AAHP

AIDS Activist History Project

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Interviewee:	Hugh Ballem
Interviewers:	Alexis Shotwell & Gary Kinsman
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Persons present: Hugh Ballem – HB
Alexis Shotwell – AS
Gary Kinsman – GK

[START OF TRANSCRIPT]

AS: So, we always start by saying it's October 28th, we're in Montreal, and we're talking to Hugh Ballem. Thanks for talking to us.

HB: My pleasure.

GK: So, the first question we start with everyone is just to ask when you remember first hearing about AIDS and HIV? Do you have any memories of that?

HB: Yes. I've thought about that. Specific instances, I would have to really rummage. I did do a little journal-keeping back in the early '80s. I'll describe that a little bit later, because I have quite a bit of material from '89 and '90, which was the period that you're most interested in, in terms of ACT UP getting going here in Montreal. There are probably some references there, but I heard about it early. I was travelling back and forth to Provincetown in the early '80s. I was in contact with people from New York. I was going back and forth, on occasion, to San Francisco, so I was in contact with people there. When the news got out that something unfortunate was happening to gay men, I knew about it then. Well, I knew what the implications would be, as far as the political context at the time, and what they would be for me individually, you know, to a certain extent, although I had no idea what was coming.

GK: Right.

HB: So, I started reading. I can't say exactly – well, eventually it was only in hindsight that I realized that the epidemic was much closer to home than I thought. I started a relationship in '81 or '82 with someone who died in '84. Quite clearly KS [Kaposi Sarcoma], from what I heard from other people who knew him, and who told me about it several years later. He died at the Sloan-Kettering Institute in New York, where he'd been taken. Nobody knew what he was suffering from. This would have been about '84, I guess – '83 or '84. And his file described the lesions, although they didn't make the diagnosis at the time. So that was in the background. And, in fact, my own infection may have dated from that period. There has been some speculation as to whether there were less virulent strains in circulation at the time. That's a possible explanation of my success in beating the odds.

GK: Right.

HB: On the other hand, it didn't work in the case with Tom, for sure. He did have some predisposing health problems, but he was very healthy guy in terms of life habits and that sort of thing. Not a drinker or drug taker or anything of that sort.

GK: Right.

HB: But he went very quickly. And also, I think about the experience I had a little bit later on, in '89. I had already started working on The AIDS Memorial Quilt project. I had a friend here in Montreal who – to my surprise – had not confided in me that he was ill. And I asked him what he was doing about it. He had been doing AZT [zidovudine] but he had to withdraw from the AZT - it was too toxic. So, I said, "Listen. I am going to San Francisco to work on getting the Quilt here." This would have been, probably, February or March. "I will ask what they're doing." I had heard that they were experimenting with lots of things in San Francisco at the time, because people were dying like flies. And they did indeed have a very active community that was experimenting, with a lot of doctors involved in the process. I came back with the very good news that they had already gotten the dose down considerably, to under 1000 mg. People were not suffering as badly in that section of the study; AZT even had some health benefits. So, I was looking forward to imparting this news, but unfortunately my friend was dead by the time I got back.

GK: That's too bad.

HB: So, that was the kind of thing that was developing. I ended up, myself, interestingly enough doing AZT. But not according to the usual indication. I had a platelet crisis in 1989, December of 1989. I was hospitalized in Toronto, actually. I was supposed to be leaving for a Dominican Republic vacation with Varda, and I am not sure if Deirdre was going on that trip or not.

GK: These are people I know.

HB: You might have heard of Varda Burstyn. But, unfortunately, she suffers from multiple chemical sensitivities [MCS] and has been in total isolation for the last decade, basically.

AS: So hard.

GK: Yes.

HB: It's unbelievably difficult.

AS: So, you were going to go with them to…

HB: Yes. I was going to go with them to the Dominican Republic. I ended up at the airport with my ticket on the counter and my bags on the scales, hearing a public announcement saying, "Mr. Ballem, please contact Dr. Novac at the emergency department at Mount Sinai." I had been there that morning with this very odd blood blister on the inside of my cheeks. So, I thought, "Well, I am going off, maybe I have time this morning to drop by." They looked at it and they said, "Well, it is a blood blister, but you're the picture of health. So off you go and if our blood test indicates

anything in time, then we will communicate with you." Well, they called me at the airport. When I called, they said please very gingerly come back to the hospital, because you're in imminent danger of internal hemorrhaging. Your platelet levels are way down.

This has a connection with the whole issue of what I was doing politically and organizationally, at the time. It was my first real health crisis, but it didn't prevent me from continuing to participate in the formation of ACT UP [AIDS Coalition to Unleash Power] and the other things I was involved in, like CSAM [Comité sida aide Montréal]. It took a chunk out of my availability. Shortly after that I came back to Montreal, just before Christmas. I was hospitalized in January with a respiratory infection, which they were afraid was pneumonia (it turned out not to be). And again, in June. I had taken the route of corticosteroids to save my spleen from the scalpel. That was the hematologist's automatic response – all of the hematologists wanted my spleen out.

GK: They told other people that, too.

HB: Oh sure.

GK: Tim McCaskell actually talks about that in the interview we have with him online.

HB: Yes. Well, I told them two things. I said, my spleen is just fine. You've determined that yourself. And, secondly, the reason that you're doing this is because this is what the book tells you to do. It's the short-term solution to a platelet problem. You take out the filter and the platelets continue to circulate. The problem is that the spleen is also the place where the lymphocytes mature. And you take out the spleen and you eliminate the patient's ability to acquire new immunity. And I said, "That's not a problem for you, because you assume that I am going to be dead in a year. But I'm not making that supposition!" [laughter] "So, I am going to keep my spleen, thank you very much. And I am going to investigate the other options." Fortunately, I had a network of people, including some people – one person actually had a subscription to Medline at the time. This was very rare. Because you had to go to a library to log on. He was here in Montreal. He printed out a thick stack of stuff. Other friends put it on the bus. And I sat in the hospital in Toronto and read it. It didn't make me any friends at the hospital. [laughter] They even sicced the psychiatrist on me at one point. Because I said, "Hey, autoimmune disease. You keep on loading me up with other people's plasma. Duh. Chances of complications here." The psychiatrist thought that my approach was sane. [laughter] And said, "I side with you."

AS: You're going to have to deal with this person. Yes.

HB: Yes. You're going to have to deal with this. And their response was, "Well, we think we are going to discharge Mr. Ballem." And I said, "Mr. Ballem doesn't think so." [laughter] I'm not signing the discharge papers. I am going to leave because I'll be much more comfortable at a friend's place around the corner. But I am coming back for my blood tests. I also got, thanks to a couple of friends in Toronto, including a doctor, a suggestion to go across from the Mount Sinai to the Toronto General.

GK: Right.

HB: Where I found somebody who had considerably more experience in this kind of thing. Who validated my go-slow approach to the transfusions. And who, when after discussing the other options, said, "Well, we can do an AZT-corticosteroid treatment."

AS: Putting them together?

HB: So, you put them together. Yes. Because this has been – the platelet-boosting effect of AZT was documented back in the time when it had been originally developed for completely different medical purposes and shelved.

AS: Yes.

HB: It was only rehabilitated because it was discovered in a pretty random fashion that it had anti-HIV effects as well. So, I said I would do the AZT at 500 mg, no more. And he said that's fine. That's what we're using.

AS: And at that time people that were taking AZT to treat HIV would be taking like – how much would they be taking?

HB: Well, it's hard to say. I think… I am not even sure what the protocol was at that point. But you also could have – in order to qualify for AZT because it was likewise expensive – you had to have more clinical indications. I was just infected. And my CD4 and CD8 [cell counts] were fine. I never was under 500.

AS: Yes.

