“HIV in My Day” – Interview 43

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Interviewee: Jon Levitt (JL); Interviewer: Ben Klassen (BK)

Ben Klassen: Great. Well, thank you so much for being here.

Jon Levitt: My pleasure.

BK: Just sitting down this afternoon talking to Jon. And to get started, we like to ask folks how they first became involved in the gay community or started engaging in gay life.

JL: Really, started engaging in gay life? Well, for me that’s way back in 1970. Uh, was born and raised in Montreal. And was very closeted, up until around 1970. And met somebody, who—okay, my thought process right now is how much detail do you want? How much, you know, how’d I get involved, I met somebody, I can give you a lot of detail that this person was living in Montreal temporarily, and was going to be going to California, and basically was the perfect person for me to meet, in coming out. Was very kind, and gentle, and informative. So that was my coming out in meeting somebody in Montreal and driving to San Francisco or the Bay Area in 1970. And then just getting right into the gay community, just meeting people, just coming out with my gayness at that time. And so, I lived there for four years, in San Francisco, as an illegal alien. Don’t pass this to the border crossing. It was really the heyday of gay liberation, in 1970 to 1974. Just enormous changes in those four years. So that was my first getting into the gay community, and then I moved from there in 1974 to Vancouver. But again, I can go into a lot more detail about that. It was quite an amazing four years.

BK: I’m always a little curious about what the community looked like in the seventies, so you can go into a bit more detail at least.

JL: Okay, here goes. In 1970, there were a few gay bars scattered around San Francisco. There was no real gay area. And there was one main dance bar, called *The Rendezvous* on Nob Hill, and it had almost like Woodward’s had here, had a big revolving neon “R.’ And it was upstairs, it was a dance bar upstairs that was popular on weekends. And when you went into this bar, you were—and every person was advised that it was a rule of the place that you were not allowed to touch another person, literally. On the dance floor or off. And if you were found touching another man, you were given one chance and after that you were barred from the bar. That’s what San Francisco was like in 1970. In 1974 before I left, there were bars everywhere, there were steam baths everywhere, there was sex going on in the bars, there was like complete debauchery. So—and big gay Pride parades, the whole thing. So, it was just a dramatically fast change in attitudes for gay people. And it was wild to witness that, just wild to be part of it. So, when people think about gay areas and gay people and gay communities, really didn’t exist very much even in San Francisco in 1970. But then it changed dramatically. So, it was really amazing to live through that and witness it. And people celebrating their sexuality and being very, very – I don’t like to use the word promiscuous but having a lot of sex and then lining up at the sexually transmitted diseases centre. It almost became a social place to be, to go get your gonorrhea or syphilis fix, it was all just very, very open and very wild. And of course, no thought of anything life-threatening at all, so it was all very liberating. Yeah.

BK: That sounds extremely exciting.

JL: It was. It was. And then coming to Vancouver from that was very difficult. Vancouver was a quiet small town, and very hard to get used to after that.

BK: What did the gay community look like here? Besides being much, much smaller?

JL: There were a few gay bars and it was scattered around. I didn't live in the West End, so didn't feel like part of the community. I almost felt it was a weekend thing. You know, I worked five days a week and you'd go to the bars or there was an after-hours club on the weekends, and that's when you were able to be yourself, and be out a bit. So, bars were very, very important. There was no other outlet. Unless you wanted to go to the park or something, which I wasn't that much into. You know it was working during the week and looking forward to the weekend when you can let your hair down, dance, and be with other gay men.

BK: Was it fairly liberated here too, or not so much?

JL: Good question. Fairly liberated or not, I was very careful about—I was very—still very—well I was closeted—I wasn't out to my family, who are back east. I really wasn't out to most people who I didn't know were gay. I wasn't out at work. So internalized homophobia for myself was quite strong. And again, that's why going to a bar on the weekend was so much fun, and so liberating. I missed San Francisco, I missed the whole liveliness of it. And I'd go back several times a year to visit. But I didn't—you know it was—I didn't really suffer here, it was fine. I met people.

BK: It's funny because we've heard so many stories from people moving from small towns to Vancouver and being like, "it was so big here" and your experience is, like, completely the opposite.

JL: It is the opposite – it was so quiet. But like I said, I didn't suffer for it. You know I enjoyed the nightlife the way it was, and I did meet people. So, it was okay.

BK: And the community was mostly centred around the bars at the time?

JL: From my perspective, it was. Yeah, I didn't really join any gay organizations or athletic things. You know, I wasn't really aware of other things to join, so that was basically the extent of my gay life. I don't know when the first steam baths were around, but I started going there too. I mean I did celebrate my sexuality that way. I was quite open about that. So yeah. Well, I met somebody, well I met somebody just a year after I got here, so you know I was in relationship also, for four plus years. Most of my life, I've been in some kind of relationship, I've lived for several years on my own but I always seem to meet somebody, which is very fortunate. So, I did self-identify as gay right away, from San Francisco. But when I would go back east, visit my family, I wasn't ready. I would talk about my special friend, or something like that. That took awhile, to come out to family.

BK: I can imagine.

JL: Yeah. I think I came out at work in the late-eighties, because my employer was very—had a very liberated policy, and had same-sex health plan and stuff, it was very, very—so I did come out at work, to get my other half on the health plan. Yeah, that was great. But I carried around varying degrees of homophobia for quite a while. Quite a while. I remember the exact year was in '97, I had a boyfriend and met him at a—we were going to a theatre, I met him outside the theatre, and he came and gave me a kiss. And I was just like shocked, oh what are people going to think? So even that point, of doing something out in public, took me quite a while to be comfortable with that. I think I still carry a little bit around. Although my husband now is completely the opposite, so very helpful. So, I carry a little bit, I still recognize it, but not that much.

BK: I feel like that's something that most gay guys can relate to on some level though, right? I mean it's a process for people.

JL: Yeah. Although I don't know what it's like for young people now, because there's so much sexual fluidity around. Labels are all over the place, and people are much more willing to explore and be open. Seems like there's a lot more acceptance for everything. So, I don't know, I think it would be very different now for me.

