“HIV in My Day” – Interview 73

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Interviewee: anonymous (P); Interviewer: Jackie Haywood (JH)
Interview anonymized at participant’s request

Jackie Haywood: Any questions about my part in -

Participant: No, I’m just so happy to see you involved and here, and when I asked for a female, ‘cause I just wasn’t too sure of what we were going to be talking about and where we were going to be going with the questions, I thought it might just be easier with a woman for this particular study, and then when he mentioned your name, I was like, yay, I get to see Jackie!

JH: Well, likewise. Other women have asked for a woman to interview them too, so I get that. Okay, so what is your relationship to Vancouver? Were you born here, did you move here?

P: I was born in Montreal, but we came out here when I was very, very little – I don’t remember the experience or anything like that, so I basically grew up here from my memories on the North Shore, and that’s where my family lived, over in North Van. Went to elementary and high school over there and basically worked and lived on the North Shore for a lot of time of my upbringing.

JH: How did you spend a lot of your time as a young woman here in the city?

P: Um, I would say the majority of my friends were probably a little older than me – I kind of hung with an older crowd. I used to go to rock concerts, that was the thing you kind of did back then, so that was kind of my memory of the things I did. And kind of bike riding, I’m very passionate about bike riding – I still am, so I did bike ride a lot on the North Shore. And back in my younger days – everything is a little bit fuzzy and muddled – I’m trying to figure out if it was before or after I was positive. I wanted to be a professional racer, like a cyclist, and I was training at some point when I was younger out at UBC and go into the race that they used to have, the classic bike race in Gastown that they used to – it happens on July 1st and it was kind of well-known world-wide because of the cobblestones, so it was a very challenging kind of circuit to do. I remember I’d gotten my license to go into it and everything like this, and we were training, and then unfortunately I got into a pretty scary accident on my bike coming home from training from UBC and crashed with a car and ended up flipping over the front of the car – that was back in the day they didn’t have helmets, it wasn’t a big thing back then, you know? So, really luckily, I didn’t land on my head, or that might have explained a few things these days. [Laughs] But I just was a little banged up and bruises and stuff like that, but after that, it kind of scared me, so I didn’t stay in the cycling, biking realm of things, and switched over to mountain bike.

JH: When did you first hear about HIV in your periphery, as a citizen of the world?

P: Yes, that’s a very good question. Well back then, before I was diagnosed –

JH: About what year are we talking about now? What years?

P: I would say before I was diagnosed, it would have been before ’94, so I would’ve been – I was in my early twenties and so I would say, back then, in my early twenties, I knew a little bit about, maybe little inklings of it. It was kind of maybe in my back subconscious that I was aware it was out there, but I think at the same time kind of understanding, oh, that doesn’t relate to me. I don’t have any concern over it or it’s maybe not something that I have to worry about, or…

JH: What was the information coming to you?

P: That I don’t remember. I don’t remember what I heard or what it was about other than thinking I don’t have to worry about it for some reason. You know, that I didn’t fall into that parameter or the people I associated with or… Yeah, I would say that would be my initial thinking.

JH: What about the first time you met someone that you knew was an HIV positive person – do you remember that circumstance?

P: That was after I was diagnosed.

JH: Oh, okay.

P: [Pause] It was – well, shortly after I was diagnosed, I went away travelling because I already had a trip lined up, so it would have been – if I remember correctly, it would have been overseas and it would have been complete strangers at the time because I knew I was struggling and that I needed support, that I should be talking to someone. And I was in England, in London at the time, and I know I went to a support group, and it was mainly men there, I remember that. And everyone seemed to be quite friendly if I recall, but I know that first kind of support meeting or gathering, whatever it was, it was pretty unnerving, it was scary, I think a bit upsetting, fearful, because I hadn’t had much, very little contact with any organizations before I left Canada, that was more when I came back. And when I came back to Canada, then that’s when I connected at some point. It’s all so fuzzy, it’s all overlapping, to a degree, back then that I connected. I went through the Positive Women’s Network and they connected me with a peer and that’s when I had more one-on-one conversations with a female who had been poz – I don’t know how long she’d been positive for. And that gave me a little more, I guess, insight in that aspect. And then I remember clearly actually once I went to Loon Lake to my first retreat before I came involved actually in the program, that was probably a major time when I met – it was the first time I met like a lot of HIV people that I hadn’t really had much contact with a lot of positive people then, and that was probably – I’d already been positive for, gosh, I think maybe fourteen, fifteen, sixteen years by then. I’m trying to think about what happened when I got diagnosed over those sixteen years. I was probably out of the country for a good chunk of it.

JH: So, going back to when you got diagnosed, what were the circumstances to that information surfacing for you?

P: I got really sick to the point where I was in bed, bedridden. What I found out afterwards is it would have been when I was seroconverting, because I knew pretty much who I was involved with, how I contracted it, so I lined up the dots that way, kind of backtracking, and know pretty much when I was infected. So, that would have made sense when I got really sick, and I was so sick that I could barely get out of bed. I felt like an eighty, ninety-year-old person, I could barely walk up the stairs – like, three, four steps of stairs in the house where I lived. I couldn't eat food, I was on a liquid diet because my throat was so sore and everything, so it was popsicles all the time, and of course my mom and her husband at the time – well, still is – were kind of very concerned because no one could figure out what was wrong with me. And then I decided – you know, it's strange because I'm sure I phoned up like a HIV hotline or AIDS hotline back then, because everything would have been AIDS back then, not so much the HIV piece, and I don't remember them giving me a whole lot of information – thinking that I was HIV positive at that time. Maybe because of my background and things like that, they probably figured it couldn't be that or something – I don't know.

JH: Because you didn't fit the stereotypes, like you were saying.

P: Yes, I think you're very right there, I didn't fit the stereotypes, because I know that even to this day, everything is so stereotypical, and depending on which questions you ask – and I know just over the years being in the health field – if you present well, oh, well you don't fall in that area, whether it's HIV, whether it's mental health, whether it's suicide. You know, it's amazing what I've learned over the years and just hearing other stories from other people or things that have happened within my family.

JH: So, your family was concerned, no one could figure it out.

P: Right, so in the end I took myself or decided I guess that I should… I'm just thinking back. It was a person – I think in the end, when I look back and the person I was involved with, and I found some information that they left in my apartment when we had been involved. And on it, it was some information from St. Paul's and I don't remember if it was doctors' names or if it was organizations or departments within St. Paul's, but all the HIV stuff or AIDS stuff was highlighted, and this is what I found in the apartment. And so, I think I kind of probably connected the dots or kind of wondered even though when I was very sick, I don't think I – I wouldn't have been aware of the seroconversion at all at that point, I wouldn't have been educated or had any information. And I know, I think back then when I saw my GP on the North Shore, they wouldn't have known anything, because when he did finally diagnose me – and I don't know if he just decided that maybe that's a test we should do or not, I don't know, it's very fuzzy, but I know…

Aha, sorry, it's coming back to me now. I ended up going to the disease, Infectious Disease Centre or Clinic connected to VGH [Vancouver General Hospital], and I went there and talked to a – I don't know if she was a social worker or a nurse there, got my testing done, came back and had an appointment, and they told me I was positive. She was lovely, I remember that – she was very, very nice. Very warm, very compassionate, very empathetic. I remember it being, even though it was extremely upsetting, I remember it being a good – you know, a good experience I guess – I don't know if that's the right word, but experience with that person, she was warm. It wasn't – you hear some horror stories out there. And from there, I went to my GP on the North Shore, and from there I believe I was his first patient ever being diagnosed with HIV, and he referred me to a doctor downtown because they had no education or understanding or experience on the North Shore. And when I went to the doctor down here, I don't even remember who that doctor was, don't have a clue of what his name is or anything of that sort, he thought I should – he should send me for a pregnancy test also. I don't know why that was. I don't know if I had shared some information with him about maybe my breasts were tender or something like that – I can't quite remember. And then he told me, I think it was a week or two weeks after I found out I was HIV positive, I found out I was pregnant. But that was after I seroconverted. And that was with a different person that I got pregnant by, because of the timing of everything.

