

## **“HIV in My Day”**

**October 8, 2019**

**Participant:** Laura Mervin (LM); **Interviewers:** Art Holbrook (AH), Charlene Anderson (CA)

**AH:** Would you please introduce yourself, who you are.

**LM:** Okay, my name's Laura Mervin. Uhhm, I am not sure what to say next.

**AH:** Well, what do you do, what do you—

**LM:** I'm retired and I live on Salt Spring. I retired from living in Vancouver and being a social worker, and working mostly with people living with HIV. And before that I was a family member of somebody living with HIV and AIDS who eventually died. And before that, I was an IV drug user. And so the--and I came out as a lesbian in nineteen-ninety. So between those three things I have been very involved with the HIV community although I am not positive myself.

**AH:** So uhm, where did you live before Salt Spring?

**LM:** I lived in Vancouver for about thirty years.

**AH:** Okay. So what was Vancouver like before HIV?

**LM:** Well I lived in Vancouver, by the time I moved back to Vancouver—I lived in Vancouver when I was really young—but when I moved back to Vancouver HIV was in my life because my brother had been diagnosed. He was a hemophiliac. And uhm I think, I'm pretty sure even before there was an actual virus to be detected that they knew that he had contracted it, like symptoms and so on. He was receiving the blood products, and many of the same blood products that you know people were getting all over the world. And we knew that there was problem pretty early on. I didn't believe it at first. It was denial. It was, you know it sounded so vague, it seemed like there was all kinds of room for I don't know, conspiracy theories popped up. Anything to make it not be true. So it took me awhile, I think before he had—until he had the actual test and the actual specific diagnosis of the virus before I really got it. Was pretty ignorant, like a lot of us.

**CA:** What year was that?

**LM:** I think, well he was seventeen when I knew, he was born in sixty-four so he was seventeen when we knew something was really wrong and suspected that that's what it was. And then I think it would've been maybe eighty-four, eighty-three I'm not sure the exact dates when he had the very specific diagnosis. And yeah it was no longer really deniable.

**AH:** So had you heard about HIV/AIDS before then?

**LM:** Mostly just vague stuff in the papers and you know this crazy thing that was—everybody was afraid of and I remember, who was it? Was it Vander Zalm back then—but I remember the politician, I think it was Vander Zalm—talking about quarantine, and you began to realize that it was actually really, really crazy out there. And very scary. At some point, I had moved into a housing co-op and eventually my brother and his partner moved in. And it was a really good kind of community in most ways. And then I was involved with the co-op housing confederation, and in maybe it was the late, it was sometime in the nineties maybe even late nineties. But we were talking about trying to set aside units for people living

with HIV, like a subsidized unit for people living with HIV. And it generated a lot of discussion in our co-op, and up until that point I would've said that it was a lot of really progressive, really kind people. And then we had a meeting about it. And then that generated more meetings. And people—neighbours—that I thought were intelligent, you know people who thought about things and had some awareness, were saying the most ignorant, terrible things. And they didn't know of course that they had somebody living with HIV right there. It was awful. It just, it really made me realize you know what people were up against. And just how, I don't know, the ignorance and the stigma, it brought it home to me in a way that nothing else really had. It was pretty, pretty harsh.

**AH:** How did you first learn about the disease?

**LM:** I think because of him, because of my bro—of John. Uhm I remember newspaper articles, but I actually don't remember the sequence of exactly how it went. But I remember knowing that this very heavy thing was hanging over my brother. And I wasn't in the best—I was at that, like when he was first diagnosed I was an IV drug user. So I wasn't getting a lot of good accurate information. Anything I got besides that would've been probably from the province or something, sensational headlines. But once—by the time that we knew exactly what it was I was learning it myself from the hemophilia society gave out lots of information, and from him of course I was learning a lot. And then the information that he was getting through community organizations and so on, and eventually I ended up uh—well actually I'm leaping ahead, kind of. Shall I just sort of meander here, or?

**AH:** You can if you that's—

**LM:** If you have a direction you'd like me to go, go ahead.

**AH:** No you dictate the direction here. I've got a series of questions here we're using here but you go ahead.

**LM:** Okay, good. So uhm, let's see, okay I lost track.

**CA:** I have a question. So in the early eighties, when you were an IV drug user was that a concern in that community?

**LM:** No.

**CA:** Or were you not part of that community?

**LM:** I was, and we weren't really talking about it. I mean there's a level of denial you have to be in just to survive as a drug user. Because you know that, I mean if you stop to think about it rationally you would know that you are at risk all the time. Death, or disease or whatever. And so you perfect your denial. And I don't think, the people that I knew weren't talking about it much. At that point I was still in Chilliwack. Living out in Chilliwack so it was more small town. And no, I mean, yeah no. I remember we were all, you know for years we'd been affected by non-A non-B hepatitis, and it was before they had a diagnosis for that one—a test for that one too—and the same thing, denial. I mean we knew what it was but you couldn't afford to, you couldn't afford to worry about it enough and still survive. So, yeah.

**CA:** It takes a lot of energy.

**LM:** It takes a lot of energy, and it's scary enough as it is. I did contract hep C way early on, but somehow I like—I had, there was about a year where I am surprised that I didn't contract it. And when I cleaned

up and then eventually started working in Vancouver, well at AIDS Vancouver there were a lot of people that I had known coming in. And then less, because a lot of them died. But in a sense of like how—how did I miss that, I don't know. And then I had a son in nineteen-eighty-seven who also had hemophilia. And he was really lucky he was within a very short period of time where he would've been taking exactly the same blood products and he would've been exposed. So, yeah.

**AH:** So you learned about it at that point especially with your brother—how did you respond to HIV when you learned about it?