BK: Yeah probably, I think you're right. So, do you remember when you first heard about HIV? Or wouldn't probably have been called HIV yet, but when you first heard of this thing?

JL: Yeah. I first heard of what they were calling the gay cancer – there was something else they were referring to, but I forget what it was. And something happening in the gay community, gay men getting infected and what's this all about, and great fear factor. Nobody knew what was happening, and people with very large lymph nodes. I heard about it here. I went down with my lover at the time, we'd go down quite a bit and party. And I remember distinctly being in a coffee shop talking about it with my partner, saying, "You think maybe we should be a bit more careful? This thing's going on. And what's it all about?" And not knowing much at all. Just this hearsay basically. So that's my first recollection of it. And then, I mentioned to you before we were doing this recording, but the doctor I was seeing at the time told me about a study going on because of gay men having these enlarged lymph nodes. And a study of a—and I always have a hard time saying it—a lymphadenopathy study. And that they were, you know, just taking blood samples and trying to figure out what was going on in gay men's blood. I felt totally healthy, I was fine—so I thought… It was just as a—to help out—I volunteered, to give my blood, sample of my blood, in my doctor's office. And I was told that was going to be coded, it would be totally confidential, my name wouldn't be attached to it, there's a number code.

And I don't know if I found out then or afterwards, it was sent to some lab someplace in Ottawa, frozen and stored in case it was needed to be looked at in future, which I thought was quite a neat idea. I don't remember what year that was. That was way before the virus was discovered. It could've been as late as—well I don't know, you might have a date for that study—but whatever, that study was probably early, very early eighties, '82 maybe, or something like that. Or '81, '82, something like that. So my blood was taken for that and when the virus was discovered and much more was being known about this syndrome, this uh, acquired immune deficiency syndrome, I went and asked for that blood to be studied, to ask for the code to be broken and for them to tell me if I was infected with the virus or not. And I found out I was. The doctor just told me. And at that time, you know, we didn't have things in place for how to tell people and how to give some support, emotional support or counselling or anything like that. And I remember, I didn't think that much about it. Of course, I was a little bit shocked and dismayed and whatever. And I remember telling my other half, just on the beach, said, "By the way, you know…" And he was furious at me. Absolutely furious. "How can you do that without telling me first? How do you think I feel?" It was all about him. Anyway, he was just really, really angry that I had done that, and I found out and he didn't know. Anyway, that was the start of it all for me, finding out that way.

BK: And so that was still in like the mid-eighties, or early eighties that you found out?

JL: I think that was before mid-eighties. I think that was '84, but I'm not sure of it. I think it was around '84, because this partner of mine, we met in '82, so it was early on in the relationship. Sometime between '82 and '84, that was.

BK: So, the doctor wasn't able to say, "Hey, go to this place for support." There was nothing.

JL: There wasn't any.

BK: So, how did you cope with that?

JL: You know, I'll tell you in general how I coped right through the years, because I think that's the only answer for that. I don't know if you knew of—she's no longer with us, unfortunately—of a social worker at St. Paul's, her name was Judy Krugel. Other men might have mentioned her name. She worked full-time with HIV people at St. Paul's, that was her full-time job. She was a miracle worker, she was just amazing, she was an angel. And I saw her both professionally and on a friendship basis over the years, and I got a lot of counselling from her. For instance, she counselled me a lot before I left work, because my doctor was saying maybe I should leave work and it was a very difficult decision to make. But what she told me was, she had this phrase she used for me. She said I operated under positive denial. And I think she hit the nail on the head. It wasn't that I was denying that I was positive, or denying I had something serious, but I didn't have the sense of morbidity, or that I was going to die, or that it was going to be horrible. It just didn't – my mind just didn't work that way. I just kind of accepted it day by day and took it one step at a time. I'm not saying that it's because I was so wise and I was so together or whatever, it was just in retrospect just the way I kind of I handled it. So, okay, I had this thing, I had to deal with it and whatever. I'll deal with it.

I mean, it was difficult, as you know, taking the whatever medication was around to begin with. It was also very difficult because I knew – I was friends with somebody who I think was the first person to die of AIDS in Vancouver, and seeing what he went through, and seeing all the fear in the hospital. The intense fear, the intense stigma, the intense freak outs, you know. That was horrible. It was horrible seeing other people go through it. It was horrible seeing my friends die. Um, I'm getting emotional now. It's funny, because I don't often get emotional about this, so long ago. But it's bringing it up. But that was the hard part, seeing what other people were going through. Yeah. It's hard. Surprised I'm getting emotional so fast. Yeah so, my partner turned out to be very difficult. You know, early on in our relationship, I didn't realize it, but it was somewhat of uhh… not heavily but mildly or moderately abusive relationship. And so, that kind of reaction I told you that he had was kind of indicative of him. So, that didn't really help much either. But I had other friends who were remarkable. I had friends who were the originators of people living with AIDS, and AIDS Vancouver. I knew people who were at the very start of all that, so that was very encouraging and uplifting. So, there was a balance there.

BK: So, a lot of your support was coming from friends?

JL: Yeah, and I had the most incredible doctor on earth, Doctor Voigt, Doctor Robert Voigt, who was—basically, I think he saved my life, quite literally. He was willing to do things other doctors weren't. He really pushed for access to experimental drugs. I mean, I know AZT was terrible, but I was one of the first to be on it. I went out to UBC when they were just starting to research it. So, I was always on cutting edge, the cutting edge of drugs and the cutting edge therapies. And so, I had the best of care medically, and I had support from friends, so, I was fortunate for that. And I had this social worker, Judy Krugel, who was amazing. You know, just incredible people to help me. And I started – I don't know what year it was but I did go into a support group, HIV support group, and weekly support group. So, there was a lot of that kind of support.

BK: Was that support group through PWA or…?

