HIV In My Day—Interview #32

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JH: Well let's start with where you living when you first heard about HIV/AIDS?

SL: I was living in Honolulu.

JH: Okay.

SL: Actually uhm, I heard it called many different things before I heard HIV and AIDS. Myself I was diagnosed with GRID. And it was totally accidental, uhm, under—some of my—I owned a drag show at the time, and some of my boys were getting sick. And, from the days when I had my own profession—I'm honest, as maybe to a fault, on my life—but when I owned whorehouses I had doctors on contract. And so, one of the retired doctors, I had remained friends with. What was happening was you were going to the free clinic, what back in the day was the VD clinic. Right? If you were working you had to have a blue slip every week in order to be able to work. Those same blood tests were being done at the Diamondhead Clinic, uhm so, all we really knew was it had something to do with your T-cell count. And what was supposed to be anonymous testing, guys were losing their insurance, and their jobs, and it obviously wasn't so anonymous. So I contacted the retired doctor who was a friend of mine, and we started doing what was called Tuesday Tea Parties, which in the gay community means lots of different things. Uhhm, and we would go out for lunch, we would go out for cocktails, whatever, and then we'd go over to the doctor's place and he'd take blood samples from them. And the following week you would come back and he'd tell you what your count was. To some of the people, it was just a great social event. But uhm, December uh, eighty-two, we were doing a, planning a Christmas Party, and, so there were not only the people in my little group that came religiously every Tuesday, but friends, family and stuff like that that they invited to be there with them. And one of the guys made a comment and said, Sheryl, for many years you taught us safe leather, and now, you've been here for us at this point, and you said nobody is safe, everybody is at risk, we've got to get over the stigma of calling it gay cancer.' And they looked and they said, 'so how come when we come in and we give blood every week you don't?' And I went I went well—I and you know I stumbled through it sort of like I am still today how many years later. I told them I said, 'I've never had sex with men, I've never had blood by-products, and I've never shot a needle in my arm. But I've told you all that nobody is safe, so fine, go ahead and take blood.' And the doctor called me the next day said, 'you're not going to believe this.' He said 'you know I've had you as a patient for years and years and years and never thought anything of it, but you're count is really, really low.' And my count was under two hundred and that was nineteen-eighty-two. I really truly, it became sort of almost a mantra to me: it doesn't matter how you got it, you've got it now deal with it.' Now of course over time, and, I really kept it quite secret in my community, because I had already sort of started some organizations and affiliations and I didn't want people to think I was doing it because I was positive. And we didn't know much about it at that point to really have the knowledge that we have today.

So my friends and family, you know like what I call my chosen family, knew. But I continued to be active in the gay community and in the AIDS community just as an ally, until finally, you know like it became quite obvious. I got really, really sick several times. Uhh, anyway, I am going on an and on it's probably going to be in your questions so I don't want to answer them first.

JH: Just you know—

SL: Just keep going? Okay.

JH: But I'd be curious to know what your community looked like before HIV/AIDS, and then the shift, if you'd like to talk about that?

SL: I was, even here in Vancouver before I left Vancouver, I partied with the boys. I didn't really socialize with the girls, if I wanted to get laid I'd go into Safeway was my standard joke. I don't do gardening, I don't wear plaid, it bores me. Uhm, but it, it was so obvious that we were a family, that we were a community, because I remember going into hospitals to visit people, and you know, being ordered to put on all the garb, and I wouldn't. And some nurses would let me in and some wouldn't. Uhm, I remember the days when no funeral homes would take it. I remember having to put people in garbage bags, yeah, to get them out of the hospital. Uhm… it was evil, you know, I mean I would watch... and today, that's something that that just brought back, is because I had a homecare worker, within the last year, who I could never figure out why it took her so long when she buzzed in to my apartment to get in. Until finally I went outside like, 'are you there?' And I realized that she was taking all of her stuff, putting it in a plastic bag, putting on gloves, putting on a mask and everything up, before she even walked into my apartment. So don't think the horrors of the eighties don't still exist today. That is the thing that I uh, you know, every once in awhile I go well why's it happen to me, because it means something to me and I'm not going to let it happen to anybody else.

JH: Did you find yourself and your crew educating others?