**LM:** Well at first, because of the denial I was angry. But I was angry in this weird confused way that people were spreading—fear mongering. Like I truly just refused to believe it. But as he began to get sick then—I felt powerless. I just felt the most powerless I've ever felt. You know there's no—there's no way I knew how to help, at all. And he was—he was born with hemophilia, he was a severe hemophiliac which means that his joints were badly compromised. That his mobility was poor. When he was a little kid he was always in braces and hobbling in wheelchairs. And as he got older his hemophilia—well it happens sometimes with hemophiliacs when you're young, you're a kid, you're a clutz, you're constantly re-injuring yourself, but when you get older sometimes it gets a lot better for the guys. And it was getting better for him. And like I was watching—I have this very clear memory of him playing hackey-sack, you know with his legs going like this and thinking, oh my God look at him, he's okay. But then also knowing that, you know now he was dealing with HIV which was on its way to becoming AIDS at that point. And it was just so—then I was angry too, I mean really angry too, it was so unfair. Yeah, it's a horrible, nobody should ever, ever have had to deal with that. And I'm grateful that I've been around long enough to see how different it is and how many things have changed. But you know, like all of us we lost too many people, that didn't make it.

**AH:** So how did your—your identity, or your identity as the sister of someone with it I guess, shape your experience of the epidemic?

**LM:** Well I think because I end up coming at it almost from three different ways, it wasn't just as being a sister. Because that—you know by the time I accepted what was happening with him I realized what was happening with other drug users, in the gay community I had come out as a lesbian right around, like just after this. No, no it would be before he died actually—two, three years before he died—four years before he died. And uh, so I was kind of aware of it from several different directions. Yeah, for him it was the blood products. And there was a thing happening within the hemophilia community as well, there was that older—the majority of the older guys especially the severe hemophiliacs had HIV. But the young ones, like the young ones were being born with hemophilia, they were getting clean blood products and so they weren't. And then there was this whole kind of division within the hemophilia society of the folks that, you know there were parents with young children with hemophilia, and they wanted the focus to be on hemophilia. But then we had all of the people who had been there all along who were positive and AIDS was like this enormous issue. And then there was the whole compensation—anyway it created a lot of divisions within the hemophilia community as well, which was quite painful. And then because I had overlap with other communities, there was that whole kind of thing, you'd see it in the news about the undeserving, or the you know, the innocent victims. Everybody was an innocent victim! There was nobody who wasn't an innocent victim, and yet you know some people had this niche that made it feel—that made it seem like it was worse, somehow. And it wasn't worse. And then there was the fight for compensation for the people with hemophilia. I mean I think

compensation should've happened, I think that was important because there was a lot of wrong doing. There were a lot of people who wouldn't have become positive if people had acted correctly, with responsibility and you know, ethically. But it also—I know what I watched of my brother's last years is he was fighting all the time, he lost a lot of living based on that anger and that battling. It was—I've always felt really sad about that.

**AH:** But then you went to work, did you say for AIDS Vancouver?

**LM:** Yeah I was in—I had gone back to—or gone to university and I was taking political science when he was getting really, really sick. And uhm—and I—I was having a really hard time, and then when he died I dropped out. And at that point I knew I needed to do something. Like I just—I said before how helpless I'd been. So I decided to go into social work. So I switched over from that and did my degree through UVic. And my first practicum was at BC PWA, Positive Living and then at AIDS Vancouver was my second practicum and then I continued working there for years. I think thirteen or fourteen years.

**AH:** Let's wait a moment while planes make too much noise here.

**LM:** They do.

**AH:** They're coming to the house.

**LM:** It does sound like that, fortunately it only happens a few times a day. Yeah you kind of get used to it, like trains if you live near train tracks.

**AH:** There it's gone quieter now. Uh, some of these things you've already answered but uh—

**CA:** So what did you do at—so you were at AIDS Vancouver—what did you do there?

**LM:** Yeah I was at AIDS Vancouver, I was a case manager there. And we were called case managers at that point. And so it was a whole combination of, advocacy comes across as one of the things I did the very most. Because you know so many people like even if you were coming from a solid place, odds were pretty good you lost your job and you couldn't work and all that, and so things were falling apart. And then there were a lot of people that were already vulnerable already because they were marginalized, and also need a humungous amount of advocacy. But there was a counselling component, there was like referral stuff, back in those days it was like people were really afraid to take the medication, with good reason. So a lot of it was trying to help people in their process of figuring out whether to do it or not. And creating community. I mean between Positive Living and AIDS Vancouver and other services and other kind of organizations, people were coming together. And you know, not so isolated. So I saw that as a big part of my job as well.

**AH:** So how many hemophiliacs were involved with AIDS Vancouver?

**LM:** Well actually not that many. Partly because of the compensation thing. So a lot of times when we saw people at AIDS Vancouver, like a lot of that advocacy would be around loss of income. And so for the hemophiliacs there wasn't as much of that. So they—I mean and the hemophilia society provided an awful lot of what people would have needed as well. Like really good connections, I mean they were connected with mostly, well actually I knew some of them up at Oak Tree, but a lot of them were at St. Paul's, what IDC eventually became. And they didn't tend to have quite as many needs, I think some

people would come down there when they were initially diagnosed, to go through some of that, I don't know, just dealing with new diagnosis. But a lot of those people also had the IDC up at St. Paul's, so there were social workers there. Wonderful ones.

**CA:** What's IDC?

**LM:** Oh—what is it? Sorry, it's out of St. Paul's, it's the infectious disease centre? Clinic? IDC: Infectious disease clinic. Funny, those initials just sort of take over and that's what you think of them as. But they had a really great program, and some amazing social workers and inter-disciplinary group. So a lot of those needs got met too. And they would refer people to us but really often it was around issues of like legal kind of stuff, or financial issues, and so on.