HB: So, I would not normally have qualified.

AS: Right.

HB: But I did qualify for this particular approach. And I said, "Okay. I'll do it." And maybe it will give me some benefit, as far as the infection is concerned.

AS: This is probably too detailed, but I'm just really interested – was the spleen protocol for everyone? Or was it a protocol that the doctors would have been following only for people who were positive?

HB: In this particular case, I'd have to look at my notes to see if I have the name of the doctor [Dr. Santiago Ferro]. He was Argentinian. He was from outside of Canada. And he knew exactly what I was talking about when I presented my case. He said, "Well, the first thing we do is nothing, because we have an appreciable number of patients who rebound, and their platelet crisis resorbs." Well, it took me seven years to get the same result, but I eventually did. I was able to withdraw from the corticosteroids. I've got my spleen. And my platelets are completely normal.

AS: Amazing.

HB: Yes. I was very lucky in that respect. But I did have to do this type of dance with the steroids all that time.

AS: Yes.

HB: Raising and lowering the dose depending on – because I had determined that I really didn't need any more than 35,000 platelets to avoid any of the internal hemorrhage stuff. And that their levels were a little bit arbitrary, and that the idea that I had to have 110,000 was absurd.

GK: Right.

HB: I wasn't aiming for that. I was aiming for survival on as low a dose as I could possibly get away with. Because the side effects of steroids are devastating. The first thing I did after my first dose was to go to a bookstore in Toronto on Queen Street and buy a book on drugs. And I blanched when I read [laughter] the list of side effects of the dose I was taking. And also, the fact that there is steroid rebound if you try to withdraw.

AS: Right.

HB: So, it took me six months to get off. Which brings us back to that whole set of health crises. I started on the steroids. I came back to Montreal. I went to see my doctor. I said, "We need to start tapering, please." We started tapering. But I only got it down to a level where I could sleep without drugs, and this sort of thing, in June. That coincided with the AIDS Conference, and with The Quilt, out of the Names Project, of which I was the main organizer, along with Raymond Blain.

AS: And you'd continue doing that through this whole crisis?

HB: Oh, yes.

AS: Amazing.

HB: Yes. Also, I went briefly to a family thing in Cincinnati. When I came back I started breaking out in something. And my sister said, "Oh. That sounds like poison ivy. You must have gotten it in the back yard." Or something like that. So, I went – it took me three trips to the hospital. They kept sending me away with ointments. On the third trip, I said, "No. I want to be seen in ophthalmology because there's a pattern here. It's a square. And I'm beginning to break out in lesions on my nose. So, this is, in my view, ophthalmic shingles." They said, "Oh my god." [laughter]. They took me to ophthalmology. They confirmed the diagnosis. And within a day or two I was hospitalized on intravenous acyclovir, probably. And morphine, actually, because of the pain.

AS: It must have been incredibly painful.

HB: Yes. But my eye was saved. You know, I had scarring and that sort of thing. But I got away with it. But that was another hit to my ability to function as a militant [laughter]. But The Quilt was a huge success.

GK: Right.

HB: I was very, very, very satisfied. And it was really great for the community here at the time. That was its purpose, in a sense. To create something local that would connect with something global. That would also interface with the AIDS Conference, because it opened the evening before the conference itself. And it was specifically targeted, amongst other things, to the delegates. To get them outside of their meetings space and into a collective memory mode to see that there were other dimensions. The human dimension of the crisis.

AS: Yes.

HB: And locally it meant that, you know, a huge number of panels were made. We borrowed a couple of hundred.

GK: Right.

HB: But all the rest were made locally.

AS: And could you talk about how you did that? You had made this connection with the folks in San Francisco …

HB: Yes. We had the project – or the idea. And that is a little bit hazy because I don't have – I haven't found any notes specifically on the genesis. Unfortunately, just this morning I went to rummage – and I do have some diskettes and things on odd formats that are no longer readable by anything. And I don't know if you come across this, in terms of people trying to access archives on old media. But there are probably quite a few secrets, with respect to all this history in there. Including all the minutes of ACT UP from the first meeting on.

GK: Really.

HB: At the beginning, I took all the minutes, and I translated them all.

AS: Wow.

HB: We began planning at least, if not actual ACT UP meetings, in September or October. Because I have my first mentions in my diaries of meeting with Blane post-Conference. Then there were other mentions of meetings in connection with a couple of other campaigns. I know we did one ACT UP thing around the Joe Rose anniversary. In fact, if I'm not mistaken, that is what this is. [shows picture]

GK: Yes. That's the picture that probably Rene took. We actually saw this yesterday in the archives. Is that the same picture?

HB: Yes. This is just a blow up of a detail of it.

AS: And who are those people?

GK: If you could identify them.

HB: Okay. Well, I can identify a couple people here.

AS: Okay.

HB: Yes. Definitely. So, this is a fellow who I…

AS: I'm just going to film during this.

HB: These are two people who are involved in the Naessens Campaign. I don't know if you know about Gaston Naessens?

GK: No.

HB: Well, I'll tell you that in a minute. It was a big deal because it was a perfect example of the medical pharmacological complex killing alternative avenues of research.

GK: Right.

HB: Naessens was a researcher who, because of the War [WWII] was unable to complete his medical studies. And he eventually, having run into problems with his research, which was highly original, ended up coming to Quebec. And he developed a microscope that was beyond what anything the people in science had seen. And we developed quite a bit of documentation on that. He also, as a result of this, began finding things and developing a new theory of disease. And therapies. I think this fellow's name was Bernard Baril, if I'm not mistaken. [pointing] This one here.

AS: I keep identifying all kinds of people.

GK: There are many Bernards.

HB: Yes. There are lots of Bernards. There are long lists of Erics, as well. [laughter] This woman I think was, her name is, Julia, if I'm not mistaken. And this is Eric Smith.

GK: Right.

HB: I don't know if you – has the name come up?

GK: He was also involved in Réaction SIDA.

HB: Oh good. I think this may be Varda interviewing me.

GK: That does look like Varda.

HB: I think this gentleman is Allan Conter, who did some of the ACT UP meetings later on. Probably just turned out for the event. And anybody else, here… Oh, and here's Michael. Here. [points] Michael Hendricks.

GK: Right.

HB: Now this is Jamie Marois.

AS: Okay. Great.

GK: Because Glenn Betteridge talked to us about Jamie, but there was no visual image of who Jamie was.

HB: Oh, yes. Jamie was spectacular and full of life. And I was totally shocked to learn that he died, especially because he was doing research in the area. And I thought to myself, "How is this possible?" And he was well connected. He was working with Wainberg. So, what happened, in terms of his access to timely treatment, I don't know. But I think he died – I was doing a search one day and I found a reference to it. And I thought, "This is not possible." It was 2003, maybe. And then I came across a short thing by Wainberg, regretting his passing.

GK: You may want to check Glenn Betteridge's interview. It's online now. He actually talks a bit about Jamie's death.

HB: Good.

AS: So, there's several things. So Naessens…

HB: Why Naessens is particularly important to this context was that he had begun treating people. He began to treat a number of different conditions, actually. The medical establishment here – the Medical Association – decided that he was going to be a good target for repression.

AS: Because his license was from another…?

HB: No. He wasn't even a licensed MD because, as I said, all of this happened during the Nazi regime. And his schooling was interrupted during the Occupation, and he never got back into the university network.

AS: Ok.

HB: We did hold a meeting where Naessens met with doctors, publicly. We had decided that we would carry this forward. Not only because he was being persecuted, literally. But also, because it was important for people to know that he was at least attempting to do something about a variety of conditions, including HIV. Some people had found out what he was doing. And what he was using on the basis of his microscope. And he got invited to one of the scientific programs at the AIDS Conference. And he was supposed to make a presentation.