SL: Absolutely. I mean, but it was done on such a social level then. But like I say when I said it was showing what a family the gay community was I mean that in every sense of the word. I don't have to have eleven initials or more to say what the gay community is, it's the gay community. And I watched gay women being the ones who came and cleaned the houses and cleaned the mess, because we were busy at the hospital doing other, you know, taking care of the ones that were still alive. For how long was about as good a guess as anybody could ever make. Uhm, I think you might remember I used to wear, well this one is because of Parkland, I used to always wear a chain everyday and some days you would see me walk around kinda like this, and I always grab it because it makes noise, and I'm not really trying to draw attention to it. But I because did crystal healing, and I did you know like, I'm a jewelry slut, you know I have lots of different things like that. Lots of my friends and people that I was close to, when they knew they were dying or when I was at the hospital or something they'd give me something. A piece of jewelry or a rock or something. And as years went by I would always, you know wake up every morning and go, well who's going with me today? And I was at a conference in Prince George, probably about twenty years ago, I had just come to Vancouver, come back to Vancouver, and, uhm, I'd never been in a thrift store and the girls thought it would be so cute to take me to a Value Village. And I went to Value Village with them and it was funny because I walked in and I was like, 'we're in Prince George. How come I'm picking up Dolce and Gabbana, and Matsu jackets?' Everybody's going you have an eye for this sorta thing, it just shocked me. Anyway when we left I had bags and bags of stuff in lots of sizes, because most of it wasn't for me, but I get back to the hotel and as I'm getting out of the cab, I go to grab it and I realize it's not there. And I freak out and I go okay I'm calling the store and I call them and they say sorry we haven't found anything. I said I would never forgive myself, so I got back in the cab and went back to the store and as we drove, as the cab drove into the parking lot, this woman, this older woman—and I laugh because she was probably my age and I just don't think of myself as an older woman—anyway she had it in her hand, and she says, 'I'm the lady that answered the phone when you called, I was the cashier, and the next woman that came through my till opened her purse to get out her wallet and I saw it, and I remembered you because it made noise.' Anyway so I went home after the conference was over, and I looked at it, and I went into the chest and I said, maybe I don't need--they're already with me, maybe I don't need to wear them all the time. Because I'd really feel bad if I lost it for real. And in going through the chest I realized there were more than seven hundred pieces in the chest. And uhm, in twenty, twenty years I have lost more than—and this, this isn't just acquaintances right, because I mean, they took the thought to give me something—and so, I mean most people I guess would be overwhelmed having that many friends in their life. But I've been very blessed, I've been very fortunate. But the reality is, is that when you see so many of the posters today and it says, 'we've lost a generation.' We've lost three generations, we're still losing.

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JH: Once you knew—thank you—once you knew and were involved in HIV/AIDS, how did your behaviour, did it change your behaviour? In your interactions, your personal life and sexual life and—

SL: Uhm, it didn't change my behaviour, as much as it changed the gay community's behaviour. We had just had about a decade of finding our politics. And we, you know like I mean, we were a pretty tight group right? And we were seeing wins in our future, and then, this happened, and all of our time and energy went to burying our friends. And our politics took a back step. The problem is, the opposition did not. And when things became more like, I won't say normal, but I guess, I mean more than half of my life has been the AIDS crisis so I guess it is normal to me. But uhm, yeah like I said at the very beginning I used to teach safe sex in leather, and I taught safe sex on blood products, uhm products—ha ha—on body fluids. Uhhm…

JH: But what about—

SL: I'm really offended by one thing. And here we are, thirty plus years later. And we talk of what a misogynist world that we live in, straight or gay, the we all do the same things, but it's only the penis that is thought about. There are condoms available everywhere you go. I'm not going into saying well what about the women's condom that came out. I'm saying that from day one 'till now, one of the things that I have probably been loudest about is, gay or straight, male or female, you have sex with more than just a penis. And why are there not other barriers available? Or even talked about? I remember just shortly after I moved back to Canada, somebody asked me to sit in, they were putting together a brochure on safer sex. And I said 'oh god I've had this conversation so many times.' The thing is it came out exactly the same. You know there's a little diagram on how to cut a condom to make a dental dam and I'm like, really, you think a condom is inconvenient? Who the hell is carrying around a pair of manicure scissors! You know like, I mean it's just so ridiculous. But, like I said it's not just about a penis, it's about every orifice. I mean a dental dam is not just for women having sex. And what about gloves? You know I remember fighting the government here in Canada, when the BC provincial government said that condoms would be supplied to people on welfare and disability. And I went in and said what about other barriers? They now pay for my calving gloves.

JH: …Okay. Now, your identity, how was or is your identity, how did that play out in shaping your response to HIV/AIDS? You talk about the leather community, and what about other communities, other people…

SL: Well I guess I've always been a sort of an outspoken personality, so, it wasn't surprising back then to always be asked to speaker's bureaus or that kind of thing. Doesn't happen now. But back then, I remember being thrilled the first time I was asked into a tenth and eleventh grade class, but we took what we did there and within three years we were in fifth and sixth grade classes. But not through the school board. So what we did, is we got, we educated the teachers themselves, and got invited by the teachers, rather than the actual school. And then after it was done they could come and complain, but then it was done.

JH: That's great. Now the media, let's shift to the media. What was the response like? Roll it back and then bring it forward.