**AH:** Did you uh—were the intravenous drug users—IDU's here instead of IDC's—were they beginning to come into AIDS Vancouver at that point?

**LM:** Oh yes. A lot.

**AH:** What dates are we talking about here?

**LM:** I started at AIDS Vancouver in—well I started at I was at Positive Living in ninety-six and then at AIDS Vancouver ninety-seven, yeah ninety-seven was when I started. So yeah, there were—we had the main population was gay men, and then IV drug users, more and more and more. And then that's when we started seeing the women more. And as I worked there, there was more and more women coming. But at first we saw way more men.

**CA:** So you've seen the tides shift over the years?

**LM:** Yeah, lots of shifts. That's for sure, it's a different world out there.

**AH:** So uh, this sheet of questions we have takes a leap here, what was the government response, what did that look like at that point?

**LM:** Well the first government response I remembered was Vander Zalm wanting to quarantine everybody. But, that was way back, the government response, I think the government responded when they got pushed really, really hard. And maybe I'm being unfair maybe they were doing things more than that, but it seemed to me like it took every bit of energy and push and solidarity to—and outrageous things, ACT out—to really make people realize that they weren't dealing with just statistics or them. It's, yeah, pretty terrible. And then just in practical terms, getting people the supports, like financial or other supports that they needed, was changing. When I first started working at—well when I was up at Positive Living and then still when I was going down to AIDS Vancouver at that point people had been able to get provincial disability and also CPP and have enough to actually live on. And they were clawing that back when I started, so we spent a lot of time battling, and we lost the battle they clawed back the CPP and people were living on—I can't remember how much it was a month then but it was very little. I bet you it was seven something. And then you had to jump through more hoops to add another hundred for this or another forty for that. Too many hoops. Like it was not the kind of hoops

that people themselves could leap through. You know, there was no way to access all that without having some kind of support. It was really crazy.

**AH:** So was that a big part of your job, helping people fill out the forms and battle their way through the bureaucracy?

**LM:** Absolutely. Yeah, I did more disability applications with people than I can even remember. And I always felt bad about that, because that is a painful thing for people to go through. You have like two, three hours of interviews. Maybe you break it up, maybe you have it two or three times in a row, and you are asking people to talk about the very worst things in their lives. And everybody had to go through that, and get it done well, if they wanted to get on disability. It's a horrible thing to put somebody through. I mean—I learned so much from people during that process, but you know, the outcome was good, it was good if people actually got what they were going after. But the process was humiliating and depressing. And degrading. And I had to help coach people to say how bad was it, you know like, are you able to walk from room to room without diarrhea. You know like awful things that nobody wants to talk about, or acknowledge, for me. Yeah it was hard, but in some ways maybe it wasn't always terrible for people in the long run because they'd actually said it all out loud. I don't know. A lot of those people that was when they were newly diagnosed, and a lot of them got really involved and became powerful leaders. Yeah, just strong folks living their lives.

**AH:** What about the response of the medical community?

**LM:** That varied. The GPs, people that were only seeing GPs and had not yet connected with one of the clinics, the HIV clinics. It could be really bad. I mean there were people who had great doctors, but ignorant mostly. You know they just didn't know. And I think maybe that's part of the reason, but other doctors were rejecting patients. They were saying I can't take care of you, or you need to go somewhere else. Then as the population became more and more IDUs, then there were more doctors saying oh no, I can't deal with you. And the excuse was that they were using drugs, or drug seeking, or chaotic they couldn't—just so many excuses. And again, thank god for those clinics. It was a safe place for people, mostly. And it changed everything, but yeah, I wouldn't have wanted very many people to have to have gotten their care through GPs.

**CA:** What about the hemophilia community?

**LM:** Well we had, mostly the hemophilia community like we had the hemophilia doctors, and the hemophilia doctors very quickly realized that HIV was, you know it was part of their job. Even if they weren't infectious disease folks. I think they worked really well with the infectious disease folks, you know with the clinics. I think they did quite well, but they were—there weren't a lot of them. You know it used to be that you would bring your kids, you know your little kids with hemophilia down from wherever you happened to live and you would have an all day appointment, and then you would go down every three months or something like that. Six months for follow-ups depending on how your health was. So we weren't super staffed, there wasn't a lot of resources there. So again I think they worked really well with the clinics.

**AH:** So how did you see the public reacting from when you were becoming involved?

**LM:** I would've said that I thought, you know up to a certain point I would've thought most people weren't that ignorant. But as I was talking about in that co-op meeting, and then many other things after that, I couldn't believe that just sane, ordinary, intelligent people were ignorant. And it was ignorance. It was ignorance that was worse than anything I think. There was—the ignorance fed the stigma. I mean I was ignorant at first. I—this isn't something I talk about very often—but when my brother's partner became pregnant and he was positive, she didn't contract HIV, and the people at the hemophilia clinic talked to me about it and said no, if she doesn't have it she can't pass it on. But in my ignorance I just, I thought well they don't really know very much, so she shouldn't breastfeed and maybe she shouldn't have the baby. Like I was just as ignorant as everybody else, and I'm so ashamed of that now, of the stress that I put her through talking to her about it, and him. Yeah, it caused a huge rift in our family and I felt like I had a lot to make up for after that.

**AH:** Are you still in touch with that person?

**LM:** No, I'm not. She-she—kind of moved away, they split up and she moved away from the family and we have not, haven't been in touch. I used to see her sometimes, because we lived in the same—she also lived in the co-op for awhile after that. But I've recently got in touch with her daughter, with my niece. And uhm, that's been an amazing experience, it's been really wonderful. But I know how much she was hurt and her mother was hurt by all that, and there was more, stuff that wasn't to do with that. But still, that was a piece of it, that was a big piece of it. It was another reason why I felt like I had to get involved and do things right.

