AAHP
AIDS Activist History Project

Interview Transcript 2014.003

Interviewee:	Eric Mykhalovskiy
Interviewers:	Alexis Shotwell & Gary Kinsman
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Persons present: Eric Mykhalovskiy – EM
Alexis Shotwell – AS
Gary Kinsman – GK

[START OF TRANSCRIPT]

GK: We're asking people what they were doing before AIDS and before connections with AIDS activism. I know you were a student at York and I know you were involved in other forms of activism before AIDS activism…

EM: So, you want to know about activist histories prior to AIDS? Okay. There are two pieces that were relevant for me. I was a student actually at King's College in Western Ontario, which is a Catholic institution, but it had these really great Marxist feminist sociologists for some strange reason. And I kind of got in with them, a little bit. This was the early '80s – like, 1981-82-83, something like that, maybe 82-83-84. I can't remember. So, nuclear proliferation was huge. People were freaking out, and so I – with some other, two or three other students – we formed a little campus group called Dialogue for Peace. I was a little peacenik I guess. You know, we did like what you did at a university. We got people together and we had debates and we had educational things. We had events. We made petitions. There was a huge peace march in Canada in Winnipeg – Caravan for Peace. I can't remember what it was. We were delegates to this peace thing. So, that was one thing. But it was really tied into what happens at a university. We weren't actually, I was going to say, white because we weren't all white, but what middle-classy kinds of kids do when they… but it was far-away stuff, right, in a sense.

And then the second piece then I came to Toronto and I became involved in Central American solidarity stuff, particularly with Nicaragua and the Sandinistas. I went to Nicaragua for a couple of months and interviewed trade unionists, and that was hooked into my work as a Master's student. But I did a little solidarity work around that. And, again, it was far-away stuff and it was sort of connected into my schoolwork. I did something to do with international trade union solidarity or whatever and barely squeezed out and finished a Master's degree. I almost dropped out and somehow I managed to stay in. I just was very dissatisfied with that kind of work because it was so alienated from me. And so I'd come out before that, sort of in between, toward the end of my time at London. What happened after that? Well, then I just needed to get a job. I couldn't find any work. And so I ended up working at a temp agency as a secretary, and I worked in different government offices. This was the time of the temps – big time. And so there was a thing called "Go Temp," which was the temporary service for the Ontario government. I worked in different government offices and then I landed a gig in the Legislative Assembly. They hired me on as a full-time person, so I was working really as a secretary, as administrative assistant in the Committees Branch of the Legislature.

HIV is always on the brain, but I think somehow I started to recognize that I could do stuff politically that was a little bit more close to home. Like, there was this whole thing then about, "Oh, you did this solidarity work in Central America." That was the big deal. It just didn't work for me and I was very disappointed by the end of it. I wanted to do something around HIV. I think you had asked about, when did you first…

AS: Yeah

EM: So, I would've had the quintessential middle class connection to HIV. I remember sitting in my parent's – this must've been in the summer as an undergraduate student – sitting in their family room reading the *Toronto Star* about GRID ["Gay-Related Immune Deficiency"]. And I was just coming out, so I was just starting to understand what this was. By the time I had come to Toronto I wanted to get connected and what to do? I remember I would go downtown and pick up *Xtra* or *Rites* and stuff; and I started to get involved with *Rites* and that was one of the things that connected me into HIV. I came into it sort of internationally, because I would copy edit the International pieces somehow. I can't remember exactly what it was.

GK: In the News section?

EM: And so there was that. But then I remember somehow I got – I can't remember what it was called – AIDS Action Now!'s not Treatment Update, but the other publication. I can't remember what it was called.

GK: The newsletter?

EM: The newsletter, yeah. And it would just describe things that they were doing. I would read and I'd think, "Oh wow, that is so cool." By that point I was living on Parliament Street, but I was so shy and I had so little confidence in myself as a person then that I couldn't imagine that I had anything to offer.

AS: Walking into a meeting.

EM: No. There was no way I would've done that. I was way too timid. I really had a bad time in university getting out of the Master's degree and I left thinking I had nothing. And so I remember sitting there and just thinking, "Oh, it would be so great but I have nothing to offer these people. Like, they're so smart; they're so, you know, everything." So, what I did is I volunteered at ACT because that was an easier thing to do. That was a channel that was less threatening to me somehow.

GK: Right.

EM: I remember the intake and I remember the face of the volunteer coordinator – she obviously doesn't work there anymore – sat down and then you do this history thing – "who are you?" kind of thing. And then they plop you into whatever they want or whatever they need. So, they plopped me into the library, which made sense because here's this little kid who worked in the Legislative Assembly – I was still working at the Legislative Assembly at that time – and who had a Master's degree. So yeah, he can read articles and go do the research at the library. And so I started to do that for quite some time, that would've been in… it must've been in '88 or '89, maybe. And so that was where I started to become more connected to reading about HIV, and I read a lot of the treatment stuff. They would have boxes of things to read and file. It was an elaborate filing system of codes and stuff, and so you'd read the stuff and code it. I did that on Tuesday nights. And so that was how it started, but then I was working at the Legislative Assembly at the same time and I tried to make something happen there because I was overqualified for this job – although it was a great job, you'd just sit around and you didn't have to do much. It was really quite easy, and we used to… actually, we used to watch a lot of television because you had to monitor the proceedings of the House. So we had cable. [laughter] And I remember watching the French Open, the tennis open whenever that was, in May, because there wasn't a lot to do. It was free. But, also, you could see it was not a very invigorating environment. I had a great boss and he tried to find, what's the word? You know, help me to get a better position and there was just nothing available. I interviewed at the Ombudsman and there was nothing and there were also no positions for the Clerks, which is what I was the secretary to – the Clerks of the Committees Branch of the Legislative Assembly. But then, the fact of it was that the Clerks were secretaries themselves – procedural experts on how the different consultations with community were to occur, and the proceedings of committees and so forth. And so he said, "Get out, get out of this job. You shouldn't be doing this." It was great. So, this job came up – the coordinator for the TIE [Treatment Information Exchange] project and I was still, you know, not a confident person. But John Dunham, who was the librarian at ACT at that point, he said you have to apply for this position. And so I did, and I was interviewed for it and somehow they picked me. I don't know why. I know there were three of us at the end who were interviewed, who were shortlisted. It was Sarah Forer, who later became a volunteer at the TIE project, and Ron Foley, who did work for us on the TIE Project in the very early years. And I remember going to that interview actually.

GK: Do you know who you were interviewed by?

EM: Yeah. It was George [Smith].

GK: Right.

EM: Mary-Louise Adams, who hated me apparently.

GK: Really?

EM: Yup. She thought I was like a prissy little fag with my little… she's got a very clear memory of this, but I don't. I had some kind of… the thing that you put your notepad in, like a leather folder or carrying case. I wasn't like that though. I actually really wasn't, but I guess I was trying to impress.

GK: Yeah, a dossier or such.

EM: Yeah, a little leatherette thing or whatever. And Alan Cornwall would've been there. I don't think Maggie Atkinson was there.

GK: Right. Maggie's later.

EM: Yeah. Who else would've been? Russell Armstrong was probably in the interview, but definitely George and Mary-Louise as I remember and maybe… I don't know if Linda Gardner would've been there. She was definitely involved, so those people. And it was funny because that morning I have, you can't see, but I have a beauty mark here. And that morning I was so excited, and I cut it shaving. And when you cut it, it just bleeds, like it doesn't stop bleeding. I walked into the interview with this little piece of paper stuck to my thing, right. I thought, "Fuck, I've blown it." But it worked out okay, I guess. I don't know. They hired me. That was the end of 1989. By then, what I had started to do was I went to demos of AIDS ACTION NOW!, but that's about all I did. And by the end of that year - I was hired and in January 1990 – the place opened. And so my involvement with AIDS ACTION NOW! And Brent will tell you, when you interview Brent he'll say he was the first staff person of AIDS ACTION NOW!, which isn't true because I was the first staff person of AIDS ACTION NOW! I was actually hired as a staff of the TIE project.

GK: Which is part of AIDS Action Now!

EM: So, my relationship was as a person who was employed by AIDS Action Now! and that meant things were different for me than for other people. It was, in some respects, a little more complicated. And the reason that the TIE project was established was – and a good person to talk about this if you can connect with is Russell Armstrong – was that there was such a focus within existing community-based AIDS organizations, and I would call it that deliberately rather than AIDS Service organization, which is a later term. So, community-based organizations at that time were so focused around HIV prevention and we can talk about George's stuff around that. Or providing certain kinds of practical assistance, either in the forms of some assistance with accessing social services or, particularly, welfare or family benefits at that time. Or doing things like care teams and buddies. That was big and yet there was nothing around the more specific health needs of people with HIV, particularly around treatment. This is where things are complicated because at that time health was conceptualized through treatment primarily. It was about access to treatments. And there was nothing, nothing, and so people were pissed off that the needs of people with HIV weren't being addressed and the services, which were provided, which were so-focused around prevention – preventing HIV transmission. And so they got money. They got money from… put in an application to the Trillium foundation, which was the lottery proceeds. Then they got three-years of funding to establish the Treatment Information Exchange.

GK: I was going to come back to that. You described AIDS Action Now! as being really cool and interesting and you went to demonstrations. Do you have any more memories of that – about what AIDS Action Now! was like before you got involved as an employee of it?