JL: Uh, no, it was through St. Paul's. Yeah, St. Paul's Social Worker Judy Krugel, uh, Harvey uh, Cormer? Cor? Corma I think his name was. So, it was a support group there at St. Paul's, yeah, St. Paul's, that I was—belonged to. I was kind of reluctant to start there at first, but I was encouraged and yeah, it was good.

BK: Just to be in a room with other people who were going through the same things as you, in some respects?

JL: Yeah, and actually seeing how other people were having a much harder time than I was. So, feeling that I didn't have it as bad as other people did. And just kind of – don't like the word normal but normalizing it – you know, I'm not the only one. Just being a part of that HIV community. Then I got a little bit involved with the organizations, I volunteered for both. I was even a delegate to—well I helped with PWA as a delegate to the International AIDS Conference in the Netherlands one year, so I was a bit active in doing that. And I also did my own workshop through Friends for Life. The workshop was on leaving work due to illness, because I knew how hard that was for me. Leaving work, that's around forty-five or so, and that was not an easy thing to do. I needed a lot of counselling for that. And I was completely secretive, closeted about HIV at work. And if I had to do it over again, I would do it differently, but at the time there was just so much stigma, so much fear, so much misinformation. Stop me if I'm rambling too much.

But I’ll tell you one example of that is I was living in a, co-op, a housing co-op in the West End, with my partner. And you know we had a communal laundry room. And when one of the neighbours found out I was HIV, she complained and said that—she complained that she couldn’t do her laundry because she refused to use laundry machines. Seriously. She would not use the laundry machines because I was HIV positive. So, when that kind of stigma’s out there, and knowing that some dentists weren’t taking patients, there was no way I was going to tell anybody at work. So, when I finally did decide to quit, with a lot of counselling from Judy the social worker, I just picked Easter vacation, and didn’t go back to work. I did go to the – I keep on hesitating saying where I was working. I don’t know why, so I’m just going to do it. I was working for the City of Vancouver, and the City of Vancouver really was very progressive as an employer, with same-sex benefits and they did start some HIV awareness training quite early on. But I wasn’t—I just wasn’t ready. But I did have to tell the doctor, the doctor that was working – the HR doctor. And I insisted that it remained confidential, and he assured me that it would. So, I left work due to an illness that was not told to my colleagues, my department. I was supervising a group of about seventy-five people, so there was a lot of people involved. And I just didn’t go back to work. As I said, in retrospect, I would’ve done it much differently. But that’s how it was back then. It was tough.

BK: And it does give you a sense—or give me a sense—of how intense the stigma was at the time, or at least your perception of that stigma. What did the mainstream response look like? I mean, I guess the mainstream response looked like a neighbour not wanting to do her laundry in the same machine as you, but…

JL: Well, you heard of people – you know, you heard of swimming pools where people wouldn’t take their kids to the swimming pool because there are people with HIV using the swimming pool. You know, people didn’t want to share coffee cups, people didn’t want to use the same toilet. And you know, I wasn’t totally innocent myself. I just remembered that when I went back east to visit my family, and at that point they knew I was HIV positive, but I remember being in the kitchen with my mother and I cut my finger, and I just freaked. I left the room. I went and, you know, bandaged it up really well. I knew she saw it. And you know, it was a little bit of blood, like people freaked. You know, “You’re gonna get AIDS!” So, it was—people were very, very afraid. I mean, it was fear and it was the unknown, the information wasn’t out. The education wasn’t out. Nothing was out. So, you carried that around with you a lot.

BK: And did you know, like, at the finger cutting incident, did you have information at the time that said like, hey, that’s not actually how that works?

JL: Hard to answer that question. I probably was aware of it, but I still—you know, you take on some of the fear too. You know, it was my mother. I don’t want to do anything, in any case, in any small degree endanger her. So—but it was just—it wasn’t just the cut, it wasn’t just my reaction, it was bringing it home that had the whole awareness home, and the whole topic was there. You couldn’t just brush it aside. It wasn’t like you had diabetes. It was something really unique, and scary. It was something that, I don’t know, and it was all over the papers and it was this misinformation and all this everything, so… You had to deal with what people were reading in the media too. And everybody's dying. People were dying all over the place. So, obviously people were afraid. And for myself – maybe a little tangent – you know, walking along the streets in the West End and seeing people that you know, either very casually or just as an acquaintance or someone you talked to a few weeks or months earlier, and seeing how they totally changed physically. And there was that look. And you knew that, oh my god, I might never see that person again. Which did happen. You would see somebody and then you wouldn't see them again. It was terrifying.

BK: When did that information start to come out? Like when did you start to have access to better information?

JL: Oh, um, possibly… my memory's not very good for years and stuff.

BK: Oh, it doesn't have to be the exact date—

JL: People can pick years out of the air. I can't do that—

BK: --but like, what kinds of sources, I guess, were you starting to see that were better?

JL: Well, again, I was very blessed with my doctor, and the social worker, and the group I was in, so those were my best sources of information. And there, you know, I got more information from that. And then we had the gay press which was helpful as well. Of course, there was no internet or anything like that. So, your question is how—when did I start feeling that things were improving with information?

BK: Yeah.

JL: Well the PWA—people living with AIDS, before Positive Living and AIDS Vancouver, they were very important. That's what they were there for. And we started having things like the AIDS Walk and being more public about it, education campaigns. So, I don't know, it was all very gradual as it came out. Uh, not sure where to go with that. Ask me specific questions if you like, I'm not sure where to go with that. It was a gradual thing.

BK: Do you recall condoms or safe sex becoming a major topic of conversation?

JL: Oh yes, I was just thinking about that before you said it actually. Yeah, no, I remember that of course. The condom campaign, I remember the backlash to. I remember the Provincial Government not wanting to even be any part of any condom campaign. And I remember having to fight for that. Well, I remember the whole thing about, "Well, it's gay men's fault, they shouldn't be butt-fucking. It's like, just don't do it, it's your fault anyway. Just if you didn't do it, you wouldn't have this problem." So, a lot of gay shame, gay-shaming and rampant homophobia. "Well, obviously, it's a gay thing because only gays are getting sick." So, I remember the condom campaign, I also remember all the misinformation. Oh, it's poppers, it's fist-fucking, these are all the things, the different possible causes and incriminations. And further on, I remember getting angry myself about people who weren't practicing safe sex, who refused condoms. I'm not talking about today – now things have changed drastically. But when it was proven that basically most transmission was from anal sex and condoms prevented it, and people weren't using them, I spoke a lot about that. I was—yeah, I couldn't believe that people weren't practicing safe sex.