SL: Good and bad. Obviously we just passed an anniversary with Ronald Reagan saying AIDS for the first time, three years after the fact. About the media… See I still long for those days, good or bad press we got press. Today, pharmaceutical companies get press, doctors with a reputation of being media whores get press. But the average person living or dying with HIV, doesn't get press.

JH: How did it begin, and where did you see it shift—

SL: Well it began out of fear. But like I say, good or bad, it was something to bring to the table in conversation. Right? So as bas as the press was, people starting talking. And, I see the same fear happening today, especially with the T-man that was elected down south. But everybody says, 'that's America', and I say, 'excuse me, but have you checked up Scheer's platform?' It is—how much anti-gay violence, well how much fear-based violence is happening all over the world today because that man has made it normal? He has let fear out of the closet, so to speak. And uhm, you ask about media and like I say and yeah it was horrible, but at least they were asking. They don't ask any more.

JH: About discrimination, stigma, homophobia, did you experience any of that yourself, or those around you?

SL: Yes, but I'm fortunate, I'm blessed, uhm, it was my community. I can't imagine what it would've been like without them. Uhm, when I moved here, I had never really thought about dividing us up into different little groups. Like when I came to Vancouver and I went, why in the hell do I have to join a women's group, right? And then I realized for childbirth, for like breastfeeding, there's all kinds of issues that are specific to each group, it's just, each group then, how do I say this? It's about money, we're a commodity now, and each group fights with each other over the dollar. You know, uhm, so for all of the negative things, I hate to say it and maybe this is why I am the dinosaur that I am, uhm, we really took care of each other back then. Totally and absolute strangers you embraced in a moment without question, around this virus. And the other thing about this virus is, we didn't have funding, we didn't have grants, we didn't have any of that. We did it because it was the right thing to do. But I have watched every other health issue learn from us. I don't think we get the credit that we deserve. For the fact that we taught people that its, to take control of the business of your health. Uhm, I watch everybody else do it better than us now. For one reason, they have a bigger budget, and they don't have stigma. So why all these years later is that the thing that we're still fighting?

JH: Could you answer your own question?

SL: Uhm, yeah, could I? Here's an example I use quite often. You can take a child—and please understand I've had cancer as well so it's not like I'm pitting one disease against another—uhm, you can take a child with a bald head, take a picture, and pull on people's heart strings. You would never do that in North America because even still today the stigma that that child would endure is not tolerable. But, if you notice funding how much easier it is to raise money for HIV and AIDS globally, and show that baby and pull on people's heart strings. Uhm, I have watched, I will use this as an example and I don't know if it's crossing a line but, I have watched national AIDS walk, it happens on pretty much same day across the country, but yet other illnesses choose that same day to do fundraisers for their own organizations. And not only do that, I have watched as an example because I used a child with a bald head before, I remember the first time at an AIDS walk here, they had hairdressers that put up a tent and were doing haircuts. So the politicians and the people that were going to be on stage came and got their haircut. And the next year it didn't happen. And I kind of questioned why it didn't happen and then I realized, because cancer did a shave your head for pediatric cancer. And those same politicians who had been there for their photo-op, had shaved their head, so there was no hair to cut. There are three hundred-sixty-five days a year, why, if you'd never done that event before did you do it then? And like I say, it happens between illnesses but it happens between our own community today. Right. It's about, I'm raising money for this, well I'm raising money for this, well choose different dates, but you don't. You don't think about it, you don't even think about each other in your own community. And try to work it out. There are three-hundred-sixty-five days a year. There's enough weekends, enough parties, that you don't have to step on each other's toes. And I'm sorry I get political that way, and I'm passionate about it, I just wish, you ask me historically and I say we didn't do that back then. Because it's a business now.

JH: Now talking about fringing on activism, could you talk about your activism? And some of the things that you were involved with, organizations, campaigns?

SL: Well I was raised, as I told you I was adopted into a Canadian family when I was two years old. The family I was adopted into was fundamental Christians. Uhm, and I was, I have an older brother who was their biological child. He had wanted a baby sister, his mother attempted for several years and after eleven miscarriages the doctor said 'you can't try anymore, you have to stop.' And so I was the, I was that present. My birthday is two days after his, I literally was his birthday present. But the thing is, what do little girls do? They try to be, get the attention of their father. Uhm, and my father was very involved with the social credit party, so as a kid I would go to conventions. And I came out when I was eleven. And I wasn't asked to go to the conventions anymore, but I had learned enough politics from being in that, to know what I was, not only know what I believed but to know what I was fighting against. To know how they operated. And so literally my entire adult life has been political .Whether it was human rights, whether it was gay rights, whether it was HIV rights. Right, like I've always tried to be involved with more than just what affects my life. Uhm, but like I say it was really, it's very easy to transition from one to the other. Because what you're fighting against is the same – right wing politics.

JH: What organizations in Vancouver, in that example?