**AH:** Is there a reconciliation in the offing?

**LM:** I don't know. I hope so.

**AH:** Reach out.

**LM:** Yeah, I'm trying. Some kind of hurts don't go away though, or they take a long time.

**AH:** Do you have some examples of the kind of ignorant comments that you heard?

[30:00]

**LM:** Ugh, well aside from what I was telling you about in that co-op meeting, it was just the casual comments people would throw off. Oh yeah, look at somebody with AIDS. Or you know like the fear, all that fear stuff about well I don't want my children in school with somebody whose parent has AIDS, or has AIDS themselves. Nobody ever called it HIV it was always AIDS. And such a derogatory term like you could hardly hear it without it sounding like AIDS! As opposed to Acquired Immune Deficiency Syndrome, you know AIDS. Like it just, the tone was so terrible. And the way it became so casual, like kids in school yards. And then later I worked with women and families, and you know all these children with HIV and what they went through. Like god forbid a kid should play soccer because what if she cut herself and there was blood and everybody else got AIDS. And this is from intelligent people. I remember when I was working at AIDS Vancouver having discussions or like trying to advocate for people with Ministry of Children and Families and even some of those folks like talking to social workers who were talking about removal of children from the home because the parent was positive. And just like not being able to get through to them. How can that be? They're educated, it's their responsibility

to understand, to get educated, if they don't know something they need to find out. And yet even at that late date. And that was probably into the—it was very late nineties, and early two thousands. And even later, maybe not quite as blatant later, but it was still there later.

**AH:** Were children removed from families?

**LM:** Yeah. Yeah. I think the excuse could've been, you know it could've been various reasons for excuse because a lot of them were from—a lot of the people I'm talking about had some kind of marginalization happening anyway. A lot of—oh god so many first nations people—you know about that, about how many children were removed. Well that can absolutely be a part of it. Oh she can't care for her children because of this, oh well she's not looking after herself so she's at risk to infect her children. And so on, and so on and so on. Like who—who is she bringing into the home, somebody else with AIDS. Like it just—I don't want to say they were all like that, they're not. There's so many good people out there also fighting, and as—like most of us as we became a bit educated about it and learned more maybe we stopped being quite so ignorant. And hopefully that meant that we felt responsibility to do something. You know to change, and kind of help other people change.

**AH:** So you were doing this in your advocacy role at AIDS Vancouver?

**LM:** We were actually case—it wasn't just advocacy, advocacy was a piece of the work we did. We were also kind of coordinating care, and connecting people with other positive folks. Yeah, and the—I guess it's later that this came about—but the sort of early variety of leadership stuff, like people would get involved. Like Positive Living was amazing because the board members, everybody was positive and people were moving up and finding their power. And they were creating a way for that to happen. So we were quite connected with that, although AIDS Van—well never mind that.

[laughter]

**LM:** Old time organizational history. Well actually we were in the same building, that was the funny thing. But you know we came—different focuses, different mandates.

**AH:** You guys are on a private joke here. Don't bother to get into that.

**LM:** You know rivalry, inter-organizational rivalry stuff is the simplest way to put it.

**AH:** You know, I was involved with VARCS in Victoria, in the bad old days when it was VARCS and PWA versus AVI, or AVI and PWA versus VARCS depending on the time. So yes, I'm familiar with that kind of inter-agency rivalry.

**LM:** You know I think in most non-profits you're gonna find that kind of stuff, we're always underfunded, we're always—there are just so many reason.

**CA:** There's only so many dollars to go around, and so many things that overlap.

**LM:** Yep. And the people that were involved in both—probably all those organizations—we were keeners. Nobody was there just for a job. I don't think there was anybody that came and just put in their time and left. So we had strong feelings about everything and things were intense. So intense. You know the people we were working with were dying—they were dying, right? It was—yeah, a lot of intensity.

**CA:** Lots of very big feelings and big reactions.

**LM:** Yeah, and pain and anger that's kinda underground and it's going to come out somewhere.

**AH:** Were you personally involved with any—I think you've gone through a number of my questions here, shooting through this—were you involved with any aspects of AIDS activism?

**LM:** Harm reduction. It was to do with AIDS, powered a lot by AIDS. When harm reduction came out, I can't remember the year now but that whole—it was an exciting time, it was really exciting. We were—I remember there was a die-in. But we were meeting on a regular basis to try and put in harm reduction facilities so that—you know now there's safe—safe fixing sites, I can't remember.

**CA:** Safe injection sites.

**LM:** Safe injection sites thank you. But yeah, like various things like that. But back then there was nothing. And again there were things like people getting turned away and not getting meds because they were using drugs. And there was a lot of room for activism. And a lot happened in that Vancouver agreement, the four pillars Vancouver agreement.

**CA:** What's that?

**LM:** Well that was—again I can't remember the exact date—but that was when there had been a lot of this, there had been an awful lot of activism happening, a lot of meeting. VANDU was very active in it, do you know Vancouver Area Network of Drug Users? Yeah, okay so VANDU was very active in it, lots of the street nurses and those organizations, people from AIDS Vancouver. People from all the organizations and just people who came who weren't affiliated with anybody but knew that what was happening was wrong were involved. And it made a huge difference, just even—it was such a triumph even getting free needles that we could give out. And it was really challenging at first, the hoops were enormous and the resistance was enormous. Just for people to have something safe to use so they won't end up with HIV or hep C or any of that. Like that shouldn't have been an issue, and it was it was a big issue.

**CA:** So what were the four pillars?

**LM:** Oh, can I stop and Google? I'm just trying to remember, it would've had to do with, I'm sure there was legal, medical... I can't remember. It'll probably come back to me in a few minutes when we're talking about something else.