AS: Wow.

HB: Well, the Quebec Medical Association had him arrested a week before the conference. Literally. I mean, they took him to jail. So, he was behind bars when the AIDS Conference took place.

GK: Really. I didn't know that.

HB: So, we raised this as an issue, demanding that he be freed. Subsequently we were trying to have him heard. So, my comment about the evening when we met with the doctors was that he and the people around him obviously had not thought in terms of how to make their case in a cogent way to a more general public. And that was disappointing. It didn't have the impact that we were looking for.

GK: So, you're referring to organizing for the '89 AIDS Conference…

HB: Yes. Well. It wasn't really on the radar.

GK: Okay.

HB: Until we heard that he had been arrested. So, we did have a little thing going organizationally, because we were doing The Quilt. And I didn't have a hand in what ACT UP did at the conference.

GK: You're talking about ACT UP in New York City and people from the States?

HB: Yes. When they arrived. Because that was – their whole operation was pretty improvised. I mean that it was improvised in the sense that it wasn't a coordinated effort between the people in Montreal who knew that they were coming.

GK: Actually, it was.

HB: Oh, it was? Okay.

AS: So, there are lots of threads.

HB: Yes.

AS: So maybe we could just make sure to close The Quilt loop. Because you had just started talking about it… I want to hear how you got all the people who made panels here. Why you contacted them, how that happened.

HB: Well, as I say, I wish I had more documents, more of these files. Because I took a lot of notes at the time. I would have had lists of people. But the person who was the mainstay of the operation, aside from myself, was Raymond Blain – who was a city councillor, actually. A really great guy. He died in '94. We had a lot of support through his contacts and his ability to organize and speak to people. We got the seating space. A lot of coverage we wouldn't have otherwise achieved. Who the other people are, I'm not quite sure. I wouldn't be surprised if it was through The Quilt that I met a fellow by the name of Kalpesh [Oza].

GK: Oh yes.

HB: Yes. Have you had any…?

GK: Oh yes. We actually dedicated the talk we gave last night to Kalpesh.

AS: But it would be wonderful to hear more about him.

HB: Yes. He was a total character. [laughter] I am pretty sure that it was around The Quilt that he and I started working – we did work at CSAM and CPAVIH as well. He was very involved in CPAVIH [Comité des Personnes Atteintes du VIH du Québec]. And that's where I met this woman by the name of Julia whose last name I am unable to find. But she was at that ACT UP Joe Rose demonstration.

AS: Ah, yes.

HB: Again, if I find the way to crack the files…

GK: Especially the minutes. We would love to see them.

AS: Yes.

HB: I mean, they would be all there. We had a debate as to what would be the appropriate way to frame this, and we saw the AIDS Conference opportunity. We figured that it would also be really great if it wasn't simply some symbol that was abstract and that was happening elsewhere. But it was actually happening here. We were able to get people to – we had space at the CSAM / CPAVIH office on Prince Arthur. We took over that space, and had people come in, and people from a church-affiliated group in the Village. They turned up with sewing machines and material. Family members came in with ideas and we held regular sessions of quilt making. And people would go off and continue and contact other people saying, "Would you be interested?" We explained what – the only thing was the size.

GK: Right.

HB: It had to fit into the patchwork.

GK: Right.

HB: So, I went off – as I said – to San Francisco to negotiate the conditions of the use of the name and the things they wanted included in the presentation. And the transportation and safe keeping of the panels that they were entrusting to us. So, this is the invitation that they issued. It's the English version. And here is the French version here. And here is a picture of The Quilt here.

AS: That's here?

HB: Actually, no. Anyway. Our Quilt was at least this size.

GK: That's great.

AS: Amazing.

HB: And…

AS: Is that the Olympic Stadium?

HB: Yes.

AS: Wow.

HB: It was at the Biodome. Oh, here we are. More details than I thought. I hadn't even opened this thing up. Look at this, we've got the Organizing Committee. Yes, I was going to mention Alain Leclerc, who was also with the City at the time. He was really good. Well, you got the names of the other members of the Organizing Committee. And what else does it say about the – registration forms, where you could sign up and make a panel.

GK: Right.

AS: So, were any of the people who were involved in The Quilt project – did they continue to be involved with ACT UP?

HB: Yes, for sure. Because of when we had the idea of forming a Montreal chapter of ACT UP, it was the natural pool.

AS: Yes.

HB: And people were also looking for other things to do.

AS: Yes.

HB: And were excited by the idea of direct action. Talk wasn't getting us very far, at the time.

GK: Yes. So, maybe just a step back before going into the formation of ACT UP… I mean, you were also involved in CPAVIH? Could you tell us a little bit about that?

HB: Well, that was subsequent.

GK: Okay. That was later.

HB: Yes. And I would say that my involvement there was more to support Kalpesh's work. But we also used their resources. Because CPAVIH, being an AIDS support group, had a lawyer on staff. Or somebody they contracted out to… I don't know if she was there full-time.

AS: Yes.

HB: I have a reference in one of my journals to a meeting with her. To prepare the papers to register ACT UP. I can find the specific dates of that.

GK: That would be great.

HB: Yes. Because the material is there. It just needs to be teased out of the mass of other things that are completely unrelated. Or, never completely unrelated, because there are lots of emotional involvements with many of the participants.

GK: So, one question we usually ask people that you've sort of hinted at, but not directly talked about, is we always ask people about involvements in other movements and organizing experiences they would have brought with them and might have assisted in AIDS activism. But before that back to The Quilt organizing.

HB: We were able to pull in quite a few people.

GK: Yes.

HB: My friend Barbara Scales from Latitude 45 was particularly good, too. Because she knew René-Daniel Dubois very well. He wrote a really nice piece for the opening ceremony, of which I happen to have the script because I wrote it myself. I didn't say everything, but I arranged the ordering.

AS: Right.

HB: And the translated text, that sort of thing.

AS: Amazing.

HB: Why I happen to still have that, I am not sure. [laughter] Because some of these things got thrown out at the time. But at least I did keep a couple copies of that, which is good.

AS: Yes. That's fantastic.

AS: So, you had been political before all of this?

HB: Yes. I had been involved since I arrived in '71 in Montreal. I'd come because it was one of the more exciting places to be in North America at the time.

AS: Why was that?

HB: Well, I finished my degree in Halifax in the fall of '70. And I missed the October events here in Quebec because I had already decided that I was leaving Halifax and North America and was going off for an extended period of time. And I packed all the books that I hadn't had a chance to read while getting my degree and left for Europe. I wandered around for a better part of a year in

Europe and North Africa and Italy. Then I came back, and by that time I had decided that I wanted to go into Anthropology.

GK: Right.

HB: I arrived here because they had – at least on paper – the most compelling program. The way the Anthropology department presented itself here in Montreal was like light years away. And it was interesting, because it was a little bit of a mix of in terms of presentation. So, the pragmatic school, there were those that actually, the actual description of the kinds of courses. But it was clearly not the empiricism that was very prevalent in Anglo-Saxon social sciences at the time. And my time here at the University of Montreal was very good from that point of view, because I had spent all of my time in Halifax fighting my professors and saying, "I disagree, I disagree, I disagree." And doing the research outside of class and coming in to say, "I disagree, I disagree, I disagree." That's where Kim C. and I met. Because we ended up in a statistics class. [laughter] In Sociology.

GK: I can't even imagine Kim C. in a statistics class.

HB: Yes. Well, we went ballistic against the same professor, right? And we looked at each other. We agreed. [laughter] That was a really long-standing friendship.