The person who infected me, they vanished and disappeared basically, and then shortly after that ended, I seroconverted, so that's why I knew. And after I did my research and digging about this person, I met someone else he knew, 'cause I tracked down – I went back to a bar that he took me to in the Downtown Eastside, kind of just on the edge of it, and he knew a guy that was a bartender there, and I believe I went back to that bar and talked to this guy or something, or I don't know if I bumped into him – again, it's all a little bit fuzzy. But for some reason, I feel as if I went back to that bar to track this guy down, because I could tell when I originally met him, I knew that they were friends of some sort and stuff like this, and when I did find out and talk to him, I found out that he got infected by the same person. So, I found out that this guy fell into the high-risk category which I was not aware of beforehand or I just didn't know his background enough, we didn't know each other super well. And I found out also that he swung both ways, which I did not know about either. And the one thing that I do remember in that relationship though with him is that he didn't seem to be overly interested in sex, it was more oral sex, and we didn't have a lot of intercourse, which I felt for a man was interesting, because usually men are, you know – that's their kind of top priority. So afterwards I guess, it helped me to kind of put the pieces together, understand all the dots of where this person – what their background was.

They were not from Vancouver, they were from Alberta – he was from Alberta and he was originally from Edmonton, and the little bit of information I did have on him, I did track down his information, and I tracked down his father and I ended up tracking down a telephone number for him. I don't remember the time frame on this, it's very fuzzy. I did this after I came back from travelling – I don't believe I did this before because I was too raw, and yeah, so it would have happened afterwards, and I confronted him. And that's when I knew I was right, that he was the person that infected me, because he was like, "Oh, well now we can…" I forget the exact words he said. "Now we can…" I don't know, "…get together or be free about it," or whatever. And I said, I was extremely angry of course, and I said, "If I ever see you again, the next time it will be in court." But I also found out in my research at that time HIV people had very few rights back then, and that – I found out kind of the hard way. I know I'm kind of jumping around here, but at a later date, I end up living in Calgary for a time and working there, and when I was there, I remember watching TV and there was a commercial. And I believe it was from the police, like the Calgary police, saying, "If you know anybody who's infecting people who's HIV, give us a call." So, I was like, wow, I know this person, I know he – if he didn't deliberately infect me, I knew he understood that there was probably a high risk that he was infected or he fell in that category or something, and what he was doing, well, it wasn't correct.

And I found out that he was – I don't know if he was still married or separated or divorced, and that he had children, so I was kind of concerned about that piece, whether his ex-partner knew or if the children were infected, or if his ex-wife was infected, and things like this. So, when I did phone into the police and ask quite cautiously about, you know, okay, what protection do I have if I share this information, do I have with this other person? Do they find out that I've shared this information, or what protection do I have? And they basically told me none – the person can find out clearly who told or shared this information with the police. So, I gave them the basic information, and I can't remember if I blocked my number when I phoned them, but I'm sure they had their ways to find out who I was when I called. But I did not feel comfortable talking to them, because the person was not warm on the phone, they were very cold, they weren't helpful in the sense that I was giving them information that there was a predator out there possibly infecting people when he knew he was HIV positive, and so, you know, I gave them very little information except his information. I didn't share any information about myself or give them any details, just saying you might want to look into this person, and that was it. I was trying to do my due diligence since I was not given the option myself. So, that was I guess when I learned at that time, felt like I had zero rights to go after this person. And I was thinking at one time, because I had picture of him, I was going to put a poster – get a poster with his name and information on it, and I was going to drive to Edmonton and plaster the information around town basically. And I found out also, I don't know who or what – I know I found out or asked someone legally that they said I could get in a lot of trouble and that could backfire on me, so again, I felt like I had no rights of doing anything against this person who I know deliberately – well, in so many ways, infected me. So yeah.

JH: Did the trail end there?

P: Yes. Because by the time I think when it came out when maybe we had some rights or maybe there was – I don't know, maybe some organizations we could turn to or anything like that, I think it was beyond the years that you could go around and charge someone. I think I don't – I didn't look too far into it, but I think after so many – I think ten, fifteen years, somewhere in there, I don't think you're able to go back and charge someone. I think it depends on what the charge is and what it is. I think that was my understanding at the time and I had to let it go.

JH: Your parents, your family, at what point did you talk to them about your diagnosis? What was it like with your family and yourself?

P: I shared very little with my family. I probably wouldn't have shared it with my family because I was going away travelling, but since the piece came in where I found out I was pregnant, I had to decide whether or not to keep the child, and that is when someone… Well, after I was newly diagnosed, somehow I got, someone gave me, connected me with St. Paul's and I remember speaking with a woman – I don't remember her name – and she was a lovely woman. I believe she was maybe a counsellor or a social worker, and you might know her because this is going back a ways. She had a dog and that's the main thing I remember about her, because when she had her therapy, she always had her dog there, and I was brought up with dogs and animals…

JH: Was it Judy was her first name?

P: That sounds familiar.

JH: Petite and blonde-ish?

P: I can't even remember what she looked like, but Judy, yes.

JH: It just rings a bell.

P: Yeah, it rings a bell for her first name. And I remember going to see her there, and she was lovely, and the dog was just lovely because pets are so wonderful when they know you're upset and hurting and struggling, and he would just sit there and… I just – it was…

JH: Because that woman I'm referring to was a social worker at St. Paul's.

P: Yes, I'm sure that was it, because that was in the very early years.

JH: And IDC.

P: And it might have been VGH, the clinic that I went to there that might have referred me to her as kind of the first stepping point, because that's the only – that's the first thing I remember of any engagement with anyone about my HIV status per se. And then, I don't know if it was through her or through the doctor when I found out I was pregnant, that someone connected me with Dr. Pick at the Oak Tree Clinic so that she could get me in contact with a peer who had a child, who had been pregnant, so I could talk to someone about it and decide whether or not I wanted to keep the child or not. Because it was my understanding, since I knew pretty much the window when I was diagnosed and where my counts were at and the research, I could look at keeping the child and there's a good chance that the child would come out negative was my understanding. Like, the odds were quite good. Nowadays, it's pretty much, yeah, the children will come out negative and they have these steps and things in place, so it's kind of a no-brainer now that, oh yes, if you're HIV positive and want a child, it's not a problem at all. Back then, I was still trying to figure it out whether or not to keep the child, because at the same time, I also was told that you have five to ten years to live, so I'm like, okay, I'm pregnant, I've only got this much time to live. If I decide to keep this child, who's going to look after this child because I can't make that choice or leave that responsibility – that's a huge responsibility and I could not make that decision without asking my family.

So, this is where I'm going back to my family. It was only that piece probably why I spoke and shared that information with my mom and her husband at the time – or sorry, her husband, my step-dad – because I had to ask to see whether or not once I passed, died, if they would look after this child and make my decision kind of from there. And it's interesting, because I remember that so clearly. It's weird the things that are fuzzy and the other things that it's as if they just happened yesterday. And years and years later when I – I don't know why it came up and I was in a conversation with them – they don't remember that piece, they don't even remember what the answers and that I had an abortion, which I thought that was interesting. So, for them in their mind, the HIV piece was probably more the memory, I guess, where with me, it was a combination of the both, because it was kind of my understanding if I wanted to have children this was going to be my best opportunity to do it, because I was just newly diagnosed, I was newly infected. But they said that, no, because they were going to be basically in their retirement years when they would have to look after this child. So, I understood where they were coming from and when I look back on things, I know I made the right decision. And it's interesting how the world and the universe works, because I have niece who would have been around similar age if I kept the child, and she lives with them and they've been a big support, off and on – she's been a big piece in their life over her upbringing and things like that just because of different dynamics with my sister being divorced and parents, and things like this, and so they stepped up and helped wherever they could. So, I just thought that it was interesting. As much as they weren't able to support me, they ended up in that situation anyways, which I felt was very interesting how the world works.

But still, I still feel when I look back on things that with everything I went through, the denial I was in for so long, I would say, you know, yeah, it would have been I think so challenging bringing up a child. These days, I think it would be much better and healthier just because of everything we understand, the resources out there, but back then and the struggles I've dealt with in – I think I'm in my twenty-four years now of being poz – I… I can't even fathom what it would have been like. Maybe that little person would have been a joy of some sort, you know, of coming into my life and maybe that would have been a buffer and a help – I haven't got a clue. But it wouldn't have been easy being a single mom, I'm sure, especially the struggles I've had just over the last few years, with having to stop work and finances and being on disability, so I can't even imagine what it would have been back there, and being a single mom and trying to work and dealing with my health and everything. So, going back to the piece of who I disclosed to, it was only them before I went away. That is my only memory of disclosure.

JH: How did this diagnosis affect your social life when you were travelling, or what impact did it have on your social life and dating, or not dating, or sexual activity?