**AH:** I'm struggling to get them. I remember that too, but I can't remember what they were.

**LM:** It was a long time, it's been almost thirty years ago I think. Nineteen—yeah it's been a long time, but it made huge changes, enormous. And it wasn't just in Vancouver, it was something that was coming up all over the world. Like we had people from Frankfurt coming here and talking to us because Frankfurt was very progressive, Australia was amazingly progressive. More recently I think Portugal, but almost everywhere was more progress—well almost everywhere is more progressive than the US—but many of them were way more progressive than we were too. So bringing those models in and having people. Was it judiciary—ah, it might come.

**AH:** Never mind. We'll sit here and scratch our heads. So how did the community—define as you will—deal with the intense burden of care and support, as well as people dying? What did you see?

**LM:** I think it was pretty amazing, really, I mean if we're talking like outside of the official organizations. The volunteers, the people that were caring—lesbians! And you know, that was another way that I was

hooked in there. But you know lesbians have been very, very active right along in terms of fighting, caring, whatever. But I remember when I was first at AIDS Vancouver and we had a buddy program, and we had people who went into the homes and stuff, but so many people just step up and want to do it, even if they weren't already connected with somebody who was living with that. It was pretty amazing really. Like within the community. And bit by bit people were learning, you know people who hadn't been a part of it or hadn't you know, understood what was going on. Anyway bit by bit more and more people were connecting.

**AH:** So how has the epidemic changed the community?

**LM:** Changed the community...

**AH:** Or define it—you're involved from several different communities so how—

**LM:** Well, I'd say the empowerment piece, I'll start with the real positives. The empowerment piece has been huge because I think that every year there's more realization that people with HIV need to do things for themselves.

**CA:** [inaudible]

**LM:** What's that? Oh, by and for themselves—

**CA:** [inaudible]

**LM:** Oh you found it, the four agreements? What were the four pillars?

**CA:** Prevention, treatment, enforcement and harm reduction.

**LM:** That's it. Yes! It was awesome. It was an amazing triumph, it really was. I am so proud to have been just a tiny piece of that and to have watch it all happening—

**CA:** That was two-thousand-fourteen.

**LM:** Was it that late? The four pillars was started in twenty-fourteen? No.

**AH:** No it started before that. Yeah.

**CA:** It started in two-thousand.

**LM:** It was the late nineties when we working and working towards it.

**AH:** That sounds about right, yeah.

**LM:** Yeah it was big.

**AH:** Anyway when you were rudely interrupted.

**LM:** So changes in the community. So changes in the community... Well if I go to now I'd say I ended up working at Oak Tree Clinic for a lot of years after AIDS Vancouver, and so when things had changed really quite radically. And we had so many people coming in who were diagnosed really fast. And got on treatment really fast, and who's lives are completely different than the people that I had known and all along. Because you know HIV—and it's not right across the board of course—but there were people who didn't lose everything when they became positive. Who didn't have to give up their previous life

and start all over. People who found a way to deal with it medically, and ideally you know in terms of losing the isolation being with other positive people but it wasn't as essential for them anymore.

**CA:** What's Oak Tree?

**LM:** It's an inter-disciplinary clinic at BC Women's Hospital. It's outpatient. And it has—we have doctors, NP's, pharmacists, nutritionists, social workers, outreach workers, counsellors. Just kind of really a lot of things right there, and a lot of super caring, super devoted people. And they've been around for a long, long time. I think we celebrated was it twenty-five years, a twenty-five year anniversary when I was there in I don't know, maybe twenty-twelve, twenty-thirteen, I don't remember the dates so well.

**CA:** Was that for anybody who was positive?

**LM:** Well it was women and families, so it was more specifically for them. But certainly during the time I was there, partners and husbands were being more and more involved. And some of the hemophiliacs had actually gone to that clinic right away, I think that they were seeing one of the doctors, one of the founders of the clinic. So they were kind of grandfathered in, so finally, I was actually seeing the hemophilia folks as well when I went there. I don't think that was what you asked me though, you asked how the community had changed?

**AH:** Yes. And you were involved from several different communities as you've mentioned. How was the lesbian community changed by it?

**LM:** I think it's possible that there was just a level of awareness out, and involvement and commitment that wouldn't have been obvious if you weren't from the gay community, the IDU community to some extent. Although I think for a lot of those folks it was leadership programs like there are now and so on, really help people know that they have something to say. And you know they have something to offer in a way that a lot of those people wouldn't have had then. I think I'm still off topic though?

**AH:** No, you're doing okay.

**LM:** Okay.

**AH:** How about the intravenous drug using community has that changed?

**LM:** I think that has changed too, and that's partly because of harm reduction. Like VANDU, Vancouver Area Network of Drug Users were quite extraordinary. In my experience there was nothing like that the years I was using, you know we'd go to our methadone clinics or something but there was no kind of common purpose and ideas that we had some rights. And you know, that we had a right to be safe and you know, respect. People using drugs don't go do criminal activities because they have other options. You know if we could've worked we probably would have, and some people did and they managed it. I didn't. But I think that's changed a lot, there are lots of IDU's in leadership positions now and making things happen. Like making important things happen. That would not have happened back in those days, before VANDU. And I'm sure there were other organizations like that in other places but they were brand new to me, and it had never occurred to me that as an IDU I could step out and be listened to. You know have something to say and be listened to. So that's really extraordinary.