AS: So, it was academically a good fit. And then politically…

HB: Yes. Academically a good fit. And politically as well. Although my intention was not to get into politics when I came. The thing is, Kim was involved in politics. And it's funny, because at one point we looked at each other and he said, "You know, this is actually working out a lot better than I thought. Because I was looking at you and saying, here's this intelligent, attractive, well-rounded, petty bourgeois [laughter] who I am going to share an apartment with." And I looked at him and said, "Well, you know, I was also walking into something that was completely unknown, because when I arrived I realized that you were involved in a political organization that I had no familiarity with." You know? And I joined his camp and he joined mine. [laughter]

GK: Right.

AS: And so, what was that like? Or how did that politics go?

HB: Well, the politics… We were initially very marginal. A very small group [the GMR, Groupe Marxiste Révolutionnaire]. We were actually a splinter group of a group which was pretty marginal, at the time. Our main point of contention with the group we were splitting off with was around the national question.

GK: Right.

HB: Which was only really getting up to speed. Although it was getting up to speed very quickly. I arrived, and within a year we had to confront the '72 Common Front strike, which resulted in

takeovers of a couple of cities by strikers. Well, I mean, that hadn't happened since 1919. Things were percolating in a couple people's minds and it was pretty obvious that the labour movement here in Quebec had tremendous potential. But there was considerable confusion around what to do with the national question, which was anything but resolved. I mean, the Parti Québécois wasn't even a thought at the time.

GK: Right.

HB: Much less the PQ in government in '76 for the first time.

AS: Yes.

HB: And, as was to be expected, it was swept to power largely thanks to the support of the labour movement and workers who saw change on the horizon. Thanks to the Parti Québécois, we knew that the Parti Québécois was going to have to end up having to deal with that dynamic. And we hoped that we would be able to build a current within the movement that would be prepared to stick by a workers' program as opposed to selling out. Which is what happened. In fact, the movement got completely demobilized and they lost the first referendum. And then Jacques Parizeau, the guy who was most responsible for losing the first referendum, eventually held the second.

GK: Alright. So, were there things you could have taken out of that organizing experience with you when you got involved with the AIDS organizing?

HB: Yes. Definitely. Because the thing that was most interesting about the 4th International, at the time, was that it was the continuation of the best human and intellectual and artistic, creative strains that had been present in the revolutionary movement up until Stalinization. And the catastrophe of the rise of the Second World War, and the rise of Fascism in its various forms in various places. And the consequences thereof. Not only within the countries that fell under bureaucratic government, but also the polarization that resulted in the world, and the entire half of the continent of Europe caught in the middle. Anyway, it was an opportunity. It was the only current that was open to women. At least recognizing the need for feminism, grappling with the inability of revolutionary organizations to really allow women to lead. Although [laughter] our English Canadian organization [the Revolutionary Marxist Group] was basically headed by women. Jackie, Varda, Deidre. Which was fantastic. They were similarly open to issues of minority rights, sexual freedom, gay rights, and even ecology, interestingly enough. Nobody was talking much about it at the time. But, there's another thing, which was that the resurgence of the healthier elements of the 4th International occurred around the events in May 1968 in France, primarily, coinciding with the wave of revolutionary upheaval elsewhere in the world. The events in Czechoslovakia, which proved a lot of the theses - which was predicted by the theses - and which unfolded according to the perspective of what was going on in China with the Cultural Revolution. Also, it was readily understandable in the same terms as what was going on the bureaucratic states. And what was happening just about everywhere else in the world with the rise of liberation movements in South America, the rise of the Civil Rights Movement, and the women's rights movement, in the States. So, all of that was bubbling up at the same time. People

were grappling with tactics and strategies. And direct action was proving to be an extremely effective tool to get your message out there and to inspire people to come out into the streets and engage in a conversation. And so, we were very open to original forms of organizing. And Kim was definitely the most brilliant conceptualizer of the direct action approach. We might have been small in number, but we, on occasion, produced a very big impact. One example of this was during the campaign we set up following the coup d'état in Chile in September '73. The labour movement put together a Solidarity Committee, and it was pretty obvious from the outset that was going to be dominated by the bureaucrats. Although the bureaucrats, at that time, were pretty far to the left. The heads of the unions had just come out of jail from the Common Front a year before. They were talking in pretty radical terms. But as to what they were prepared to do, to pressure, and to mobilize their ranks around a question like this – that was a lot less likely.

So, we developed our own campaign. We did a blitz, for instance, in the universities and colleges. We set up a mobile Solidarity Day operation. It was literally a commando. It was a campaign in a box, in a sense. All it took was a van. And we practiced. And we developed the props. Everything folded out and everything folded back in. And we had presentations. And music – the whole thing. We would arrive and within fifteen minutes we had taken over a cafeteria, or the entrance to a cafeteria. The cafeterias were great because they were our buttress against the cops. If the administration decided to call the cops, either we had spotters so we would either try to rally the students, which more often than not worked. Because if the students defended our right to have this place, then the administration often had to call off the cops. So, we were pretty successful. If that looked unlikely, if we didn't have enough time to develop local support, we could fold our tent and whoosh, very quickly.

The crowning example of an effective campaign that had reached far beyond our numbers was the first of May, the following year, '74. So, what we did to begin with, and in fact I had the pictures in my office, we organized, we had a source of information in Foreign Affairs. And that source had provided us with telegrams, cablegrams, between the Canadian Embassy in Chile and Foreign Affairs in Ottawa. This was scandalous material. This was Ambassador Ross complaining about the fact that he couldn't get the "riffraff" out of the embassy – who had come in during the coup. They had been given shelter by the employees. It was 35 people who had gotten in, and they were saved from being rounded up. And when he came back from buying a car in Buenos Aires, he couldn't get them out. That didn't prevent him from holding, from inviting the person that the coup d'état appointed as the Minister of Health, while they were killing people, for dinner at the embassy. All of this was in the cables, which we got. So, we assembled the stuff in a readable form. And we occupied simultaneously five Chilean Consulates here in Montreal, Toronto, and across the country and held press conferences to bring this information of complicity, clear complicity with the dictatorship. This was very fresh in people's minds.

AS: Yes.

HB: And our demand was for safe conduct for the people who were still in the Embassy. And to open our borders … you know, that Canada would immediately communicate to the Red Cross to get people out of camps.

AS: Yes. I see.

HB: And that was the source of the first influx of Chilean refugees, who were very much part of the community here now. A couple hundred got in right away. Now on that day, [laughter] we got arrested at the Consulate by – we are not sure that the consul actually wanted the cops to arrest us, because they eventually dropped the charges, because they didn't want the publicity. But we were able to get out, and right after that there was a big solidarity meeting at which Isabel Allende was going to be present. So, we thought to ourselves, "Hmmm. How can we give a slightly more militant revolutionary tone to this meeting of, probably, 40-50,000 people that turned up at the forum for the event." And we did it basically with visuals. So, we created huge banners. I mean we're talking huge. Probably about 70 feet across, 120 feet long, which we sewed here.

AS: Wow.

HB: Over the banisters and down the stairwell with the material - Colette will tell you - with the sewing machine here in the kitchen. People were walking through with the material to sew it.

AS: Wow.

HB: And we also developed a technique to print the stuff on it. We had access to a Cégep gymnasium and we would lay the material out on the floor and we would use projectors from up on the wall.

AS: Ah, yes.

HB: It was like doing stencils. We would project the image and people down on the floor would go around and outline the shapes. So, we had these gigantic banners with hammers and sickles, Chile in the shape of a gun, and so on, so forth. Which, at the moment when Isabel Allende arrived and mounted to the stage to general applause, and people on their feet, the banners magically unfurled from above as the backdrop for her. So, she comes on stage, and she looks up, and when she realizes the message she starts to applaud. And we had won. Because it was our message, and not the bureaucrats', that basically carried in that particular instance.