SL: In Vancouver? Uhm, it's funny 'cause I was just at, it was just an anniversary of gay pride in Hawai'i, and I was made a grand—a lifetime grand marshall—eight years ago. And on the poster which somebody sent me on the third of June, uhm, it had a list, and maybe I'll give you a copy of it, it literally took up the whole page. And the guy said, 'well normally you know, like we'd say, she started the first gay pride parade and that would be great, but…' And then they listed all the other things, there were forty-seven other organizations that I was either on the board of, had founded, or was somehow involved with. When I moved back to Vancouver, I said I'm not, I was on twenty-six boards, and I said, I'm going to take five years if I live that long, because I didn't like… I didn't like the way the law is written in Canada, I still don't. Non-profit licensing in Canada is a very antiquated law. It needs to be updated, it is a law that is so transparent for scam artist. It's so easy to become a non-profit in Canada. That I questioned it a lot. Uhm, anyway, that's a whole 'nother story unto itself.

When I said I was going to take five years, I arrived here on the basis that my family found out. And I literally had already sold my home, sold everything in my life, uhm, like I said when I was diagnosed I was told I wouldn't live out the month, let alone years. Uhm, and eleven years later I was still alive, my community was taking care of me. So when I say yeah, I was staying in the gay hotel everybody kind of goes 'oh.' You know when you say you were living in a hotel in Vancouver it means something totally different. No these rooms were seven hundred dollars plus a night, and that was thirty years ago. But I moved out of a seven-thousand-square-foot house. Uhm, so life was really different, but I came here and said I'm going to take five years. I got into, my fam—I'm sorry I'm going to backtrack just a minute—my family picked me up at the airport. I had been taken out of the hospital, drove by which I knew several of their properties. But, took me to the Sheraton on Twelfth and Cambie and said that the hotel was paid for, for three months. They gave me a pretty big file folder filled with stuff. And he said, 'I've put together a dossier, of every organization, every government official, everything that you will need, to get you to the point where my tax dollars are doing what they supposed to and you'll be on disability and then I don't need to see or speak to you again.' Uhhm, I was determined and I got into Helmcken House before the three months was up. I got here the last day of November, I was in Helmcken House the first week of January.

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JH: What year was that?

SL: Ninety-three. Ninety-four. I got here ninety-three, January of ninety-four I was in Helmcken House. Uhm, and I admire McLaren because they do one thing. They don't get involved with all the other organi—like I was living in Helmcken House, which was perfect—for a moment—because park was right across, kitty corner. So you had AIDS Vancouver, you had BCPWA, and you had Positive Women's Network, which was just for me. Right? So I had all of the—and surprisingly enough in that dossier were all those same things, all the listings of all those organizations. And I remember saying to him, 'you know you always talk about how much money your taxes are, did it ever occur to you that with all your government connections, you got more information from the gay people than you did from your government?' Anyway, point being is that, I also very shortly after met David Holtzman, and he was the executive director of Loving Spoonful at that time. Because somebody had said I had needed that help, I was seventy-seven pounds at that time. And in three months I almost hit a hundred pounds. Uhm, so I said maybe I'm going to re-think organizations. And I, my first offer was McLaren, and McLaren didn't accept clients on the board. And that became my next fight. I found most organizations didn't. Of course

Positive—what was then BCPWA was different—but they were different to the other extreme, they didn't allow non-positive persons on the board. And I'm old school so I was nominated a few times and I said no. Because being positive doesn't make you a lawyer, or an accountant, or any of these other professions that you need in a non-profit. So you're spending your hard-earned donated dollars to pay for those services. I said no that's not for me. So David and my friendship got stronger and stronger and so Loving Spoonful was the first board I joined. And I was the first out positive person on the board. There were some other people that were there that weren't so out about their status, and that's fine, that's their life. Uhm, I was on Positive Living—I mean I was on Loving Spoonful's board for ten years. There were changes as with in any organization, our chair had left, our staffing was changing, David had already died, and I thought it was, ten years was a good number. It was time for me to do something else. And uhm, chair had become the chair at Friends for Life. And so that's where I went. So then I was on Friends for Life board for five years. Which… I can't say anything but good things about the organization, it was just a bad time. A very bad time. And I, last year I chose to leave. Uhm, I was also on the Pride Society's board at some point in time during that, uhm, and a couple of other not HIV related organizations, but—

JH: Could you talk a bit about what it was like for positive women in Vancouver?