EM: I have one particularly embarrassing thing I could say.

GK: Okay.

EM: It does not put me in a great light, people. [laughter] But I remember going to one demo. It was at Cawthra Square. And there was this women with this very short copperishy coloured hair and this copper-like trench coat-type thing talking about women and HIV. And I was like, "What the fuck is she talking about women and HIV for? This is about gay men," and it was Darien. And it just showed at that point what I understood was pretty narrow, pretty limited. But she was incredible. She was such a remarkable speaker, and I was mesmerized, transfixed really, by her. The way she could connect with an audience and how she could express complicated things in a way that was easy. And she was one person throughout who… you know, I've seen her speak many, many times, particularly in that early period. And she was always just remarkable in her social presence and her ability to convey her stuff, but go beyond her stuff in ways that connected up with other people. So, I remember thinking, "Oh, these are these cool activists," and I just felt like I can't be part of that. They're just way too cool for me. And they're just way too smart. It's just too complicated. But there was a kind of – and AIDS Action Now! struggled with this – it was difficult to get new people because it was like, no one had a lot of time to do… there was a lot of insider knowledge and the place was structured in terms of people's connections – their relationships with each other, their friendships. And so much of the work that AIDS Action Now! did at that time was in meetings with people face-to-face or in someone's kitchen, or in someone's, you know, whatever, or on the phone. It wasn't like you could go online and read about stuff. You had to be part of the network. You had to get in, you had to be part of this thing, and it was a bit cliquey. And they struggled with how to bring people in because it was such a specialized vocabulary around treatment, and the issues that were being dealt with were complicated. If you think about what was known back then, you would really struggle to try to get involved. And so I did go to meetings, but I stayed back. And then I was the staff person. I had to have a disconnect. I wanted to have a disconnect because I worked like until nine o'clock most nights from Monday through to Friday, Saturday sometimes, and I was exhausted all the time. I couldn't do anymore. I didn't want to and I couldn't. I established friendships with most of those people, but I wasn't central to AIDS Action Now! organizing in that early period, it was later. And my involvement was mediated by the fact that I was an employee and I did the work that was associated with the TIE project. And then that became CATIE [Canadian AIDS Treatment Information Exchange], but there was still a real huge overlap with who was doing CATIE and who was doing AIDS Action Now! They were together, connected. Like, at least in the first few years, the board of the TIE project was all of course first AIDS Action Now! folks. And then later, once it was established as CATIE, it was also primarily people from AIDS Action Now! in the first period...

GK: We're obviously really interested in hearing about the type of work you would've done and what was the project of TIE. We'll come back to CATIE in a bit.

EM: Well, it was very interesting because it was a service, right. It was new for AIDS Action Now! because AIDS Action Now! was an activist organization focused primarily around direct action, and also creating alternative ways of thinking about what should be done in terms of policy. And so a lot of the documents that were created were really along that level, and it was activism of that sort – not about direct service. How everyone would've imagined that or not functioning as an organization that was working in that model. It was a grassroots social movement type of thing, not an organization with an office that had to distinguish itself from other AIDS organizations that were functioning at that time.

I remember there were three, two or three, objectives in the proposal. One of them was to establish a mechanism for physicians who were primary care physicians to connect with one another around and enhance their knowledge of treatment options, and to do that in some type of forum with regular meetings. I can't remember exactly how it was articulated in the proposal. That never happened, not quite as it had been imagined. And another goal was to use people with HIV – use their knowledge of their bodies, of their relationships to treatments, their experience of providers, and piggyback on the model of a buddy system, which was more around dealing with their HIV. Like, willing to come out with their HIV and how to deal with their life and focus it more around treatment. And that kind of happened, but in a slightly different fashion than I think it was understood or perhaps anticipated. What we did, there was an office on College Street – which is now a condo, of course, like everything else in this city – and there were two rooms empty completely and there was an office. It was a building where there were all these small community groups because the rents were low. So, eventually, Voices of Positive Women was just above us. The Advocacy for People with Disabilities – it was a legal… I don't know actually if they were a legal clinic, they might've been. They were there. A lot of very small organizations were located in this building, so it was kind of like, "Here's the key. Okay, get it going. Start doing something." [laughter] Yeah. And it was new for those folks because they weren't people who were in this world of developing organizations, or whatever, right. Nor was I, you know. It was like, "Wow. Well, okay. We'll see what we can do." [laughter] And it was also the case that, it was very much, we didn't have this model of organizing where we had a governance board that was going to be at arm's length from what staff were doing. Well, there was no staff other than me anyway.

AS: At arm's length from what Eric was doing.

EM: Yeah. These people were in your face because they were from AIDS Action Now! The TIE project, it was part of AIDS Action Now! really at that point. And so people like Chris Bearchell were on the board initially; Michael Smith was on the board; Russell Armstrong was on the board; George, of course, was on the board; Mary Louise Adams, Linda Gardiner, Alan Cornwall. Those folks were all AIDS Action Now! – steering committee members or otherwise. And part of it was trying to create something organizationally that didn't mimic the politics of an ACT, for example – no offense ACT. But, you know, that's not what we wanted to do. That's certainly not what… I was smart enough to know that that wasn't the direction to take things. And so I remember there just being a lot of meetings and everybody had their own idea of what was supposed to happen, and everybody wanted their vision to come to fruition.

But it's funny that what actually occurred followed not through some grand plan. It's not like we sat down with the proposal and identified how we were going to meet. No, nobody did that. It wasn't structured like that. It was much more like, whatever; just do whatever, what we feel like. But at the same time there was incredible pressure from George in particular to do something quickly. The standard approach would have been for me to have done nothing except more staff – my job would've been to get more funding and get more staff and do a needs assessment and that was not on. George was like, "Forget it; start doing something now." And, as smart as he was, he was brilliant; he wasn't so good at realizing how much work it took to do basic things. You know, he just didn't get it. And half of my time was paying the rent, getting volunteers, dealing with them, dealing with the phone, all just basic maintenance. And that was - slowly people realized, "Oh shit." This is part of the story, when you go this route, is that you spend a shitload of time on crap that doesn't amount to anything in terms of what you're doing for somebody else. So, we had a phone… you know, the first stop was getting furniture. Like, wow, getting furniture, getting the place to be an office, to figure out where the phone was going to go, all this … It was an empty room – two empty rooms. But there was a phone. We had a phone. And as soon as the phone was publicized it was game-over, because people called and they wanted you to answer their questions. We did decide that… so, there was one staff person and one way. We couldn't provide meaningful direct service in the sense of people coming in and visiting. We didn't do that, but we did establish a treatment hotline. And so people immediately started to call and ask about AZT [zidovudine], about ddI [didanosine], DDC [zalcitabine], you know, about what's good, how do I deal… and the full gamut into a complementary alternative approaches, which were very important and significant in the early years. So, the first thing was being able to answer those calls, being able to provide something meaningful to people. I organized a bunch of volunteers to help me better understand the field of treatments so that I could better answer questions. And so I had about maybe seven volunteers who would come and we quickly established subscriptions to the key community, activist, publications around treatment that were coming out of the US – *AIDS Treatment News* and *amfAR [The American Foundation for AIDS Research]*, even *amfAR* stuff out of other… oh, I can't remember their names, some of them are still around. Anyways, there were a number of them, and a bunch of other things, and made files – still paper files – and established hours for when people could call. Advertise that I would answer people's calls about their various issues.

And that's another question because very soon part of what was at issue was that AIDS Action Now! – those were middle class people for the most part that were on the steering committee, and they were all very competent, extremely. Like, beyond competent, but it wasn't as though the concerns were just about treatment narrowly defined as this little box. It was their whole lives were entering into these conversations, and it was never just simply about a particular issue, even though I've sort of suggested it was in how I described it a moment ago. It was more about – my life is falling apart and I don't have a house; I don't have a place to live. And all these things were intersecting. It was difficult to figure out how to think about treatment in that context because one thing is there was pressure to be treatment focused. And there's all these other organizations that do that, so just refer them out, which didn't really work because people are calling you on the phone. You can't just say, "Oh, well, just go to the PWA [People with HIV/AIDS] Foundation for that" or "Just go to ACT for your counseling needs." So, there was a model… how to conceptualize what those phone interactions were and who the folks were that were coming into contact with the TIE project and later CATIE – Community AIDS Treatment Information Exchange – and what the service would be. Those were the beginnings of those types of questions, which did get resolved in a particular way, years down the road. So, that was one thing, making sense that we could… I wouldn't use this term of 'branding,' but recognizing we were *different*. And we did. And we created pamphlets to describe what we were doing and what we wanted to do, and started doing something. That was the one thing.

The second thing that we did very early on, actually immediately, was take over the production of *Treatment Update*, which was the publication that Sean Hosein had been writing with some guidance, I think, from George in perhaps the early years. The conceptualization around *Treatment Update* was that this would be a document that would, not force doctors, but kind of force doctors to be more aggressive in their treatment around HIV, because in the very early years doctors were either not particularly interested or they were overwhelmed by the complexity. They didn't want to get into very complicated issues around experimental medications, or they viewed HIV as something that was basically about palliation. And so the whole impetus behind AIDS Action Now!, obviously, was a kind of politics of life; a figure that focused on making it possible for people with HIV to live. The main focus was to get treatments and all of that made perfect sense at that time, absolutely. So, what Sean did was follow the journals, the most cutting edge stuff that was happening and reassemble it, offer some interpretation, provide references and deal with specific issues that were of concern. And you can go back and see all the various things that he wrote about. And that soon became the flagship publication for the TIE project, and later CATIE. It was interesting because, you know, it was really hard to read. It wasn't hard to read, but it was not the community; it wasn't for people.