AS: Amazing.

HB: Just because of the visual effect. So that was – in a sense – also what this was about in my mind, The Quilt. There's nothing like a powerful visual.

AS: Yes.

GK: Right.

AS: But also stitching together all that work, right, to make that.

HB: Yes.

GK: For sure.

HB: So that's why we clicked with ACT UP as a direct action approach. And I knew how to organize committees and that sort of thing.

GK: Maybe you could tell us a little bit about how ACT UP came to be? You were mentioning there were meetings in the fall after the AIDS conference. And you were meeting with Blane, but how does that all come together?

HB: Well, as I say, things are a little bit fuzzy in the absence of the minutes. I have lots of references in my diary to various meetings. And I can give you dates another time after trying to sift through everything. I was trying to do a timeline. If I had another week, I could come up with something quite impressive.

GK: Yes.

HB: Because the more you reflect… Well, yesterday I was up here [pointing] and I was taking down my appointment books. I am missing 1990 of the whole stretch, from '78 on.

AS: Wow.

HB: 1990 is the only one that's missing. But I was looking at '89 today. And it's kind of hard to extract a lot of useful information, but there were a couple of names and meeting dates in there that would bare a little bit examination to get the timeline a little more fleshed out. But, yes. I started talking – let me see now, I'll go back to '89, here, and look for the first instance of Blane. Okay, I'll go to the top. So, this would have been - let me find a date, here - end of September or the beginning October. Okay, somewhere around the 29th at this public meeting with Naessens. And Blane and Ian and another member of ACT UP were in attendance.

GK: Blane from New York City?

HB: From New York City, yes.

GK: Okay.

HB: And I'd say, in here, that I invited Blane to come have a bite to eat. And we talked at length about ACT UP and the Naessens affair. We agreed that we should start working together in Montreal. So, it was around the Naessens thing that they had come to that. Because we had organized a couple of other things. We had actually occupied the – now this is probably under CSAM. I am not sure under whose auspices we did this, but we occupied the offices of the Quebec Medical Association. It was one of several efforts to dislodge a fellow by the name of Augustin Roy, who was a very, very conservative career doctor and head of the Association. He never practiced, but he made a practice of witch-hunting and excluding. He was eventually pushed out by the Government, who were embarrassed by his sexist remarks. But, yes. Naessens was very much part

of that, at that time. So, Naessens was the thing that actually brought people together in the same room for the first time. And then we began meeting separately. So, let me see what the next instance of Blane would be. The 11th of October. And I see the name of somebody else who got involved in the committee, Puelo Dier, whose name has come up.

GK: I've heard that name before.

HB: Well, he has been very involved with organizing Pride here in Montreal.

AS: Okay.

HB: Yes. So here I am saying on the 29th that I was translating some stuff for ACT UP and The Quilt. Okay. There was a meeting on Thursday at CSAM, probably connected with Naessens. And there was a meeting of ACT UP, at which a number of new people had turned up. Okay. The Friday before we had the last meeting of The Quilt planning committee – the local Quilt. Probably to wrap things up at that point. And this next meeting was an ACT UP meeting. And a number of new people had turned up, including Jamie Marois, who was there for the first time.

GK: So that would be in…?

HB: That was in October.

GK: October of 1989.

HB: Of '89, yes. So, around the 11th. And Jamie and I went off and had a conversation about Naessens and ACT UP and where to take it. And I met with Raymond to produce the reports for The Quilt, which we had to submit. And that evening, after I met with Raymond, we went out to a club called Lazar to attend a performance by Blane. Because Blane was doing performance work at the time. Have you interviewed Blane?

GK: Blane hasn't been interviewed by us. I did meet him at the '89 conference. Other people have mentioned Blane, but he's also been interviewed by the ACT UP Oral History Project in New York City. So, you can access his interview that they have done with him.

HB: So, he was doing something that he referred to as voguing.

GK: Right.

AS: And this would have been bringing voguing to Montreal?

HB: Yes. This would be bringing voguing to Montreal. He was very colourful, Blane. We had a good time. So, after that, in November on the 25th, something else with ACT UP… Anyway, the meetings continued. I was taken out of commission in December because I was hospitalized in Toronto. And then I was taken out of commission again a little bit in January. And again, in June. It was around then that I already began to try and delegate, because there were meetings I had to miss. At one

point, I think in April, I made a comment about returning for my first meeting in a while and being very pleased to see a couple of people I asked to, you know, organize and prepare agendas. Because these are not spontaneous skills. And meetings go nowhere without them.

GK: Right.

HB: So, people have to agree to a certain structure at the beginning, points to discuss, proposals, who's going to do what. If we think of these things in advance, then the meeting is productive, and people want to come again. That was the kind of dynamic we were trying to build. I do make it clear, I see the expression in my journals from 1990. "To get it up and going again." So, there are probably a couple of occasions in which the attendance lagged for this kind of reason. And I began withdrawing from active involvement during the summer of '90.

AS: In those meetings in the beginning, were there sometimes people meeting at your apartment? Is that right?

HB: Well, probably side meetings.

AS: Yes.

GK: Glenn Betteridge describes your apartment.

AS: Glenn Betteridge loved your apartment. [laughter]

HB: And I know that later they met on Saint-Laurent, but, at the time that I was involved, we didn't meet on Saint-Laurent. We met quite frequently on St. Catherine's in the Village.

AS: Yes.

GK: And what's your memory of who was the core group that was involved in ACT UP when you were involved?

HB: Well, Blane, certainly, and myself, Jamie, Glenn. Eric Smith was really good. I think I have a couple more names.

GK: Was Michael Hendricks involved?

HB: Michael Hendricks, oh yes, definitely. And there are a lot of references to Michael in the spring of '90, in particular. We were moving in the direction of commemorating Joe Rose's death. And there's also the Sex Garage stuff.

AS: That summer, yes.

HB: Yes. And I unfortunately didn't attend the party because I wasn't well. And I wasn't actively engaged in the aftermath, after that. But it's out of that that Puelo and a number of other people

took some energy, from all of that, to eventually build the organization that resulted in Pride. And Michael, of course, and René led the charge on the civil liberties front.

GK: Right.

HB: So, at that time I was physically exhausted. And needed a break.

GK: Yes.

HB: And needed to focus on hanging in there.

AS: Yes.

HB: For the longer term.

GK: It sounds like you played a really crucial part in planning to get an ACT UP chapter growing here in its initial steps.

HB: Oh, yes.

GK: But do you remember… Were you at the first action on the anniversary of Joe Rose's death?

HB: I can't say… I didn't take notes on it.

GK: But you knew you were there. That's good.

HB: Well, it's impossible that I would have missed ACT UP's first action.

AS: Yes.

GK: Yes. Do you remember any other actions that would take place?

HB: As I say, at this particular event, which is ACT UP… [referring to photos]

AS: I think that is the first one.

HB: I am the spokesperson.

GK: That's why you're being interviewed by someone who looks like Varda, but it's not Varda. [laughter]

HB: Yes. And one of the issues we had been raising at that point was that some doctors had expressed their unwillingness to treat people with HIV. And we issued a formal demand that the

province require that all doctors either provide the treatment or refer their patients to people who were willing to provide treatment.

GK: So when you were still involved, because Michael has described to us this sort of three-year campaign – that ACT UP and CPAVIH were involved in, or at least people from CPAVIH were involved in – to get drugs funded. Right? Was that starting when you were around?

HB: Yes, it was.

GK: Could you maybe tell us anything about that?

HB: I can't.

GK: Okay. That's fine.

HB: After reading a little bit more, and trying to piece things together, perhaps. I realize that I allowed quite a thick fog to settle upon that period for various reasons. I mean, it was extremely tumultuous, emotionally, for me, at that time. Very tumultuous. And that's why I ended up withdrawing because, it was just – my circuits were shorting.