BK: Was your perception that that was—you know condomless sex—was your perception that that was still pretty common, at the time?

JL: Uh, yeah, too common. And I had my own encounters with that. I remember going to the steam bath one night and on two separate occasions that night, two different people refused to have sex with me because I wanted to use a condom. They said, nope, they refused. And I'm not talking about somebody who couldn't use a condom because they were afraid of having an erection. It was the opposite, it was, you know, I was going to use the condom, but nope, wouldn't do it. So, I just—that freaked me. You know, from all the people I knew who died and knowing about what was going on with the epidemic, and people were being that brazen, and haphazard, and just irresponsible about it. Not taking any responsibility for themselves or the community, that just really freaked me out. I was very angry about that.

BK: What do you think was going on? I guess like the messaging was kind of getting out there around safer sex, right?

JL: It was getting out, that was part of my anger, it was getting out. The message was getting out. There was already this thing about people just wanting to get infected so they get it over with. Or not caring, or just this youth sense of immortality, or I don't care, worry about that later, just want to have fun now. There was a movie that was shown at the queer film festival early on, and it was—I forget the name of it—but a movie some documentary person made, about gay men having sex and these phrases of "seeding" and "wanting to be bred" and "breeding and seeding" and all that. There you go, yeah. And it was part of the gay film festival, and there was a panel discussion afterwards. I remember one of the persons on the panel was Dan Savage, he was coming from Seattle. And then there were three people I think from around here, working in the health field. And one of the persons on the panel from here, said that they didn't think this was a big problem, that it didn't really exist. And Dan Savage said, "Well, it certainly does exist where I'm from." They said, "Oh no, in Canada it's not really a big problem." And I stood up in this big auditorium, and I just raged at them. I said, you know, "Get your head out of the sand. Of course this is happening here. You've got to recognize it. How can you as a health professional say it's not happening?"

So, even to that extent, people were denying it. People were in denial that people were having unsafe sex, in large numbers. And you know, that was the intent of this film, to point this out, and yet even people on a panel to discuss, who were from the health community here, were downplaying it quite a lot. So, I'm not to say the name of that person, but I did write a letter of complaint about that. And actually, they posted it at PWA on the wall. I was a big rabble-rouser in that sense, because I got a lot of—I stirred up the muck, for that. I really stirred it up. I thought this is outrageous. Got to get the message out, can't deny it. I mean, everybody was in the midst of it, you know, and it was like, people had different ways of dealing with it, of looking at it. In retrospect it's all much easier, looking back at it all. I wish I could remember the name of that film, because it's gotta be accessible somewhere. It was horrible to watch. In the height of the epidemic, people intentionally going out having unsafe sex. Young people.

BK: Knowing what the risks were?

JL: Well, yeah, I mean I would think so. These are way before the successful cocktail days. This is not like, oh yeah, well, if I do get infected, I just need to take a pill. This is way before that. So, it just blew my mind. And again, especially knowing and having witnessed so many people dying, people close to me. Um, try to say this not crying, but I mean the hardest was my best friend. So, it was difficult, it was very difficult. You know, we were in our forties. It's pretty young to be getting – not only dying but really suffering. A suffering dying. So, and to see people who were—weren't totally aware of – didn't care or just brushed it aside, got me angry. Yeah.

BK: I think that's completely understandable given what you saw and experienced. We talked a little bit about stigma. Was stigma something that was a big factor within the community as well, in the early years?

JL: Yes, yes it was. It had to have been. Because I saw it, and I felt it. Yeah, like I said, people had a hard time finding a dentist. If you visited a friend in the hospital, you had to gown up and put a mask on. And let's see, other examples of stigma… Not sure what else to say about it. I'm sure I can think of a lot of things later on. Just you know, I think mainly people didn't want to be close to anybody with HIV, didn't want to take any of that risk. So, you felt like you were this – well you were a carrier, you were infected, you know, you weren't going to get cured. And I guess other people felt the same way. And yeah, I guess I'm missing something, I guess we touched on before—it was pure homophobia. It was the stigma of not only being HIV but being gay and HIV. You were—I mean—you didn't have gay sitcoms then. You didn't have people talking about being gay; it was all underground basically. And I don't know what it was, in the sixties or seventies, in the American Medical Association it was still listed as a mental illness. So, it was a double whammy. And lot of people hadn't come out until after they were HIV, so people carried both of that stuff around. So, the stigma of being this pervert with this disease of perverts was, of course, a lot of stigma attached to it. And then there were a lot of people who had KS, KS lesions and that was very hard for… And as I said, you could see who was in advanced stages of AIDS, just walking along the street. I feel I'm not addressing the stigma totally. I don't know how else to describe it, but if I think of something else, I'll say.

BK: Yeah, we can certainly circle back to some of these questions later if we need to. But I think that kind of paints a picture. It was very in your face and like HIV was very in your face.

JL: Oh, and the other thing was—I just thought of something else is if you wanted to meet somebody. If you were single and you wanted to date, and whatever, that was huge. 'Cause nobody wanted to be with—no negative person wanted to be with an HIV positive, very few did anyway, in the early years. So, a lot of HIV positive people just gave up on dating or having sex, because sex became a dirty thing, or whatever.