SL: Gosh, see there we go back to the thing of, I learned an awful lot because of things like the retreats where it more than just an office space where you actually had time to get to know these people, and get to know more about their lives. And I understood, I learned to understand the need and the purpose for having a specific women's-only organization, but again I felt different, and blessed, because when I was diagnosed it was almost like, it's my family, I mean why should I be any different than anybody else I knew. We were all positive at the same time. Whereas these women had gone through horrific experiences, whether it be with doctor or families, or any—you know I remember hearing stories of, you know, I was told my test results over the phone, or on an answering machine. I remember stories of a woman going in for a pregnancy test and the doctor coming back and saying, 'yes she was pregnant but she was HIV positive.' And made an appointment for her abortion on that same day. Uhm, yeah they needed an organization that was uniquely for women. I don't know necessarily, I remember being asked to fight the fight for them, at one point very early on, on transgendered women, because they weren't included, and then there was a post-op person that was on their board that made the ruling that post-op was okay but not pre-op. I think those are still issues that they need to, that they should've worked harder on. It's really funny because, telling you all that this was HIV long-term survivors awareness day. One of the things I saw earlier this week was—and I knew they existed I just forgot about it—that there was Positive Women's Network USA. And the reason they're called Positive Women's Network USA is because BC, Vancouver, had a Positive Women's Network. So it was the first. And, Positive Women's Network USA still exists. Big time.

JH: Is there anything now specifically for HIV positive women that you have—

SL: Hmm. Positive Women's Network closed it's doors last year. Uhm, Positive Living Society and AIDS Vancouver had moved uhm, on a deal that was made with the City of Vancouver for their old location to be re-developed. They moved to Hastings Street for three years, and uhm, just recently less than six months ago, moved back to their old location on the first four floors of the new building. In the way that building was designed, or those four floors were designed, there is a space specifically for women, uhm, and there was an office in there. Uhh the office was—oh also I guess I didn't tell you when I was saying boards, when I left Friends for Life the timing was a little difficult and they had a meeting with the community to tell the community they were closing their doors, on the same day as the Positive Gathering started. And I went to the, I was at the Positive Gathering, and I was asked not to attend any of those meetings. I hadn't left their board yet, officially. When they had the opening at the Positive Gathering and so many people came from that meeting, and told me you know, what had happened, sort of like what's my opinion why wasn't I there, it was sort of hectic. But by the end of that weekend conference, one of the people who I had known years ago and hadn't really kept in touch with, came to me and he said, 'would you be interested in joining our board?' And I said, 'oh I'd have to think about that.' Right? It was like I've been asked before I have issues about that. I did go home, and very seriously thought about it, because of the fact that I believe staying busy is my best medicine. What was I going to do. It's also the time I decided to take my first research project here. And joined the Positive Living board all at the same time. So uhm, when that new building, uhm I was very clear with them when they asked me to join the board that I would not be the women's rep, because they didn't have a woman on the board at that time. They had had some in the past that had left for personal or business reasons, and I said I would be on the board, but I would not be the women's rep. There is a group called ViVa that has existed for several years but built on the angst of everything has to be by us, for us, and that's another one of those things that doesn't sit real well with me. Allies are really important, always have been. But I also was here at the beginning when that same sort of fight happened, with the start of Positive Women's Network. Where there was an Executive Director brought in that wasn't positive, and the people who had basically built that organization were thrown to the side. Uhm, I see a lot of that again, and that's not my fight. I'm not critiquing it, I'm not saying whether they're right or wrong. But I choose to be on a board to help everyone, not anyone who fits specifics. And I didn't want my gender to be looked at as the reason I was on that board. I see funding cuts happening everywhere, and it really bothers me because what's getting cut is the things that we built as what we needed at the very beginning. We needed support, we needed advocacy, and those are the things that for some reason government feels don't need to be funded. But yet if you go to the government and try to get help, they will send you to an ASO to get it. I mean I have dealt with this on any, a number of issues including what I was talking about homecare. And my belief is what I've witnessed, and I'm going to be specific here to Canada, to Vancouver since I've returned here, is that once, it all ties together, because once it was a topic a conversation, it went beyond the scare tactics of the beginning of the epidemic, and once it was realized that it was the government's job to, for this to be part of the healthcare programme, and funding need to come in, most positive people were pushed aside and professionals were put in to replace them. And I'm not talking allies, I'm talking about professionals. And what has happened is, uhm, we're a commodity. I have watched people, some good some bad, but come in as volunteers, get an education as to what is needed, move into a paid staff position, and then move all the way up to Executive Director, and then move from organization to organization to government, because they have all of the education. None of it from school, all of it from our lives. Like I say, some are good some are bad. I grew from that belief that everyone involved had to be positive, because the generation that founded, that put all of these services in order, the professionals were established in their life. They had been in their job for many years, they had built a nice home, you know, they were established, they had money and time to give to organizations. Most of those people are dead. What we have today are people who are building their businesses, who are building their lives, they don't have the time or the dollars to do free work. Right? So we've changed on that basis. For good and bad, but the strongest thing that I can say is, in my ideal world, in my euphoria, I would say, let government pay for what government should pay for. Let our donated dollars go to direct services only. The administration of these organizations should be the responsibility of the government. You don't see them allowing, the falling apart of a local hospital board, you know, the government would step in in a minute to make sure it was saved. Our organizations do a service that is needed and will always be needed, because not only is about the medication that the doctors pat themselves on the back, and the pharmaceutical companies fill their bank accounts with. It's not chronic and manageable. There are too many people that fall through the cracks. There are also proven that HIV positive people suffer—oh I hate that word—endure the same aging issues, but ten to twenty years earlier than a person who is not positive. Also the thing that I need to say that I can't yell from the top of a rooftop loud enough is—oh my god it just left my mind—ha, ha.