P: I was very angry. I was very upset, because I basically found out about my diagnosis – I found out basically in January '94 of my diagnosis and being pregnant, and I was supposed to go away travelling in the beginning of February. So, before I decided to disclose to my parents, I had my ticket bought and everything and a plane booked and I was ready to take off, I lied to them and said, oh – because this happened once before when I was travelling – the flight's overbooked, and they need people to, you know, take a few hundred bucks and go on a later flight another day. So, I told them that because I was still trying to figure out what to do with the pregnancy, disclose to them, and all of that – I was still trying to decide what to do here. And I went and I changed my ticket, and I don't remember for how long – it must have been a month or six weeks, or something like this. I put it off for a little bit. And then I went off travelling, so I only delayed it for a month or two and then went off travelling. I went and got the abortion in North Vancouver at – I forget the name of the hospital over there.

JH: Lions Gate?

P: Yes, Lions Gate. A very bad experience. Date that, get that in writing and recorded before I answer the other part of your question there. They knew – you know, I told them I has HIV positive, they knew the reason I was coming to get this done and everything. It was obviously bold, highlighted and everything on my chart, and I did the procedure. After the procedure in recovery, a nurse came in and she was just horrible, not a nice person, saying, "You should have told me or told us," or whatever that I was HIV positive. And you know, I was still very new to this, and as far as I knew, it's there, it's in my records, it's in my documentation, it's in the chart at the end of my bed I'm sure. So, I found out afterwards that it wasn't my responsibility – like, it was my responsibility initially to tell them, which I did, so they could do all the protective stuff that they needed to, but just her interacting with me afterwards, it seemed as if I was supposed to tell her that information just lying there in the bed as if she had any way of contracting it or as if I had any threat to her after I had just gone through…

JH: A very vulnerable time for you.

P: Yes. And that was one experience I will never forget. And I guess if I was in another place at that time, I would have gone back and spoken to that person. Sometimes – I guess all the time, being HIV positive is exhausting. But even to this day, because I had an incident happen here at St. Paul's not too long ago, at IDC.

JH: Can you share that one?

P: Yup. Dealing with, it would have been nurse yet again, and I had basically gotten rid of my doctor at Spectrum, I basically fired him – and I can say the names because I know all the names will be deleted [laughs] because of the research, but it was Dr. [name]. I highly respected him for a very long time until it came to a point where I felt he was no longer supporting me and my needs in what I need to do with my health. Because I had just – my mom has Alzheimer's, and so I found out, well, in the HIV community, we have so many problems with cognitive, memory, and mental health and all this, and at the time I was having a lot of those problems myself, so I wasn't too sure if I had dementia and things like this. So, I wanted to get a referral to UBC and follow-up and get some testing done, and all of this, and I had gotten some initial testing done, and there was just some different stuff that I wanted to research and look into and find out, which I felt was intertwined with my HIV stuff. And I was not getting the support I needed from him and I found him to be very short with me when I asked him about it afterwards. I felt he kind of pushed me off and there was a student there, and the student came in to talk to me when I had all this information I wanted to discuss with him. And he didn't come in, he didn't ask me if it was okay to see a student, he didn't ask me, he didn't follow-up afterwards with the student, and I think she was a little nervous because she had to ask all the questions in between that.

And in the end when I did finally have an appointment with him and confronted him and said, hey, I wasn't really happy with how all of this happened, I ended up in tears because of his attitude and the way he spoke to me. And afterwards, I had an appointment with my psychiatrist, and I said, "Okay, am I overreacting here?" And she said, "Absolutely not." Because I was so vulnerable at that time and I was struggling so much with my health, that was the last thing I needed. That only happened about a year or so ago. And so, I needed to get a new GP because even though you have your HIV specialist, they like you to have a GP, even though I didn't see a GP very often, and that even was more upsetting. I didn't think I was a pester for a patient, I didn't bother him, I saw him maybe once or twice a year, and a lot of times I'd just see the nurse at Spectrum because they can just do the basic shots that you needed, but for this other stuff I needed to actually talk to him to see how he could guide me and direct me, but we were on completely different pages. So, I parted ways with him and I spoke openly and voiced my concerns with him, to the point where I almost went to the medical board with my complaints with him, but I had so much going on with my health that I thought, [name], pick your fights and battles. So, I decided not to go that route.

And when I switched over to IDC and there was a doctor there that decided she would take me on, because again, at IDC they don't usually take you on if you're already a client at Oak Tree and have a specialist there, but she said because of the upsetting experience I had at Spectrum with the doctor, she showed me compassion and said, "I'll take you on." And I said, "Great, thank you." But before I saw her, you kind of need to see a nurse and do a little intake so they can kind of guide you to the right doctor who might be the right fit depending on your background. And the way the nurse approached the questions to figure out what my background was, the stereotypical background of an HIV positive person, I was disgusted with. And to come out and ask me – and I know, because I, by that time, I had been involved as an interviewer, as a peer, and when I asked those questions to the participant and I don't know their background, I am very careful how I ask those questions – either open-ended, "I don't know if this applies to you," or, "Hey, there's some sensitive questions coming up. I don't know if this is your background or not. They're general questions we need to ask everyone, so please do not take this personally." And the fact that this is a nurse working at IDC and has a medical background and didn't show me, I felt, the same compassion, empathy, or respect, I was shocked. And she just outright said, "Are you on methadone?" Or, "Do you do drugs?" And I said, "No." And she said, "You're not on methadone?" And because of my being a peer in research, I knew what methadone was, so I thought that was kind of, wow, she didn't respect my first answer, and to outright ask me if I was on that, which I thought was, you know, a little bit rude. And then she said, "You don't even smoke marijuana?" So, what – to me, it seemed like her thinking was everyone does drugs, or that's how most HIV people are, get it, or whatever. I just felt stereotyped. And this is after being positive for how many years now – over twenty plus years?

And I was thinking, if I was newly diagnosed and I had a drug background, and a nurse was asking me questions like that, I would have felt horrible walking out of that – I would have felt shame and disgust because of the way she was asking it. And I felt uncomfortable and upset when I left that appointment, and I'm not even a drug user. And I had planned to talk to her and follow up with her at my next appointment when I went there, because I had to see the doctor and she said that she would be seeing me before I saw the doctor, but when I went back to see the doctor, I never saw the nurse, I never – that piece never happened, I went in directly to see the doctor. And I had so much on my plate with my health that I was struggling and I was just barely keeping my head afloat above water, I don't think I mentioned it to the doctor, which I should have, and got back and purposely spoke to that nurse one-on-one. But it's exhausting when I'm trying to keep on top of my own health and I have to educate these people at the same time, or advocate for other people or myself, or just say, shit, you guys should have your shit together.

JH: And this is a big city.

P: Yes. And due to the fact that this just happened a year, a year and a half ago, two years max, it is appalling and I shouldn't have to be in that place, especially at IDC. But at the same time, I've told myself – and I think it was my therapist told me a very long time ago, "[Name], it's not your responsibility to educate everybody on HIV." So, I think that is what I tell myself because there's times I just – I don't have the energy.

JH: I think they said it right, it's exhausting. Who educates people in this city around HIV – who do you think?

P: I think the people that have the…

JH: Any agencies?

P: Yes, I would say it's mainly the agencies that are the most passionate, have the best I would say knowledge and education going out there over the years, because they're more on the front lines, more so than the medical field, because depending where they are, if it's medical field that's HIV-specific, you would think they would be educated, but they might be educated but they might not have the tools or skills to properly interact with HIV positive people. Or they might be in the medical field and have no background dealing with HIV positive people or education or anything – they're totally ignorant and then they ostracize you and treat you as if you have the plague, depending in the past on what year it was. And I've had battles in the past with my HIV and disclosure, to the point where I had to sue an insurance company, and this is what they specialize in – healthcare, through a work environment. So, I've fought hard over the years. And I think at IDC it caught me off-guard, and I was in shock, because…

JH: After all those years…

P: After all these years and to be in that specific clinic that's HIV-specific, I would say they got maybe a little bit compliant, because I know a lot of people that attend that clinic have a drug background, whether they're still using or not. I would say they've become a little bit too compliant in the way treat the people there who are or aren't or are in recovery. I feel that it shouldn't be that way.

JH: So, where do you go now for support or peer interaction?

P: Well, before answering that, your original question – I know these answers kind of go on tangents – you asked me when I was travelling, what happened, where I went, and things like that, and that would have been back in, I guess it would have been in '95.

JH: Thank you for bringing it back.

P: That's okay.

JH: I didn't want to press, but I wanted to know.