BK: You also mentioned briefly the Vander Zalm government, I guess. How were they responding? You mentioned the refusal to…

JL: The refusal to fund the condom programs. Unbelievable. Well, sure didn't help much. To have a reactionary government, and a government who—well again, you know the right-wing or fundamentalists, not just Christian but all religions basically, fundamentalist religions, not helping at all. And you know, "It's god's wrath, you deserve it, you shouldn't be a pervert like that." And, "No, we're not going to fund those perverts. They should just stop what they're doing." Abstain. Abstention. So, it – yeah, it kind of brings me back to what we were saying before about the heyday in San Francisco in the early years and gay liberation and freedom, and people starting to accept gay people more, and Pride parades and all that, and everybody rejoicing, and it all just came crashing down. It just came crashing down. That whole freedom and liberation thing, it got shut down. People stopped going out a lot, and yeah, people hibernated, and I don't know, there was just a lot of homophobic backlash to what was becoming very liberating.

BK: And was there anything else you wanted to say about the early medical response? Sounds like you very quickly became – you found a really good doctor, which is fantastic, but anything else you wanted to say about that early response?

JL: Well, it was very difficult. I think it did save my life that I went on meds as soon as possible. I did know other people who rejected the meds and were going with complementary type, you know, holistic methods. And I know of a few of those who got a lot sicker because they rejected meds. And some who at the last minute went on meds, and then lasted awhile but then it was too late. It was very difficult. The side effects were horrendous, the early HIV and some of the others after that, I think. I mean, I had to take them every four hours around the clock. So, you had to time yourself, you had to get up at night. As I said before, I didn't tell anybody at work, so I had my meds at work, and sneaking meds every four hours. It was – they were difficult to handle physically, the effects on the body, and it was difficult emotionally because it was always on your mind. So, you were always being aware of being HIV and taking your meds, even if people around you had no idea. I remember going to Hawaii with my mother, she knew at that point, and I was taking DDI or DDT – there were two DD's. And one of them at the time were in packets, one dose was a large packet, almost like those if you're aware of these hot chocolate mixes come in. So, it was that size, and that takes several a day, so I had two shoeboxfuls of packets for a ten-day or two-week holiday in Hawaii. And we were going to Hawaii, and I had to ask my mother to put that in her luggage, because if it was found I—you couldn't cross a border being HIV. So, I had to ask my mother to carry my meds for me, which you know, it's, it's all kinds, all that stuff, all these everyday things were part of your life. So, the early meds, yeah, it went from one to another.

I stopped the AZT by myself, I didn't even ask my doctor, because I had a very strong intuition that it was causing more harm than good, that it was basically killing me. Especially the heavy doses I was on. So, I just stopped it. I went on to other things afterwards. I don't know how much they helped. They helped somewhat, I'm sure, 'cause I did survive until '95, '96. In '95, I was very ill, I had full-blown AIDS and I got pneumocystis pneumonia. I couldn't eat much, I couldn't walk more than a block. I knew how ill I was, but again I didn't have this kind of morbid thought around it. I didn't think, oh, I'm going to be dead in a year, I better do everything I want to do now. Don't ask me why, I don't know, I don't understand it myself. I just—my brain didn't operate that way. I knew I was really sick, and I just went from day to day. But it was difficult, a lot of terrible side effects, really difficult. I remember a friend who was living in my apartment building came down one day and said, "You've got to eat something." I didn't have much in the house, and half carried, arm around me to a restaurant and made me eat a sandwich. So, it got that bad. It was kind of just the way life was for people who were HIV positive. And being part of that support group, I saw a lot of other people were going through, and thought, this is it, this is the way life is right now. Basically, the way I looked at it. So, the meds got easier to take as it went on, but still my counts were going down, and pneumocystis and all that, I was pretty ill. And then, when the first protease inhibitor started to come, was in experimental stage, my doctor, Doctor Voigt, pulled a lot of strings, and got me again to UBC and got me starting on that. And that was after the pneumocystis, that's after I was really ill. I was—he didn't expect me to survive, I was really close to dying. And in a matter of, I think it was something like six weeks, my counts just started climbing like crazy, my CD4 and all that. I just started getting well. It was a miracle, a miracle drug, quite literally. And that's when you know, everybody realized, well, maybe there are medications that are starting to work. And the protease inhibitors were good. If you can get them, and if you had the right doctor, and if you could take them and were willing to take them, and all this stuff. I was very fortunate.

BK: Yeah, regardless of some of those barriers, it's pretty amazing that they—when those emerged, that just turned so many people's lives completely around.

JL: Totally. Completely, totally. Sadly, it was too late for a lot of people. Maybe a little tangent here but something else just came to mind. Have you ever heard of the author Louise Hay?

BK: Mmhm.

JL: And this whole thing about, you know, you can cure yourself and you just have to love yourself. Oh, that angered me. I've had friends that definitely loved themselves that didn't want to die, and took care of themselves, and got sick and died. And I've heard since from other people that, you know, she wasn't a bad person, she didn't mean to – I don't know. She put that message out there though, and again, that triggered my anger. Because that's just not the case. Because my best friend was a very spiritual, and really wanted to live. And he had the same lifestyle as I did, we did basically the same things together. And he got sick and died. And it was nothing to do with self-loathing or anything like that, or doing the wrong things. So those kind of messages coming out, I don't know if they help anybody or not. Maybe they did help some people, but I sure didn't like them. I sure – you know, the whole thing about, I know that people have negative feelings about the pharmaceutical industry, as do I, and I know they're a huge money maker, and I know they operate out of self-greed, self-need and greed. I know all that. But I also knew that there was a lot to say for western medicine, that there are a lot of good things about it. And I think people like Louise Hay didn't help that much. You just need to be good to yourself, and love yourself and all that. No, it was wrong. You needed to get the right medication.

BK: It's a virus.

JL: There's a virus, exactly. Exactly. Yeah, so there's a lot going on. And actually, I appreciate this talk because I don't think about it a lot. And you know, when you put it all together, it is huge. I'm glad you guys are doing this, because it's something I lived through. I don't on day to day now with this label of being HIV positive. I tell people I am, but it's not a big part of my life. But back then, it was huge. It was like so many things were affecting your life.

BK: Even that in itself is interesting. Because yeah, it would've defined who you were then in a totally different way than it does now.

JL: Yes, well-put. I would totally agree with that. Yeah, it did define who you were.