JH: Aging and HIV--?

SL: Yeah just a second. When we were diagnosed we were told, 'put your affairs in order. Get ready to die.' If you were so fortunate enough to have any good health left in you at that time they were like, take that trip! Go and do whatever you wanted to do in your life, do it now. And then, the money's all gone and you're still alive. And you're changing your entire life, trying to be happy living in poverty because you're alive. Uhm, poverty affects everybody in the sense that we lost the professionals, we are learning to educate ourselves to be the professionals, but we can't do it five days a week, seven, you know, full-time. Uhm, and like I say the people who are healthy enough are building their lives. They're not, we have put the word out their for so long that this is chronic and manageable that we feel guilty if we're sick. Uhm, nobody should be made to believe some hype that a pharmaceutical company is giving in order to sell their medications, that we don't live up to their, and we educate, HIV education is pretty young man at the gym saying, 'I take a vitamin pill everyday what's the big deal if I have to take an anti-retroviral. What if I, so what if I get positive. It's just the way it is. It's my community. It's not going to alter my life.'

JH: How has the medical community reacted to this, third-wave, let's say?

SL: New and different stigma. Uhm, it was bad enough that it was HIV, called gay cancer when we were stupid, when we were ignorant. But now it's a combination of new money, like well gay men sort of fell by the wayside, and then it was IV drug use. And then the pov—all the poverty organizations got involved well they sort of forgot about that gay man who has isolated himself from the world. He stays at home, he could probably go out, I was talking about this the other day, yeah, it's our own fault. But the gay community even more so than society in general puts youth and beauty on a pedestal. So under the best of conditions and old man doesn't have a lot of places to go and things to do. Especially not if he's HIV positive, it's limited even more. And the sense of isolation, it's like it's new 'it' word. Like, it's been happening for thirty years guys. Like, you just noticed? You know like I start questioning our own sense of community when I heard that somebody was left dead in their house for two or three days. Because there was no connection. You know like you used to have a caseworker, and I hate to say it, but the government was almost the best friend you had if you weren't social. But you don't have those anymore you have an eight-hundred number that's somewhere in the province. And from what I've been told on the inside their rules are you've got three minutes and if you can't solve the problem tell them to call a supervisor.

JH: Do you think there's a fatigue, a burnout, with let's say the outlying community, or let's say our own community, or care?

SL: Okay but can I, and again I hate to say this but is there a burnout on cancer? I see a friggen commercial as least once or twice in watching a movie on TV, 'cause they've got the budget to do it, but I mean, every other health group in ways that they never did before, off of what we did. Like I mean a red ribbon, why do you think we have a red ribbon? 'Cause we were gay and we had dressmakers among us and we could get it cheap. Now do you remember that there used to be a safety pin in that red ribbon? But now we have mass-produced ribbons with the little thing that pops on the back of 'em, and nobody remembers that the safety pin meant safety. Meant safe sex, safe drug use, safe whatever. But, cancer now actually has a rainbow ribbon. For multiple cancer diagnosis. I mean, everybody's got a ribbon now. We did it because we had no money.

JH: What about the introduction of HAART and the treatment as prevention, has this—

SL: You know you're talking to the wrong person on this one. I know you guys are gonna, doctors and everybody's gonna hate me on this one, and I don't want to make it a big deal, it was my personal choice. But I have been off meds for over twenty years. I never went back on meds when I came to Canada. Uhm, yes I, I'll be the first to admit it would be a lot easier, and the drugs are a lot better now but, I'm not going to have a doctor or pharmaceutical company say they kept me alive. When for some reason, twenty-plus years later without them I'm still alive. My numbers suck, I don't even do bloodwork anymore it doesn't mean anything to me. I don't have an AIDS doctor I don't actually have a GP anymore. So yeah, yeah I struggle uhm, but like I say, I'm, until somebody says 'let's study why she's still alive, without them', I'm not going to give into having them anymore. I mean, in the beginning I did them years before everybody else did. Right? We paid money to get them released before FDA approved them. And I believed that I was doing it for my community and I was going to die and they would learn something from my dead body. The reality is they didn't want, back then they told us we're not going to. You know like we can't get rid of your body fast enough, nobody wants to touch your body let alone research it. But like I say, I was on such high doses the toxicity was intolerable and I wanted to live not just survive. So I made that decision. So like I say, when I first came here I remember fighting the good fight and loving to get into a battle with the doctors over it. Right now I'm, there's much more important things to fight.