AS: It was directed at the doctors?

EM: It was directed at the… but a lot of the people with publications coming out everywhere were complicated. Like, you had to know your stuff to really get them sometimes. And in the end that delivered, in the sense, that did deliver on the first objective of the proposal was to get people, to get physicians, together in more face-to-face stuff. I think actually, maybe we even did try to do that, but the physicians were not going to be governed by us; they're like, forget it. So, I think in fact, as I remember, there were some efforts to try to do that, but it was very clear early on that Sean had a job, and then he was doing all this work on the side. And then, you know, the volunteers were stuffing the envelopes and doing all other… all that production then came here. They were already organized, but we assisted in the organizing of the translation of the document into French, because it was bilingual. And there were people like Bernard Courte and there was a whole team of translators who I would then coordinate, and I would do more of the little copy-editing and the production of it. Like, the desktopping of it. And then we would print them off, and I had volunteers to manage the… we got a database, organized the thing into a proper… it was hilarious because it was like a Word Perfect thing. I remember this… it was Word Perfect? No. What was before Word Perfect? What is it that we used on the Mac? Word? No. It was Word Perfect, the other one.

AS: I think there was a thing before that. Like, Pages or something.

EM: It was definitely Word Perfect. That was another piece of it was managing this database, and there was a lot. There were hundreds and hundreds of people from all over the place. And then starting to charge, generate a little bit of revenues from it, very minor, but then managing that piece.

AS: You charged subscribers?

EM: We didn't charge a lot. It was more voluntary stuff people wanted, because we wanted to get it out. So, we also set up all the hospital clinics, AIDS service organizations with binders to hold the thing and things to display the publication to create a bit more of a presence in different community settings for the publication. So, I guess those were the two main early things that were happening in that first year of work, getting the publication up and smoothly functioning, and that took some time, actually – although, you know, Sean did all his own writing and work and on his own. It wasn't that we were writing the stuff – he did that – it was more the production end of it.

AS: And how did he come to do that? Do you know?

EM: You'd have to ask him.

GK: Yes. We're going to have to. He started writing Treatment Update as a column in *Rites* magazine. That's where it really started and then it developed from there.

EM: I think he was really smart and had a job that wasn't realizing his potential. Well, the backstory… part of it is that George really wanted to support Sean in realizing that potential, and CATIE was part of that was a mechanism that helped that happen. Eventually, Sean was able to be employed by CATIE and then do this work fulltime and get paid for it, which was great.

AS: I guess I'm asking that partly because… so, all of the people that are involved in producing all the various things, and even when you're at ACT doing the library stuff, it's just amazing that people are starting to be able to read these things and parse them and think about them.

EM: It's totally autodidact, right. For Sean, he would go to the library and go and get the physical journals, and read them.

AS: Is that also true of other people who were volunteering for the TIE project? Did they come in and say, "I have a lot of medical expertise and I want to do this," or…?

EM: No.

AS: Then, would you teach them stuff? How did they…?

EM: They would try. Some were better than others. Yeah. Some were more adept at that than others. And so I would try to channel those folks into doing that, and others would be doing more of the grunt work around the publication. Like, the letter stuffing and managing the data, getting all the, you know… everyday you would get five or so that were sent back because the addresses were wrong. So, just taking them off the list because it was a waste of postage and just doing all that stuff. But there are others who were more keen on learning, and on learning more about treatment information.

GK: We're sort of talking about TIE and I think we're starting to move in a little bit to the transition between the TIE project and CATIE.

EM: Yeah.

AS: But there were several things you said you wanted to say.

EM: There were several things? Okay.

AS: There's at least one thing you said you wanted to say.

EM: Well, there was a tension. Eventually there was a problem that the TIE project could not continue to function as part of AIDS Action Now! And there were some personality conflicts. Tim will be able to tell you more about that because I don't remember exactly what they were about, but there was tensions between George and other people involved in the TIE project and the steering committee of AIDS Action Now! Certainly one of the problems was that AIDS Action Now! will talk about how AIDS Action Now! doesn't accept funds from pharma or from the state to do anything. Well, it's not true because the Trillium Foundation, it's money from the lottery… maybe it was a bit of a drain as well. Like, all the effort going into running an organization was not what people wanted to have. And then, also to cut the apron strings so the TIE project could sort of have its own fund-raising possibilities. So, it was established as a charitable organization. And so by then, Alan Cornwall must have provided legal services to set that up. I can't remember the details of how… I'm sure he did it. Because there were growing concerns around, you know, having liability disclaimers on the various things that we would put out and all this kind of stuff, which wasn't what, I think, people at AIDS Action Now! were really interested in those kind of concerns. It is clear that this is going to take off as an organization. It didn't need it to have its own capacity to generate funds and would need to build itself as some type of organizational model that was somehow approximated – a service of some kind, right, and that there would be more staff.

One of the things that did happen was that, I just remembered… okay, I'm going to forget all this. It's like Swiss cheese, honestly. So, I have to write it down. What does that say when you have to write stuff down to remember it, like in the midst of trying to talk about it? Now, I've already forgotten what it was now. Oh yeah. I'm okay. [laughter] So, the thing that happened is that I thought, "I need help. I can't do this on my own. This is way too hard." And eventually I had a nervous breakdown and had to leave. That's basically what happened. I lost it. I just couldn't do it anymore. Actually, it's a good story. We would get the amFAR directory, which was a fairly big document that listed various trials and shit happening in the US. And they would send them to us in bulk and we would distribute them around, and we'd entered into some kind of relationship with them to distribute their document in the Toronto area. And so it would come in a big box and you'd have to go to the post office to get it. And so I would send a volunteer to get it because I was supposed to be the coordinator, right. [laughter] And that worked often, no problem. And somehow this time the volunteer went and they sent him back because he wasn't the named person on the box. They said no. He just said, "They sent me back. I couldn't get it." I was like, "Fuck." And so in the midst of trying to do administrative kind of shit, which was half the job in the end… I was just so burnt out already because some of the volunteers had died already at that point, you know. And it was that stuff and all the other… and I didn't have any help... like, I did. I had the folks on the steering committee who were great, who were really just amazing people, but I didn't have any help from nine to five with the volunteers. There was more work; actually spent more time… sometimes it was like I could've done more on my own than having to work with them. So, this is the typical organizing/building stuff. In any case, I had to go to pick up this stupid fucking box, right. The last thing I needed to do. I went and they wouldn't give it to me. And I said, "I'm the coordinator of the program we talked about." "Well, your name isn't on it. It says Sean Hosein on it," because somehow we had had Sean's name on it. And I completely, completely lost it. I was screaming. I took those little airmail things that are in these little glass things; I took them and threw them all over the place. And I started screaming at the guy. And I think eventually he actually gave me the box, but I went home... I went to the office. I went home and I realized I had to quit my job that day, which I did. And then I stayed for like, three months to ease the process of finding someone else. Anyway, a little story.

But what I wanted to say really was something about how I realized that I needed to get some help. So, this would've been still in 1990, the first year. And so we made an application to get funds to hire somebody. And this was an interesting thing because one of the problems that we faced was that we did not fit any of the pockets of funding, which were simply prevention funds, right. So, you could get funds to do education. You could get funds to write pamphlets. You could get funds to do safer sex workshop or, you know, whatever it was. We didn't do any of that. It was like, how are we going to get any money? And it was with George's help we researched prevention – the history of the concept of prevention within public health. And I remember finding stuff. This is where it was good to have gone through university. You could find stuff and read it; and being able to make a distinction between primary, secondary, and tertiary prevention within the history of public health. So, tertiary prevention… this is going to be all wrong, but anyway this is what I remember, folks. Tertiary prevention was preventing death. And so I wrote a proposal to the City of Toronto Public Health, which was funding a lot of HIV prevention – that's how a lot of their prevention work was done, was by funding local AIDS organizations to do it. And so I made this application. I wrote it up, and it was directed towards the creation of something that I called "Managing your health." But in the proposal I fit it into prevention under the banner of tertiary prevention and cited all these like things from the *American Journal of Public Health*. I remember this – that talked about tertiary prevention as preventing death, and then wrote about our work as fitting into prevention because we were actually going to prevent people from dying by first encouraging them to test for HIV and to make treatment information available to them and help them to start taking treatments and manage their health, to address their health. And then there was a person from AIDS Action Now! who was on the Board of Health. You know what? There was a Rand Corporation study on something to do with this. I found it. I can't remember. And it was Mark Freamo, who was on the Board of Health at that time, and he said afterwards, "You know what the clincher was?" The Rand Corporation reference or something – that he was able to use, because the proposal was started up in the way that you have to tart it up – was in a form that was amenable to him being able to advocate for it being funded. And it was an interesting example of trying to work out of the confines of how the framing of HIV as a prevention problem excluded questions of treatment from the main business of responding to HIV; how we were able to work within that, open up a space for funding treatment initiatives. That was the first time a treatment project had been funded through the City. And it was very helpful that AIDS Action Now! had Mark on the Board of Health. I'm pretty sure that's… I may have made that up somehow. Some of it could be wrong. But I know the other part is not; the part about the application is not wrong, but it might not have been… I'm pretty sure it was Mark. It seems like early days for him though, but maybe. I'm pretty sure. So, that was a really important piece of the development of the TIE project because we could secure some state funds through the prevention envelope and frame our work in ways that did not compromise what we were doing, but also could fit their reasoning. And so that was brilliant. Then, those funds went to hire Brent – not Brent Southam, but Brent Paterson – who was then the second staff person of the TIE project. It may have already become the Community AIDS Treatment Information Exchange at that point.

