

AAHP  
**AIDS Activist History Project**

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<b>Interviewee:</b>	Jose Sousa
<b>Interviewers:</b>	Ryan Conrad
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Persons Present: Jose Sousa [JS]  
Ryan Conrad [RC]

[START OF TRANSCRIPT]

**RC: I'm here with Jose Sousa and we're going to be talking about AIDS activism in Montreal, focused from the 1980s to the 1990s, until about '96, and then we might go a little bit further. Again, for the record, you don't need to answer any questions you don't want to and we can substitute questions if you feel like there's something better, and we'll leave it pretty open-ended. But the first question that we always ask everyone is "When did you first hear about AIDS, and what was it that you heard?" So your earliest memories.**

JS: Well... It was GRID. Gay-Related Immunodeficiency Disease? Before they even knew it was a virus. There were people with Kaposi's Sarcoma and PCP that were dying in some of the major cities like LA, New York, Montreal. That would be the very beginning of the '80s that we started hearing about it.

**RC: And how did you hear about it? Was it on the television or in articles in the newspapers?**

JS: It was television, you know? The sensationalistic news story: "Men are dying, there's some strange disease—gay men are dying there's some strange diseases." Some of them even called it "the gay plague" but it really, a lot of us were, like, "That's happening there, and that's something weird that they're doing. We're just doing the same old thing here, so it's not going to reach here." And, even when it did reach, when we started seeing people sick, in '85 we got the test that actually measured the, if you had been in contact with it? Because there was Gallo and the other one [Luc Montagnier], who found the virus. Then the test was available in Canada, I think it was December '84, but I don't think anybody really got tested until like '85. When I got tested positive, I figured "Well, apparently a lot of people are positive, a lot of people are healthy, so it doesn't mean it's going to affect me. It apparently only affects some people." Kind of the reverse of the CCR5 mutation. Some people can't get infected, we just thought all of us that were healthy couldn't get infected. Or it wasn't as bad, or there was some other co-factor. Kind of like the movie *Zero Patience*?

**RC: Yeah.**

JS: We have the dancing with all the co-factors? It's like, we get a lot of stuff that people don't get. I mean, we can contract CMV, all kinds of macro bacteria, avian complex, a whole bunch of other things that other people don't get as much.

**RC: Right. Do you remember where you were? Were you in Montreal?**

JS: Oh, yeah. In the beginning, I was in Montreal. Yeah. Life in the gay village continued as usual. And, besides, when one of those people would, you started, it was very visible, was the AIDS, HIV wasting. Which we called the slimming disease. Which is the same thing the Africans called AIDS

there, was the slimming disease. A lot of those people, like in the beginning of the '80s, they would kind of, like, get out of the picture. They wouldn't... until there was more of them, and you felt strong enough to come out and realize that there is a fight, and we can do this. So more of those people who were visually infected came out.

**RC: Is there a certain point you remember where AIDS becomes explicitly a political problem, and not just a medical problem?**

JS: A political problem... for me, I really noticed it was. I took a trip in '89. I took a year off work, figuring that would be my last year because I got infected. '85 already showed that I was infected. That's really when I got into the political. I'd heard about it. Like the AZT is available, but nobody can access it, and we really didn't know anything about it. But, for me it was basically 1989 when I really got involved.

**RC: And you were traveling?**

JS: Yeah. I took a year off from '89 to '90, so I spent three months in Provincetown, where I was one of the founders of Provincetown ACT UP, and it actually went pretty good. We had meetings with Anthony Peltier in Washington and, what was her name? From Peptide T. We thought that was the cure. I forget the researcher's name. So we helped her out a lot. There were a lot of alternative therapies. Some very weird ones. We had doctors come, a couple of young, lady doctors come, from I think it was Sweden, or Switzerland. And their thing was urine therapy. And, if you listen to a proposal, it does make a lot of sense. Your HIV is killed and is out through your urine. Your urine cannot infect anyone because the HIV is not alive in there. So it was kind of like, what do you vaccinate? Do you vaccinate with, kind of like the vaccine that they did for HIV and for Polio, is wholly inactivated virus. So, drinking your pee would make sense as something to get your body starting to fight against it. And the pee, itself, wouldn't make any more harm, because it's dead virus. So... we were quite a few in Ptown who had that therapy.

**RC: That's amazing. Yeah, there's lots of people that talk about alternative therapies. That's a very important part of their—**

JS: Oh, yeah. Some very weird ones.

**RC: Yeah. Like, people eating sea cucumbers, and...**

JS: Oh. Sea cucumbers were not supposed to be eaten.

**RC: Oh? How was it? What it a tea, or something like this?**

JS: You made a kind of tea with it, and there's an enema.

**RC: There's an enema!**

JS: Yes.

**RC: I did not know this! I was like, “Oh, sea cucumbers. Gross”. [laughing]**

JS: Well... I did taste it, and it really doesn't taste good. But it was... You make a batch, and you'd have enough for an enema, for the week, and then buy some more and make a tea out of it, and... keep doing it.

**RC: So, at what point do you come back to Montreal? Is it sometime in 1990?**

JS: I came back in the end, the very end of '90. So I left around June in '89, and came back towards November of '90.

**RC: Okay. So you left just before, or around, when the AIDS Conference is happening in Montreal.**

JS: Yep. Yep.

**RC: Okay. And so you don't have any connection—**

JS: I wasn't involved in Montreal at that point yet, no.

**RC: Okay, the timing is really interesting. At this point in the '90s, or early 1990, you become involved in AIDS activism. Did you bring any, like, had you experienced or been part of other activist things prior to that?**

JS: Gay rights. Gay rights.

**RC: Okay. So can you talk a little bit about what that experience did for you? Did you translate any of that into activism around HIV/AIDS?**

JS: Oh, yeah. It was basically the same thing. It was... stigma and people thinking you're the devil because you suck dick, or you're the devil, or that god is punishing you because you suck dick, so now you've got the HIV. It was all based on hatred, because if HIV came out, and it was, or if they were smart enough to look at, in Africa, it's a heterosexual disease. It's not a gay disease. So... we felt it. Yeah, there was definitely a “gay thing” to it.

**RC: Yeah. And were you involved in any particular gay activist groups?**

JS: Yes and no. When I came back in '91, I knew Michael Hendricks and I went to CSAM and met Kalpesh [Oza] and Christopher Cockerell. They were looking for a roommate, so I moved in with them on Saint Urbain, near Duluth. And that's really when I... The other, the other gay activism. I know I was arrested once, because we stopped traffic on St Mathieu and the Maisonneuve, where there was a police station. And I think it was after the raid—

**RC: Sex Garage.**

JS: Yeah. Some of us got arrested. One poor guy lost his ball. Testicle.

**RC: Yeah, people have told me about that. It was actually a Native guy.**

JS: Well. You know, we're taught, before— any good organization will teach you, before going into a manifestation like that? And the thing is, he was... there's no excuse for it, but the cops were taking him off the street, and we were— you're just supposed to go down. But he was, as cops grabbing him with the leg, and he was giving kisses to all the cameras. I guess that pissed off the cop. Because when he got in, they just... the stick in the balls. And he was in there for way, way longer. They waited until the ambulance and paparazzi went away, before they actually took him to the hospital.

**RC: Ugh... that, that seems like quite the moment. And there's a lot of, there's actually a lot of video footage of the actual event, because it was all caught on the news, right?**

JS: He had a lot of cameras to send out kisses, so I imagine, but I guess I wasn't paying attention.

**RC: And I know there was another woman who was on crutches, who was dragged away with her crutches, like, by her side. It was pretty dramatic.**

JS: I think I was right beside her. What's her name? Tall, big-boned woman.

**RC: I can't remember.**

JS: Black hair. ... And I used to know her very well. We used to get along great.

**RC: Was it Jo-Anne Pickle?**

JS: Could be.

**RC: I know Jo-Anne was there, but I'm not sure if it was her that was on the crutches. Paula Sypnowich?**

JS: Paula! It's Paula!

**RC: [laughing] I was like, it's either Jo-Anne or Paula.**

JS: Yeah. I think it was Paula.