JH: What would your advice be to medical and health supporters and professionals?

SL: Make the patient believe if they don't already, that they are the textbook for the doctor to learn from. The doctor doesn't have, no doctor does, they don't have it in their body, they don't know what it feels like, they don't know what it's doing, and no book can teach them that. So I am all for saying mix alternative and allopathic, I think in most cases they both have a place in your medical care. I just, I made my decision for other reasons, like I say, that's a whole other nother story unto itself. We as a society put doctors on a pedestal, especially when you go back to the fifties and the sixties. The reality is their egos got blown out of proportion, and then they realized that they didn't, they couldn't say, 'I don't know.' So they just, you do without the knowledge. Uhm, I think, I still hear people saying, 'well, he doesn't like the fact that I do alternative, but…' What the hell do you care what he likes? You make, but do it through education. Like don't just spontaneously do things because you read it on the internet or something like that. Like there's a million, I mean I remember when I came here what I was doing alternatively, I proved on paper, was twenty-two cents on the dollar of what they prescribed me pharmaceutically. But I couldn't have the twenty-two cents. So I said I'm not going to have any of it.

JH: Is that available in Vancouver? Are there many people that participate?

SL: Alternative?

JH: Yeah.

SL: The government realized the benefits to the extent that they expanded the list of what was covered. But it used to be just four thing**SL:** chiropractic, naturopathic, massage, and something else—

JH: Acupuncture?

SL: No, acupuncture came many years later. What was the fourth…physio. But you had twelve visits of each per year, and that makes sense. Because the way alternative medicine works is consistency. Then they added acupuncture, traditional Chinese medicine, several other things to list, but maxed it at ten visits total per year, so none of them, even if you use ten of one per year, you're still not giving your body optimum chance for it to work. And then of course we had organizations like Friends for Life, that opened up a wellness centre, but again it's about—and now Positive Living, and Doctor Peter—all of them offer a certain amount of alternative, but the reality is there's not enough, as to the need. So you're still picking and choosing what you can get, and it's not consistent, and so you can't prove that it's working or not working. It's difficult, I mean you don't want none, but how do you complain that it's not enough? It's hard to fight. Sorry.

SL: No… About advice for future generations, have we as a community of lessons learned, remembering and setting an example?

JH: No. It shocks me even within our own community how little people know of their history. Like I said, the safety pin in a red ribbon, ask the average person, they would just kind of go, oh it was easy. Right? A safety pin. I remember having a hissy fit when they went to straight pin that was like, even more insulting. But uhm, I just read, and Vancouver should be very proud, there was a particular man in Vancouver who had archived the gay community up the ying yang, and he has it all in his own house. And over the last little while everybody's been like, like there are thousands and thousands of pieces, you know newspaper articles photographs, all of this. And he's older, and people have sort of nudged him, and he's was like, no, I'm not giving it up. And he just willed it to the City of Vancouver's archives. Which is fabulous. But even that, it's like any research, I didn't do any research for a long time in Vancouver for a reason that I did one particular project that offended me when it was over. It was funded for four years, and the promise of the way that it was written, we were to go out to some of the most vulnerable populations, and interview them, and it was like very little funding you know. So you were giving them like, five dollars or a sandwich, like just minimal whatever. But I participated in it because the fourth phase of it was to go back into that community, not saying you were gonna solve every one of the problems that they stated, but that you were going to work with them to move forward on trying to tackle those problems if by four years later they weren't already resolved. What ended up happening is, as the third year of it was over and I was questioning you know, how come we're not meeting, like there's so much more work to do by this fourth phase, and they said, oh no we're shutting this project down we're starting another one. And they started a website with the money that was supposed to be for this project. And I said that's it, I will never do this again, ever. You know like I, it bothered me because you would have this, these great research projects that then go on to a library shelf. And if somebody is writing a dissertation or writing a thesis they'll pull out several and maybe take a paragraph from one or the other, and put it in their paper. I don't see the results given at the end. Right? There's a million people who have said this more eloquently than I could, but, we know the problems now what are we going to do about them. Instead of just breaking it down into more and more funding for more and more research. I want more attention on at least trying, I can't say we're going to solve every problem, but at least going back to the people and saying that they were worthwhile, that what they said to you, what they gave to you of their life meant something more than getting dusty on a shelf. So what I fear, history. You know, people have a tendency to say, 'but we're moving forward.' You're moving forward on the death of my friends. Graveyards filled with people around the world. You owe them more.

JH: Thinking back, are there things that you may have done differently?

SL: Hmmm…

JH: Not that there are wrong and right, just different.