P: I was angry and I was trying to get support overseas when I was in London, and through the resources over there, I did follow up with a therapist – I don't if she was a therapist, social worker – but I had a hard time making it to the appointments. And she said, "If you miss one more appointment, I can't give you anymore care," type thing, we can't have these conversations, which I understood. I wasn't ready to talk, I wasn't ready to share. I was still so vulnerable and so raw and so newly diagnosed – I was probably maybe six months in, so I don't think I was ready to do anything. I wanted to party, because I still drank back in those days, I smoked back in those days, so I wanted to have fun. And I know before I left on my travelling, my mom said, "Are you going to stop drinking and smoking?" And I said, "Why, Mom? I only have five to ten years, so I shorten my life span by a few years, but I may as well live it up and have good time in the meantime." That was my thinking back then. So, that's what I did.

And as crazy as those days were back then, I met some really good people, and they accepted me exactly for who I am, still to this day, because I went back, and those probably would have been my worst days in the sense of my anger coming out, especially you bring in drinking. And I had a nickname back then and I was known as the antichrist [laughs] – the devil, the antichrist would come out sometimes when I was drinking if people pushed my wrong buttons. And the people I knew and travelled with and lived with in London afterwards who ended up being really, really wonderful, great people who I still know to this day, who did not know my status, it was a like a running joke with them when this came out. And one of those people who I knew, I ended up disclosing to, and she was wonderful, she was great, she was not a problem at all, and she was one support I had. She kind of knew. She said, "Something's going on with you. Do you have like, you know…" She had an inkling that I either had a serious health issue, something going on, something like that, so she was pretty on the money when I shared with her.

And literally years later, I would say maybe five, six, seven years ago, I went back and I visited all those people after we hadn't seen each other in about fifteen years, and it was like I'd seen them yesterday, and it was such a wonderful experience. And then when I came back to Vancouver, and shortly after that, I chose – I'd been in Vancouver for a good five, seven years by then – maybe five years – I decided to disclose openly to everyone because it was getting too confusing at that point, and so I sent an email out to them, to all those people in my travels, included them in disclosing my status, because it wasn't very long after I'd just seen them, but I didn't want to disclose in person when I was there because I didn't want that to affect the experience that we were having after we hadn't seen each other for a very long time, and I just wanted to see them, you know, and have a good experience. And afterwards, when I sent that email and they knew of it, you know, I think that probably helped them connect the dots maybe back in the days when we knew each other, when I was younger. Every one of them got back to me and they didn't bat an eye, they were full of support, and it was just so wonderful, because for them to accept me back then when I was having such a hard time – they just truly accept me.

Because I remember, when I woke up in the morning, when I was travelling with these people, I was just a grumpy bitch in the morning before I had my coffee and a smoke, and everyone knew not to come near me, like you didn't mess with me in the morning. And that just, you know – I was just a very hard, angry, probably scared, fearful girl, or woman, you know. I was, what, twenty-three – somewhere around there – twenty-three, twenty-four when I was diagnosed, so I was still pretty young. So yeah, my travelling days were pretty darn crazy. I did have sexual relations back then, and always gave them the choice, I always disclosed. In my travelling over the years when I travelled, I tried different tactics – do I tell the person right away? Do I tell them after the first kiss? Do I tell them before the kiss? And still to this day, I don't know if there's any right, wrong way of doing it. One way might work for one person, not another.

I know through the years, many years later, I disclosed to my first love, who I knew and was involved with before I was HIV positive, and he was a person who I knew from Vancouver but had moved back to his homeland, which was Cape Town, Africa, because that was where he was originally from. And he was Afrikaans – was he Afrikaans? I guess so. But he was Caucasian, so he fell into the white part of things, but he knew a lot of coloured people down there, he was fully versed, educated on the HIV status when I met him many, many, many years ago. So, when I did tell him, I figured out of all the people I ever disclosed to, he would be no problems, no issues, because of where he lived, his education and his background that I had known about that. And the experience disclosing to him was the worst I've ever had disclosing to anyone in my entire life, because at that point, of course we were going to be sitting somewhere, and we were looking at seeing if there were any sparks between us, because when we'd originally known each other – I was like eighteen, I was in grade twelve, so it was a long time. And now he was divorced, had kids, and we were both single and thought we'd see. And so, of course, the first night that we were together, you know, I didn't want to disclose over the Internet or anything like that or over the phone – I didn't think it was appropriate since we'd known each other so long and things like this. But before we had intercourse or anything like that, I wanted to give him a choice or an option. And as soon as I told him, the wall was put up and he basically told me that he couldn't stomach it, he had a knot in his stomach, and that was the end of that. And we were supposed to have ten days together, and as soon as we finished at this game park, because I went to Africa and met him there, he basically drove me right to the airport and wanted nothing more to do with me. He couldn't basically get rid of me fast enough in so many words.

So yeah, I've had – and there's other people, like more recently, I disclosed to someone who I just more recently got involved with sexually, and you know, again, it was complicated because you can never go with flow and live in the moment sexually when it comes to being HIV positive, I don't feel, because of all – especially with the laws in Canada. I thought it was a little bit easier outside of Canada when I was involved with people, because I knew as long as I wore a condom, I was protecting them, and things like that, but relations in Canada are more complicated and I have to be more careful and things like this. And this person recently that I disclosed to, you know, he was really open-minded and didn't bat an eye, said he had no problems with it. And I told him, I said, well there's certain hoops we need to go through, and certain testing we need to do, and I need to sign this document because we're in Canada, and he had no problem with it. Yes, I had to do a lot of explaining about it, which I was fine with. So again, night and day differences.

And the episode that happened with this other guy in Africa, that wasn't that long ago, you know – you're talking maybe, gosh, it would have been back say 2008, 2009, somewhere around then, so it wasn't that long ago. By then, there was a lot of information out there, there was medication back then, so it's not as if we were back, you know, back in the '80s or early '90s type thing. So yeah, my travelling days were sort of all over the map. And there were some people I met travelling that I disclosed to, and this guy, he said, no, but I gave him an option and it was totally fine, because in the end we ended up having a wonderful relationship. And he's like a brother to me, I'm like a sister to him, he's the brother I never had, I'm the sister he never had, and we're still in contact to this day, and he's always been so, so supportive about me and my HIV condition. Because when I travelled, I did not disclose, I usually only disclosed to my sexual partners and that was it, and I was very careful when to disclose that, depending on who they knew, because I never knew when the information was going to come out through disclosing pieces.

JH: It's emotionally kind of dangerous. You don't know what's going to come back at you.

P: Yes. And when it comes to the disclosure piece, when I lived down in the Caribbean, again, if I was involved with anyone sexually, I lived on a small island, I had to be very careful because I had to know whether I could trust the person I was disclosing to, because if the relationship didn't work out, I worked in the tourism industry. If anybody found out about my status, the whole island would find out – like it was small. And I had had that happen before in the past when I saw a medical doctor who was educated in the States, but this was down in Honduras at the time, I was travelling down there, I was running a little business, a little breakfast café. You know, it was a lot of fun. I met another girl from Holland and it was like, hey, let's do this – it was something easy to do down there. And I had to go to a medical doctor because I had a urine infection and of course I had to tell her the HIV meds I was on because she was going to prescribe me some medication, so I had to make sure there were no interactions. Being a white Caucasian woman in a foreign country, and this is going back a ways, it was a surprise for them because of the stereotyping, I didn't fall into the class. So, this was interesting information, I guess, on her side of things even though she was fully educated in the States, so we can't put any blame on that, that she was uneducated, and didn't… being brought up as a doctor in a foreign country – that wasn't it.

She went home and disclosed my status to her family, and her son was one of the people that heard it, and I found out through the grapevine, this guy came up to me who I knew on the island – he was quite drunk – he said, "[Name], no matter what, I still love you." And that's how I found out that on this teeny little island, because that one was really small, the little area that I lived in – it was maybe, I don't know, three blocks, four blocks long, this little strip we lived on on this little island, kind of the touristy area. And I left the island I think within twenty-four to forty-eight hours, because I was concerned of everyone finding out about my health status, because I knew obviously people already knew. And my partner knew because I was in business with her of course, and the sexual partner that I was involved with on the island at the time already knew too, but it was very scary. So yeah, you're constantly having to watch your back or figure out these different relationships.