**RC: So then, moving into what you got involved in here in Montreal, in terms of AIDS activism—what were you involved with? Were you connected to CSAM?**

JS: Well, I was basically Kalpesh's little mentoree. I was always talking to him. We were always talking about everything medical and stuff like that. Because him, it's the medical aspects and social behaviours and ethics and all that, that he was very much into. So I really fed a lot off of him. So, basically, anything he was doing, I was doing. But, I mean... What exactly did I do? I mean, we

wrote papers, I've been to Parliament in Ottawa to speak there. Spoke at, with what's-his-name – the asshole premier we have now. He was, at that time, Minister of Health. Couillard.

**RC: Couillard. Yeah.**

JS: What an asshole. And you can tell. He was across the table from me, because I was the end, and this was us. And you can tell that guy has no fucking empathy.

**RC: Yep. And what about, you would have also been around when Bourassa was the Premier, right? I think he was Premier until '94.**

JS: Bourassa was Premier until '94?

**RC: I believe so. Because ACT UP Montreal, most of their actions were around, they called him "Booboo" at that point.**

JS: I know I went to a couple. And it was what's-his-name, one of the big leaders who died... Very good-looking guy. He was executive director...

**RC: Douglas [Buckley-Couvrette]?**

JS: Douglas!

**RC: Yeah.**

JS: I don't remember names, but yeah.

**RC: It's a good thing I've read all these transcripts, so I know these people, but I don't actually know them like you know them, ha!**

JS: Yeah. So Douglas was the executive director... and now's the, I lose my train of thought all the time, when I'm talking. What were we talking about?

**RC: Well, I was just interested in how you got involved. What were you involved with?**

JS: Yeah it was a lot of demonstrations. A lot of letter-writing to companies. Demonstrations in front of companies. A lot of that kind of stuff, just to get things out. And the big things was, when there was an international conference, that's when the big things would come out. And over here [in Quebec], it was the Pharmacare thing, to get access to drugs here, because it's provincially and, unfortunately for some of our smaller provinces, Canada is not equal because some of them can't, I mean, PEI? Most of them... I think all of them would go to New Brunswick in order to get treatment, because there was no specialist in PEI.

**RC: And that campaign to get the medication, was CPAVIH (Comité des personnes atteintes du VIH du Québec) specifically involved in that? Or was, I know, because ACT UP—**

JS: That was basically everybody at—

**RC: Everybody.**

JS: But each province had their own thing. And we would get together, but, yes, CPAVIH would be one of the big ones in there.

**RC: Yeah. Because the, the campaign was “Maladie Sur Pied”?**

JS: Malades Sur Pied. Yeah.

**RC: Yeah. That’s my understanding is that ACT UP Montreal was pushing for the inclusion of HIV infection as part of that drug program. Which was initially around diabetes and cancer, right?**

JS: Right. So it was basically diseases that, if the people couldn’t afford it, it would have been worse for society, because it would cost them more. So, we got that. But then, there was also the change of the Pharmacare system. Where Quebec government took all of the – which is a totally stupid thing because it was just to satisfy pharma, because we have a lot of pharma in Quebec. So what – and to satisfy the insurance companies. Insurance companies basically got... the healthy people. Basically, people who have insurance through work. Anyone who doesn’t have insurance through work falls into the RAMQ thing. And that’s all the poor people, that’s all the people on welfare, that’s all the people with lower-paying jobs, it’s all the people who could never work because they are sick. So it would, I still think that it was very uneven and it should be changed. Because—

**RC: I think a lot of people don’t realize that Pharmacare in Quebec, when it’s introduced in ’97, is a public-private system. Like, if you can get insurance through your work, you’re required to do it.**

JS: Yep.

**RC: But if you can’t, then we’ll cover you.**

JS: Kind of like a net. If you can’t get it.

**RC: I mean, I have a similar critique of big pharma. Where... In the states, you know, they pass Obamacare, which is basically filling the pockets of pharmaceutical companies, and the Pharmacare in Quebec... is not the same, but—**

JS: It’s pretty much the same.

**RC: It has similar aspects, yeah. Like, at the end of the day, where does the money go?**

JS: I mean, we’re always under. They keep putting us under and the insurance companies are profiting. You see them on the TSX.

**RC: And it's my understanding that the Malades Sur Pied is... '95? It's when the PQ comes to power in '95, and then the change in Pharmacare doesn't actually happen until '97.**

JS: I'm not sure.

**RC: Yeah. Anyways, it's around that time frame—**

JS: I'm not going to question you on it. Yeah.

**RC: I mean, this is based on the memories of other people, right, and they might not have it exactly right either. [laughing] Yeah, that's the funny thing about oral history.**

JS: But it's also oral history with people who had, basically, brain damage. A lot of us do have what they call "HAND" – HIV-associated neurocognitive disorder. We've also got a lot of mental illness. Because of HIV, but also... people who tend to get HIV tend to already be predisposed or have mental illness. Just like— You can't say a drug addict doesn't have a mental illness. He had it before he went into drugs. So.

**RC: It's one of the big unaddressed pieces, in terms of HIV/AIDS, is the mental health piece. People today still aren't talking about it.**

JS: Nope. Because it's a problem with psychiatry. To me, that's also one of the soft sciences. I like clinical trials and stuff like that, where A could B. But when you go into psychiatry, there's too many variables, and there's no— I mean, look at all of the antidepressants. First of all, they're usually slightly better than placebo. That's all. And placebo's very high in mental illness. I think Prozac got approved because it had 45% efficacy compared to 35% on placebo arm. The mental illness is a big part. And also, me, my memory is electroshock treatment. That fucks up your memory too. So I like to use that one as an excuse?

**RC: [laughing] Yeah. I mean, you don't need an excuse. Can you tell us any of the sort of nuts and bolts type stuff about CPAVIH? How it was organized? Who was involved? Where the office was? Things like this?**

JS: CPAVIH, at the beginning... I don't know if it got started on a... We talked about it, I know, on Hotel de Ville, but I don't know if we actually had this, I think we got the second floor. So I think it actually started from there. And then they moved, and was always in places that the city would give us for free. One time, I think it was St Andre, or something... And, for the longest time, it's been at Plessis. But even that... We had Plessis and — Part of it was on Plessis, and part of it was on Parc La Fontaine. Like, the community groups and all that. I mean, I remember once we had a take-over of CPAVIH, with Jean-Pierre Bélisle. Who was a, he was a professor at... it's Université de Montreal? He was a mathematician. Anyway, we kind of threw the Board out because it was going really badly. And, unfortunately, I was part of the revolution. We met at my place and decided to just go and take over, because things weren't going well and money was not available. They didn't seem to be spending on the right things. So Jean-Pierre Bélisle became the executive director after that. He's the one, also, who started the campaign to get out the old people. Because it was basically... people didn't want to change. They were just, there was no movement. But Jean-Pierre

Bélisle's was too, and everybody kind of, like, turned off to him, and eventually, a little later, it was gone.

**RC: Okay. And around what time is this? Do you know?**

JS: ... No idea.

**RC: Sometime in the '90s, though, I imagine.**

JS: Yeah. Should be.

**RC: Because CPAVIH outlasts CSAM.**

JS: Oh, yeah. CSAM was, I don't think it went much past when we were on Hotel de Ville. And I have a lot of other shit there, but... maybe in the activism letters. Because things went pretty quickly at one time. Like, I remember CATIE was supposed to be here, in Hotel Dieu. But then they... there wasn't enough mass to actually – organizational mass – to keep it here. Toronto was very big about that. That, AIDS ACTION NOW! and, they're absolutely the top, and it's not because they're the biggest city. I think, sometimes, it's the francophone in us. There's a culture where "government will take care of it." There's also less volunteerism in Quebec than in other places in Canada. It's a different culture.

**RC: Yep.**

JS: I keep losing my train of thought. Was it? Yeah. It had to be the '90s.

**RC: Yeah.**

JS: Yeah. Because '94, I was still there. Ken Monteith would probably be a better person to ask for, he'd have a better memory. Have you talked to Ken?