BK: What does it mean to you now?

JL: What does what mean to me now?

BK: HIV.

JL: What it means to me now is that I was diagnosed with this illness. I do think of it as somewhat like a diabetes type of thing, that I have an illness that is completely under control. I take the right medication for it and it keeps me healthy. That it's not much different than—oh, actually, it is different than some other illnesses. I'm fortunate because other illnesses are degenerative, you know, shorten people's lives. I feel healthy and well, and I take my pills during the day, every day. And I am somebody who – well, I do think of myself as a long-term survivor, I survived it and I have no qualms about talking about it. It was just a terrible thing to go through. I still see stigma around, I still see ignorance around. I still see people on the internet saying, "I won't have a relationship with anybody HIV positive." But I also see the huge benefits of the information age. You know, that now it's coming out that undetectable equals untransmissible, that people are starting to realize what undetectable means. So, more access to information makes a huge difference. And people being educated and knowing about it helps me not have to be concerned about talking with people about what I have and who I am.

BK: Yeah, undetectability is now like, sometimes a category that you can select on sex apps. That's pretty cool.

JL: Yeah, it is pretty cool. And even some people prefer to meet someone's who undetectable rather than somebody who says they're negative. So, it's evolving, things are changing. I mean it's still – it's horrendous that elsewhere in the world people are not getting proper care. And that's politics and economics and the craziness that's our planet. We all know how crazy the world is now, politically, and we don't have to go into that in more detail but it sure is. And I mean that's a real shame. I said a couple things about St. Paul's before, and the social workers and the support groups, and how great my doctor is. But I always feel, have always felt for years that I'm completely blessed with being in Vancouver and having St. Paul's, Centre for Excellence, and Doctor Montaner who is there, who I've seen many times. And how cutting edge we've been here. And despite the Vander Zalms – you know how the government does pay for my meds, right? And very, very, very fortunate to be here. So, I don't underestimate that. And whoever, I don't whoever, I don't know who they are, the sisters who – they don't run St. Paul's but they're kind of overseer – who are they? I should know them. But you know, they still have some connection with St. Paul's and they were always very open about having the Centre for Excellence in HIV there. It just all came together very well in Vancouver. And Dr. Peter and all that. So, we've had a—we're a very good place for people, helping people with HIV. And that's not to mention all the other ones – YouthCO and HIM and everybody else that's come since then.

BK: And especially given the size of Vancouver in comparison to the other big epicentres, right? It was a small city, in the eighties especially.

JL: Yeah, that's totally right. Don't really know how it all came about, but it's fortunate circumstances.

BK: You mentioned a few different community organizations that you worked with in different proximities, you were volunteering. Did you want to say anything about those organizations or what you were doing at those organizations?

JL: I wasn't as active as a lot of other people were. I was volunteer coordinator for awhile with AIDS Vancouver, and so I helped out in the office and I did – I was involved with a project as I think I mentioned with an AIDS conference. And it was kind of my area of interest was this whole thing about being able to work or not being able to work. And you know, the effect of insurance companies and employers. So, I did volunteer with them. I was never at the forefront. But I also went to an AIDS conference in Toronto one year and took part in a big demonstration there. So, I was kind of—I wasn't a leader, but I was active with other people in the organizations. And then have you heard of GayWay?

BK: The predecessor to HIM?

JL: Yes, yeah. So, I was part of GayWay, and I actually started a support group. It wasn't specifically HIV. It was for—it was called the Forty-Fifty Club—it was for men in their forties and fifties. So, I started that and this weekly group of men just coming and talking. And a lot of them were HIV positive. So, I was volunteering in the community. But I wasn't on the board or anything, of AIDS Vancouver or PWA, I wasn't—didn't go that far. To be honest, I would volunteer for a year and then take time off. I kind of got burnt out here and there. So, I would just do my volunteer stints now and again. And to be totally honest, I got fed up a number of times about politics in these organizations. So, I just—I didn't want to deal with the political part of it, and the infighting and stuff. I'm grateful for people who are there, who were there all these years. Like Jackie Haywood, just amazing, the contributions that she's made. So, I put, I put what I wanted to put in. And I volunteered for Loving Spoonful, you know, here and there all of them once in awhile. And since I wasn't working, I was doing volunteer work. And Friends for Life.

BK: Yeah, it's pretty amazing to look at that cross-section of all the organizations that were around at the same time, and just the massive amount of support that was available.

JL: In some ways there were too many of them, in some ways they should've amalgamated. At some point AIDS Vancouver and PWA would've done better together. But they did a lot of good work. They sure did.

BK: Were a lot of those organizations doing kind of similar types of work?

JL: I thought so. I thought a lot were and they were vying for funding and they could've been more efficient, and better together. But that's the way it evolved. I mean, you know, I did think there were too many paid staff members sometimes, and too much money going into things that weren't directly going to people who needed it. But I also didn't do very much about it.

BK: Because, yeah, those organizations started with almost no paid staff, but these days, AIDS Vancouver and PWA…

JL: [coughs] Excuse me.

BK: …I guess by the mid-nineties, it was already starting to become a much more, like, staffed and much more paid staff.

JL: Yeah. But the first ones, you know the first people who—I knew some of them—who you know, came out in public and were interviewed and on TV, they were very brave people. And very out there and really, you know, the whole ACT UP thing. And demanding government to recognize and fund medications and condoms. I mean, these were really brave leaders. We owe a lot to them.

BK: Did you get involved in any activism, or anything of that nature?

JL: Oh, a little bit, a little bit. You know, when there were some demonstrations, I would kind of take part, but again, I can't say that I was on the forefront or that I was one of the leaders. I was one of the maybe supporters.

BK: Do you remember any of those actions in particular, or any of the things you might have been at?

JL: I remember a demonstration outside of St. Paul's one time, demanding more funding. Demanding funding for meds. Let's see, I did write a couple letters to government saying, you know, medications are needed and should be funded. I could've done a lot more. But yeah, I just didn't. I don't know, I didn't have that outgoing leadership quality. Activism, I wasn't – it just wasn't part of me.