Because then when I lived in the Caribbean another time, unfortunately the same thing happened yet again, but not through a medical doctor. I was involved with one gentleman, it didn't work out, and I told him please do not share it with anybody, and I guess this is stereotypical to say, but men being men spoke to each other. One bragged saying, "Oh yeah, I just slept with her," when we had not – we had kissed and went skinny-dipping together. And so, the other guy piped up, the one I had been involved with said, "Well, did she tell you about her HIV status?" Well, that guy totally freaked out, went off the deep end, was in tears, because I was actually in the bar, in the pub, when this all went down. And his friends couldn't figure out why he was so upset. I tried to say just give me a minute of your time so I could explain – he would have absolutely nothing to do with me. And the owner of the bar – I was really upset, I was in tears, and the owner of the bar wanted me to leave, and he was the one I was involved with originally, sexually in a partnership, that he no longer wanted to be involved with. And I said no, because I was angry also. And then he basically confronted me and looked at me, because he could tell I was angry. He said, “Go ahead,” because he knew I wanted to basically punch the guy who had disclosed my status to this other young guy.

And this other young guy, he was a pup – he was just a young guy, we were out drinking, having fun, kissing, skinny dipping, yeah, that was it, and he wanted sex and I said no, because I didn’t want to have to disclose and I knew it wasn’t going to go anywhere, and afterwards we went back to the bar, and that’s what I thought was the end of it. I was just trying to have fun and be a young person like everybody else. And so, when the owner confronted me and said, “Yeah, go ahead,” I said okay. I figured that was an open invitation if he’s going to say that to me, so I pounced on him, and it took two men to pull me off of him, because I was pounding and punching at him. And I was banned from the pub after that, of course. I went up afterwards – weeks or months later, I went because I knew where he lived and stuff like that, and I sat down and had a conversation with him. And he goes, “I understand now why you told me not to disclose anything,” and he apologized I believe, if I remember. And he said, “Yeah, you did quite a doozy on me, I had a lot of bruises.” I said, well yeah – I didn’t feel too bad for him, but I think he learned the lesson in that, sharing. And then after that I went into a deep depression, and it took me a long time to get myself back on my feet in that situation.

And I ran into that younger guy, oh, I don’t know, probably a year later or something, a long time later on the island, because I lived down on the island working in the tourism industry for four to five years, and I saw him at a bar, and I didn’t go up to him and talk to him, all I did was order a beer and send it down to him. And when he looked down the bar and saw it was from me, and the look he gave me, it was of disgust, that he wanted absolutely nothing to do with me. It’s just weird how things get twisted about. So, those are the different experiences I’ve had sharing my status with people, and I think when I look back on relationships, it’s always been easier for me not to get too involved or when you know you’re overseas and going to have involvement, it’s not going to be a big commitment, it might not last, it was just – or have a one-night stand, it was just easier that way, you know? I think because of all the different experience I’ve had with when I tried to disclose or try to give people the option…

JH: You mentioned signing a document.

P: Yes, that I did just recently, because most of my involvement sexually have been outside of Canada, but this person was coming here to visit me, they’re not from here but they’re coming here to visit me in Canada, so I said, well… When we were in his country, I disclosed there, so he knew and he decided that it was okay, and I told him we could wear a condom, but I said when you’re coming here to visit me, I need you to sign a document, know that I’ve disclosed my status, you understand it, and then we need to do some STD testing so I know that you’re negative and that you don’t have any other STDs so that we can decide where to go from there in our sexual relationship. Because I’m on medication and things like this and we could choose to do condomless sex – if we wanted to, that’s an option from all the research and people I’ve talked to and my doctors, and things like this. In the past, that wasn’t an option, even though in the past and over the years, for many, many, many years before the research came out with anything that’s actually publicized and the doctors speak openly about, my doctors always said that as long as you're wearing a condom, you would be of no risk to someone else when you're having intercourse. So yeah, I just thought I better do everything by the book here in Canada, because I feel – still feel that we have little rights, 'cause I feel as soon as you're HIV positive, you're automatically the – you're not the victim, you're the – I guess you could be perceived as being the predator or the – well, as we are in some aspects.

JH: So, this document, was this something you wrote, or is it easily available online?

P: Yeah, it was the one that was done through PWN – I don't know who put it together, I don't know if it was PWN or if it was CATIE. It's just a general document and I think it even states generally on it – it's the only one that's out there that talks about the criminalization piece, just really basic, and I think it even states it isn't necessarily going to hold up in court or anything like that, it's just one of those pieces to protect yourself. Because I didn't want to have to put condoms in freezers and label and date them and all that kind of stuff either. I'm very careful, or I try to be careful who I get involved with, and in the past, if I did have any one-night stands where I wasn't going to disclose my status, I always insisted on a condom, and I always carried condoms with me if they didn't have them, and I wouldn't have sex any other way.

JH: I've never heard of the condoms in the freezer and labelling.

P: Yes, that was through one of the movies I've watched, I think it was through PWN again – the Positive Women's Network – where I went to a workshop and it had to do with disclosure, and it had to do with a handful of different women, different backgrounds, ethnic backgrounds, countries and places they've lived, and experiences where some had been charged or some were in the process of being charged or going to jail, because of all of this stuff, of being HIV positive. And even in some of those cases where the women have been abused or raped and things like this, and it's just like, wow, now you're going to try to charge these people when they were the victim to begin with? So, watching some of these movies gives you an inkling of what danger you can be, whether it's in your own country or whether it could be in a foreign country. So, watching one of these movies, that's what one of the women does, she says that any person that she's involved with, she takes the condom, she takes the freezer, because even with the law that we have now, the key word here is proof – you have to prove that you have an undetectable viral load, which easily done if you see your doctor on a medical, and you have to prove that you wore a condom. Well, I'm a woman, how do I prove that I've used a condom with a male? And that's one of the stipulations of the legal law that we have in place to this day. Well, how do I prove that unless I'm gonna keep the condoms in the freezer, and when could this come back to me? I could be involved with someone and someone could be knocking on my door a year, two years, five years down the road. So, that was the only way I knew if I came to that situation, to be able to protect myself in Canada anyways. Outside in other countries, I didn't concern myself as much because the laws would have been different, and I know it would have been harder for them being a foreign country and me being a foreigner for them to do much, and I knew I had practiced safe sex.

And so, you asked me where do I get my support and things like that, and over the years, it would be through – most of it would probably have been through the Positive Women's Network, and that has been a great loss within the community, because I learned through them.

Because a lot of times, I kind of felt – I didn't always use the services because I didn't feel as if – well, you know, back then I was working full-time, I thought, well, you know, it's only HIV-specific. And then, later on when I wasn't working as much, because I was having more problems with my health, they said, [name], no, these services, it doesn't matter what problems you're having with your life, it doesn't have to be HIV-specific, you know, they're all intertwined. Whatever's going on, whether it's your family life, your workplace, or relationships, we're here to support you on all of those different levels, and the services that we have here, you can use them, even if you're working – it's okay. Because I didn't want to take away from other people and things like this, so that was a big turning point for me or something I remember very clearly, because I started using their services, their support, to having someone to talk to about the different things that were going on in my life and figure out, oh okay. And it was really nice to know that that was there no matter what I was struggling with, because I guess now that I look back on those things, those things hampered my health at the same time as being HIV positive because they would have been – they were all stress-related things.

And I think because I was diagnosed with HIV at such a young age in my twenties, I've lived in fight or flight I believe for the majority of my life, and I think that's where a lot of my stresses stem from, where a lot of depression has stemmed from, even though I have depression on my dad's side of the family. I'm sure this was just the tipping point, being HIV positive on top of it, and also a lot of poz people have depression issues, side effects from the medications – so kind of a double whammy on the depression side of things. And I have had many bouts of depression where they have taken me out at the knees, and you go into that black hole, and I've had to decide whether or not I'm going to get back on that saddle again, and that has been extremely challenging over the years. And then, the point where my health is now or in the last six years, I have chronic fatigue, and that I would say is another type of depression to a degree, where it takes you out at the knees, where you get to the point where you're bedridden, and you have to build your life all over again from scratch, trying to put it back together to get back up to a living point where you can interact with people, where you can just function just at a basic level, just to try to get your head above water. And with the chronic fatigue that's happened twice now. So, I'd say, you add in the depression, there's probably been about six times from my early twenties to being almost fifty where I've been slammed really hard with depression and health issues like that where I have to rebuild – I always feel as if you're rebuilding things back up to getting to the point where you can get on with your life.

JH: That's what it sounds like, you fill yourself…

P: Back up, yes, that's a good way of looking at it. And I'm still in the process of doing that right now, and every time I have a health crash with the chronic fatigue, it takes a minimum of two years to get – I don't even know if I can say stable, just to a functioning point. And I'm trying so hard this time to make sure that I get a really solid foundation and do everything possible to get to really strengthen that, because if I have another health crisis, crash, whether it's the fatigue, whether it's the depression, I don't think I'll come back.