**RC: No. But now we have his name.**

JS: He's executive director now of COCQ-SIDA.

**RC: Okay. He's at COCQ-SIDA.**

JS: Yeah. And he's been around for a long time.

**RC: Yeah, because at a certain point, most activist things seem to dissipate and turn into service organizations. And then they're all part of the COCQ-SIDA coalition?**

Yeah. Basically COCQ-SIDA is the Canadian AIDS Society of Quebec. Everybody becomes a member, at least thirty-five out of forty type of thing. And COCQ-SIDA took over a few of the things from CPAVIH. The legal thing... and I can't remember the rest. Can't remember how it kind of just dissipated. Then we were creating CTAC [Canadian Treatment Action Council] also around that

time. And then they were supposed to create something called “Wake Up Canada.” I remember, in a conference, we all brought our alarm clocks, and we all went in with alarm clocks ringing, “Wake up Canada!” That was supposed to be our new group to face CTAC, because we found CTAC a little... for the privileged.

**RC: Can you say just a little bit about what CTAC was?**

JS: CTAC was mainly started by – I forget his name... In New Brunswick. He was really the force behind it. But ended up that Louise Binder kind of took it all over. And almost became President For Life, or until she wanted to go. But that’s... the other privileged thing, because she used to be a lawyer and has a great pension. So she can do whatever she wants. You’re limited with the amount you get on welfare, you can’t do all that traveling, you can’t. Even just energy-wise. I mean, she can get a maid to do her house. And probably does.

**RC: [laughing]**

JS: I’ve always found some type of elite in the movement. Even back then. Now, it’s mainly them. I mean, when you talk to leaders, it’s like... they’re getting very healthy salaries and all we did, everything was... there was no pay. Because, first of all, if you got paid, you wouldn’t get your welfare, but there was actually no money for activism, or for the little guy. And then they started, the groups basically started following the money. Which became a problem, because the money was associated with services. That’s how it changed into services. But even then, we had trouble. Because the money was dedicated to services, you couldn’t. It was by law, those letters would tell you, “You cannot use this for activism.” So it kind of changed a bit and... quite a few people got great careers. And others just got... kind of pissed off at the whole thing, and went to different areas. I went mainly into the medical, because of Kalpesh. So when CAQ – Community Advisory Board of CTN, which now is CIHR-CTN, which... I started there around ’94. But just as a visitor with Kalpesh. And those were kind of more, it was more rewarding? You’d get a token pay, but just for your time and, you’d get your trips paid for and stuff like that. So it’s not—

**RC: It’s not a job, but it’s something.**

JS: Well. Now it is.

**RC: Yeah. [laughing]**

JS: When I stopped being Chair, the new Chair now gets twice, at least twice, the amount of money that I used to get. Because it was just basically enough money to cover your hours, which doesn’t cover your hours but... Anyway. CTN was a good thing, because then we started trials and it was with the input of community. Although nothing like it is today. Before, we used to evaluate trials, the vast majority of them were pharma-driven. So it was to test their drugs and stuff like that. And we would only be able to evaluate the informed consent form and the trial summary. It took years for us to, I think it was close to the year 2000, or a few years before, that we started getting the full protocols. Because it, to me it was, like... That’s tokenism. How can you expect us to evaluate a trial when we don’t even have it in front of us? And that’s after signing confidentiality agreements and swearing that every paper we had would be shredded. It was tokenism. But, I guess, sometimes

you get your foot in the door and then you keep pressing, you keep pressing. And now they always get us the full protocols.

**RC: But that didn't really start until the, you said the early 2000s?**

JS: Yeah. Late '90s. Yeah, I would say late '90s. But before 2000. For the first few years, it was just... There would be some full protocols, if it was investigator-driven. The investigators would give us a full protocol. But companies are still very secret. I remember having companies donate money for whatever topic we were having a discussion for the general public. But if Merck donated, that person would kick out every pharma rep that was there from any other company. Which is kind of like... "What do you got to hide?" But things did change a lot.

**RC: It sounds like you've been involved in treatment activism... since you started doing AIDS activism.**

JS: Yeah. Since '90. 1990. Yep. Well. '89, with the ACT UP Provincetown. And now I'm just tired. Because people don't see the importance of it. People already have... The new people, I mean, you get infected, you get one pill, once a day. Most of the time very few side-effects, if any. So people, there's no younger people coming to fight for access to drugs or... One of the problems we're going to have in the future is access to drugs that cost a fortune. Because, more and more, and if they're going with these nanotechnologies and all that, and taking your CD4s and collect, like, H004? HE004? Which is a study which, you do leukapheresis and they take your white blood samples, they fix them outside the body with zinc fingers that basically creates someone who has the delta-32 deletion, which makes them... HIV can't enter those cells. But those things are going to be just too, too expensive. I'm wondering... I wonder, for years now, why are we fighting for these things if it's not going to be accessible to all? I mean, there's no way... Even a few of the drugs we have now, like the Fuzeon [Enfuvirtide] thing. That would never be able to be used in Africa. It needs to be refrigerated. A whole bunch of things. I think we should start fighting more, we should fight for generics which, so many are generics now, but they just cost a few bucks less than the regular thing!

**RC: Yeah.**

JS: But... In Africa, I know that they had the trio. Nevirapine and I think AZT-3tc? For a dollar-fifteen a pill. Something like that, no? Because it was only a hundred something for a year's worth, for an African. This was made by... I forget the company in India.

**RC: Yeah. It's the generic company in India. I remember this around the Clinton Foundation and all that stuff.**

JS: Yeah. All of these drugs we have can be made so cheaply. Which, I don't understand why we're still paying... and then, in Quebec, it's another fucking pain in the ass. Because, sometimes, you can't get a certain drug. Because... a generic has to be within, I think it's sixty percent or less from the real drug. But generic companies, if they put a little higher, Quebec won't pay for it. But they'll pay for the regular one. But there should be more, not "If you don't put it at sixty percent, the price," should be "Don't make it unless it's fifty percent less" type of thing. What the real cost is.

**RC: I think another piece that people miss is around questions of intellectual property, right? Like, generics need intellectual property rights to change.**

JS: We have to go through a lot, to learn a lot about that.

**RC: Yep. And the thing happening today, that I think about, is the, you know, the TPP, the Trans-Pacific Partnership, right?**

JS: Ugh!

**RC: Like, what does it say about patents on life-saving medication, right? Not a lot of people are talking about this stuff.**

JS: Nope! And it's like... Okay. We're a pretty good country, but some of the countries in the TPP, they're probably going to have to pay the same price as, or some equivalent, of what we pay. When, if there was no TPP, they could just make it on their own. Although there is international treaties, even with India. And India has decided to not accept it. But, actually even before that, they started a thing about first, second, third... countries? Like, so like, Brazil can do their own drugs. I forget them all, but it is better. But the newest drug that came out is not approved in Canada yet. The monoclonal antibody, which is only being used in people who have no more options. Basically, they're resistant to everything. But it's over a hundred thousand dollars a year! And this is not like Hepatitis C where it's eighty thousand dollars, but you get ninety-six to a hundred percent cure rate. That's one thing, because you cure it. No cure, right, and you're already paying a hundred thousand for one year? That's not going to last long.

**RC: Yeah if you can even do it at all.**

JS: They're going to have to cut it. It's going to be people with great insurance.

**RC: It's really depressing, actually... Coming back to CPAVIH? We went down a rabbit hole, but it was really productive. I mean, I'm a hundred percent on board with you.**

JS: I always do that. You'd have to steer me.

**RC: Could you tell me a little bit more about, I mean you've mentioned Kalpesh and Chris, but if you want to say more about them. Who they were to you personally, but also, like, as part of CPAVIH, would be great to learn more about.**

JS: They were the, them and... fuck... I always remember his name, and now I forget it. He was also at the CAP. Hold on... [rummaging through papers]

**RC: Take your time.**

JS: That's AIDS on Rollerblades.

**RC: Oh my god. This is amazing!**

JS: [rummaging] These are Kalpesh's papers. It won't have CPAVIH.