AS: Overloaded. Yes. Well, it was also really clear, starting to piece together some of what was happening. When we were preparing a little bit to talk last night about what we've learned so far, just the incredible density of campaigns that were happening and the amazing array of things that ACT UP was doing then. So, treatment access, doing work about women and the ways they were being affected by the virus. It's remarkable to me when people can remember anything about that time. So maybe if you wanted to say something about what the emotional texture of that time was, or what the feeling of it was?

HB: Well, I would certainly echo the surprise that we were able to do so many things at once. And I look back and I say, "And you were in the hospital. How did you do that?" [laughter]. But I was, you know, fielding calls from the hospital in Toronto. And, at one point, when I was hospitalized in January, I'd fortunately brought materials with me, you know, my phone contacts and so on so forth. I had a subsequent hospitalization nearly ten years later where I fortunately also took my computer and my modem and my printer.

AS: Wow.

HB: I wouldn't have survived my stay there if I had not been equipped to do some research and to counter what they were trying to do to me.

GK: Right.

AS: I am so struck by this because it's really remarkable to be, you know, to be in the hospital and to have people that are supposed to be taking care of you recommending things that could make it worse or kill you.

HB: And kill you, yes.

AS: And so, it's really amazing and impressive to me to have the resources and the orientation in a period before there's Web MD [laughter] to do this. Can you say something about how you came into this?

HB: Well, I came by my medical skepticism quite honestly, because my father was a doctor and there were doctors all around me. And family members. It was kind of assumed that I myself would become a doctor. I knew that I was not going to become a doctor, because there was a great narrowness of mind, unfortunately. My father was in many other respects an extraordinarily open-minded individual. And he even very much surprised me at one point when I asked him seeing materials in his office - which was also the place where I played piano - inviting him to a conference on acupuncture. And he was an anesthesiologist. And I said, "Well, what do you think?"

AS: Yes. That is interesting.

HB: And he said, "Well, I'd be interested in going, but I can't go to this particular one." But this was just after the Surgeon General of the US had been to China and had watched open heart surgery under acupuncture, with no anesthesia. And my father said, "Well, hey, we don't know ultimately how drugs work in anesthesia. All we know is empirically what they do, and how much to give and in what sequence, and so on and so forth, the mechanisms. So, if needles can do the same thing, why not?" So, he was very open in that respect, but very closed in the sense that, for him, the medical profession was something where there were rites of passage. And the rites of passage in the medical profession were residency and internship, where they kept you up for 76 hours at a time.

GK: Yes.

HB: And that sort of thing. If you survived, then you were part of the club. And there were very few women at the time.

AS: Yes.

HB: Very few women. So, that was definitely not for me. The other things I heard my father talk about were other doctors, and the practice of medicine, and the mistakes that were made and so on and so forth. I realize what made him a good anesthesiologist was not just that he knew his chemicals, but that he was a great person. A people person, yes. There was an intuitive side to his success with patients. Because he was the last person the patients saw before going into the operating room. And often the first person they saw coming out.

AS: Yes.

HB: That very much determined their experience of that part of their treatment. Whatever it was. Anyway, I also ended up in an experimental class as a kid. And because of everything that was

going on in the family, I took refuge there. Once I realized that this awful experience, this torture that I was being submitted to because I was taken out of my school and had to walk miles and all of my playmates were left behind. But when I had my mind opened, I realized that this was my escape into the universe.

AS: Yes.

HB: I ran for it.

AS: Yes.

HB: And became a ravenous reader, to the point where I actually entertained for decades the idea that I was a rational person. [laughter] Well, a person who – I am a rational person in some respects, but I actually laboured under the illusion that my life was planned and rational. Whereas looking back, it was nothing but a trail of coincidences and whims and emotional undercurrents, and so on and so forth, that took me here and took me there. But one of the things that my main intellectual influence from that period taught me, was that the important thing was not what you know at a particular point of time, but knowing what you don't know and how to get the information that you need.

AS: Yes.

HB: So, that was basically the approach that I applied in my own instance, and for the people around me. So, I was involved with – on the fringe of – the Men's Health Organizations in San Francisco and New York, corresponding with Sean in Toronto.

GK: Sean Hosein.

HB: Yes.

AS: Yes. When we talked to Sean it's this amazing capacity of when people talk about Kalpesh, right? That these capacities to take that orientation and say, "I don't know. Is this right? Like, is this how medicine should be treating this virus?" But, if you remember anything about how people in CPAVIH… I imagine that a lot of people would not have had the kind of literacy or approach…?

HB: Oh, of course. Yes. Well, I mean, that's why the organization existed. [laughter] Because people did not have access. More often than not, the door didn't open. Or, if they got in, they got ejected.

AS: Yes.

HB: People were losing their housing, and so on. So, CPAVIH played a very important role in that respect, because it defended people's rights and it helped get them access to treatment.

AS: Yes. And helped them understand what treatments do…

HB: Well, yes, what the options were.

AS: That's amazing.

HB: And fortunately, there were some really good people. I think of Marlene Daley, for instance, who is still an AIDS counsellor here in Montreal, with whom I met recently after many years. In fact, I met her because I thought maybe she would help jog my memory around this. Because she attended one of the first meetings.

GK: Of ACT UP?

HB: Of ACT UP. And I remember having a discussion with her. And she said, "Well, I really like this, and I really like the group and what's being discussed, but given my job, I probably can't be too visible. And I said, "Well, your job is an extremely important one." She was doing outreach.

GK: Yes.

HB: And counselling. Because we were getting to the point where, I mean, the blood tests existed. So, getting people to get tested was a big deal. And that was Marlene's job. And she has done a great job over the years.

AS: So, in that moment where the blood test existed, it was possible to get tested, but there weren't really useful treatments. How did people talk about that? Or think about it?

HB: Well, it was the direct result of a conversation I had one evening. We got together in Montreal with Varda and, the name, I had it on the tip of my tongue… Heather-Jon Maroney.

GK: Yes.

HB: Maroney…

GK: Yes. Maroney.

HB: Yes. So, we had dinner together, and we were talking about this and talking about that. And treatments. And alternative approaches to health. So, the next day I happen to have an appointment with my doctor. He was one of the eminent AIDS physicians in Montreal at the time, who eventually moved the clinic right into the Village, where it became the centre of treatment during the heavy-duty years. Anyway, I was seeing a fellow by the name of Clément Olivier, who was very knowledgeable and very dedicated. It was good to have somebody to bounce ideas off of, who was open to talking about alternatives. But that came later. I was seeing him as my regular physician. And it was just a bonus that he happened to be gay, himself. Also practicing at the clinic was Michel Marchand, who unfortunately died of AIDS in, probably, '91 or '92. Anyway, so this would have been in '89. Early spring '89. I know the day that I received the news was the 7th of March. I had this regular appointment, I went in, and he said, "Well, look, everything is great." So, I

said, "looks like it might be time to do the test." And he looked back at me and said, "Do you really want to do the test? The outcome can be quite stressful." And I said, "Yes. I figure if everything is going fine, that this is the best time…"

AS: To know.

HB: To know. Because I don't want to be one of these people who wake up after a crisis on a hospital bed.

AS: Yes.

HB: To be told that it's too late to do anything.

AS: Yes.

HB: Having seen all too many people ending up in a situation like that. So, I said, "Yes. I want to do the test." And he said, "You know there's no treatment?" And I said, "Well, of course I know there's no treatment, but what you're saying is there's no pharmacological treatment."

AS: Right.