JH: You've been through a lot and shown a lot of strength, [name], an amazing amount of strength when I listen to your story.

P: Thank you for saying that. I know a lot of times I present well, and people don't know what goes on behind my closed door, because that's where I was brought up, so over the years, it has not been easy to ask for help, it has not been easy to ask for the support I've needed. And I have a wonderful therapist who I met through Friends for Life, and I've been dealing with her probably – since probably 2009, and she has just been a lifesaver and has helped me over the years to get through these things and get the support I've needed. Because as much as friends and family try, they just don't get it, they don't understand it, because these are things people can't see.

JH: They see you in a different way. Like you said, you present well, excellently well, and so…

P: So, people, they don't know when you're suffering and you have suicidal thoughts, they don't see it. I don't show people, let people see that. I'll share that with my therapist, I'll share that with my psychiatrist, but friends and relatives, no – not my family. And they can't see the HIV, they can't see the chronic fatigue – well, sometimes you can see the chronic fatigue when I'm really, really bad. I've had some people tell me afterwards, "Wow, a year ago, you were looking really rough." I'm glad at least someone could realize that.

JH: What motivated you to come in and talk about this and add to history and help other women and to educate?

P: That's a good question, Jackie. I was a bit nervous about coming today, I'll be honest. I tried not to think too much about it, because I had not been in here and done something like this in a while, and I wasn't – since this was history, I knew we were going to be digging to the bottom of the barrel, and I wasn't too sure what would come out or what I remember, or what you were going to ask me and what I was willing to share. And I kept telling myself with research you only have to share what you're comfortable sharing. If they ask you any questions you don't want answer, they respect that, you don't have to share with that. Because at the same time, as much as I like to help research, and I find that this information is very important because I know with the histories of the '80s, with a lot of the research I know history pieces that you have been involved in and I have seen and learned over the years through workshops or events that they've had through Positive Living Society, and I know that you have been involved, because you've been in some of the pictures and the history pieces. I found those to be very interesting and just helped me understand what it was like back then in the '80s, which was mind boggling. And I think because I left the country and I was gone for three years, and I was only supposed to be gone for three months, I was gone for three years, that is when a lot of stuff happened in Vancouver that I did not see back in '94, '95, with I think a lot of stuff going on in the news – hospital, medical fields. And I would say with the history timeline and things that come up through retreats and things like that, or talks and conferences, I've learned some of that stuff, not realizing that happened when I was out of the country. But at the same time, certain aspects of research I don't like to share because I don't want to be a stereotypical statistic

JH: In your story, you're so not stereotypical, and that's what just shines from your story. People are going to learn from that.

P: Thank you for saying that. I hope so. And interestingly enough, last week I did another research one that came up and it was another one that was out there – I wasn't too sure if I'd be able to share too much. It had to do with incentives, and sure they were looking for not necessarily HIV-specific people but peers that worked in the field, but they wanted to talk to either social workers, medical people. So, it wasn't necessarily HIV-specific, but since I'm a peer and I've worked on both sides of the fence, receiving incentives and giving incentives in different ways, I thought, well, I'll see if I can help out. And I didn't think I'd be able to provide information. And it was a short talk, it was only forty minutes to an hour type of thing, and she gave me wonderful feedback – "Wow, you answered all my questions. I don't have any questions for you because you've answered them all in your storytelling." And she said, "This feedback has just been so helpful." And I really appreciated what she had to say, because I wasn't too sure if I had much to share to begin with, and she confirmed that I did, and it was nice to know that that information was helpful. Because since I haven't been on this side of the fence in a while, sharing, I guess I forgot how valuable that information can be no matter what the research is, and kind of put any concerns or fears or uncertainties aside. And also, from a financial point of view, the money helps out a great deal, because I've had to stop working, because working was basically killing me, and my health was spiralling rapidly, and I was working less than part-time hours. So, I finally had to go on disability and I've been trying to – I've only been on disability just over a year now, and I had to stop work, and it's only been just over a year since I've stopped work to try to get my health back on track.

JH: Was there a lot of hoops, because you aren't the stereotype?

P: I feel sometimes that because – yes. I feel sometimes I don't – I fall in the cracks because I don't fall into a stereotype because sometimes you get more – more things are offered or you're entitled to more things because you fall into that stereotypical piece, so sometimes it was a little bit frustrating. But when Positive Women's was here, I just felt a lot of times that they were good sounding boards, and sometimes they could help you to figure out a way around if you didn't fall into that parameter – let's see what else we can find out for you, depending on what services or needs you are needing. And I don't feel – well, that is gone now, there's no replacing it, there's nothing – there's no women's-specific things like that. I know Oak Tree Clinic tries the best they can to pick up the pieces and support with their social workers – I don't know if that will ever expand for them. I think if it could, it would be very helpful to have a resource for the women. But yes, the… And when you're that sick and that vulnerable, and you need services at the point where you're getting so desperate, over the years when I've had to apply for support, government pieces, even if they're temporary or even if they're through my workplace, I found out it's not always best to tell the truth – you've got to play the game. That if you're honest and truthful, you get denied. And when you're that sick and you have tried to get all the pieces and paper work together, and they come back and deny you, it is – I don't even know how to put it into words. It's taking me out. It is so upsetting to feel that you have no support or help from a financial point of view, and you've got to go home not knowing what you're going to do. Yeah, I can't even put a word – it just destroys you to a degree, and you haven't solved your problem yet. And you still have to go back and appeal and figure out that whole process after you've just gone through the initial process, which was hell to begin with.

JH: Another hell to come.

P: Another hell, yes. So, I've learned over the years how to play the game and not necessarily always be truthful or exaggerate or stretch the truth or bend it – whatever I have to do, because I'm at the point now that I tell myself I deserve every goddam service that's out there that I can get my hands on, because I'm so sick and tired of scraping by. And I've worked my ass off over the years when I've been positive, pulling my weight and working as long as I possibly could, and for someone to come back now – and even my doctor telling me quite a few years ago when I was contemplating it but didn't, "Gees, I don't know if you'll be able to get it. It might be more challenging." Because being HIV now is no problem, it's manageable, you know? But have they looked at the long-time survivors? I don't think they've taken that piece out because I feel if you're a long-time survivor, you have more health issues as you're aging compared to someone who was maybe diagnosed over the last ten years or fifteen years, because I know people, I have peers and I don't get it. They're older than me by say ten years, they're diagnosed later than me, so then they got on medication right away because that was the protocol then, and they have no health issues, they live a normal life, and they're still working full-time.

JH: Is this mainly men?

P: Nope, it was both men and women. So, the only thing I can figure out is because I'm a long-time survivor, I've had it for a good ten or fifteen years longer than they have, you weren't supposed to go on medication at the time that I was diagnosed – they waited for your CD4 count to drop. And now they've learned through research there are certain cells that you will never get back again to support your health, because they've waited for that drop in your CD4 and you will never recover and get those cells back again. There are just certain cells that your body just doesn't rejuvenate. And it's my understanding through research and different workshops I've gone to, and listened to HIV specialist doctors or ones that work in that industry connected to St. Paul's, that is a true finding and fact that seems to be… I asked Dr. [name], saying that we're more susceptible now to all these health risks as we age for being a long-time survivor. And she outright said, "Yes, you are."

So, back to the hoops, when I had to recently apply for disability, I was turned down and I had – it took me four months to put this application together, and I had a novel of a thing. I just about had a relapse with my fatigue because it was so draining and just having to go through, and you have to do a back date, and you have to do a timeline, and you gotta put all this paper work together and get support letters, because I was going through federal for support, not provincial. Provincial is a lot easier to get but since I'd worked for so many years, I wanted to apply for the CPP, because that's going to help me at retirement, because I found out through my research, if you get CPP as your main disability, that will lock-in your pension for the years that I don't work. So, the people that haven't done that, unfortunately, and haven't been told this information, all those years they didn't work are going to be used against them at retirement, so their pension will be very, very, very little – it will be subtracted. And so, this is why I wanted to do it the reverse way. CPP is my major and then my provincial is my secondary, and they would top it up. But again, as much research as I tried to do, and I'm a big a researcher – and everyone told me, oh, you'll get approved the first time around. You know, you've got some much information here and everything.