**RC: Oh... Getting a copy of this would be amazing.**

JS: That would be no problem. I have a big one of that. [rummaging]

**RC: Because we know there was a memorial in Toronto and in Montreal.**

JS: Yeah, his ashes were divided in three. Montreal, Toronto, and India. And that's his obituary.

**RC: Wow.**

JS: Well, that you should find... Ah! They're even mentioning CPAVIH in there somewhere.

**RC: Oh, it has that rollerblade picture. Amazing. ACT UP Montreal. CPAVIH. AIDS ACTION NOW!... CATIE. Yeah, Kalpesh was involved in everything.**

JS: Oh, yeah. ... And he was definitely a shit disturber. In a good way.

**RC: Yep. [laughing] ... Do you remember what this was printed in? The...**

JS: That was probably *The Mirror*.

**RC: Okay. That would make sense.**

JS: Okay. Here's something else. [rummaging] Sam Friedman's still alive. Paul, I'm not sure... David Hellmen. Sherry Pigeon... Eugit... [rummaging] Lachapelle! Claude Lachapelle! See?

**RC: [laughing]**

JS: That was the other big guy who started, who had a big part in starting CPAVIH.

**RC: Okay. So it was Claude, Kalpesh, and Chris? And you?**

JS: Claude, Kalpesh, Chris, me to a certain extent, because I felt more like a follower at that time.

**RC: Yeah. And you were living with them, so... [laughing]**

JS: Yeah.

**RC: You didn't have a choice.**

JS: It was just part of life.

**RC: Yeah. ... I would love to hear about, like, I mean part of it's complicated, because it was just part of life, right? But I'm curious. What were CPAVIH meetings and gatherings like. What was the atmosphere? How did things work?**

JS: Atmosphere, most of the time, wasn't that great. There was always a few against the old. I guess like anything else, the old establishment wants the status quo, and... new people want new ideas and to do new things. So there was quite a bit of friction.

**RC: How were decisions made as a group?**

JS: It was always, each one had their own vote. Each one had their own say. It didn't have to be anonymous. Everybody on the Board had to be HIV positive. It was trouble getting women on it. Even today, there's still trouble in a lot of groups to get women in it.

**RC: I mean that's the one big difference between CPAVIH and ACT UP Montreal which was mostly HIV negative people. Réaction SIDA, mostly negative people. So CPAVIH plays this really particular and important role. And even CSAM, like who was running CSAM, and who was working at CSAM. Some well-meaning and some fraudulent people, but...**

JS: Even some of the HIV-positive were fraudulent. Like, an executive director billing CPAVIH and billing the pharmaceutical company for the same conference. Yeah. There's bad apples in there, everywhere.

**RC: And especially when the government starts putting money into things, and then suddenly there's a bunch of money there that wasn't there before? It's...**

JS: Yep. People get excited.

**RC: People get excited. I think [laughing] that's the nicest way of putting it. Money changes things. And when money certainly is there, after not being there for almost a decade...**

JS: But it's only... I only found a certain amount of people would go for that.

**RC: Yeah.**

JS: Because, even today, there's still those who don't... but usually they're of the older. The only one I can think of is Tracy Conway, from Sault Ste Marie. And she's been at it for years. But she's not as presentable-pretty as the leader is now. So, she does all the work, and the other ones get all the credit. A lot of that shit's going on which turned me off to a lot of groups.

**RC: Well, then maybe we can segue into a bit about LIPO-ACTION! Because that's what continues sort of after a lot of that stuff fizzles out.**

JS: Well, LIPO-ACTION! was... Suzanne was a big part of it. She's the one who created the masks. And I just came across a mask two weeks ago. Anyway. One of the reasons for the mask is it was a lot of people who had lipodystrophy and didn't want to be recognized. So we all wore masks.

**RC: When you did demonstrations or actions?**

JS: Yeah.

**RC: Can you tell me a bit about what those actions were?**

JS: The video will tell you.

**RC: [laughing]**

JS: I know, once, we did one in front of Place des Arts.

**RC: Who was your target with these actions?**

JS: That was mainly trying to target the media so that it gets out in the media, so it puts pressure on the government for corrective surgeries. And then we got the bylaw committed, which we were kind of excited – never really got to be paid by the government. Some people had managed, but they might have had insurance or something. But usually you didn't get access to Bio-Alcamid unless you were part of a trial. And unsurprisingly, one of the richest ones was part of the trial. Unfortunately, the Bio-Alcamid didn't work. Or too many side-effects? Maybe had the lactic acid, poly-L-lactic acid? what was the name...? Now it's called kind of like truviderm, it's kind of like truviderm. Poly-L-lactic acid, which only lasts six months to a year. And I think some people ended up getting paid, but very few of them, and you wouldn't get paid for your second treatment, and so there was... the cost came down because some doctors would do it, not charge for the work part, and only charge for the vial. It was doctor Hubert something and doctor LaPlante. We're still fighting for corrective surgeries, even Buffalo Hump, and all that. The problem then was there wasn't enough people to make a mass to change, because people who were healthy also didn't want to be associated? I don't know. That's my guess. But we're still trying. And with the Egrifta, which really doesn't work. It's a fortune, and it, like, pfft... You get two inches – that's for lipoaccumulation – you get maximum two inches off your waist after six months of daily injection. And it plateaus and, as soon as you stop, you go back. So, there really isn't anything.

**RC: Yeah. And my understanding was also fighting to make sure that AIDS service organizations gave full disclosure that the medications you might be taking could cause this side-effect, right?**

JS: Oh, yeah. There was a lot of public education, we'd call conferences about it, and lipodystrophy was a huge, brought out a lot of people, back then. Now, less, because less people suffer from it, and now it's kind of like confused and old age... because there isn't the sinking of the face much more. People now are more complaining is about the gut.

**RC: How did you convince doctors that it's not old age, but lipodystrophy?**

JS: Oh, yeah. Well, that is one of the problems and doctors will say it's old age. And others, unless you go and get a scan, and they don't do that. Because, I mean, you can get a scan, and see how

much is visceral adipose tissue as opposed to subcutaneous. You see it a lot less often nowadays. But I remember, I don't go to the village anymore really, but you'd see these people with bellies like mine, but they have the six pack. So it's like they've got very little fat underneath the skin, because you can see the six pack, but they've still got a belly. Because that's internal fat that you can't really get rid of.

**RC: And what happens to LIPO-ACTION!?**

JS: People lost interest, so we just phased it out type of thing.

**RC: So, switching, switching from LIPO-ACTION! And CPAVIH, were you involved at all around the AIDS memorial park?**

JS: Yeah! Well, that was a lot of ACT UP was doing that AIDS memorial park. I think it even died out before we actually got it.

**RC: Yes. That's true.**

JS: Yeah. I was actually, at one time, the head of it. Just in name.

**RC: The park committee?**

JS: Yeah. Comité du Parc de l'Espoir.

**RC: What do you remember about the struggle to establish the park?**

JS: It was almost like the city didn't want to have a park against/for a disease... And they wouldn't have done that unless it was a stigmatizing disease, something that you're supposed to be ashamed of. So it was like, just keep battling until they finally gave in. And we kept changing the signs. They kept putting back their sign.

**RC: I love that. I think it's so brilliant. [laughing] "No. We're just going to name this what we want."**

JS: Yep! And eventually we got it.

**RC: Because there was a big battle with, was it Jean-Doré?**

JS: Ugh. ... Yeah.

**RC: [laughing] Your facial expression was so good!**

JS: And then there's the battle amongst the people. The arts interpretation of that steel thing that rusted was supposed to be part of life and renewal and stuff like that. And a lot of people just found it ugly. There was some people who wanted to close the park. There was one who even

suggested taking axes to the park. What was her name? She's not even, she wasn't even in the gay thing, she was in the gay thing but... her name was Cathy Kirk? Cathy something. Anyway.

**RC: So it was contentious.**

JS: Yeah. Once, somebody even painted that sign that was supposed to be rusty. Which was a no-no. And the sign was not supposed, the idea was it's for everybody, and not for one person at all. So, but now there's a plaque with somebody's poem. Which, we didn't want it there. And we tried to take it out. I got four buttons out. But even amongst the community, that wasn't, because it's too... depressing. Hey! Try living it!