HB: "And what I am saying is if I get the result that I hope I won't get, that being in good health now means I have a better chance at staying in good health if I do the things that I have to do." So, once I got the result, I launched myself into a vast campaign of reading, supplements, and so on.

AS: Yes.

HB: I hooked up with what was being done in New York City and San Francisco, what they were talking about, and trying a few of the alternative substances, myself.

AS: Yes. And this is something that I feel like people, especially people who seroconvert now, it's like there's not as much talk and memory about all of the cofactors that can go into health. You know? And that listening to people, you know, it's really important to remember all the different things that people did. So, there's sometimes the feeling like, "Oh, it's like people got diagnosed, or they didn't get tested because there is no treatment, and they kind of just waited around until…"

HB: Yes. I thought that not knowing is worse than knowing, ultimately. And it's morally indefensible. Because you're relating to other people and you don't know if you're infected or not. And, are you taking the precautions that you need to take to make sure that you're not an active contributor to this crisis?

GK: Right.

AS: Yes. I try to convince my students, you know, my undergrads who have no idea… You know, they don't know from anything… But there's, like, antibiotic resistance to syphilis right now…

HB: Sure.

AS: And I try and tell them, like, "You all just need to be having sex as though everyone has everything." You know? And, "You can have wonderful sex, but you need to not have this idea that you can just sort of pretend, you know?" Which I take from the history of AIDS activism. Really, everyone just needs to be taking responsibility together.

HB: Yes. I figured that if I hadn't done that, at that point, that when I did have a problem, even if it wasn't directly relatable at the time. Although, you know, subsequently they realized that there were issues with platelets.

AS: Yes.

HB: You know, imbalances. I mean, it is an autoimmune response, but it could be HIV-related. There were enough cases accumulating by that time to make the connection. I was able to survive the crisis.

AS: Yes.

HB: And to withstand the corticosteroids. Because I was already – well, I kept myself healthy up to that point.

GK: Yes.

HB: So, we have to be prepared for those onslaughts. And, unfortunately, some people departed in the blink of an eye. Because they didn't have that resistance. And they got something trivial – like a cold or a flu or something of that sort, and ended up in the hospital. And bang, they were gone.

AS: Yes.

GK: Yes. So, you withdrew from participation in ACT UP that summer? The summer of 1990? Are you involved in just going to actions or doing anything after that, or?

HB: I would have … I don't have any clear memory of specific things that I attended. It's unlikely that I would not have. My problem was that, as I said, it was an emotional overload at that point. And since I had recruited several of the people, whom I was emotionally overloaded with, into ACT UP, that was one of the reasons why I stopped attending the meetings.

GK: That makes sense.

HB: Because it was difficult to.

GK: Yes. Ross Higgins and I were looking at some old video footage of various different ACT UP things, and there was one action at the Palais des Congrès building. I think it's a Liberal Party convention, maybe on treatment issues. And ACT UP does something inside, but there's sort of a group video shot after. And I didn't – I couldn't identify hardly anyone in them. But Ross said that you were in this picture. So, it was just sort of people waving and all together at the demonstration. I think that's in 1991 sometime, but I'm not sure. Anyway, so, it does look like you probably did go to some of the demonstrations and events. So, that's great. Anything else you remember about ACT UP that you would like to tell us?

HB: Well. Yes. I can say that after many years of not thinking very actively about the period, I went and saw *How to Survive a Plague* with great pleasure because it… It was very validating, in a sense. Hard to… [tears up] Just have to get a good hold of my vocal cords again. [laughter] No, I am fine. Yes. It was hard to plunge back into the death.

GK: There's also another movie that came up out of the ACT UP Oral History Project called *United in Anger.* Actually, the person who made *How to Survive a Plague*, David France, actually took footage from them. So, there's a conflict between them, but in some important ways a different story is told in *United in Anger*.

AS: But they both really capture that urgency and the devastation, you know, of that time and transmit something about it. Other people have said that it's hard to even watch them.

HB: Yes. It is hard to watch. But, at the same time, well, it's a great tribute to all the people who didn't make it.

GK: Yes.

HB: Because they tried. And people put a lot of heart into trying to help them survive. But it was also, if we were going to do something with our lives at that time, we said, "Silence is death." And ACT UP was precisely an affirmation of life in the face of what appeared to be a death sentence.

GK: For sure.

HB: So, it was the only thing to do for anybody who wanted to really live during that period and who had some concept of the stakes and the issues and the politics. And, more broadly, it changed the paradigm in pharmacological research.

AS: Yes. It's a good way to live. If you're going to live, it's good to do that.

HB: Yes. Absolutely. But, I mean, it's nice to incidentally have produced a paradigm shift.

AS: Yes.

HB: In the process. Which would be subsequently applied to multiple therapies.

AS: Yes. And patients – having patients involved.

HB: Yes. Patient advisory boards and all sorts of different channels for trials, and that sort of thing.

AS: Yes.

HB: Those made all the difference for many, many millions of people since.

AS: Yes.

GK: Part of what we are trying to do is to remember people who we can't talk to now because they are no longer around. So, you mentioned Kalpesh.

HB: Yes.

GK: Maybe we could just – could you tell us a little bit about him? We already do have a little bit of a memory section about him, but we try to expand it a fair bit on our site.

HB: When did he leave us?

GK: Not until 1995. He moved to Toronto and he was involved in AIDS ACTION NOW! But also became a little bit of a sort of cultural star in the South Asian community. So, he did performances at Desh Pardesh. I only met Kalpesh a couple of times.

HB: Right. I was always impressed by his thinking on some issues. On organizational issues, he sometimes seemed a little bit fuzzy. But he had a – how can I put this – a very gentle, very Indian take on so many things. In meetings when tempers would flare and this sort of thing, he would often interject and make a comment that seemed completely unrelated. And, I thought, this is either foolish or brilliant. [laughter] More often than not, the effect was brilliant because, whether he was conscious of it or not, he was diffusing the conflict by distracting people from whatever it was they had gotten caught up on. On a more personal level, he was very, very invested in everybody he came in contact with. That was quite striking. You know, he was great for his work at CPAVIH because he was so empathetic. I remember just soon after I was hospitalized in January after coming back. Well, I mean, everybody was, no surprise, because I was in Toronto … news, you know, getting out. I got calls. So, I got back and when I ended up back in the hospital, he appeared amongst the first people, with Julia in tow, to cheer me up. He hoped that I would get back in very quickly, which I ended up doing.

AS: Yes.

HB: Yes. Somebody else who is very much in my mind these days, and who did some good work with ACT UP in the initial period, was a fellow by the name of Kevin Myers. He was very, very, dear to my heart. He left Montreal in the '90s after working with my friend Barbara Scales at Latitude 45 in arts management. And he worked with the *Grands Ballets Canadiens* as tour director for a

while, then he ended up doing the same thing for the Royal Winnipeg Ballet where he met his husband to be. And they moved to BC where he performed – he was the manager, actually – for Ballet BC for a number of years. Rusty followed him there and then they went to Scottsdale for Ballet Arizona. And from there he and Rusty would become very, very avid endurance riders and had their horses.

AS: Wow.

HB: They were competing and very invested in the community. They decided to move to Colorado. He extracted himself from – they both extracted themselves from – the world of dance, and he became the marketing guy for an outfit called Easy Care, which was marketing a very revolutionary approach to hoof care. These are boots instead of iron things that you hammer with nails into the hooves of horses. So, I mean, the whole concept, really, gives you chills when you think of it. So, they were onto things. Kevin seemed to be leading the life that he had dreamt for himself. I remember back then, when I came into the office from a trip here or there, that he yearned to be free from the office. So, I said, "Well, you know, you'll do it your way one of these days." And he eventually created his own job and travelled with it, and even to Europe, to do events. And held clinics to show people how to do it. They developed this really nice community in Colorado. Married the man of his life. I got to spend a little time with them. One wonderful moment was our real reunion, after our times in Montreal which had been passionate, but sometimes highly fraught, was in 2000. I was going to Vancouver for a conference, but it also coincided with my 50th birthday, and I stayed with him and Rusty and we had a really, really nice reconnection. It made us realize why we loved each other.