**AH:** So while on the theme of communities and how they've changed, how about the hemophiliac community?

**LM:** You know, I feel like the hemophiliac community kind of back-tracked from being so involved with AIDS and HIV. They called it AIDS then. The children, so many children are born in—I don't want to generalize but—suburban communities, rural communities and so on. And those parents, they are fighting for their kids for the hemophilia and that's what they see. And I'm sure that some of that stigma stuff was happening when that community started dividing so much. It's a sad thing to say but in the time that I was there—involved with the hemophilia society—it went from being a place that was advocating, that was doing so much hands on work for the individual hemophiliacs and as a group, like internationally and nationally. That—there was a big division. And I think that the last time I was involved with the hemophilia society it had come down to being a lot more about picnics, like community get-togethers and things like that. And not too many of the original hemophiliacs were involved, and certainly not so much the ones with HIV. Some of them are still around, a lot of them died. And I think it was a big loss. It was something—I didn't take my son to very many of those things because it didn't feel relevant anymore. It was a nice social organization for people living with hemophilia, a way for parents not to feel quite so isolated, for kids to maybe meet other kids with hemophilia. But it didn't have much to do with HIV at all in any way. The board members were mostly parents. It's—yeah it changed, it changed a lot.

**AH:** Once there were safe blood products they just sort of eased away from that and left that to the gay community and the IDU community?

**LM:** Yeah. I don't know if that's the same nationally or internationally, but locally, like in the BC Yukon region that was my experience.

**AH:** Right, yeah. Well that other question—I'm just shooting through them here—how has your perspective on HIV and prevention changed over time?

**LM:** How has it changed... I'm not sure it has changed. I mean there were always obvious things that could help with prevention, you know the obvious specific ones of course, you know clean syringes, condoms and all that. And then from my perspective as a social worker there's poverty issues, there's mental health issues there's all those—dealing with those are all parts of prevention. And I mean that, we thought of ourselves—at AIDS Vancouver—as being a part of the move for prevention, because of all those foundational things. Now, I guess the fact that if you're undetectable you're not—nothing's going to happen. You know prevention is less an issue when more and more people are undetectable, so the focus turns to helping people get to that place. And getting to that place yourself if you're a positive person.

**AH:** But what about awareness for people who can contract the disease now, that's still happening, even as many people become undetectable, what happens there?

**LM:** Do you mean the people who are being diagnosed now in terms of prevention?

**AH:** Yeah and you have a population's becoming increasingly comfortable—if that's the right word—with living the disease, but other people are coming along, and many of them sort of ignorant because of the brouhaha of the eighties and nineties—

**LM:** Yeah exactly we're saying it's okay now.

**CA:** It's not sexy anymore.

**LM:** No it's not sexy anymore, no it's true. I suspect the ignorance is back in the youth, a lot of young people in particular, maybe the awareness never quite got there. I mean there are way more older people being diagnosed now who are completely shocked that they have it because they didn't fit any demographic that—they weren't IDU's and they weren't gay, and they weren't hemophiliacs so, that couldn't happen. Yeah the message still has to get out there. I was a little worried when the message went so publicly to you know, it's not an issue anymore. Because I certainly worked with and met a lot of gay men who, especially the young guys, who got that message and think oh it's alright, I'll just take a pill. Not so simple.

**AH:** I think it's been quite an uptick the people that are coming into PWA and AVI and so on, there's quite an uptick in the number of cases that have shown among young people.

**LM:** Among young people in particular? Yeah it's true, and young people oh, it's really hard to be a very young person with HIV.

**CA:** There was a pod of diagnoses at last year at UVIC actually.

**LM:** Oh was there? Wow.

**CA:** Quite something. I have a question, because I know where you worked, at Oak Tree specifically, how did you work with all the different cultures, because I know there's a lot of different cultures and ideas, and ideals, of people that come into Oak Tree.

**LM:** You listen really, really, really hard. Sometimes you don't even have a language in common and you listen really, really hard. I learned stuff from all those people. Like you have to. You have to be open in figuring out what's happening, what are the perspectives from within that culture. You know whether it's the perspective on HIV itself and what it means, like so many people from—I'm not saying this isn't the case for Canadian born folks, but there's so much shame and so much sense that I'm not worth it anymore, I can't ever have anything again because I brought this shame. From a lot of cultures, that one crosses quite a few. So trying to find ways—well again it's connecting people, connecting people with other positive folks and seeing what can be accomplished and how much worth that you truly do have, no matter what. But also there is more kind of complicated stuff about how health works. Like I mean I think we've gone to a focus on healthy living, on—oh not sure how to say this—maybe it's a more science model, but just that thing where there's a health issue and you figure out, you get all the diagnosis and you do all the medical stuff and then if you do this that will happen. One of the things that seemed really hard for people to do is—some cultures—was have a sense that once you start you have to continue. Because as soon as it seems better, and this is like a perspective, like a cultural perspective on how medicine and health works, but the idea is if you're okay you're not going to keep taking something, you're not going to keep going. So if you're feeling okay why would you. And so lot of people have a really hard time staying on the meds until they get sick, and even then, it's hard for some of them when they get better. So it's kind of up and down and up and down, and you lose ground every time you do that, so people get really sick. Well I'm generalizing so much here.

**AH:** Well of course.

**LM:** But yeah. And people who were just so isolated because they couldn't—like people couldn't tell their husband and had to find ways to hide that. Or children. You know mostly people don't want to tell their children. Or it's hard to pick a time, like when are they old enough to understand, things like that.

But if you've got the added barrier of that huge—like basically you're dead in the community if you're positive—you add that to it, and that's just I don't know—crisis after crisis. Like when it comes out it's a crisis. One of the things I used to do at Oak Tree is help people strategize like how to tell. You know how to tell their families, how to tell their children, how to tell their friends or their workplace. Depending on where they were at with that. Hard, hard thing.