**RC: Yeah.**

JS: [chuckling] Yeah, it was weird.

**RC: I think I remember learning from some other interviews that there was a committee of people. Like, Marc Pageau was one of the people. He's the architect that actually designed the park I believe. It was him and few other people that were, this is maybe 2004, 2005, were trying to start a committee to redesign the park. And it had some steam, and then... nothing really happened because it's too contentious. People don't want to deal with it. But I think it's very interesting. I mean, there's an AIDS Memorial in Vancouver, Toronto, and Montreal. There isn't one in Ottawa.**

JS: Yeah. I'm surprised by that. There should be.

**RC: There's supposedly one in the works, but...**

JS: I think Toronto's is the best.

**RC: I agree with you.**

JS: I mean, it has everybody by their names, so when I go to Toronto, that where I go to see Kalpesh. And it's not contentious, because you don't have iron that's oxidizing.

**RC: Yeah.**

JS: Oh, and they really didn't like the big, marble things, because they looked like graves, coffins.

**RC: Yeah, that's what people said.**

JS: But it was a whole meaning. It was, the front was kind of like "death" and the back had one of the the biggest hydrangea plant in Montreal, which they eventually got sick and they had to cut it down. But the idea was... You go through there from death to life in the back, and there were seats. I liked the idea. I wasn't crazy about the rusting part, because I didn't understand it, and I'm not much of an art person.

**RC: Yeah... I also know that there was some tension about what colour ribbons were in the tree? First they were black, and then they were red, at one point they were rainbow. [laughing] So you can't please everybody. There's a documentary by Tahani Rashed called *Médecins de Coeur* (1993). And it's really about Réjean Thomas?**

JS: Réjean Thomas. The star.

**RC: It's a documentary about him, however, there's a bunch of footage from ACT UP Montreal actually going and hanging up one of the park signs that they had made. So. It's interesting in that regard. I mean—**

JS: Yeah. Because Réjean Thomas ... became a star for HIV. He's not a great doctor. And, I mean, that's not just my personal opinion, but... I knew the pharmaceutical reps back then, a lot. And it's, like, "Yeah, he's... doesn't know his stuff very well." They had to make the slides for him, and stuff like that.

**RC: It seems, looking at that documentary in retrospect, it seems like he ended up in a lot of things just because no one else was doing anything? And he was the one that was there.**

JS: French media kind of, like, went to him, and he became the face of it. So it continued to be him, right?

**RC: Once it starts, it's always the person they go to. But he did seem to have good politics around sex work and stuff like that.**

JS: Oh yeah. He should. He was a whore himself. I remember giving him a blowjob in an alley.

**RC: [laughing] Getting the real details in this interview!**

JS: I mean, that was a long time ago! That was in the time when COX was on René-Lévesque. That's a least twenty years ago. I looked a lot better then, so...

**RC: [laughing] Oh, that's funny. Okay. So that's it for Parc de l'Espoir. I guess that, we've already talked about this a little bit, but it would be nice to hear your recap of what happened to AIDS activism in Montreal?**

JS: What has happened?

**RC: There were these activist groups that were doing stuff. Now, and we've sort of talked about this shift, now there's a lot of services, right? It's, like, "What happened?"**

JS: Yep. Money. And the new generation. One of the things we've always talked about was getting people to take over for us. And the young ones aren't interested. Especially after 1996, they don't. I mean, we were forced kind of. You're either going to be in insolation, or you're going into those groups. And a lot of people chose not to tell anybody that they're positive for, until they almost died. But... where were we going with this?

**RC: About the younger ones?**

JS: Yep. There was no, called in French *élèves*, to take over. So activism kind of stopped and people kind of thought, people now think “everything’s fine, there’s no need for activism.” And, even if you’re a long time infected, I’ve had my social worker say “But I thought things were okay now?” It’s like, yeah, if you get infected at twenty, and you get treatment right away, and it’s treatment that’s way less toxic, yeah, you’re fine. But, once you’ve had a certain nadir CD4 count, when it goes very low, there’re certain damages to the immune system that you’ll not get back. And the inflammation, which is constant, even on treatment, does make us age faster. And there’s studies on that. Of course, it’s always one or two studies who say “No”, but if you look at the science behind it, and if it’s retrospective or observational compared to really evaluating someone this age and someone this age, with HIV and without HIV, you’ll see a difference.

**RC: I think those studies are just actually starting to come to light. I remember one around, bone density and osteoporosis.**

JS: Yep. But... it’s never the dying thing. It’s also people are dying, and they’re dying of a heart attack. It’s not an “AIDS-related heart attack.” Because now we’re getting diseases that, at an earlier age than ordinary people get – but if you get those diseases, if it’s not one of the sixty-something that are opportunistic infections, then you “didn’t die because of HIV”. But, to me, I’m sorry, but that’s a heart attack, premature heart attack, because the person was HIV-positive. So, you lose a lot in the statistics to actually... not scare people, but to inform people of what the reality is. I mean, two years ago, I went to a presentation here in Montreal and this doctor comes back from this conference saying that now it was a “mathematical model”. They love doing those. A person with HIV gets infected at twenty, will live to about ninety. I just freaked out and went to the microphone. “What are you talking about?? So, you think, with us, with all the inflammation, even with therapy, and the toxicities of therapies, you think we’re gonna live longer than the average person?”

**RC: [laughing]**

JS: Which is eighty, eighty-one. Of course, she was a little stunned, and didn’t respond. And it really wasn’t her fault. She was just reporting a mathematical model that was shown there. But, it’s like... Critique things before you repeat them.

**RC: Thinking in the longterm, what kind of impact do you think CPAVIH had? And what was that impact? Did LIPO ACTION! Have an impact?**

JS: Yeah. They all did. Especially CPAVIH, at the beginning. I mean, the briefs we went to the government for, and the Malades Sur Pied and then the Pharmacare thing, and each time to get drugs on the formulary when they were too expensive, and governments, they don’t want to pay for it. We did good work, back then. But I guess because the fight was more life and death, that people were more involved, and now there isn’t that. Especially if you’re newly infected. So there isn’t that need to make things better.

**RC: Or at least it's not as obvious, right?**

JS: Yeah. Definitely not as obvious. But you talk to people and it's like... no, they think they're fine. And still, nowadays, you talk to people, okay, before... Well, no. It was still the same kind of thing, for a lot of people. Ask them what meds they're on, they don't even know. People don't know what meds they're on. So, to them, there's a variety of things out there, and they don't even think that if you become resistant to this one, that there's another one, they just automatically assume everything's there. But that's not the reality. And the reality is we're still not living normal lives with the medications. The older ones. The younger ones. Mathematical model. Show us otherwise. But there's still going to be a lot of damage from continuous infection.

**RC: Yeah. And if not, like, physical damage, HIV stigma still exists, right?**

JS: And worse in the gay community than anywhere else! It's really weird. [sad laughing]

**RC: Yeah, I mean, I think in the gay community there's, like, a very weird... We're at a very weird moment, like, gay marriage has passed in Canada, gay marriage has passed in the United States, and there's a bit of a new sexual orthodoxy that's really conservative. There's young guys on Grindr that are like, "I'm not here to hook up." And meanwhile, they're sucking all the dicks they can, but no-one is open or out about, you know, what they're sexual proclivities are, because there's this new moralism. Or, this is my interpretation.**

JS: No, there is in a lot of sites. I mean, there's some sites you can be more up-front type of thing? But even in those sites, like, you go to Bareback RT, and that started mainly for HIV-positive people, so that they didn't want to use condoms. But now there's others who, even if you're on PrEP, that person still doesn't, won't go with you. And it's like—

**RC: Yeah, like a sero sort of—**

JS: First of all, the PrEP thing, it's definitely not out there saying that you can't get infected. And, I mean, this came out... was four, five years ago, and the Swiss made the statement? "Undetectable, you will not pass on" and they finally did studies, and yeah, it shows that. But it's not... taken in. But people don't ever think about Hepatitis C in that way, which is much easier to get than HIV.