So, I wanted to say a little bit more about "Managing your health," but also the tensions that occurred between AIDS Action Now! and the TIE project. Eventually, this meant that the TIE project established its own self as an organization, had a separate board that then drew over time on people who were outside of AIDS Action Now!, and became a charity. And so we could start to fundraise and get money. Then, the piece around "Managing your health" – I think one of the things that happened through the TIE project and having so many people call in with questions about their lives, but also about treatments was that I was able to start to get folks to see in AIDS Action Now! that this was more complicated than the notion of "Treatment Information" would accommodate or permit. I tried, actually, to get things to be changed to the notion of health, but I couldn't. That didn't work. And I tried to get things moved out of "Information" in the narrow frame of information, and that didn't work in the end. Although, I was at least able to expand the notion of what was seen to be relevant within the scope of the organization. And so we created a document – it's still a document – called "Managing your health," which at least started to get at this stuff. And it was interesting because what it did is it produced something that was broader than – here's ddI, here's what the trials say, and then you make your decision with your doctor. Or, here's what you know ddI plus DDC and whatever combination, here's the latest information coming out of this trial versus what's happening at this trial. So, it moved out of that and into a broader set of questions. In "Managing your health" it was conceptualized as most of what you would need to try to deal with about HIV from a health perspective. There was stuff in there about HIV prevention and transmission of HIV, but not hooked into any of the anxieties we have now around the criminal law. There was stuff around disclosure and when to disclose, but as something about how you were in control of that and how it can be important to your health; both when you make those choices and who you do it with. There was stuff about accessing social services and hooking up to housing, to hooking up to welfare, family benefits, all that kind of stuff was included. And there was stuff about how to develop a relationship to a physician, but also how to develop a relationship to yourself and to your health. A little bit like as a project, the way that the Foucaultians will talk about it now, right. But the whole idea was to provide a resource that people could read and have in one spot a lot of stuff that they would need to help them think through what to do, particularly if they were newly diagnosed. And that was an important thing actually in the end. And I think it's actually still produced in various iterations, various versions of it have been produced over the years, but I'm not sure whether CATIE is still doing it. Certainly, there are a number of versions of that document that were produced over the years and people really loved it. You know, they talked about it as the Bible, because it had – kind of a strange metaphor – but that it was somehow comprehensive.

AS: And so it sounds like one of the things that it was doing was thinking about serostatus as not *just* that, right – more than thinking about people's context of their lives in terms of being positive or not. Was that something that people in the TIE project hold as a view for thinking about health, in that bigger…?

EM: I think it started. Eventually what started to happen was that I started to have people come in and I would do little counseling things with them face-to-face in circumstances where their things were complicated. And there would be things like immigration, things like – my housing is interrupted, or I can't afford to get these drugs, and all these other things. So, I was trying to show that… and people were aware of this, but there was such a focus on the idea of "treatment information," you know. It was trying to see how you could integrate some of the broader concerns that people had and not… like, we didn't use the social determinants of health language back then, but that's kind of what we were doing before that language really became en vogue.

And so yes, I think absolutely that that happened. And then it happened later even more after the hooking up project started, but this was still before that.

AS: I'm also interested in how that particular piece translated or talked between TIE and AIDS Action Now! Was there a consonance there? Do you remember?

EM: I'm not sure I can answer that question. I think people who were more central to the early work of AIDS Action Now! might be able to answer that. Although, I don't think there was that much consonance. One of the problems with AIDS Action Now! is that it was a really highly complicated discourse around trials and treatment stuff, and it wasn't about housing and… because there were organizations that were working on those issues. Like, the PWA Foundation was an incredibly important organization. It was one of the few organizations that did really amazing work with people around accessing housing services, but it was a support service; it wasn't so much about advocating for policy changes in housing. I think people's hands were full in the early years dealing with the immediate problem, which was we need to get more treatments on the go. And so it was encouraging doctors to be more active, getting doctors onside, and changes to the Emergency Drug Release Program, making that thing function for… it was a bureaucratic dinosaur that nobody used, but it was there. The mechanism was there to some extent. It was rather imperfect because you had to convince the doctor to make the request for you, and then the government had to clear it, and then the pharmaceutical company had to make the treatments available. There was no onus on them to do that. And then somebody had to pay for it, right. So, all that shit was complicated – trying to deal with a catastrophic drug policy. So, that was the Trillium project eventually, which made that possible. But that was years of work to make that. I don't know when that happened. Was it '96?

GK: At least the mid-1990s.

EM: And the beginning of that was really the beginning of AIDS Action Now! shortly thereafter, you know. First off was stuff like that stupid pentamidine trial and compassionate arms for clinical trials, getting that going and trying to have more trials that had compassionate arms. And then, a lot of work around educating. I remember George being very, very strong – and this eventually went into "Managing your health" – about making a distinction between participating in a scientific trial and accessing medical care; these were not the same. In the US, there was no distinction, but we were very careful about that – you want to participate in a trial, then go ahead and out of your commitment to the creation of scientific knowledge offer your body as part of an experiment; or access it through a compassionate arm, where you can still be monitored, and you know that you will get the treatment.

AS: Not the same thing.

EM: Yes! And those are not the same thing. So, the early focus was more about these scientific, technical, medical, biomedical interventions. It was intervening in the space of biomedicine and production of clinical trial knowledge. Really, that was the bulk of it, as well as some of the other things that Glen talked about last night, but the early focus… and it wasn't so much this sort of softer stuff around your housing and those other types of questions. But in trying to provide a meaningful community-based service that was somehow held primarily by the notion of treatment information, and yet that could get outside of the class character of the notion of treatment information, which meant that you had a competent user of treatment information and you didn't have that often. But people eventually didn't need to have that kind of stuff. You needed to do it in a way that addressed some of the broader challenges that people were facing in their lives and how the treatment needs were hooking into those challenges. So, that was part of what I tried to do through encouraging the creation of "Managing your health." And there was a bit of a challenge. I think there was pushback around that initially. In the first version that was created, which Mary-Louise Adams helped write and Tim helped write. And then, you know, George just hated it for reasons that I still don't understand and, of course, convinced everyone else to hate it, [laughter] so that it was redone. It may have been that it more strongly expressed the kind of voice that was slightly different than what they might have been accustomed to. I don't know. I was just speculating. But yeah, I think that was an important intervention – to try and bring those understandings forward a bit more. And they may have bled back and forth a little bit to AIDS Action Now! folks; certainly, George eventually.

AS: It seems strange that he hated it.

EM: I don't know what it was. Maybe he just didn't like the writing. I don't know. Well, there was another thing that it was – there was offense taken that Mary Louise had been involved in the writing and the voice was as a person with HIV. It was as though a person with HIV was speaking in some ways. So, there was that. But then Tim was also involved. So, it was kind of weird. You know, it was the height of identity politics too happening back them. But yeah, I don't really recall. Although, I do recall being very disappointed. I was like, "Oh fuck." Whatever. We just did another version. We just kept going. We kept doing it. But yeah, it was a lot of work. And I think we had already started before we made the application for that fund because Brent got in to redo it. Brent was hired to. I'm pretty sure that's what he was doing. I can't remember exactly, but that was one of the main things he did.

GK: Have you got to your three points?

EM: Yup.

GK: Okay. So, it seems to me there's three different directions we could actually go in now. I just wanted to make those visible. One is to talk more about what CATIE became. One is to talk about George and your working with George. And the other one is the Hooking Up project, which obviously is based on working with George too.