BK: I feel like it does take maybe a certain type of personality or something to—

JL: Yeah, and then a lot of courage, too.

BK: Yes. But your sense was that an organization like ACT UP was doing useful, meaningful work?

JL: Yeah, sometimes I was kind of shocked at some of their tactics. You know, sometimes even I was a little critical of them for disrupting conferences or whatever. But in retrospect it was needed, it was necessary. So, I just did my little volunteering stints here and there, I volunteered at conferences, I volunteered here and there, and that's kind of my style, with my comfort zone.

BK: And then you showed me your article that you were in, on the front page of the *Vancouver Sun*?

JL: Yep.

BK: That's kind of activism.

JL: Yeah, I think I would agree with that. It was a very big thing for me. I was asked if I wanted to do it. I had to think about it for a very long time. I realized to some degree that it might be helpful to some people. I didn't realize totally how helpful it would or could be. I think, I don't know, for some reason I really wanted to tell the story. I'm not exactly sure why, but I think I was ready to be more out there, somehow, I was ready for it. And somehow, I wanted to tell about it, and somehow, I wanted to express my thankfulness. People always say they want to give back to the community, and maybe that was my little way of really doing my thing to give back. Both to recognize my doctor and recognize that, you know, people were doing research to find drugs. And that the newspaper was interested in printing something positive for a change about HIV. So, I think I was – I was drawn to it because it was good news thing. It was something good about HIV, finally. It was something good to tell the world. And to show that somebody could beat it, I beat it and here's my story. As I said, it took a lot of thinking about it and soul-searching. They gave me the total options – I could use pseudonym, I could use my first name, I could use both names, I could have my picture taken, I could not. So, I just made up my mind to go all the way, still not realizing it was going to be on the front page, on the cover. They took a picture of me, okay, they took a picture of me, but they didn't really tell me that. But I did—I was happy with the journalist, the person writing it.

I remember I was—I went with one of my best friends at the time who was in the support group with me, we just went on a—they had the train still running up to Lillooet, you know the train going up to Whistler and beyond, regular train service, which is now gone. And we went for an overnight, just to take the train trip because it was very beautiful, very scenic train trip. So, we went to Lillooet, small town Lillooet and got a motel room there and we're walking down the one street, the main street. And there was a drug store that had just closed, I think, it was closed, and in the window there was the *Vancouver Sun*, and there I was on the front page. I just saw myself there in the papers. Wow. You know, sort of just blew me away. And then I started to realize, wow, I'm really out there, I'm really out there now. Really hit. And yeah, people stopped me on the street for weeks afterwards. People I knew, people I didn't know. You know, "Aren't you the guy who's on…" "Were you the guy in the paper? Wow, that was really good that you did that. Thanks for doing that." Yeah, I had a guy who looked me up—my last name is—was in the phone book, we had phone books back then—and this guy started calling people who sound like me and got me on the phone. And said that he was just recently diagnosed, and he was freaked out and would I mind talking to him. And I kind of had this counselling session, I did, with this guy on the phone. It was – yeah, I was really glad about that. So, it turned out to be a really good thing. And then my relatives in town who are really good people, really nice people, and I was just closeted, I didn't want to see them much or be with them much because I didn't want to hide who I was, and they didn't know about me being gay or HIV or anything. And they saw the article and phoned me up, and it started a whole new relationship with them. It was wonderful. I actually saw them today. So yeah, I showed them the article today to remind them about it. So that was – that was twenty-two years ago. So, it was a good thing to do.

BK: Well, and if people were maybe not as tied into healthcare as you were at the time, they might not have known that there were like finally some treatments that were looking like they were…

JL: No, people didn't know, this was breaking news. People didn't know at all, because it wasn't there. Because I was on it on an experimental basis, you couldn't just go to your doctor and say, "I want this drug." So, it was just the very, very first stages of it. Very first results. Yeah. And as we're saying, you know, Vancouver's pretty cutting edge, was the leader on this. Vancouver and UBC – I mean St. Paul's and UBC. And having a gay doctor who really cared, really cared about his patients and really, oh, just went so—did so much more than he had to. Just went way beyond what you'd expect a doctor to do.

BK: I guess getting to a couple of these bigger questions here, how do you think the epidemic changed the community, if it did at all? What did those changes look like?

JL: I don't know, I think I'd have to think about that for awhile. How did it change the community? You mean back then, or in the long run?

BK: Like, long run I guess. You've painted a picture of how it changed the community in a lot of ways during the peak of the epidemic.

JL: Can we come back to that question?

BK: Yeah, of course.

JL: I'm just drawing a blank.

BK: It's a meaty question.

JL: Yeah.

BK: How do you think the community dealt with the burden of care and support as a whole? How do you think people avoided fatigue and burnout?

JL: One thing comes to mind is the lesbian community, who were really at the forefront and amazing at helping gay men. And sadly, there's still some misogyny amongst gay men, back then too. But gay women were just amazing, came out and helped and did a lot for—question was how did people rally to it?

BK: How did people deal with the burden of support?

JL: How do you deal with the burden of support.

BK: Like the community, I suppose, more than individuals.

JL: Well, support groups were really important. Again, St. Paul's recognizing and funding a full-time social worker just to help people with AIDS, people with HIV, was phenomenal, because they did a lot of good work, not only for people infected with HIV, but for families. You know, families would come to visit, and parents would be freaked out. The social work support at St. Paul's was phenomenal, helping families deal with, dealing with not only HIV but often, again, with people coming out and having HIV. So, social workers rallied, doctors rallied. I don't know when Loving Spoonful started but all these different organizations started building up to get out there and help. The community itself? Well, lobbying governments and getting the word out. Yeah, not really sure how to—probably think of a lot of things later.

BK: We've definitely heard from other people as well that the lesbian community really stepped up.

JL: They did, right away. It's amazing.