**RC: Yeah. And also the multiple-drug-resistant syphilis. Like there are other things to deal with.**

JS: And who gets more sexually transmitted diseases – which, they call it the STBB-something-or-other...

**RC: Yeah, yeah. [laughing]**

JS: ...among gay men who are positive. Because that's... I guess they can feel a little more free? We went, I guess, so many decades with condoms and all that. And it really wasn't working because you always forget.

**RC: And there's definitely a fatigue around the safer sex stuff.**

JS: There's also, even now with the one pill a day, there's pill fatigue. People get tired and then try to stop, and I mean, I used to do that intermittent stopping when it was more logical to do it, just because of the toxicities of the meds. And I used to switch meds all the time, so that it wouldn't accumulate the same toxicities. But people aren't aware of a lot of, people don't want to be aware. But that's in the general population. Like, even my sister—

**RC: People just want a pill and not think about it.**

JS: My sister never, she's had two knees replaced, but she never asks questions. It's like, "It's whatever the doctor says has got to be the best thing. Who am I to question the doctor?" Well, unfortunately, I am. I've been kicked out of an emergency room once. And where else was I kicked out of? Oh, yeah. My psychiatrist fired me.

**RC: [chuckling] Oh, and coming back to LIPO ACTION!. What kind of impact did that have?**

JS: That had a very positive impact on a small group of people. Because all these people were feeling alone and like freaks. The guy with the chin down to here. The buffalo humps. So, even if it didn't get much done, it did help a lot of people accept themselves. Even if it was in a small bubble, it's still a lot better than thinking you're the only freak out there.

**RC: Yeah, totally. I mean, it's like one of the unintended consequences of activism. Like, when you think success is when we change a policy, or we get a new drug, or we get someone kicked out of office. But there's also the important stuff around making friends with people that you wouldn't otherwise connect with, breaking isolation and stigma.**

JS: Yeah. Being able to have that discussion with someone that knows about it.

**RC: It seems so basic, but it's actually kind of amazing that it happens. So I'm coming to the end of my questions. I guess one of the things we always ask people towards the end is are there any memories of people that haven't come up, that you would want to make sure are on some sort of public record of people that should be remembered?**

JS: There are sooo many. Steve. He was Dee Diamond. And he was just... he was a drag queen, basically. Used to raise money for HIV. [rummaging] Was all drag queens, but also the wife of the guy who used to sing "Oh Canada" at the hockey game, what's her name...

**RC: [laughing]**

JS: Names are horrible... Geraldine Doucette? [rummaging]

**RC: Okay. ...Dee Diamond. And you said his name was Chris?**

JS: Steve.

**RC: Steve. Sorry. Steve. Also known as Dee Daimond.**

JS: That's the whole group. That's Steve. He was six foot six I think? Then he used to put six inch heels.

**RC: [laughing] So like a seven foot tall...**

JS: And huge Dolly Parton wigs.

**RC: Oh, so good! ... That's amazing. And do you know what they were specifically raising money for?**

JS: ACCM.

**RC: ACCM. Okay. Yeah. And then there's a bunch of Bad Boy Club stuff that we've gotten to.**

JS: Yeah. They were sponsors.

**RC: Yeah, it's actually pretty amazing how many places that drag queens were integral to the funding of activist groups.**

JS: Oh, yeah. Because any show or anything it would be Drag Queens. And the Leather guys who had Leatherman of the Year.

**RC: Where was the Mississippi Club?**

JS: The Mississippi was in the Club Sandwich complex.

**RC: Ah, okay.**

JS: That's been torn down. But we also did shows even at, once, at – where's the English theatre in Montreal... Old Montreal. What's the name?

**RC: Oh... Yes. I know the one you're talking about. [laughing]**

JS: [rummaging]

**RC: Oh, this is great. "Miss Unda Stood"... So good!**

JS: Sue Ste-Marie got on there.

**RC: It's so funny. Oh, there's so many people. This is a big show.**

JS: Oh, yeah. This was, like, a lot of work. Johnny Love, I remember him. He used to be my first boyfriend.

**RC: Amazing.**

JS: These were all friends. Laura Van Norman was... She was a best friend of Barbara, and Barbara was married to a drag queen... What was her name... Was really weird times.

**RC: [laughing] Yeah, right?**

JS: Because the drag queen had children with her, and they were lovers forever, but he was also a prostitute as a woman. It's really...

**RC: That's amazing. Not that I know if you were involved in any of it, but was there any, like, sex worker organizing or prostitute organizing in Montreal, too?**

JS: Yeah. That was, would be Michael Hendricks you'd talk to.

**RC: Yeah, he was with Stella.**

JS: He was also secretary, part time at least, in Stella, which dealt with prostitutes. He would be the best one to know. Because he's not straight, not infected, and he's got this moral ethical view that things should be... he shouldn't judge people because they're prostitutes and all that. But he, gays themselves, wouldn't go and help female prostitutes.

**RC: Yeah, there's a divide.**

JS: It would be more among the trans community that they would connect type of thing.

**RC: Yeah, that's true in most places.**

JS: It was Geraldine Doucette. That's her name.

**RC: Okay. ...Don't Cry For Me, Argen Tina... That's really funny. [laughing] Oh, yeah. Here we go. ... These are great. I imagine, is this early '90s? Oh! Late nineties.**

JS: Ninety-seven. We did a few years of it. ... That's David Cassidy.

**RC: That's David Cassidy. That's funny. He's the one who started ACCM, yes?**

JS: Yep. Well, it was started as, I know he was there at the beginning when it was called MARC/ARMS, and then it became ACCM.

**RC: Then they split off. That's, that's the history that I've heard, too. Because MARC/ARMS pre-date CSAM, no?**

JS: I think it did.

**RC: Yeah. And CSAM sort of was mostly francophones, so MARC/ARMS ended up being mostly anglo, and then it splits off. Yeah that's what happens because you're like, "Oh, these were the people that were supporting this kind of stuff" and sometimes you find things that are surprising.**

JS: La Vesto de Village. That's where we all used to go. Before that, used to be Lenso's on Guy and Ste Catherine.

**RC: Mm. Yeah. It's so funny, people used to hang out on Guy Street**

JS: After the clubs. So there was La Pollon on Guy, the strippers, there was another bar on Guy, and some of the bars were on Stanley and Peele. Limelight. Trucks. Reflections.

**RC: It's just funny, because today that area is so hetero. [laughing] Like, I went to university there, so I'm just like "Mm, I can't imagine!" and this is very funny. ... Now, that must be David Cassidy...?**

JS: Yep. That's David Cassidy. There's one of them there was actually the husband of Jean-Pierre Bélisle. She was not a drag queen, but she decided to become one for the show. And she sang, I forget what the actress was, but it's a Black singer. And she had, like, black makeup on. And, to that show, I had brought my older sister, who really wasn't involved. And... she was sure she was a woman, and when I told her "She's not a woman" and then I had tell her "She's not Black, either". And my sister was, like, blown away. You know, middle aged person, getting into that milieu and it's like "Wow, this is weird!"

**RC: Yeah.**

JS: Now, Steve... That's Steve. He liked to be in pictures. Ray is still alive. Ray Battson.

**RC: Okay. Oh, all in their Habits.**

JS: Yeah. That was one of the skits.

**RC: That's great. So are there any other, any other people, like Miss Dee Diamond that you want to remember?**

JS: Oh, James Kreppner. He was, but he was Canada-wide and mainly in Toronto. I'm sure they spoke about him in Toronto. He was absolutely... you can't compare to him anyone. He would, basically... You would know if he was fighting for the gays or for the hemopheliacs, or whatever. He just fought. For everybody. But... The knowledge this guy had. And a lot of people, at the beginning – there's Brian something – were just amazing, and you saw that. And it's like these people bringing their IV tubes to meetings. And people in wheelchairs. It was kind of like, you'd look at them, and it's like "How can you not fight? Look at them." It's incredible.