EM: Those three things are all connected; though the CATIE thing less so because George became sick, really sick in '93 and became less involved, I think, with what was happening in CATIE. But I think those things are all connected. It might be easiest to talk a little bit about George. That's the first thing. I was thinking about this earlier today and, you know, he was not the easiest person to get along with. And a lot of people will I'm sure tell you stories about what an asshole he was, but he's just not given his due. He was fucking brilliant. Like, the smartest. He was shockingly bright in many different ways. And his significance historically within both the gay movement – gay and lesbian movement – but within HIV is not acknowledged. He would be on the tip of everybody's tongues if he had been in the US. He was so important, but he was challenging. You know, most folks of that sort are challenging as well. He was a really good guy; he was really a lovely human being, but with an edge. And so, I think you asked something about what did you learn from George, and I was looking at that question and I was trying to think, "Well, how would you even answer that?" Because I think I learned - it's impossible to summarize – so much from him. I think one of the things that I learned from him… and this will relate to how I spoke about my earlier experiences with whatever we would call 'activism' now were unsatisfying because the objects of activism were so disconnected from my existence, my daily life, you know. Nuclear disarmament is… you know, you feel it, but it's far. Central American solidarity is far from me, at least just like this little white Ukrainian gay boy doing stuff. One of the things that George taught me was a way of understanding that you could change something and that you would change it. Like, some of the stuff around the nuclear disarmament stuff, it was a different kind of activism, but the stuff that George was talking about was that – you with other people, we will make this thing different and we *can* do that. That was amazing. He taught a way of thinking about social transformation also in ways that began with experience. He was taking from Dorothy Smith's work; he was taking from early feminist work on experience and consciousness-raising and so forth, and translating it into the world of HIV, and gay politics and HIV. And at the same time he was a visionary. He was a real visionary; he was amazing at that kind of stuff – not so much with the practicalities of running an office, but extraordinary in terms of imagining what needed to happen. So, he taught me and other people how to think organizationally. The activism wasn't about making your choice between whatever version of Marxism was on the go. Or, it wasn't about sloganeering; or it wasn't about whatever particular ideology you could hook into or even your ideas about homophobia and hooking onto these sort of explanations about things. It was actually about learning how things worked and then doing that with other people and then fixing – changing them, changing how those things worked. So, that was extraordinary and it opened up.

What I wanted to say was that it made possible a way of understanding, a way of doing activist work that integrated. It was integrative; it wasn't alienating because it would be about you. It wouldn't be about all this other shit, right. It would be coming from you with others, and it was not alienating the way the other experiences were. So, that was profound. That was huge and that saved me. That saved me from… that saved me, yeah, because it was not going well. So, that was great. Other things about George? I think a lot of it was like it was an apprenticeship. It was so great that I had this opportunity because I worked with him closely. He was my confidant in the TIE project for sure, he was the go-to guy for me. I would always discuss things with George because he was so good, primarily, and also Linda, around things to do with the running of something. She was really excellent around that stuff. And Alan around the legal stuff. So, people did play different roles in terms of what they offered. That whole period that I knew him, which was from 1990 to 1994 was this type of intellectual and political apprenticeship through to hanging around with him. And he would just sort of hang around. You'd listen and learn just by how he talked about things and how he understood things. Slowly, I felt like I grasped this way of thinking, which eventually I could understand was hooked into the work that Dorothy had been doing, and that he had been doing. And so, yeah, thinking organizationally. He would think about what was needed. He provided this whole analysis of the public health framing of HIV and the problems it created and how what was needed was to both confront and create a treatment response, which was fundamental to guiding AIDS Action Now! and its work in the early years, and then in guiding CATIE and the TIE project. And he had visions like CATIE. So, what happened was there was ATIS [the AIDS Treatment Information Service], which was proposed early on. The vision of it was to compile data and information about treatments and what was working for people, but in a way that was different than the limitations of a clinical trial, which is now… you know, people will talk about meta-analyses and a combination of the different types of studies into synthetic reviews and evidentiary forms and so forth. And I think he was, in his typical fashion, reaching for that at a time when people weren't even thinking in those terms, but trying to create an active repository of knowledge about what was working for people and sharing that with people with HIV, so that they could have different options and have different things available to them. And that, and I remember, he was into Bayesian statistics – trying to figure out all of these alternative ways of creating knowledge. And we would have meetings at the TIE project with epidemiologists and people to figure out what were their ways of creating knowledge. There was something called HOOD – the HIV Ontario Observational Database. We tried to work with these other data sets and figure out ways of creating new ways of producing meaningful knowledge that could be directive and helpful for people's health. It was fascinating. It was amazing. And so that vision fell to us eventually through the various failures of organizations commissioned to establish it. That funded CATIE – Canadian AIDS Treatment Information Exchange. It was that way of thinking, but also for me personally what it meant was in terms of not having an alienated life, which was a savior thing for me. Yeah. I wish could've just had those conversations. I wish I still had them.

AS: Can I ask one question?

EM: Yeah.

AS: When you were talking about setting up the office, because I have never met George, you said he had this commitment to things actually starting – so, "Let's set up the study and get people working on the next grant cycle." And you said that it was not really comprehensible to him that it would actually take this much time to do all the administrative trivia. Sometimes when people are really good at math, they don't understand that it takes people who aren't as good at math a long time to do a math problem. Was he really good at those kinds of detailed things too?

EM: Well, I think he did in the end understand the work that was involved, but it wasn't his go-to place. He certainly would have known that, but it would've been something he wouldn't want to have to think about because he was so… he had such hopes for things occurring and happening that he was focused on that level, and yet the problem is that when you start an organization so much of your time is in shit that you can't even imagine. It's like, the cleaner didn't come this week and the office is a mess, or the phone, the stupid phone machine is broken; we need to get a new one. Even in a small office, right. And that kind of stuff was not his interest by any means. But he would've understood those things. However, it was challenging for me because I had to spend not most, but a lot of my time in the care and feeding of this small little organization.

AS: But then he had, it sounds like just listening to people talk about him, this very fine-grained attention to the experience of people's lives as they were navigating all these systems.

EM: Absolutely.

AS: I was just wondering if you could say something about where that came from. Do you know what I mean? How did he, in his life, come to have that kind of simultaneous attention to the big organizational needs and vision, and that kind of attention to how it actually works when people are filling out a form?

EM: I can speak to how it would've been a feature of the kind of sociology that he was hoping to create, for sure. I don't know about how it may have entered into part of how his life was organized because he lived in a collective house where all those responsibilities would have been shared. You know, he didn't have a wife who looked after his needs while he went off and thought the big thoughts. That wasn't part of his life. In fact, he troubled that. And yet when it came to his AIDS work and starting an organization, there were moments of frustration with him trying to get him to understand. He wanted so much to happen, but it was hard to say to him, "Well, you know what? For that to happen we need this, this, this and this." It's because he recognized that this was a crisis; we need things to happen quickly. And he had a consciousness of his own ill-health towards the end of his life and he wanted to do as much as he could. But certainly the sociology that he was helping to produce was one that began with people, first of all, that's helpful. [laughter] And that's where it was helpful for me because it was like – oh yeah, you can actually start with real people and what's going on. What they're doing in their lives and how those doings are geared into what's happening in other places, in what other people are doing in administrative settings, and settings of policy, and settings of government, and settings of corporations, and all sorts of other sites of activity and work that have an impact, I guess, on what's happening to you. And certainly with the Hooking Up project he would have developed – and I know he did because we had many conversations about this – a profound understanding of the intricacies of people's life work, health work, because of the number of interviews we did with people who were really from so many different social locations. I remember, and it was hard because toward the end he knew he was going to die, and so he we were going and talking to people about dying – the conditions of their death – and he saw his own, right. And we would… I remember this one interview we did, and I think they were actually almost back-to-back and we had started to be interviewing… maybe we should talk about how it got started? Should I do that first?

GK: Whichever order you want to do it in.

EM: Okay. I'll just tell the story. It was about class and dying, basically. It's a story about class and dying. We went to interview someone who lived in Cabbagetown, and the guy we were going to interview was the partner of the guy who was quite sick and was going to die soon. We wanted to learn from them about the work that was being done around trying to create conditions – what was it like? What was the work of dying? And we went in, we walked in; it was this really beautiful neighbourhood, and I know the neighbourhood. It wouldn't have been the first time, but, you know, you're seeing it. They lived in the house. It was a detached or semi-detached house and you walked in and it was sunlight inside, beautiful. He took us into his kitchen and I remember it was gorgeous, lots of light pouring in and he had a lovely table and a beautiful, beautiful environment. And he started to talk about what he was able to do. His partner was upstairs and too sick for us to talk with. And he had not only all the formal services that were available. He had been able to take time off work to be with his partner. He had a care team and he had my friend the nurse, who was on the care team, and this person and that person who all have time to do this kind of stuff and support his partner, plus all the, you know, home care and home-making services that are available. And it was just extraordinary that this guy had this possibility to die upstairs in his room. And then I think it was either before that or after, we actually interviewed somebody who - it was amazing - in the hospital in the advanced stages of HIV, but he was going to die alone in the hospital, and a poor person. I think that person was an injection drug user and was just not that… there's lots of support in that community for sure, but in this particular instance, had a really hard life. He was somebody who was not from Toronto, and isolated and had nothing, had nobody, had very little. And so the visceral contrast, right, for him and for me, talking with him about that… that was one example of seeing the fine grained, which I guess is what you asked about. The real texture of people's lives and what could be possible, and what they did and were able to do or not able to do because of certain social circumstances that they were in. Those things happened throughout that project in a really profound way for him and for me, certainly for me too. Like, I remember coming out of that… I just remember coming out of that Cabbagetown home and we walked for blocks and said nothing because it was so obvious what had happened. It was just amazing how horrible, horrible, horrible – good for him, but otherwise horrible in a way. And I know that he started to plan for his own death as well at that time. So yeah, he would certainly have been very appreciative, very aware of that level of people's lives and work and activity.

AS: Yeah.