AS: Yes.

HB: So, I tried to maintain contact over time. I didn't get to see them in Colorado, but we did communicate a little bit. And, in July, I was going out west. Before I left I wandered by Latitude 45 one morning to ask Barbara for his year of birth, which I never knew. But I was pretty sure he was coming up on his 50th birthday. And I thought, "I'm going to surprise him by turning up on his doorstep." Maybe not on the event, so not to interfere.

AS: But around.

HB: Around. Yes. She looked up and she said, "You're here about Kevin?" And I said, "What about Kevin?" And she said, "I heard through Allan Conter that he killed himself two days ago." So, he's been a lot on my mind as I've been… Thinking about all this. Because he was one of the first people that I wanted to get involved, because he had a lot of friends who were struggling and dying around him. And he'd been very depressed, being much younger, in his early 20s. And I figured that he, like Jamie and everybody else, really needed an outlet.

AS: Yes.

HB: So, there is a little bit of sadness as bookends to all this.

GK: Yes.

HB: But a life well lived.

GK: For sure.

HB: And, I think he benefitted tremendously in various ways from the experience of ACT UP, which was totally foreign to anything that he would have experienced before. But, undoubtedly, that played a role in his ability to perform the functions he fulfilled subsequently.

AS: Yes.

GK: That's great.

AS: Thank you for sharing that about him.

GK: So, we only have a few other questions left.

HB: Go ahead.

GK: So, one of them would be, as we were talking, is there anything that has sort of arisen that you haven't had an opportunity to talk about?

HB: Let me see now.

AS: Yes.

HB: So, we produced these.

GK: That was the Montreal Quilt?

HB: That was the Montreal Quilt.

GK: Yes.

HB: And I have this one – we did most of our material in English and French. Something that I think… Because we had arranged to have The Quilt go elsewhere afterwards.

GK: I know The Quilt was in Toronto at the CNE [Canadian National Exhibition], but I can't remember when. I know I went to see it, but I saw it first in Washington, DC.

HB: If I can find my notes, then I can probably find information on where we were sending it.

GK: But who would have put this button out?

HB: We did.

GK: The Quilt group?

HB: No. This is ACT UP.

GK: Yes. That's what I thought. It's interesting that ACT UP's logo and name doesn't match, that's all.

HB: We had a lot of discussions, because ACT UP doesn't mean anything in French.

AS: Right.

GK: That's right. Okay.

HB: So, our approach was to not use it as our marquee. And the message was "*Le silence égale la mort.*"

GK: That does lead to an interesting question around language politics in ACT UP.

HB: Yes.

GK: We did mean to ask.

HB: Yes. I was particularly sensitive to that, partly because I'm a translator. And – certainly because I am a translator - and the issues that had arisen there. And, I did most of the material in French.

AS: Yes.

HB: Well, in my meeting minutes and that sort of thing. And I wrote the stuff around The Quilt. And, as you can see, I put the program together for the ceremony. It was a really nice ceremony.

AS: It looks beautiful.

HB: I have to speak to Barbara to see if it was filmed. It probably was.

AS: Yes. That would be great to have.

GK: Just in terms of ACT UP and the meetings you were at, what language did people usually speak?

HB: We let people speak the language they were most comfortable in.

AS: Yes.

GK: Would people translate for other people?

HB: In some cases, yes - a few people didn't understand.

GK: Okay.

HB: And, yes. I always produced an English and French version of the minutes, usually before the meeting was finished. I would be winding down…

AS: You must have had an early laptop.

HB: Oh, yes. I was an early adopter. [laughter]

AS: I still have this image of you bringing your laptop and your modem and your printer to the hospital. It's amazing.

HB: Yes. That was a little bit later. Well, first of all, probably in '84/'85, I realized that I could no longer depend on other people to have access to mainframe computers to be able to do my freelance work. And, fortunately, the Macintosh appeared.

AS: Yes.

HB: And I went and bought myself the first 128k, single drive, you know, version. I was enchanted that I could actually assemble it without really looking at the instructions. It was so simple.

AS: Yes. [laughter

HB: And popped in the diskette which was both the operating system, programs and storage. [laughter] On 128k. I started, I came home and was in the middle of a project, and I put the thing together and I started to work on it. And I was able to complete the project on time. So, it was really great. It was even better when they came out with a second drive, and then a hard drive, and then we were off to the races. And then the printer came. And the rest is history. But I had a problem because it wasn't portable. So, my solution to that was a Model 100 built by Tandy for RadioShack. A version was used on the space missions because it was small and virtually indestructible. I am pretty sure I should have kept it. Although I know somebody in Montreal who probably still has a couple hanging around. You could literally let them drop and they would continue to function, no problem. And it was probably 40 characters across an 8-line screen, that sort of thing. But it was surprising what you could do with it. It had internal memory for about 24k and you could boost the internal memory to 32k. And you needed to boost the internal memory to 32k if you wanted to use the external drive because the driver, Tandy's external driver, took up something like 8k, itself. So, fortunately, I had somebody here in Montreal who was really clever. He came up with ways. So, this guy came up with a driver for the external drive that actually took less than 1k and the same guy wrote a program to format text. Like centre, bold, italics, and this sort of thing.

AS: Amazing.

HB: Which was also about 2k. So, I was ecstatic. I was now able to go off with something I could write with that had a fantastic key board and it was multilingual.

AS: That's amazing. And, as a result, we could have access to the minutes of ACT UP. If only we had access to the discs… [laughter]

HB: Exactly. Well, I tried to over time rescue the data from one form to another. What happened here was that I went to Kim. And I said I had a small problem. I've got this very handy portable…

AS: Yes.

HB: That I love carrying around. And it's so much easier to work on, but how do I get the files over to the computer. So, we bought the necessary cables to hook them up and he wrote a conversion program to map the characters…

AS: Amazing.

HB: The extended characters… And all of the formatted stuff that I could do on the portable so that it would appear intact on the Mac.

AS: Amazing!

GK: Basically, the last two questions we have… And it's been delightful so thank you so much for sharing the time with us. It's just if there was anything that occurred to you about ACT UP or AIDS activism, or anything that you want to talk about before we end?

HB: Yes. Well, things might come to mind subsequently, but I think I've said what I need to say at this point.

GK: And usually the final question is just if you could think of people you think we must talk to? That perhaps we haven't thought of before, in terms of ACT UP or AIDS activism in Montreal?

HB: Right. Well, you might have to ask Michael what he thinks about getting through to Puelo Dier.

GK: I think that Ross actually knows how to get hold of Puelo.

HB: And ask him if he thinks its relevant, if his role in that part of the story wasn't that significant. And his role in another part of the story is more important, but that's not your subject matter. It would be good to track down Eric Smith. He was really good.

AS: We definitely need to talk to him.

GK: That's great.

AS: Good. Thank you so much.

HB: And, as I say, as I go through this material, if I have a little bit more time in the coming days. I realize, for instance, in the format that I had my diaries, I couldn't look for information because they weren't… I had to take the PDFs and convert them into word processing files and then concatenate them so that I could do searches over a whole year.

AS: Yes.

HB: For occurrences and that sort of thing. So, I have done that for '89 and '90, but that's it.

AS: Yes.

HB: I'll start looking at other years and as I look I'll probably come across some stuff.

AS: Good.

GK: That would be great. Thanks again so much for talking to us.

[END OF TRANSCRIPT]