back this treatment bible, "The amfAR Directory" and say, "Look, we need to have these drugs in the country so we can help people with HIV and AIDS." They'd say, "Oh, you can't do it; it's just too hard... can't happen. It would just be crazy. We can't do that." Then we found out from the bureaucrats that drugs that were not approved in Canada but were needed to treat tropical diseases that we don't get or to treat cancers and stuff were routinely let into the country everyday, because there was this emergency access program and, you know, the Minister's assistants would tell us this. And so we used that to push open Health Canada to allow these vital medicines in to help people with HIV. So, that's an example. Like George had a master plan for managing AIDS in Canada. Part of it involved setting up CATIE; another part was the liberalization of the Emergency Drug Release Program, now called Special Access Program; another part was educating doctors, which is done; and another part was the establishment of an agency to run HIV clinical trials. Now there is an HIV clinical trials unit headquartered in Saint Paul's Hospital in Vancouver that works across the whole country, the Canadian HIV Trials Network. So all of these steps are in place now. And so now the medical issues are somewhat different. Today, people with HIV need help with co-infections and complications that can arise from aging. Examples of the co-infections include Hepatitis C and B and so on. Ray Glendenning who lived in the house on Seaton Street; he unfortunately died; he was a very quiet, very handsome guy.

GK: He was active on some things.

SH: You know, he died from complications of Hepatitis, and you know so many things have changed. Now people are developing complications with age that are accelerated by the inflammation caused by HIV, because when you live with HIV infection it causes a lot of complications. So, this story is not over.

GK: About Ray Glendenning?

SH: Oh yes, I remember the phone call. I assumed he died. Yeah. I think he died, because his partner was called. And Ray passed away from complications and I remember being in touch with him, trying to help him before. But there's another unmet need, right. We need better treatments for Hepatitis B, and they're working on that now – better vaccines. And we helped people with Hepatitis C... and so with drug users. Again, we see the same struggle of a despised group, you know drug users having to come out and fight for what should be routinely there. So, So, yeah, I think the legal network that came out from AIDS ACTION NOW! does a lot of interesting work; some of it's international; some of it's in Canada. This cluster of diseases that I work in that started with HIV and now extends to hepatitis, it's a really interesting place to be, and to have watched the medical system change and become more democratic over time has been fulfilling. But it's not

fully a democratic and in different specialties, they still struggle with that. I think that's about it. I mean there are many people we haven't mentioned, and I don't know. If I could see the picture again...

AS: So, we wanted to wait until we had a sort of a pretty good sampling for the interviews from across the country. So not just have Toronto, because there's so many.

SH: There's Kevin Brown in Vancouver. His work was important in bringing AZT (azidovudine) into the country, and also an experimental antibiotic. He helped form the Vancouver Persons With AIDS Coalition and then they renamed it the Society, and so on that later led into Vancouver, BC PWA (People With HIV/AIDS) as they were called, and now Positive Living BC. Being there, they've had to transform their name. We don't spell out what CATIE stands for because we went from community, which was just a Toronto thing, to a national organization and who knows where the future will take us. But we just use CATIE today. And Patrick Barnholden was part of AIDS ACTION NOW! I didn't mention him, but...

GK: Yeah, and we've already talked to him.

SH: Patrick was an important part of that, and he can also speak to the cleansing of the organization around the anarchists.

GK: Maybe just a question on this: So, this notion of the anarchists, right – obviously, there were real anarchists in AIDS ACTION NOW! like Michael Smith, Kenn Quayle, Robinski, Karen Pearlston, but there were also other people who weren't anarchists who...

SH: ...were annoying. [laughter]

GK: If that's true...

SH: ...who were pushed out and...

GK: That's what I'm trying to say, is it wasn't just anarchists.

SH: Yeah, so all these annoying people were pushed out. [laughter] Well, sorry. These people that raised difficult questions and issues that were very legitimate. But Renee du Plessis was not an anarchist and she was pushed out.

GK: Yeah. So, that's part of what...

SH: So, yeah. Thank you.

GK: I just want to... because what's interesting for me is that there seems to have been within the folk history of AIDS ACTION NOW! some notion that there was this split with the anarchists, right?

SH: Well, there was a very real split in that they wanted them out, but there were also...

GK: Okay. And who's "they" then?

SH: Well, I'm not going to say.

GK: Okay, that's fine.

SH: But you would know who they are. But they wanted them gone, but Renee du Plessis – and I think the dissidents... I think we just referred to them as anarchists because they would support each other and be together, and like what is Karen Pearlston doing now?

GK: She's a law professor at University of New Brunswick in Fredericton.

SH: Does she still wear... have green hair?

GK: I think she varies the colour of her hair, but I don't think it's green very often. She's still quite political and involved in various different things – most recently she's actually quite involved in the struggle around keeping the clinic open in Fredericton, the abortion clinic.

SH: See, a lot of the people with HIV were annoyed with some of those HIV negative people trying to broaden the agenda. So there was that.

GK: That's really helpful to let us understand this more. But basically what we're going to be doing is people's accounts will stand and they will not necessarily all be in agreement, right.