EM: But maybe I should say something about how that project started. It was funded by the National Welfare grants, which is no longer in existence, through the NHRDP – National Health Research Development Program – and they solicited a bunch of… they sent a call for proposals. They were funding a number of projects that dealt with issues of social assistance and HIV and those projects were supposed to feed into a shift in developments in the National AIDS Strategy around those issues. And so, George… I was still working at CATIE at that time. He liked me. He wanted to help; he wanted to mentor me. He wanted to get me into, you know… anyway, which was good. And I was totally available to be mentored. [laughter] It was fine. So, he approached me to be involved in putting forward this proposal, and then he approached Doug Weatherbee, who was a student at OISE [Ontario Institute for Studies in Education] at that time. And I was like, "Yeah. This will be so cool and it will be so exciting, so interesting." This was a time when there were really horrible stories. First off, of course, about the kinds of treatment people received in hospitals, but also real horror stories about what it was like to live on even family benefits, right; on social assistance, lots of poverty and HIV, lots of real stories about the inadequacy of the infrastructure of social services for people with HIV – state-funded services. And so he had this idea, he saw this call. He was a research officer at OISE and his job was to produce research, to do research, and so this was an opportunity for him. He got us together and we started to talk about what to do and what was decided was to meet with people who worked in front-line AIDS service organizations and have conversations with them about what kind of a project would be meaningful and useful to them. How would we design something that would be good? And this was in the early days of raising questions about research, right. So many people now talk about that they do community based research and it's just such bullshit, just horrible. And so before all these claims people made about how they had pioneered community based research, there was George working up a project with folks in this way because of his real concern to begin in ways that were informed by people's experiences and the actual things that they were doing, and the problems they were facing. And so the easiest way to do that was to use good front-line service workers as a proxy, kind of. So, we met with… I remember this meeting. It was in the CATIE. Well, the TIE project office, and I know that Yvette Perrault was there, from ACT. I'm sure of it. And, god… what's his name? Fuck. I forget his name. So, that guy… and maybe it was Mark. Not Mark Freamo; one of the people that Yvette worked with. Anyway, he was a really good guy. Scott Beveridge, who was involved with AIDS ACTION NOW! and, at that time, was working with young people who were street involved, was also at that meeting if my memory is correct.

So, we had a meeting. We just started talking about what was going on, and Hooking Up came out of them. They used the language of "hooking up." We tape-recorded it and we talked about different issues they were facing, and what would make a good study. And it was in that conversation that a study that looked at what they called hooking up to social services would be a useful thing to do. And so George, with some assistance from Doug and I, produced the proposal and it was funded. And then we started on this. You know, it's such a drag. I actually was looking at some of this stuff from that project and there's so much that didn't get done because George died. And it's such a shame because there's almost like, a half-written book in the file that I have. So, we did 120 interviews. We interviewed about, I think, 80 people with HIV. We interviewed a bunch of people who worked in AIDS service organizations, and then we interviewed people who worked in the government, and produced an analysis of what hooking up actually involves for people. And so we used a device of contrast between an official understanding of hooking up, which is that you sign, you fill out a form, you send it off and you're done, right. And so we contrasted that with, we used the notion of 'work,' of 'life work' – what was the life work of people with HIV? Trying to make a life under conditions of the deterioration of their health while trying to access whatever state services might exist; and that was income assistance, housing, home care, were the main things we looked at. We didn't look at other areas because we just didn't have the time. And it was, I think for me, it was pretty incredible. At that point, I had already… I wasn't supposed to be involved. I was just going to be involved and we would… but then I left CATIE and needed to do something, so I managed to get a little bit of office space in the Toronto – was it the Gay… it was a little room in one of these little houses in the U of T [University of Toronto] campus for the Queer. I don't know what it was called.

GK: Right. Queer student group?

EM: Queer student group of some kind, and they let me use the office. So, I had an office, which was great. I had an office and I stuck my computer in there and then I worked with George on this project for two years roughly. And Doug sort of dropped out. Doug was doing other things at that point, so he didn't stay involved. And, you know, it really was about… one of the questions I think was about… what was the question there?

GK: Class and poverty?

EM: Class and poverty, yeah. And so it was, I think, absolutely this way of understanding class, not only in terms where you could see people's different trajectories from work into illness; where there were those who had insurance from their work and folks who didn't and who were immediately thrust into the social service world, right. And people who were… you could see class. It was like, you could see it. I'm not sure it's a great metaphor, but that's how we understood it at that time because you would be walking from Parliament and from Cabbagetown into the Hospital. It was just like, holy shit. People planned their departure from work versus people who were fired. So, class in the sense of how you could live, what your house looked like; how you got your food; what food you had to eat; who you ate it with; how many people there were in the places that you slept; what your network of friends looked like, and what happened. All this kind of stuff was incredible. And then also the issues of one's relationship to the gay community, which was still central back then in terms of – well, it's still central in many ways – but in terms of the social services; the community services available to people with HIV, they were really still located mostly in the gay community. So, if you were unable to connect to that, you were SOL [shit out of luck] in terms of getting assistance from case managers about how to access services. And what happened is it was clear that there were all sorts of cherry-picking kinds of things where in order to preserve their relationship with some sort of state funder, the supportive housing would select the best clients. You know, the clients who could live together, right, because supportive housing; you would have to live in a shared space. And they worked very hard to try to reach… I'm not trying to make a criticism. That's not what I'm trying to say, but the system, George was very much interested in how… what was the relationship between the organization of daily life of people with HIV and the organization of services. What you'd find is that the people who were most marginalized, and who in fact needed most of these services the most, were actually excluded as a feature of how the system operated and functioned. So, if you have a shared housing setting, you need people who can get along, right. And that meant that you were predisposed to people who didn't have a long history of maybe drug use or mental health concerns, or who were psychiatric survivors, and all sorts of things; who had a criminal record. And then those folks would be less likely to be admitted into the housing because of how it operated, not because there was active discrimination.

AS: Yeah. It wasn't like some mean person…

EM: No. And so we wrote about that kind of stuff and I think in a really nice way. And so class in that sense, class produced organizationally, class produced through social location, through relations of stigma in the sense that if you didn't get help from a case manager you would wait for… you would either not get family benefits because you wouldn't know that you could even get it, or you would wait eight months to a year to get it; whereas you could get it immediately if you applied. Because there were two, at that point two – there's still two, it's still stratified – income assistance, but at that point it was just, it was understood in terms of general welfare and family benefits. And to get family benefits you had to be designated "permanently unemployable" and HIV was a categorical eligibility for that, but you needed to have a doctor… first of all, you needed to know that you could do it. You needed to disclose your HIV to somebody in the caseworker system, which lots of folks wouldn't do because they were scared. And you needed to have a physician fill out a form that said that you were permanently unemployable. So, you needed to have a physician, right. Or you needed to have a physician you had a relationship with, who you could approach to ask that. And if you could do that when you had an AIDS service organization behind you in a network, it happened much more easily than if you tried to do it alone. And you needed to have a file. You needed to have a medical file so the doctor could justify the claim through medical language and medical discourse – because I can say, "Yes, you can't work anymore." Or you needed to find a doctor who would just do it and there were many who would. But you could see how those possibilities were all structured in terms of social class, in terms of social location, and they produced class relations themselves.

So, it was very important work from that point of view, and it was a shame; it was a shame, it was a real shame, it's really too bad. He died and I tried to write the report. Well, I did write the report. It would've been so much better if he had been alive. It would've been better. There's no question. And we would've done other things. We would've gone on to write much more. You know, he had a problem with writing. George was brilliant, but he was really challenged in terms of writing stuff, so it was torturous.

AS: What happened? He would get… he would start or he would?

EM: I don't know. I'm not sure I can say, but it just took forever. And I had to say, "George, no. We just have to do this." I mean he had so much in his head, going on, and had so many ideas for how it could be expressed and nothing ever really measured up. Like, if you've read some of his work, it's so carefully put together. He was always concerned about that. And also concerned about writing in a way that expressed social organization appropriately for him and would not be given over to some type of either explanatory discourse from sociology, or would reflect categories that were in use in administering and managing people's lives through the state. So, that meant really a careful kind of writing. Also, wanting to do justice to the experiences that people were bringing forward and their complexity. It was a really complicated project, so there are many, many false starts; many, many, many, many. It took a long time and I do remember saying, you know… I do remember trying to do this… like, to package. Not package, but to restrict the scope of it so that it could actually be finished. But unfortunately, yeah, he became too sick to continue and I had to basically write it from the notes that I had. We had tons of analytic; we would meet in analytic sessions. We actually met with Carole Ann O'Brien and Laurie Bell, and they were doing a project with Central Toronto Youth Services (CTYS), which was one of the services. And so we would all meet together in these monthly meetings and talk about our projects, and tape them and we would transcribe our analytic notes. So, I had all of that stuff. And we had different versions of the report that were done and so he had worked a lot on it, and we would work together on it a lot. So, it was not like there was nothing there, but it could've been more robust. But, I think it was a pretty good piece of work, and it was certainly important for thinking through, supporting the really meaningful and significant case, you know, case management – sorry to use the term – that was being done at PWA and other organizations. And also put forward a number of recommendations for things. I know that at ACT they used the document to do some restructuring – internal restructuring of their services. Charles Roy did that. He had had some kind of connection to Chris Axworthy and the NDP. I can't remember exactly what happened. And I have stuff that I wrote to the Prime Minister with our findings and all this kind of stuff and, yeah. I think it circulated widely and informed people's thinking around some of these issues, I hope.