SL: No, I understand that and I appreciate the question. Probably learning and doing more self-care. I think we get so caught up in the fight that we breathe, like the breath of my life for twenty-five years was the fight. Was the only thing that got me out of bed in the morning. And yeah I'm older, and that's why I'm doing this study. But it took me a year-and-a-half to go and get x-rays taken when I had a fall. I mean I fall all the time but, and so, my mobility now limits what I can do for my community. And that hurts me to my heart, because it was stupid. You know. I know that sounds very superficial but it, I know so many people just like me, that get caught up in the fight, and you put all your personal stuff aside. And most people will say it's about broken relationships or it's about this, no it's about your physical body. We forget. We're like, we're worse than teenagers, we think once we've lived past twenty years with this virus we're gonna live forever. Right? If we made it past that point, no doctor thought we'd still be alive, all a sudden we forget, oh my god now it's not HIV it's all this old age shit. You know I am, I am sick, right like, no it's just my body is falling apart. I lived for thirty plus years on three to four hours of sleep a night, and I thought, and I never looked tired I never looked exhausted, I pushed, I—I thought that was natural I thought that was normal. Now all a sudden I can lay down and sleep for ten hours, and go, 'oh my god, that actually kinda feels good I'm gonna do that again.' But no, I think that is, regret, I don't ever regret my life. I like I say, I feel overly blessed in my life, I have had opportunities that nothing to can compare to. But you don't want to walk around, it's not about the celebrities or the places, it's about… this allowed me to open my heart to people that I would never have known in my life, and to learn from their experiences is so much more than anything I could've imagined. I mean like I say, I can't say anything more than yes I'm blessed because I'm still alive, I would've been happy, I would've been just fine if I had died twenty or thirty years ago. Because I had a great life. But the life I have now, as difficult as it is, is lessons that I could never teach myself. It took those other people's experience and them telling me. And I happen to be one of those people who believes this isn't my last time on earth. So I'm gonna come back with so much more than I could've given myself.

JH: Is there anything that we haven't hit on or passed through in this conversation?

SL: Hmmm…

JH: That's been brought up for you that you'd like to—

SL: It's been brought up, and I can't say it enough, and that is, there are some anniversary type things that most people don't pay attention to, but in reality, I want people to still see the ugliness that was AIDS in the nineteen-eighties. I think that is just as important as telling them, 'I'm now living with a chronic manageable disease, I'm just old that's why my body is falling apart.' But I want them to know what death looked like. Because it wasn't like going to a funeral home and seeing your grandparents in a coffin. It wasn't even like going to a hospital and seeing a loved one with cancer or a multitude of other illnesses. I'm talking about families that would not allow us to see our loved ones, because they didn't acknowledge that gay was okay. Uhm, that drug use was okay, uhm, that like, everything that gets into the headlines about this virus are done in a way to make it feel dirty, and it's not dirty. They don't make somebody with cystic fibrosis or a multitude of—or ALS, we don't make them feel guilty that they got sick. Still to this day, people are made to feel less than. And the only way that that's going to change, because I saw it change people in the eighties, when they saw somebody fifty and sixty pounds, just a skeleton with skin over, and K-S all over their bodies, and we'd get into bed with them. You know, like we'd all be there together. And no family could come and say we weren't their family. 'Cause they weren't there when he needed it, or she needed it. But then, also remember, the world we live in. We didn't have gay marriage, we didn't have any of the legal resources that we have today, and they're still not good enough look what just happened. We can't take any of this for granted, because there are politicians just waiting to change it all again.

JH: The effect of the cumulative deaths, the grief, one after another, how did the community come through that? What was that like?

SL: I don't think any of us if we dug deep enough wouldn't still feel the pain, call it PTSD or whatever, but, the love so overshadows it. I've never seen love, I've never seen a total stranger come into a hospital room and offer to clean a dead body. Not somebody who that's their job, total strangers, because they felt honored to do that for them. You don't see that anywhere else. You don't see, like I say, it's the gay community to me and I have been ragged on for this from day one, uhh you know, especially being a female I don't use the L word, it's fine if you want to call yourselves whatever you wanna call yourselves, I just have to be part of a more unified world. And I have to be part of what I call ohana, the gay community with its faults, and with its glories, is my family. And, we shared, we shared outside of our community, and I'm, I try to always focus on the good, but I'll say even within our community being told, 'oh you know, there are people here that aren't gay, so could you keep that quiet.' You know like, 'don't be so gay all the time.' No! Because we're sharing what we learned, we're sharing our resources, we're sharing our love. Don't tell me that—again—that my love isn't as good as your love. So I feel that the world in general owes so much more the HIV and AIDS, because we made death something, something so horrible, so beautiful. And I don't know if I'll ever see that again.

JH: Thank you.

SL: See you didn't cry.

JH: I was close. Any final or, I think we have a good place to end it?

SL: You're fine.

JH: Thanks.