SH: But no, I think you're right, like she wasn't an anarchist – Renee – but she was in alliance with them simply because she was being marginalized. So, when you're marginalized you have to make common cause with political allies, right. And so there was that. And it was... they raised legitimate concerns. And a similar split happened in ACT UP – New York City (and in other chapters of ACT UP), where... I remember ACT UP being criticized for their agenda, with their critics saying, "You go to the NIH (the National Institutes of Health in the US) and you tell them to work on lymphoma and herpes viruses. You know what? Those are diseases that really attack the gay men who come down with AIDS. What about the drug users and women – the diseases that affect them?" So, this is what I mean. This is a legitimate criticism, but also they had a more holistic view of health care than we did... I and others were narrowly focused on things related to HIV treatment. So, they, the anarchists and their allies raised issues that resonate with us today. And I don't know how those could have been dealt with without a massive influx of volunteers and great thinkers. I couldn't deal with all the ideas that the anarchists and their colleagues raised. They were important; but I just couldn't; there was only so much I could do. And maybe they needed to be in a different organization that dealt with those issues that worked in parallel. I don't know, because the anarchists had good ideas. It was a different time in the 1980s. It was an extraordinary health emergency. People seemed to be getting AIDS at random, again because not much was known

about it exactly who would get it, who would get these horrible infections and die and when they would die. Now there's much more certainty right; back then there was not, and there was a sense of crisis that just never ended.

I think that in the end, the argument between the anarchists, their allies and the rest of AAN! was distilled down to the power of HIV positive people, and it was a very powerful argument, especially when most of the people who were trying to broaden the depth of the organization were HIV-negative. And most of the people who were trying to focus on getting access to medicines were HIV-positive and dying. So, that was another thing. And some of the anarchists and their allies said things that were inadvertently insensitive to the health needs of HIV-positive people. And so that actually served to strengthen the argument against them. But it's very hard to manage a revolution in wartime, which is what this was; it was extremely hard, especially when your health is failing. Weighing on the minds of people then were things like studies showing stress weakens the immune system and back then, like I said, there was no treatment for HIV. So, HIV-positive people said, "You know, we can only give so much and we've must focus on this or that because the stress of fighting or repeatedly arguing is killing us." And by comparison, HIV-positive people found that the energy of these argumentative HIV-negative people seemed endless. That was also extremely frustrating and even threatening to HIV-positive people, because HIV actually saps your body's ability to generate energy, at the molecular level. And we didn't know this at the time but I can tell you – this is why this thing about fatigue and energy might have been very important to deciding what happened next. Perhaps it might've been subconscious but this frustration about energy levels probably played a bigger role than people realized at the time. And I think many of the HIV-negative people didn't appreciate that or couldn't. Yeah, they couldn't... It's hard to understand. I only became aware of it over years of talking to HIV-positive people and having them describe their lives to me and watching them – a whole range of people – and seeing how this virus sucks away at their energy. And so they actually... And again this is in retrospect, there were conversations I wasn't part of, because it was more the HIV-positive people... They came to see to some degree some of those people you described as a health threat, and then once it was framed that way, all the HIV-positive people, suddenly they all got it, and they got it very clearly and coalesced around ridding the organization of anarchists and their allies.

As I've mentioned, a similar thing happened to ACT UP in the U.S. We watched what happened to ACT UP and we could see the parallels to what was happening in Canada so clearly, and it was sad because ACT UP itself collapsed and the treatment-knowledgeable people left to form the Treatment Action Group (called TAG), which is still around today. The treatment group from AIDS ACTION NOW! was CATIE, and TAG – as they're called now – we also do some work on TB as well, and Hepatitis, and in fact I know some of them. They're good friends of mine who... and there's a straight women, but two of the big names in ACT UP... I forget one of his names. He's gone off to Yale University Law School.

GK: Which one?

SH: I think that his name is Greg Gonsalves.

GK: Oh okay.

SH: Yeah, he's from there. You know, it was living in a very exciting time. We didn't even put dates on things that we published at AIDS ACTION NOW! because we didn't think it would have a shelf-life... The situation was this: "We need this for this demonstration. Here it is." We didn't put a date. We just made it. And then when Eric came on as the staff person, he got these worker bee volunteers to file – and they and he would ask these annoying questions such as, "Your stuff doesn't have dates? When exactly was this created?" So, we had to tell them. It was kind of embarrassing. And for years we used the wrong postal code and stuff like that.

GK: We weren't doing that in solidarity with postal workers who were opposed to automation? That was a big struggle. And actually for a while it was actually CUPW said, "Do not use postal codes."

SH: Well, look at what's happened right. The technology is... I mean there's not enough stuff being sent by mail anymore. You know it's like the telegraph in a way. I mean there still will be post; it will just probably be packages and Christmas cards. That's essentially what it's come down to. But yeah look back on that political action – in retrospect, if it could have been managed and bringing everybody and keeping them together, it would've been great. Tim's health was declining; so was George's, and it was a difficult time for HIV-positive people.

AS: Uh huh. Some of the key people...

SH: Yeah.

AS: ...right in that very moment.

SH: Yeah. Chuck Grochmal died... all these vital people.

GK: Doug [Wilson] was quite sick.

SH: Doug was sick. He had PCP (pneumocystis) during the political campaign, and everybody was all hushed about it and wouldn't talk. So many people were ill and there was... and then that just left more burden on the rest of us and we had to cut back or we'd burn out. There was so much burn out in the AIDS movement. I've seen it among doctors, nurses and in people working for community groups. Even though I don't have HIV, I don't know how I survived in the sector this long. [laughter] It's very difficult, but we are lucky in that CATIE has become a very resilient, strong and focused agency and it's something George and Alan can be proud of – they are our main co-founders. And I guess I am also a co-founder of CATIE, but I didn't... I tended to downplay that for many years, but yeah... And *Rites* magazine eventually folded. *Rites* was ahead of its time in so many ways. Anyway. I'm just prattling...

GK: Great prattling.

AS: That's wonderful. Thank you so much.

SH: You're welcome. Thank you for doing this. I hope somebody can write a book out of this.

[END OF TRANSCRIPT]