**AH:** Can you give an example of the kind of strategies that you developed?

**LM:** Well, it's not so much that I developed because I would work with people using their—like what they came with. But also like a little bit of really plain, simple language information that they could present to people. Kind of going through like a role play, kind of thing. Asking really stupid questions. Like when somebody asks you this stupid question, is there an answer? And there are some answers that are you know kind of universal, but a lot of it's pretty personal to the person. And I worked with so many refugees who, you know it wasn't just their families it wasn't just all that, it was even whether they could even stay in Canada. So not, like depending on what kind of a refugee you are, if you're a convention refugee so you've already, like all that is clear before you come here it comes through the United Nations, like UNHCR or something then you have some backing and some support. But if you're claiming refugee status and you don't have—and you do have HIV—going back is a death sentence. And people are constantly at risk of going back, and terrified. And you know, I've gone with a lot of people to the review board, the immigration, refugee review board. And people get kicked out, people are going back to places where there's no medical like we try and make these arguments—anyway, health arguments and so on. I know people who died. Who went back and died. And people who lived in fear, for a lot of years. And people who couldn't get medical care. Jason Kenney, in his infinite wisdom when he was the Immigration Minister, started cutting any kind of health stuff except for immediate prevention of infection. So they would cover things like HIV meds, but they wouldn't cover say, your heart meds or your epilepsy meds or whatever. All the things that will probably make you even more vulnerable. It was unconscionable. And there was a lot of activism around that too, and a lot of medical people were involved with that activism. Because it was brutal, and it was killing people. So that got better, thank god. Got the man out, and change of government. It's better. It's not perfect, but it's better.

**CA:** Did you already ask about the caregiver burnout?

**AH:** Somewhere in there I think we covered it, but it kind of got slid around.

**LM:** Yeah, not so much the burnout I think we talked about the caregiver stuff a little bit but not so much the burnout piece.

**CA:** So what did you do, what did you see other people doing to keep going when you're watching people being turned away and dying because of lack of care—

**LM:** Mostly you just keep fighting. I think most of us went through some level of burnout, but we were so passionate about it. I mean it just mattered so much. Yeah, I mean when you get to know people who are living with this, there's no way that it's them, it's us right? It's all us, and you're losing people and you're watching people suffer. And it can't help but do something to you. I know, I wonder sometimes actually I was raising—my older son had moved out—but I was raising a young son during a lot of this time, and I carried a weight around me, and a darkness. An awareness of how bad things can be. 'Cause

it wasn't just HIV, it was all the HIV and then all the ways that poverty affect that or sexism or discrimina—you know so many different things. And I did carry it. And I think I shared too much. Like my son grew up in a world that was heavy, and unfair. And I wish I—I wish he hadn't. But—like I was the one who was there seeing the triumphs too, right? Because there are triumphs. And that's what keeps you going, all the time. The triumphs, and the people that you meet, like these strong brave people who maybe didn't start out strong and brave but had to get that way, right? I didn't think I was going to do this.

**AH:** We work to get people to do it.

**LM:** Skillful use of that question this time.

**AH:** It's part of your job.

**LM:** Yeah I—you just keep going, you keep going and you do the very best you can. I ran for along time, I would run after work and that would help lighten things.

**AH:** That's here from yesterday.

**LM:** I didn't think I would need it, I was going to tidy it up and then I just left it there. I would not have traded any of that though. I mean there are things that I would love to have done differently but I would not undo any of those years, or have not known any of those people. There's some wild folks, just wild. And it was mostly a privilege to know most of them it really was, you know barring a few people I would've like to have avoided I gotta say, but—

**AH:** A few jerks in every few.

**LM:** A few. But—

**CA:** Makes the journey more flavourful.

**LM:** It sure did. No, I wouldn't give it up at all. And of course—I mean from the time I was really, really young it has been a part of my life. When John—my brother was nine years younger than I am, he was diagnosed when—well we knew about when he was seventeen, so how old was I? Anyway I was young, I was in my twenties. And then friends, and my partner now even. It's been my world, and I feel more connected to that community and that world I think than any other one, really. Yeah.

**AH:** Just a couple more questions here. Do you have any advice for health professionals, in regards to how current prevention or support efforts can be improved?

**LM:** I don't think I do, I don't—I mean I think about youth and how to get that message out and how to make it meaningful, and I honestly don't know. I mean Oak Tree is trying some really interesting, I think partnerships with YouthCo and trying to have really a lot of youth-focused events and clinics and so on, to make it more accessible, more you know, something that the young folks will buy into. And that's treatment actually more than prevention, I suppose. But it's hard. I've been away from there for about—oh jeez—it's almost four years now, so I'm not sure what's happening right now with that. But I know that they were moving in that direction, but I wish I had more ideas. But the message has to be gotten out, the stigma's got to be dealt with, but somehow, somehow there has to be support in there for kids to know—like you don't know when you're a kid, like in terms of prevention you don't have experience, like you're invulnerable nothing's going to happen to you, so why you would go out of your

way and do awkward things like insisting on a condom when you're in the middle of something amazing and wonderful and you're invulnerable and you're young. I don't know, I really don't, I mean I think—no, I wish I had more to say about that. I might've four years ago.

**AH:** Do you have any—this one probably relates a bit to that one but—do you have any advice for future generations who have not experienced the epidemic? I mean there's gonna be another epidemic sometime it'll be completely different from HIV.

**LM:** Yep, there is. Mobilize. Mobilize. If you've got the capacity to get together with the other people who are doing that, that is how you are gonna make it work. That is how you're gonna make change. And if not, you need allies. I don't know where you find the allies, but you need them. I mean in this case it was gay men and then it was lesbians and then vari—you know other gay men and people within the community, that were pushing, pushing, pushing. In the future generation, I'm not sure. But get together. Don't be alone. Like you've got to be a part of something. The HIV movement has been so far ahead because it was a movement and it still feels in a way like a movement, and I think that's why people, like in the places where I worked people who were not living with HIV were so connected. Because it's not just a disease, it was a movement. And I think that's what it has to be if something like this comes up again. Yeah. Mobilize.