GK: But it's also one of the few things that actually raised questions of class and poverty at that time, so I think it was really quite significant.

EM: Yeah. It's too bad, you know. We should've written more stuff, but we didn't have an opportunity to.

AS: You were finishing that just after, or as George was dying and after he died? What was the timeline? That just seems extraordinary.

EM: It was. Yes, it was. And you know what? I turned it off. I shut it off and I just did it at that point. He died in '94 and it was released in '94.

GK: And he died in mid-fall or something like that. Yeah.

EM: But he had become very sick, so he wasn't able to participate in the final stages of writing the report. Although, there was so much that he had done that he had made it easier for me in many ways.

GK: Okay. We've still got some more time. You want to keep going?

EM: Yeah. Do you have some other questions? It would help me to ask me specific questions at this point.

GK: Well, one thing you talked about, but perhaps could in a slightly more elaborated way, is the relationship between AIDS Action Now! pushing this AIDS treatment information issue, which was the central thing we pushed for in the new National AIDS strategy, and this funding – I think as it was originally called, which you referred to – and how that eventually gets to CATIE as a central funding source. So, CATIE ends up being the Treatment Information arm of the National AIDS strategy in terms of its funding. Could you tell us a little bit more about that in terms of what you remember?

EM: Yeah. It's vague in terms of my memories. But the stuff around AIDS Action Now! was about making treatments available. It wasn't so much about treatment information. The TIE project was organized around the notion of information and the significance of information in helping people around their health. And so it was at that time the emergence of the consumer, the health… you know, all that stuff that AIDS propelled, that HIV propelled, and the centrality of lay medical connections and connections between lay knowledge and medical knowledge. So, what happened was that there was just a series of failures with the organizations that went to bid for ATIS. There was Kathryn Taylor from the University of Toronto. I think it was eventually somehow partially awarded to her to try to set this up through U of T, but then she got into a scandal, some type of corruption scandal. Remember this?

GK: Yup. I do. I remember that.

EM: So, that collapsed. Then there was something to do with Hopital Dieu in Montreal, and that collapsed, I think. And other private organizations were bidding, and none of them worked, and so eventually CATIE put in a bid. I remember I was on the board of CATIE at that point. So, what happened was I stopped, I resigned from my position at the TIE project and I worked on the Hooking Up project. And then, when that was over, I became involved on the board of CATIE. Enough time had passed; they had already gone through another staff member who came and went, and then they had a third by that point – a third person who was then, it was an executive director model at that point. His name was Wayne Hellard. And so my work at that point was very much hooked into CATIE and with Darien Taylor and Alan Cornwall and the Gardners; I think, those were the central folks, I would say. There were other people as well. And Craig McClure was working at CATIE at that point, and then Glen worked at CATIE as the ED later on. And I was on the board. Yeah, I would've been on the board because I remember the competition for the Executive Director position when Glen became the Executive Director. So, I was still on the board at that point. I think that what happened was that there were a series of fuck-ups, right. It's kind of great that Kathryn Taylor screwed up and got involved in that sort of corruption. I can't remember what it was. This is in the press, right. It was really pretty big. And so then Wayne Hellard was the executive director of CATIE at that point and I think he was basically like, "You know what? Everybody's fucking this thing up, let's put in a bid," and we did, and he did. Like, he with other folks – the Gardners and the rest of us, and got the money, which was huge.

It was interesting we had things survive from the early days – Treatment Update remained and it still remains, the phone line stayed and they hired staff to function as Treatment Information counselors. I don't think that exists anymore because it's not needed really, but it did there for some time. And "Managing your health" happened, but all sorts of other kinds of information related services. There were still struggles around the limitations of information and the text modes, the text-based forms of knowledge, and who connects with those and who has more challenges with that. That's when Craig McClure, Darien, myself, and Michael Bresalier, Liza McCoy, Loralee Gillis and Michelle Webber, we did the "Making Care Visible" project later, which took up some of these questions in terms of what people… one of the things that was emphasized in people's conversations with us – and this would've been '96 I think, by that point – was the real significance of face-to-face, and needing to have somebody to mediate between biomedical discourse and my life. Like, I can't do it myself; I need you to help me. And it can't be that we just have to write up a pamphlet. And I think that that work started to become more generalized in a number of other AIDS organizations by that time, which started to have more of a… you know, the SHARP – prevention-treatment thing started to collapse. So, that's not a very robust discussion of the ATIS stuff, but AIDS Action Now! was working hard to establish ATIS and was involved in these discussions around the different bidding processes, because I remember that; and I do remember things just falling apart. And it wasn't clear what it was supposed to be. It was like – oh, you have this vision, but not concretized. And there is a lot of concern about some of the private pharma companies who were trying to get in on the action. There was I think a proposal out of York and the YMCA, I think, had something that they were putting. Like, all sorts of really all-over-the-map type of possibilities for it, but because of the failures CATIE started to go for it.

AS: In terms of your own path it seems like there's, for some people, a real shift as they come in and there's this sense of a real change in what the work is. And for some people that's also a space where they're tired and needed to reshape their lives. But you're still

involved with AIDS Action Now!? Was there a break for you? Or have you just steadily continued work all along? And you don't have to… I know it's past the time that we're talking about.

EM: So my trajectory was through the Treatment Information Exchange into a long involvement with CATIE, then that stopped, right. So, what stopped for me was CATIE stopped. I became actually more involved with AIDS Action Now! after '96. And I started to do more stuff. Then – I don't know at what point I started my PhD, maybe it was then; I can't remember – that took me away a little bit, because you got to do this PhD. It takes a lot of time, right. But I stayed connected with people. At that point, I had relationships with a lot of the folks and so there was overlap, but I wasn't central. Although, I did more actually with AIDS Action Now! after I stopped being involved with CATIE. And then I moved to Halifax, so that stopped. And then I came back and when I came back, I really got involved on the steering committee very shortly after I think I arrived. And I've stayed on the steering committee ever since.

AS: When was that? When did you come back?

EM: 2004.

AS: Yeah.

EM: And so when the AIDS conference in Toronto… what was that – 2005? 2006? That's when there was more AIDS Action Now!... there were periods along the way. I remember going to sunset meetings for AIDS Action Now! Like, what to do with AIDS Action Now!? And going to Oakham House and having these meetings and stuff. So, I can't really remember a lot of the details. But then, I do remember that Toronto was this moment of the new energy around activism because the conference had been here. And then there were these young people, and it was kind of great – the people you met last night – Alex and Nicole and Jessica. I don't want to miss any names… Jordan and Zoe and everybody else, also Glenn Betteridge, who had done AIDS activism in Montreal in the early years. He became involved with AIDS ACTION NOW! largely through the HIV criminalization route. And so, actually, there was a round of people before that. I forgot that Tim and I tried to organize and Brent tried to organize and we did a few things, a few demos and things that we organized. But then those folks, they went off to law school, as these people tend to do. And so then it was that group. Then, there was a second group after that, which was these who have stuck – like, Alex and Jessica and Nicole and so forth. So yeah, I've worked with them and I think partly why is because I felt that I wish that I done more with AIDS Action Now! earlier on.

AS: You got kind of seconded into the…

EM: Yeah. I got into the TIE project and the CATIE thing when there was quite an overlap in terms of personnel, so that was fine. But I wished… I think maybe it was partly also responding to this sense of my early incompetence [laughter] and the lack of… I think I thought it was bad that I thought that I had nothing to give. And I thought, "Well, do it now" because I certainly didn't feel that way anymore. So, I can do this now. There were other circumstances, but I can help younger people, right.

AS: Yeah.

EM: Yeah. So, that was, I suppose, what happened.

GK: But the other side of it is also that your work and research in the university often had a relationship to this type of activism too. Do you want to talk a little bit about that?

EM: Sure. I have had a very troubled relationship to the university as I tried to describe during my Master's degree. I kind of hated it all in the end, and barely, as I said, barely got through. And then I worked in the community. I'd been a secretary. I worked in the community for a number of years. I did this community based research project. I thought, "Fuck, what am I going to do?" And I decided to apply to do a PhD and I got, actually, rejected. And I came and fought it and they accepted me. And I didn't do my PhD on HIV-related stuff because what started to happen is that HIV started to get instrumentalized within these applied research relations that are supported primarily through the OHTN – the Ontario HIV Treatment Network. It got this professionalized approach to doing community based research, and a lot of epidemiologist-type folks and applied health scientists started to get together and start to fund projects and work together on these. I wasn't interested in any of that. I just thought it was horrible. Sorry, but I didn't want it. I wasn't part of that world, so I did something else for my PhD. But then, at the same time that I did my PhD, I was also working on the "Making Care Visible" project. And so it was very central in that sense. I did start to then try to build HIV into my work in the academy. So, that did result in a number of publications and so forth, and more significant interest in trying to create a space for me as a sociologist, as a sociologist doing work on HIV. And yet, I'm sure I do not fit the mold of the HIV researcher because there is an HIV researcher that's known in that now applied health sciences kind of world, but I'm not. I think they must think I'm kind of nuts or something. I don't know what they think about me. And so I don't really do that kind of work. Though, I had developed a relationship with CATIE through the "Making Care Visible" project and through the "Hooking Up" in doing more activist research – what I considered to be more activist research – which then carried forward into the work on criminalization, which has been really, for me, in some respects, almost the fruition of some of that early work in being able to work, not in partnership with AIDS service organizations. No, it's working politically with activists around a really challenging problem that people with HIV are facing and trying to work with them, and work with them as them. Like, I'm part of the Ontario Working Group on Criminal Law and HIV Exposure just as much as anybody else is. It's not like I'm doing some research for them. We work together. And so that has been fabulous. That's been a moment of creating a meaningful life in the university that wouldn't have been the case had not all this earlier stuff occurred. It's interesting what you're saying, so I'm glad that you asked me that. Thank you for asking me that. It's hard to describe the contours and character of that kind of intellectual work because it is very different from even those who like to study social movements, or those who have a more theoretical interest in HIV or whatever else, of which there are still many who do that kind of stuff. This is a good thing to end with because George did not complete his PhD, although he had wrote a thesis on… what's that philosopher? Charles Pierce.