BK: I guess they—

JL: And you know, they weren't directly affected, they were helping, you know. I hate to ask, but would it have worked the other way around? Would gay men have rallied to something affecting the lesbian community? I would hope so, but I don't know. They're very special. Very special. And some of the businesses rallied too, the gay businesses. They were fundraising things, and fundraising events, stuff like that. And I don't know when the first AIDS march or walk was, but a lot of not only community but the broader community came out and helped.

BK: That's great. And as a long-term survivor, do you have any advice for health professionals, I guess in terms of current prevention—in terms of how we can improve current prevention and or support efforts?

JL: Education, education, education. I mean, PrEP is out there, making it known that you do not have to get infected with HIV. You can do basically everything you want, great sex life, you can do anything you want. So, really getting the education out and getting the information out that you don't need to get infected. But I know it's still happening. And it's important to recognize that the medications do work if you take them – if you take them. And it's very simple, you just have to have the acceptance and know what you've got and know that it's something that you can very easily live with. Yeah, you know, to me it just seems so simple now. Maybe it isn't for a lot of people, but to me it just seems so simple. So, I could be totally off the mark there, because I might – I don't talk to other young people who are recently seroconverted or whatever, but to me it's – if you're living in this society, you're fortunate enough to be here, you have access to the proper medication, that's basically it. But I'm sure other people would say something different, but from what I've lived through, what I've seen, to me it's just so simple today.

BK: That bleeds into my next question, which is essentially what you've just been starting to talk about. Do you have any advice for folks who are newly diagnosed, or for younger gay men today who might not be diagnosed but are living in a time when HIV means something very different?

JL: Yeah, I hear you. And you know, I'm not—I'm not an expert at it, maybe I'm not the one who knows best how to advise them, even though I've been through all I've been through. Because I maybe don't know what it's like to get on PrEP, and stay on it, and maybe I don't know what it's like to be cautious of certain sexual activities still. So maybe it's a bit of warped viewpoint to say it's so simple. But I say to young people it's certainly dressed way different than what it used to be. That huge understatement, it's not a death sentence. It's something that's liveable, and definitely not something to be ashamed of. It's – you're either looking at preventing this particular disease, or you're looking at dealing with this particular disease. And that's what it is. And syphilis used to be a death sentence, so you know, we have different diseases over the ages. We have HIV around, there's no—there's nothing to completely stop it, we don't know of anything that can completely stop it for everybody. But we have the means to live with it, and live a good life with it, and uh, yeah. I guess there's a certain degree of self responsibility, and education, self responsibility, and I think there is still a sense of a need to be, to have a degree of responsibility for the community, other gay men. And still maintain the dialogue of HIV being here, you don't have to get it if you're—take some precautions, or you know, or on PrEP, but if you do, you don't have to beat yourself up about it, you can manage it and you can live with it quite well. You don't even have to give yourself a needle everyday, you know, it's a simple pill. Other people have diseases that are far worse to deal with.

BK: As I mentioned before we started talking on camera, one of the things that we're hoping to do is to generate some kind of intergenerational dialogue. Did I mention that? Maybe I didn't mention that.

JL: No, you didn't.

BK: Well, because YouthCO is one of our partners on the project, and so one of the things that we've been thinking a lot about is how can we bring the experiences of long-term survivors, for instance, into conversation with the experiences of young queer people today. But it's a challenging question, you know?

JL: Yeah, of how to do it. Well, communication, and communication, communication. Just talking, and, yeah, I think… It's a lot. Communication, education. But I think it's a great idea. And you know, I am very disconnected from gay youth today. I just don't have a lot of friends who are in that age group, and so I am, yeah, a bit disconnected. I really don't know how they're viewing it. It would be interesting to know.

BK: Well, we'll keep you posted.

JL: Great.

BK: I think I'm out of my more formal questions. We always like to ask if there's anything you wanted to discuss that we didn't cover, or anything you want to expand upon or circle back to that we might not have had a chance to talk about as extensively as you'd like.

JL: Hm… Nothing's coming to mind immediately. Probably will later.

BK: Yes, that's the way this tends to work.

JL: Yeah, I'm not sure. I'm thinking right now of how relevant it is. I don't know, but you know, just different attitudes that people can have or do have towards HIV. Because I was very fortunate to meet a wonderful man in the nineties, and I was of course positive and he was negative. This is way before PrEP and everything, and wasn't freaked out by having a relationship with me, and was fine with condom use and other people were just completely freaked out about it. And I remember this particular guy, who's still one of my best friends, in Germany, he was just here doing his PhD at UBC when I met him, so he was only here for – I only knew him for three years here but still a friend of mine. But what I'm getting at is, people had different attitudes, he was fine with having a relationship, a sexual relationship with me. But I do remember one time the condom broke, and I was the one who freaked, like totally freaked. I was just so terrified and scared and, you know, ran to the doctor the next day, and insisted to put him on some medication, and that was before PrEP. So, I guess I don't know how relevant it is, but just completely different attitudes of different people. There was no one way of dealing with this. You didn't know what to expect from interacting with other people.

BK: That is really interesting.

JL: And the fear that I carry around, as a positive person, not wanting to infect anybody. Yeah, I don't know what else I could say. I really appreciate you guys doing this. I appreciate it even more now after talking to you. Before coming in, I thought it was a great idea, but it's, kind of an honour to be able to tell the story and grateful that people want to hear it and make sure it stays there, somewhere. So, thank you, that's was what I want to say.

BK: Thank you so much, but I can honestly say that it's really a privilege for me to be able to hear your story.

JL: Thank you.

BK: So, I think on that note, maybe I'll stop this for now, unless there's anything else you want to…

JL: I don't think so, I don't think so. You know, I do feel—I'm surprised at how emotional I've gotten during this conversation, because I've talked about this many times over the years. I think the conversation we've had just put so much of it together, that it was a real experience for me to do that. So, I know I'm going to be thinking about this a lot after I leave here. And absolutely if there's anything else you want to ask me later on, I'd be very happy to have any other contact.

BK: Absolutely, and if anything comes up for you that you really want to share with us or with me, I’d be very happy to do so.

JL: Great, wonderful.

BK: Well, thanks again.