So, I figured I was good to go, but when I talked to CPP, they said, "Can you still work?" I was working ten hours a week, twelve hours a week, because I needed to work to pay my rent. Ninety-five percent or pretty much ninety-nine percent of my earnings were going to my rent, and so I needed to keep working to keep my housing, but now I had to get disability, so it's a catch-22 when you're making this transition. And they came back and basically denied me because I was still working, even though when I originally called them up and said, "Could I still be working," and they said, "Yeah, you could still be working a little bit. Full-time, of course not, because you're applying for disability." And that was used against me. And I said, "You guys told me I could still be working a little bit." So, I was devastated yet again – I was so angry, so angry, and so upset at the same time, because I didn't know what to do. And at that point, that was the last straw that put me over the top.

JH: Because it was your home, it was a roof over your head, it was groceries.

P: Well yeah, I figured if I could just get this support now, then – and that just dropped my health even further. So yeah, trying to receive these supports and then being denied, and then having to reapply – it's my understanding that's how government weeds people out, to see if you're serious – it's made my health worse over the years numerous times, to the point where it's not something you just recover from in a week – you're looking at six months, years to get recovery back, because it has been that impactful, to the point where it's taken you out again at the knees, or just taken you down so far, that you just have to pick yourself off the floor again. So, in the end, with the CPP, I ended up hiring a lawyer. I found out this great organization that runs out of back east in PEI, Newfoundland, because they understand how many people struggle with disability and don't get approved, and they do it all for free, and they take a percentage of the money that was backdated, and they take a percentage of that money, so you don't have to pay any money up front. It was a blessing, and they were the ones that got it approved for me very rapidly, yes. So, I just thanked my angels for that, it was just wonderful, but it was a whole year process that I had to go through, literally from January 1st and I found out a couple days before Christmas – that was the best Christmas gift to find out. And they actually personally phoned me up, the nurse from Canadian Pension Plan phoned me up and said, "Wanted to let you know that you've been approved." And I could barely speak on the phone when she told me.

JH: Good work.

P: So yeah, so all the hard work paid off but what it does to a person's health – well, I'm still working on my health, it's still not stabilized, and that happened in 2016 – what are we now? We're 2019, it would have been around 2017, '18 – I relapsed in 2016 with my health, and it was in late 2017 that I had to stop working and I had to start, and I think it was in 2017 that I was working on getting the disability, so it's been over two years since I had the health crash, and I'm all sure that stuff in between didn't help, to get it to where it needs to be. Yeah, and just having to fight in my past work experience when the insurance company disclosed basically I feel my confidentiality to my workplace through an email. They might not have been aware of it, but I sure was, and it was a breach in the law. I forget the actual wording of it, because it was PPI or something, your personal rights of confidential rights and everything, and the main office in Ottawa and I told them of the situation and what happened, and they came back and said, yup, your confidentiality has been breached, and so then I knew I had a case to go and sue.

JH: Another uphill.

P: Yeah, that was another uphill battle because I had to do it on my own, even though there's a lot of legal organizations out there, but throughout all of Canada in those types of situations, there's no lawyers that can support you. I couldn't find – I had to go to the library here and basically be my own advocate, and apply and go through the court system here on my own. PWN was very supportive, they did go with me, because I was very nervous when I had to go to court – we're talking a huge insurance company like [company], [other company], because technically I'm not allowed to say the name, because we resolved it out of court and I'm not supposed to talk about it. But I know you guys don't use the names in here, so you can get the gist of it.

JH: Where can HIV positive women in this city go for help and support and comradery?

P: It's thinning, because I work now doing volunteer work, honourarium work, helping out with the women's groups that Oak Tree puts on, because that is something I can do from my bed if I need to on a computer with the organization skills that I do behind the scenes. It's not like I have to go to the office every day, so when I'm having a bad day, I can be in bed and do the work I need to do, so it's been really conducive to my health condition. And we've had a hard time getting women out to the groups, you know. Some great stuff from the groups has happened that a lot of women have been coming there for a long time have got jobs and gone back to work, so they've had some financial support to go along with the disability, so I think that has helped them get to that place to be able to get work and feel confident enough to do that, so I think that has been a really good feedback from the groups. But trying to get new women or making women aware of these groups and getting new women in is a huge piece missing, because as far as I can tell from my personal experience, research, talking to women, I feel the Positive Women's Network was the communication hub for all the women, so no matter what was going on, what organization, whoever was putting whatever event on, Positive Women's Network always knew about it, and they reached out to women either on the phone, by physical mail, or by email, or through someone popping into the agency. So, they had many different ways of reaching the women or they knew specifically how that woman could be reached. We don't have those tools, none of that information was passed on, it was all lost – for confidentiality reasons maybe it couldn't have been passed on, I do not know. But it's very hard to reach women now. It's an ongoing situation, I don't know how to reach the women, because I'm part of the part of trying to get the information out and try to reach the women and do postering, and it's been a difficult piece. So, I know they put more women's support groups on at IDC, so I think that is one area, and then Oak Tree works with the Positive Living Society, but that group is Indigenous-specific. And we just recently had to cut one of our groups because of budget cuts now, and we don't have enough attendance to warrant having three groups, so we had to cut down to two.

JH: I think Friends for Life has got something that they're starting.

P: Um, yes. I'm not too sure of all the pieces, but what they have, the recent project that they're doing right now that is available is, I know it as the Women's Wellness Project, which is the first piece that has come out that has been a refreshing project for women-specific, and it's not Hep C-specific, it's not Indigenous-specific, it's not HIV-specific, because I'm really happy all those different populations are getting the supports they needed and I don't mean to be judgmental and I don't mean to come back and this being racist in any piece or any way at all, but I feel Caucasian white people are being missed out of here, because everything is so focused on Hep C and Indigenous. It's like okaym yeah, what about us white folk that don't fall into these little pigeonholes or demographics, because that's where all the funding seems to get pumped into. And I know it's a long time coming, especially for the Indigenous people, so I'm happy they're getting that attention, and that's been pushed from the government and budget. And I'm not the only person that thinks that way either, that we feel like we're kind of like… Because a lot of the support groups that come out, some of them are Indigenous-specific for women. So yeah, it's definitely a piece that's being missed. I don't know if I recall the actual question you asked, Jackie.

JH: About places for women, and I think you answered it just fine.

P: Oh, it was the Wellness Project, yes, that's what I was going to touch back about – that is the first piece that I was saying, oh yes – it's for all women. There's nothing specific other than being generally HIV, and it's for all women all over BC, so everyone can access it. You don't have to live here, so that's good so the out-of-towners don't feel excluded too, because I know a lot of the out-of-towners get missed in all of the stuff that happens in Vancouver because you have to live here, and it's not something that can be done online or on the phone. And with this piece what's really nice is you don't have to jump through a lot of loopholes – it's low barrier. Because I know when I've applied just to go to some conferences as a peer, as an HIV positive person, the loops and questionnaires that I had to do on that was like, oh my god. Like, the last one I did, it took me like three hours to put together. So, when this came out, I was like oh god, what am I going to have to put together to get whatever they're offering, and anything written, written pieces are a challenge for me because I'm dyslexic, so I just cringe and put my back up, and it's just extra difficult for me, and it takes me so long to do. When I looked at the questions, they had like four questions, and I'm like, that's it? I'm like, wow.

So, I know why I was all excited, and I knew about it before it was officially announced because I knew the person running it, and I was like, great. So, as soon as it came out, that weekend I was on it, and I put it all together because I was waiting for it to come out, and it wasn't too difficult to put together. And it was great because I could just find something that worked for me, and right now I spend, all my money goes towards supporting my health and trying to get my health stabilized. And all those things aren't covered because technically medically, they can't do anything for me. Okay, we're looking after your HIV, your other memory stuff, your chronic fatigue stuff, there's nothing we can do for you there. You've got to pace yourself, just kind of do that. They might be able to stick you on medications, but all those medications have side effects and cause more health issues for me. So, I've had to look towards alternative stuff, naturopath, holistic allergist testing, all kinds of these things, and all of those things, you know, pain management, therapy, acupuncture – none of those things are covered. So, every single dime I have every year goes to trying to stabilize my health, and so when a wellness project like this comes up, when they're offering to give you money for what works for you, what resonates for you, how we can support you – and it can be whatever creative idea you come up with, I was like, wow, this is amazing.