AS: Oh, he did? I didn't know that.

EM: He had a… like Dorothy says, its all this shit. It's there. And then he was, I guess, working on a second PhD, which he didn't complete.

GK: Which is around occupation classifications, social organization of work in some ways.

EM: Yeah. So, I must've been expressing an interest at the time. And he was really encouraging. Through the "Hooking Up" project he was really encouraging me to go. Yeah, because he wrote a letter of reference for me to York University, he wrote my letter at the time that I got rejected. So, the timing I screwed up here somehow. He wrote a letter for me to enter the PhD program at York, so that must've been '93 that I did that. I don't know. I can't remember. Yeah, that could be right – '93 – because I finished my PhD in 1999; the end of 1999 and 2000. So, '93 I would've started.

AS: You would've been applying.

EM: I would've been applying because I know he wrote me… because he said to me, "Oh no. Get somebody else to write your letter." And so we were talking about it. I said, "I want you to write the letter. It's important for me that you write a letter for me," which he did. And he encouraged me to go to do the PhD because, he said, "This will create possibilities for you to do things that you cannot do without it, and you can use this in your life politically. So, do it for that," which is really strong and I did. I think I did. Like, I think that's what I've tried to do, which I think distinguishes that kind of practice – intellectual practice – which is just, you know, from somebody who is a community based researcher, who wants to partner with organizations to do whatever. And there are tons of folks now; that's de rigueur now. But like that, what he helped me see as a possibility for my life, I guess, and modeled in terms of his own intellectual work and his own political work, which were so connected fundamentally. And it was about studies in the social organization of knowledge as a way to think politically. That worked, right. Like, it worked. And so I know that I've been able to do that, and I just… there are so many times when you think, "Ah man. I wish George was here because I wonder what he would say about this shit that we're dealing with in terms of the criminal law." Like, he would've been all over it.

We actually did use, in the very early stages of responding to criminalization was very much initially based on… I remember sitting in the room thinking – oh fuck. Because Linda Gardner invited me to go, as an AIDS ACTION NOW! representative, to a meeting that was happening around women with HIV and criminalization. And so I'm sitting in the meeting and talking and they're talking about stuff, and I just think, "Shit, what's going on?" And Glen Betteridge was there and I didn't know him at that point, and I'm looking at him and it's clear that he's a lawyer. And then there's all these other people speaking from a service, an AIDS service-type, perspective. And that's really important because – how do you deal with clients, and what do I need to disclose to whom in terms of what's going on? How do we deal with this issue – very important. But I was like, "What's going on? What am I doing? Who's going to do something about this?" And I phoned him and I said, "Tim, you have to come to this next meeting because somebody… we have to get a strategy – legal defense – going for people. Something has to happen around that. The Canadian HIV/AIDS Legal Network has been operating on this issue for years at the high levels, but they don't provide legal services, so we can." Tim then became involved in the issue as well, and it was drawing on Right to Privacy Committee thinking in terms of, one of the ways that you deal with the issue is you try to make Crown Prosecutors lose criminal cases. And the more cases they lose, the less likely they're going to continue to go after it. That actually didn't unfortunately pan out as easily as we hoped, for various reasons. And that's a whole other thing and not necessary for this, but the point is just to bring forward how that kind of thinking organizationally – thinking about how the justice system works and how you intervene in a way that will potentially, hopefully get you the result that you want – was informing the response even then. You know, going back to some of the early work on the Right to Privacy Committee. So yeah, it's just very interesting to see how some of those ways of working and thinking continue.

GK: So, I think we're coming to the end. Is there anything that has cropped up during the discussion that you still wanted to talk a bit more about? I mean you made the notes earlier; I think we've gone through those things.

EM: There were these things.

GK: I did want to ask you to talk about Michael Smith a bit.

EM: Yeah. I could talk a little bit about Michael Smith. He was on the steering committee of the TIE project, and he was a lovely person in my experience of him in terms of his involvement with the TIE project. What he was able to do was mobilize the moral force of a person with HIV identity almost all the time in a really compelling fashion. I remember him, for example, screaming at somebody who was making a point with, it was either to get some kind of service or maybe it was some kind of research project that somebody participate in and they set the meeting at nine a.m., and like, "how ridiculous!" "What idiot who knows nothing about HIV would set an appointment with someone living with HIV at nine in the morning?!" He was just enraged and it was so great. He had this incredible energy and he was like a hippy, a real hippy; but a gentle, really gentle person. I have this memory of him in this mini-bus thing – you know, cars with little small wheels? Minis. We went somewhere and it had something to do with the TIE project, I can't remember. Maybe he borrowed this bus from somebody or maybe it was his? I have just this vision of being in this little – you know, those little buses. Like, those little mini-vans with the little wheels. It was some shitbox. I don't know where it came from, and we were driving around getting something. I can't remember. But he would come to the meetings of the TIE project and was very committed to the vision of what was going on and brought this really strong PWA voice to the work that we were doing. And unfortunately, he did get sick fairly soon and died, but he was great. And then the other person that I wanted to mention… I have to get this thing because I wanted you to see this. It's Barry Way.

GK: Uh huh. That name is familiar, but I can't place that face.

EM: Oh. Where is it? […]

GK: It's lost in the files.

EM: No. This is his file.

GK: Okay.

EM: So, Barry Way was one of the working class guys that were involved with AIDS ACTION NOW! – one of the other guys was Rick Hatt. And Barry was a poor person living in circumstances of being on FBA [Family Benefits Assistance] and he was amazing. How much he worked to improve his life in terms of income while being on Family Benefits. So, this file, which he gave to me before he died, is full of all these letters that he wrote to the Ministry of the Community Social Services about how inadequate funding was on Family Benefits. All these foundations and stuff that he would write to and things, and this was the list of lawyers where he would cut and paste these letters and write to folks. And I'm not laughing because this is laughable. I'm smiling at his doggedness. I remember he was relentless around… he was so angry with the inadequacies of the system, and it affected his life really in a significant way. And so he would meticulously document his expenses and try to advocate for himself to get better coverage and better services. It just struck me that, in terms of AIDS ACTION NOW!, to bring forward his memory because a lot of the folks that were involved in AIDS ACTION NOW!, or at least who directed, who were on the steering committee, were really middle class people. And Barry was one of the folks who connected with AIDS ACTION NOW! in some way that was really meaningful to him and he carried forward the issues that were about poverty and about accessing social services and the inadequacies of the system. And he embodied in his own life a kind of activism to really make changes in how Family Benefits Assistance operated and so forth. It's maybe good to end with a little note about Barry Way. Yeah.

GK: Can you remember when he died? When that would have been around? The name's really familiar to me.

EM: Early nineties, very early nineties.

GK: I wonder if he's a friend of Greg's – Greg Pavelich.

EM: Might've been.

GK: I think that may actually have been how he got connected, but we can figure that out some other way.

EM: Yeah, because I don't think other people will mention him.

GK: No, so that's really great.

AS: And you knew him through CATIE?

EM: Yup, through the TIE project. I don't know when he died. And I can't remember why I have his stuff. I can't remember him… I can't remember the circumstances. It might've been related to the "Hooking Up" project, that he wanted me to have some of these documents. And we interviewed him for it – what I am saying – we interviewed him.

AS: And he was tracing – this is what it actually costs to live my life.

EM: Yeah. He's got lists of things.

GK: But also, *as an individual*, he was trying to make changes, but not obviously. It's interesting in the sense that, as a member of AIDS ACTION NOW!, this wouldn't have been taken up collectively as an issue for AIDS ACTION NOW! He was doing this on his own.

EM: You need to ask somebody how much traction that got. It certainly wasn't the main business of AIDS ACTION NOW! But there were people trying. There are different people in different periods trying to do different things through AIDS ACTION NOW! The strongest voice throughout was the Treatment Access stuff.

GK: Yeah. Anything else?

EM: I think it's good. I think I've said the most important things to say, for me at least, I think.

GK: That's great. Thank you.

EM: Thank you. No. Thank both of you. It's amazing what you're doing, that you're taking the time to… first of all, that you got the funds to do this, and that you're making this project in the way that you're making it, which is connected to communities of people and not this big academic thing. I know there's an academic component, which is important and it's a piece of work that is a gift to a wide group of people and it's amazing that you're doing it. I think it's like the point that you made last night about the significance of historical memory for the current work that's being done, but that is really relevant. I don't feel like it's just some kind of nostalgia project at all.

[END OF TRANSCRIPT]