**RC: Yeah, I bet. I imagine that kind of sight would be very motivating. Or, if not, induce guilt and shame about why you're not doing enough, right? [laughing]**

JS: Yep... Paula Braunstein, who's now in Africa. She was not infected, but she's very good. Maude Boinion. Which, now I think she's a microbiologist? But I remember me and her, in Vancouver—

**RC: At the AIDS Conference there?**

JS: Yeah, and there was a segment of people who said "It's the drugs, and not the HIV, that's killing us".

**RC: Right.**

JS: Forget the name of that stupid mother fucker. Anyways. So, they didn't want to let us talk. And we didn't want to let them talk. So we got into an agreement. "We'll talk first, and then the AIDS-deniers will go." Without any combination, without talking about it with anybody, me and Maude decided "Okay. You go to that speaker, I'll go to this speaker, as soon as he starts talking? Unplug the speaker." Oh was he pissed off! We almost had a fist fight.

**RC: And this is at the AIDS Conference in Vancouver. Wow. No-one has told us anything about things like that.**

JS: Oh, yeah.

**RC: Yeah. I mean, the AIDS-denialism is an interesting thing, because there's, you know, people like Miss HIV in *Zero Patience*, Michael Callen, who actually had quite nuanced theories about, a multi-factorial theory or like... also being very clear that AZT was being administered at toxic levels. Right?**

JS: It was!

**RC: But he, I think people like him, and other people that were, you know, were very questioning of medicine, are lumped in with the AIDS-denialists?**

JS: Yep. And it's not—

**RC: It's not the same thing. It's actually much more nuanced and people were like, "Well, what was the medical establishment doing to gay people before this moment, right? Electroshock therapy and locking people up and..."**

JS: [bitter laughing] Well. We've got a vice president in the U.S. who still believes in therapy to change.

**RC: But it's interesting that AIDS-denialists who absolutely have no grasp on reality...**

JS: Nothing. It was nothing based on science and... But, like, the president of South Africa, Mbeki.

**RC: Yeah. Mbeki, too. I think Coleman Jones is another one who, he's a Toronto guy, but he was a bit more nuanced in thinking about toxicity of medicine and multi-factorial theories.**

JS: And there is multi-factorial theories. I mean, most people are not fighting CMV, and most people with HIV, even though you control it when your CD4s are at a certain height, CMV can kill you. That was one of the things that made you blind and could kill you. So there was, probably more back then, because once you get more advanced in AIDS, that's when all those other co-factors really beat you down. Because that's the opportunistic infections that doesn't happen in healthy people.

**RC: Right. Right. Well, is there anything that we haven't covered that you think is something we should?**

JS: I can probably think of a million things, but... no, it was just the... It was a war. It was, I mean some people don't agree, but I know a lot of them do. A lot of us have PTSD. I mean, we had people dying every week. Like, my friend who just took his life... People are still dying.

**RC: Yeah. There's the question about long-term survivors and, you know, it's not just a medical but, like, what do you do with people who have had that war-like experience?**

JS: Yeah.

**RC: In a war that happened... that no-one acknowledged was going on. Right? Like, I think that's something we do a really poor job of. And, I mean, part of it's, part of why I'm involved in the AIDS Activist History Project was because I want people to know those stories. And this really important thing happened, and people went to war, so people like me could live and no-one ever talked about that.**

JS: People will forget. I mean, people are already forgetting about "lest we forget" and the war years, war veterans from World War II and World War I. People are already forgetting. The fucking last mayor changed one of the, a park in Outremont called Vimy Ridge. Changed it to the name of a previous Premier because he happened to live in front of the park. So it's like, you cannot get rid of a park that's named Vimy Ridge, and then expect society to remember things.

**RC: Well, let's hope Parc de l'Espoir, for all its problems, doesn't get renamed something really horrendous like...**

JS: No, but I wouldn't be surprised.

**RC: ...Parc Couillard or something. [laughing] That would be really heinous.**

JS: But it wouldn't surprise me if they definitely changed the style of park.

**RC: Great. Well, I think that wraps up the formal part. I would be curious to see some of the papers, if you think there's anything that would be particularly exciting to look at.**

[the remainder of the transcript takes place while looking through boxes of ephemera]

JS: Well, that's just— I'm not sure, because I've thrown a lot out. Well, let's go through the Kalpesh papers. This is Kalpesh. And Christopher. We were all at one point on triple teraphan, because at that time, in '91, we had D-14, PVI, AZT, and PBC. And I remember us taking three drugs at the same time.

**RC: Yeah.**

JS: So, and I saw printed somewhere that this was the early '90s. Just saying that, a lot of times, the community knew more than what the scientists knew. Because scientists like to go step by step, and this was something new. And we did change the FDA and Health Canada and the way they approved drugs. There was never drugs available like that, or compassionate accesses for thousands and thousands of people, that was our fight that now is a model for cancer and other diseases. Because, before, if you weren't on the study – and, first of all, in a study, you'd be... fifty percent chance of getting it and fifty percent chance of not].

**RC: Yeah, the placebos.**

JS: And, of course, there was that big study of AZT where people shared their pills, so that everybody can— It probably turned out making a lot of people live because a lot of them were dying from the toxicity, but if you mix the drugs, you're getting half the dose, which is probably the best dose. [Laughing]

**RC: Yeah, it's pretty wild.**

JS: [Flipping through papers] I seem to have a lot of... Canadian Trials Network (CTN)...

**RC: And CTN's late '90s, early 2000s? When it starts?**

JS: Early '90s.

**RC: Early '90s. Okay.**

JS: I think it was '93, '94.

**RC: That's earlier than I thought.**

JS: Yeah. That started off, Canadian AIDS Society had a committee of people who were HIV-positive but more experts in the medications. The drugs, the antiretrovirals. And drugs to treat the opportunistic infections. And those people, most of those, went into the CTN to become the Community Advisory Committee.

**RC: And remind me what CAS was?**

JS: Canadian AIDS Society. It's still there, but kind of...

**RC: Yes of course.**

JS: Yeah... They're not very popular, nowadays.

**RC: Oh, yeah?**

JS: Because there's another group that just popped up, the CPPN? Or CPPP? In Ontario? But it's Canada-wide, and they're basically saying CAS is not doing their work, so they're going to, they're kind of taking over.

**RC: They're going to take over.**

JS: [Sighing] Yeah. [Flipping through papers] By the way... Who's sponsoring this? Is it OHTN?

**RC: No, it's Social Sciences and Humanities Research Counsel grant.**

JS: Oh!

**RC: So it's SSHRC. Yeah, it's not— Because it's not scientific research, we don't fall into CIHR, or any of those other categories.**

JS: But isn't it, like, social sciences?

**RC: Yep. But it's also a miracle that we got the grant. Because no-one actually cares about AIDS? So...**

JS: Yeah.

**RC: Yeah. I think we just got really lucky. [Flipping through papers] This is an old Xtra article... I cannot believe that rollerblades picture, that is so funny.**

JS: [chuckling] [Flipping through papers] What date is this? Oh, that's it.

**Both: [Flipping through papers]**

JS: Wow. Somehow this looks so old, but it's only 2008.

**RC: [Laughing] Isn't that funny? [Flipping through papers] ...Oh, this is cool.**

JS: [Flipping through papers] I didn't even know I had this. It's kind of like a community CV? For the community work I've done?

**RC: Yeah. That's really good. ... Oh, I'm just going to write down the proper... I wasn't sure if LIPO Action was similar to AIDS ACTION NOW! where they only use capital letters? But I see**

**it's just the LIPO that's capitalized, so I'm going to correct that, so it's proper. So you have LIPO Action? With...?**

JS: Yeah. The 'A', I know, is capitalized. I don't remember the rest. [Flipping through papers] ...Did you ever get to see the, what was the name of that thing? It was this funny magazine, out of San Francisco...

**RC: Diseased Pariah News?**

JS: Yeah!!

**RC: Oh, it's so good!**

JS: Fuck, that was hilarious!

**RC: Yeah. I think those guys were, like, some of the first guys to have it right, in terms of that kind of humour?**

JS: Yeah. But it very offensive to some.