**AH:** And is there anything else you can think of that you want to say?

**LM:** I think just that it has been an amazing thing to have been involved from so far back to know and have seen the changes. And to know so many strong powerful out there functioning in the world people living with HIV that it doesn't have to be the primary identity. It is a part of who people are. It should've been like that all along, but I'm not sure—I know it hasn't been for people who weren't living with HIV, and even for people living with HIV. I think it's pretty hard to—at first—to see yourself as separate from this thing. This virus.

**AH:** Thank you, thank you very much.

**CA:** It's awesome to get different perspectives.

**LM:** It totally is, it would be, I can completely get that.

**CA:** There's so many different people involved.

**LM:** And there's so much going on, like it was such a huge thing. So many different things that were going on too, and different people have little pieces of it. And this is kind of creating the overview, right?

**CA:** Well where we were earlier today, two gay men they have completely different—and very well educated—completely different perspectives.

**LM:** It's amazing. You know I remember when the IDU community and the gay community and it was tense at Positive Living, not AIDS Vancouver, but that was a tense time because there was—are we still filming—okay, because there was the sense that it was gay folks that were part of that movement at first, it wasn't everybody else, it certainly wasn't IDUs to begin with. And they had managed to get some of the basics, some of the things that they needed and they didn't necessarily want to have to share all of it with people who hadn't been a part of that. And I don't mean because of selfishness but simply

because of a sense that again, scarce resources. And how are they going to cope with all this. Plus, there's the stigma of the IDU and all that too but—

**CA:** There's stigma within communities.

**LM:** Absolutely, way within. And the divisions. Oh ethnically as well, like different new Canadians different new folks from different places, similarly. But watching a board of people with two or three IDUs on a board with well-educated gay men, less educated gay men, just a whole range, right? And then eventually women. Wow that was a concept, women.

**CA:** I've been on that board.

**LM:** Wild. Just—pretty neat when it's working. Pretty amazing when it's all working.

**CA:** And it's interesting to watch it implode and then grow back up again.

**LM:** And grow back up stronger, stronger and better I think, for sure.

**CA:** That was one question, do you think that HIV has made the gay community—or any of these communities affected by it—stronger?

**LM:** Yeah, oh yeah I would say so. Especially the gay community and the IDU community. Because I don't think the IDU community would've come together if it wasn't for the virus. I really don't think so. That definitely created that and the sense of solidarity in the gay community. But there are I don't know, African women's groups, they're amazing some of those groups and some of the things they do and how they support each other.

**AH:** I've had the privilege of seeing some of those people in Africa.

**LM:** Kick-ass hey?

**CA:** They are indomitable spirits.

**LM:** Oh yes. Thank goodness for them. Yeah, I think the good things came out of it.

**AH:** There's some people who have said that the gay community is weaker. In the interviews we've done we've heard different answers.

**LM:** Really?

**AH:** Because of the losses.

**LM:** Yeah, absolutely. That—I mean you talked about caregiver fatigue and I'm sure that you've heard a lot about that. And you know that cumulative loss thing can certainly wear you down, and yet—I don't know, maybe I didn't know the gay community before. So, I'm not sure that I can compare in a valid kind of a way, but I would say that community is still very strong, has a very strong sense of who they are as a group. Yeah I don't know.

**AH:** Do you think it has helped to allow the gay community to become more open and more apart of society?

**LM:** Not at the beginning, but I would say since, probably. You know again, people in a place of leadership and a with a sense of being a part of something. Uhm, yeah, that doesn't just relate to fighting the disease, that relates to everything, who we are. Look you know, we're strong. We came through this, and we can do it, you know we can do anything. That would be my perspective.

**AH:** I would agree with that though, we've heard other answers on this that people think it hasn't had any effect on people becoming more accepted in the wider community, but to me it seems as though they have.

**LM:** It does to me too, it does. I mean I can't speak for other people's individual experience, I mean I came out as a lesbian in the most perfect time in the world. It was the year of the Gay Games in Vancouver so there were people from everywhere there, you know I started college and took Women's Studies. My family and my friends, my ex—the father of my son said, 'well yeah, we weren't surprised.' Everybody seemed to know before I did. But I was surrounded—and then I got involved in the HIV community, and it's just not been a big issue for me, beyond those times where you're walking down the street with somebody and you're holding hands with a woman and somebody's saying mean things or being threatening. But in a real way I don't feel that I've had a lot of discrimination, or separation from the heterosexual community. I've been lucky.

**CA:** People might say things you don't notice.

**LM:** Yeah it just doesn't matter that much does it? I recently went to a family reunion with a whole bunch of my cousins were all raised very fundamentalist. Like about as fundamentalist Christian as you can get. And I haven't seen them since I was a kid, most of them. Just one cousin I've seen and she knows that I'm a lesbian and accepts it entirely. But I got there and I had no idea what I was going to find, and we're in small town Alberta, like a town of six blocks square max, and a lot of farms. And you know, they accepted us. Like at first—because Cath, my partner came with me—and at first people were kind of a little hesitant, but might've been because we hadn't seen each other since we were kids too. And then one by one by one everybody came up and talked, and it was fine. That's not an experience I ever would have expected to have. They are not the people I would've expected to accept me and Cath.

**CA:** Love it.

**LM:** Yeah me too, it was wonderful. I mean it helps being a woman. I think the discrimination that gay men face tends to be more violent, and more everything—I can stop talking now.

**CA:** No you can keep talking, actually this is some of the best stuff.