**RC: I know!**

JS: And, actually, it was more offensive to the non-HIV community.

**RC: Totally, yeah. I could see that.**

JS: They thought it was just too far... Now this is something Kalpesh wrote about personal health promotion strategy back in 1993. So it was, like, what supplements to take—

**RC: Yeah, like nutrition, like a more holistic approach?**

JS: Yeah. Yeah, it's interesting how that develops, too. Because, you know, a lot of the treatment action, or treatment activism, was around the "drugs into bodies, drugs into bodies", and then there was other people being like "It's not just drugs into bodies." Alternative treatments...

**RC: And just, like, eat well, sleep well, take care of yourself. Things you would do to generally take care of yourself, but that become more important when your immune system is compromised.**

JS: Wow, I didn't even know this one: "Plants can carry bacteria and fungus. Herbs can carry those two as well as parasites".

**RC: "Don't touch anything!" [Laughing]**

JS: Basically, that was it! We couldn't have cats because of the toxoplasmosis.

**RC: Yeah. I even still think about that, today.**

JS: Well, basically, most people have it.

**RC: Yeah, but it's also why I feel like I'm a dog person. I'm like "And cats are disgusting. Toxoplasmosis".**

JS: Well, your dog sniffs cat shit all the time.

**RC: Yeah, I mean, I know it's totally irrational. But in my head, I'm like... Because I've been studying HIV for twelve years, and— not HIV, but the history and activism— I'm like "Oh, yeah. Cats. Cats are bad". [Laughing] Which is totally ridiculous.**

JS: Birds. We weren't allowed. It was cryptosporidium or cryptococcus—

**RC: Yeah. Something like that. From birds, right? This is amazing stuff. I do hope you still get this to the Archives Gaies du Quebec someday.**

JS: I should, but I just... find no order that... It's kind of like going "Here! Some of this is garbage and some of it might not be!" That LIPO Action tape bothers me though. But I'm pretty sure that it's on YouTube by now. Let's see... So, CPAVIH was still on in 2003.

**RC: Wow! That's way later than I thought.**

JS: Yeah, me too. This is a brief we wrote, and that's one of the ones that I probably presented. The guy's name that I was trying to remember, from Toronto, used to come with his IV stick. Brian Farlinger. I'm sure you heard of him in Toronto?

**RC: Doesn't ring a bell, but... it could be, I think there's twenty interviews in Toronto, and I haven't indexed all of them yet, but...**

JS: He died early on, but... some of his pictures. Brian Farlinger. Yeah, if you've talked to AIDS ACTION NOW!, so this is '94, he probably died very soon after.

**RC: We've talked to a bunch of people from AIDS ACTION NOW!... It's so funny, because Kalpesh titles his papers very similarly. Like, they're all, like, very formal? It's really funny.**

JS: Well, they were big university geeks. I mean, Kalpesh has at least two degrees.

**RC: I love this thing about the incident report with Kalpesh and... Kajma? Like, and I can tell these are Kalpesh's notes, rights?**

JS: Yeah! [Laughing]

**RC: [Chuckling] Kalpesh... That's too funny.**

JS: He was, like, ninety pounds.

**RC: I heard he was tiny!**

JS: Teeny-tiny! And I remember us sitting in the window of this café, we were all together, and then he left to take a cab and it was a really windy day. He was so light, that when he went and grabbed the door of the cab, the wind just... made him horizontal, and he fell. That's how light he was. [Flipping through papers] See, I like titles like this: "AIDS as a Clinically Curable Disease: The Growing Optimism" and this was '96.

**RC: [Laughing] 1996. Yeah.**

JS: It had a lot of optimism. [Rummaging] This is another cure thing. The 714X! Oh, I don't even have any pills left in it. That's one of the ones I'm ready to throw in the garbage. Oh, here's some... I don't know if you're interested in stuff that was in...

**RC: Oh, man. This is his original proposal for AIDS on Rollerblades.**

JS: Oh!

**RC: That's cool!**

JS: That's great! [Rummaging] ...Ah, there's Mo Doinion. Oh, god... Look at her. She's got adult children now!

**RC: Wow... Oh, amazing! That's you!**

JS: ... Yeah, I think it was in the CPAVIH office.

**RC: That's great.**

JS: Yeah... well... [Rummaging] [Laughing] Boy, am I a big mouth! That's why I kept this one!

**RC: [Chuckling]**

JS: Screaming my lungs out, as usual. ... Oh, and it was in Toronto.

**RC: Yeah. Yeah, because I was trying to figure out what, like, which square that is, and then I was like "Wellesley Central Hospital"? I don't think we have one of those in Montreal.**

JS: [Laughing] No. [Flipping through papers] Hm... And if there's any of these papers you want to take, it's fine with me. I have some of the AIDS things, and I think I have a big one of Kalpesh on the rollerblades. [Shifting boxes] This was Montreal HIV '95. That's an old one.

**RC: Oh, wow...**

JS: I don't know from where, though. Probably got it at a conference.

**RC: Oh, yeah, it has a 902 area code, so that's very good... Whoever's in Nova Scotia would at least give you an idea for where it was from...**

JS: Ah! I had it blown up a bit.

**RC: [Laughing] Someone else, I don't remember if it was, maybe it was Ross Higgins. He was talking about Kalpesh, like, sucking dick and getting caught. It was, like, between two cars or something like this, and getting caught. And, like, I don't know. There was some long story. I don't remember all the details now, because it's been a while since I read it, but... the police came, and it was a bad scene. And then he was going to have to deal with his family, and, yeah... Kalpesh seems like a total character.**

JS: His brother was actually a Member of Parliament, in India.

**RC: Oh my god... I wonder how he managed that... I would like to take, you have three copies of this so I feel less bad about asking to take it, but scanning in this from Xtra would be... would be pretty great, and it gives a context for Kalpesh's AIDS on Rollerblades project.**

JS: Yep. And you have that.

**RC: Yeah. It's, like, these reports... Like, the only reason I wouldn't want to take any of this is because this should all stay together. Like, if you end up giving these to an archive.**

JS: Well, to me, as long as they're available and public, and the thing is, I'm so... I don't know. I basically don't know where to go for all this, or even giving it without having some kind of a story to it. Just going, "Here, pick and choose?"

**RC: Yeah, because without context, people wouldn't know what some of this stuff is, right?**

JS: I mean, some of them probably won't even know. Because, really, the papers I have now are, like, one tenth of what I used to have. But I used to have everything paper copy and didn't leave things in the computer.

**RC: Yeah. That's smart. Because then something changes on the computer, or... something happens. Let's see. Yeah, I guess I'm, the things I'm most excited about is this Remembering Kalpesh stuff. Just because we could really easily integrate this into what we already have up? And it would provide more visual stuff.**

JS: Uh-huh? And, to me, he really was one of the top, because he could speak about whatever to the, whether it be David Hoe, Robert Gallo, or whoever, he could speak to them on their level because he had the knowledge behind.

**RC: He was a trained biochemist at McGill, right?**

JS: Yeah. Extremely, extremely intelligent guy. A little whore too.

**RC: I mean if he was caught sucking dick between two cars in the village and got arrested...  
[Laughing]**

JS: Well, he once, I remember one time, telling me he went to Amsterdam, where they have a lot of a back rooms. So he's cruising this guy, and the guy goes "You want to go to the back room?" "Yeah." And, on the way there, the guy goes "Do you have HIV?" He goes "No." And then, once they're done, coming out, the guy finds out he is HIV positive, because, I don't know, not sure the reasons, the guy goes "But you told me you weren't HIV positive!" "Really? You think I'm going to tell you the truth, right?" It's like, you're about to pop your cock out.

**RC: Yeah! [Laughing]**

JS: It's, like, not the time for that conversation! And it's like, and Kalpesh is right, if he's going with me in there, here's going to go with a lot of people in there, who don't even know they're positive. To me, it takes two to tango, it takes two to take the responsibility, because the reality is, what is it? Fifteen to twenty percent of people don't even know they're positive? And those are the ones, in the beginning of the disease, with a very high viral load.

[END OF TRANSCRIPT]