And they gave – I wasn't sure if I would be applicable or not, because what I wanted to do – and what I wanted to do is right now I'm doing a big detox and I've had to invest like literally thousands of dollars on this, because out of the States, you've got the exchange, you've got to pay for shipping, and then you've got duty and taxes, but it's the only thing out there left that I know might be able to help me and support my health, so this is kind of my last choice and option. So, I wasn't sure if it would fall into their parameters, and once she gave all these different examples, it does – I'm supporting my health, it's intertwined with HIV stuff, and it's about getting me well so I can have a quality of life, because I feel my quality of life has not been there for years now, over six years, ten years – it's been… And it's not good enough for me, it's not good enough where I'm at right now. It is improving, my health is slowly getting better, but after two years, over two years now, almost two-and-a-half years and it's still not stable, and the challenges every day, and I'm not even fifty yet. What's my second decade going to look like unless I can sort something out here? So, this wellness project from a financial point, I don't know if I'm going to get it or not, I don't yet, we find out at the end of this month, but whether they give me $500 or up to $2500, anything that they give me will be a huge blessing and help.

JH: I was very lifted when I heard about it. I thought, oh great, this sounds like – and I also know the person that's involved, and I was happy to learn that she was part of growing this.

P: It's right up her alley. She's good at it and reliable and on top of it, and really supportive. I work with that same person, because she's also involved with the support groups at Oak Tree, and she has so many creative ideas bubbling out of her, it just blows my mind every time we have a meeting. I'm like, okay, I can't write fast enough to get them all down.

JH: Yeah, bubbling is a good word. So, what would your advice be to newly diagnosed HIV positive woman, or even an HIV positive woman in the throes of living and thriving? What advice would you…?

P: The advice I would say, whether you're newly diagnosed or been poz for many, many years, don't believe everything that you're told, even if it's from a medical doctor. Do what works best for you, even if your medical doctor disagrees or your peers disagree. I worked together with my doctor – key thing – we work together as a team. I do not agree with everything with my doctor, because I'm the one who's on the frontline taking the medications and things like this, and I know my body best, what is or isn't working. And from a medical point of view, doctors will say – or from the research point of view, so it's not necessarily their fault – side effects only happen within the first six weeks of when you're on a medication of when you're starting something new. Well, I say that's bullshit [laughs], that's a load of BS, because I've been extremely fortunate with side effects that when I started medications I don't seem to have any. It's two, three, four years down the road, that's when I start having side effects, and I found out through my peers, "Oh yeah, that's side effects, I had that." And then I decided to change the medications, and when I went off the medications, those side effects have gone. So, I know now that's what works for me. But my medical doctor, I had to really advocate with my doctor, saying, hey, I want to try something, do some testing or something and see, and I want off these meds.

If you're able to stay in some sort of contact with your peers, whether – if you don't want to go support groups or stuff like that, or that's not your thing, that's fine, but somehow stay engaged. So, whether you go to a conference, whether you go to a retreat, whether you go to – sometimes they have dinners and talks in the evenings at the Chateau. I find I learn information from just little short conversations or whatever they might be presenting, or questions that are asked that could possibly help me and what I'm going through. So, a lot of times, I don't necessarily have to be asking the question but the information can be extremely helpful. Make sure you do your own research too, if you're that type of person. Some people aren't, some people don't feel comfortable with that, but I've had to do a lot of research on the side to do with my chronic fatigue, because there's nothing that can be done with that, so if I wanted to improve my health – because the only reason I feel I have chronic fatigue is because I've been HIV positive for so long, and it's a circle, they're all interconnected. And try new things, constantly try new things, whatever they might be. Like, a lot of agencies may offer massage or acupuncture or an opportunity to see a naturopath – try those different things out. You might be surprised by how some of the alternative medicine can actually help your HIV or whatever elements you might be struggling with.

And try to stay on top of the educational pieces, even if you just read little blurbs, just highlights from – I've noticed what a lot of people do now when they're sending out information, they do a paragraph at the beginning and give the highlights, and if you want to read the whole piece of paper… For me that's great, they didn't use to do that, but then that gives me an idea of whether or not I need to read the whole piece. Even if you just do that, I find even those little bits, when I get emails from CATIE and things like that, or even newsletters from different organizations, it helps me to stay in the loop of what's going on from either peers' point of view, criminalization, medical point of view, just in the HIV community in general, or in the society. Because I found in the past when I've met other men who are HIV positive that I've gotten involved with in a partnership, in a relationship, the background medical information that some of things they've been having problems with, I'm like, that's a side effect of your HIV meds and I would get off those right away and switch to this. So, that's what I've learned through the past where some of these people just – well, the doctor said it was okay, and some of these doctors aren't HIV-specific doctors, they're not specialists, they're just in the care and have knowledge around it, but they might not be as versed as someone who practices and studies it all the time. And that's what I've found actually with people who live out of town, so they might not have the same tools of the people here or the doctor hasn't thought – that they see every six months, hasn't thought to put them over to another doctor.

JH: Well, peers are support and information even, the casual conversations over coffee – you learn so much from each other. So, what about advice to the medical community? What notes or advice would you like them to know?

P: Okay. Before I jump there, you're right. Just a perfect example of a small conversation with a peer, I'm on a board for a women's-only project so we have meetings every three or four months, so they can get feedback from the women to do with the women's-specific research project. And just at the end of the meeting that we had, someone brought up about how HIV meds – not all people but some people are being switched over to the no-name brand, the generic brand. Well, people are having side effects now, aren't we? That's what's coming out in conversation when I talk to other peers, and we can move into the medical piece that you just asked me about – no one told me about it. I only realized it because I looked at my label, and you know, when I have to call in to say I need my next month's supply, I'm like that doesn't look right, that's not the medication I'm on. So, no one brought it to my attention that we were going to switch over to generics, so number one, I was not pleased with that, because I know usually when I go to the pharmacy, they usually tell you or they ask you, or usually when I'm in with my doctor too, my HIV specialist, if we're doing something, she says, well it's going to be the generic brand to you, and I'm like, fine. They give you a heads up. There was no heads up given to me with my HIV meds, and I was a bit skeptical about it. And these other two peers that I talked to, both of them said they had side effects since they started, and I haven't been on it long enough to see, but I documented on my calendar, made a note exactly when I started these to see. And the only thing I've noticed, but I don't know if it interacted to the change of those, that my CD4 dropped drastically, so I have to repeat my blood work now in a month to six weeks to see if it was just a glitch or what, and I'll see whether or not maybe it has to do with that.

So now, this is another thing I have to be aware of, and basically if I – I would probably need to find some kind of proof to go back to my doctor and say, hey, I don't want to be on those ones, I want to be on the original ones, because it goes back to the medical field and them saving a buck and budget and all that bullshit and crap. And to tell you the truth, I don't care – if I have this condition, I don't like being on the medications because I think they're way too toxic and due to the fact that everyone across the board gets the exact same dose does not sit well with me. So, if you're fifty pounds or three hundred pounds, you're all getting the same dose of medications. In all other stuff that you're diagnosed with and you're given, it's all done on different dosings – male, female, all this kind of stuff. And then when I asked about why they haven't done any research on that, why would they want to do research on that? It doesn't benefit any of the researchers, the pharmaceutical companies that fork out the bucks that get this research, so it's not beneficial for them to know that information. So, I'm going to do my own research project coming up soon here, which I know my doctor is not going to be happy with, but I want to know – I want to know that. And now if I'm switching here to a generic one, has there been any research done on it? What are the side effects? What is the difference with the medication? They've done all the research on the other ones and now you're switching over to the generic. No one's given me any information on that. I probably have to do more research on it.

JH: So, you would say to the medical community…

P: They need to make HIV people aware of when they're making those changes, number one. I don't know, bring out some sort of paper or website or give out some documentation or anything that I can read going, okay, so this is what you guys have researched or you haven't researched – I want more detailed information on that so I can ask questions around it, because this is my health and I'm the one that has to deal with the side effects if they happen or there's any problems or issues, then I know, okay, this is the only change that's happened in the last six months or year, this is what I'm going to look at type of thing. From a general point on the medical field, they need to get themselves either better educated or refreshed training or make sure they are up on things, or the medical departments should be refreshing them on a yearly basis, every six months. To know that HIV is still out there and we are still struggling, we are still suffering, we still have challenges, and everything isn't a bowl of cherries and everything's rosy, and everyone that's diagnosed now, hey, life is just golden and everything is perfect, and they have no side effects and they're working and everything, and everything is just fine. I'm sorry, but that is just a load of crap. Maybe for the newly diagnosed people, yes, they have all these agencies now and everything is so much more dialed and placed to support them – yes, I feel that they can live a long, rich life, and it can be much easier for them with less hurdles. But at the same time, the long-term survivors are still dealing with this and dealing with things that they're just slowly getting into with research, like HIV and aging, and stuff like that, and what it's like for a long-term survivor, and what are issues and concerns – those are slowly coming out now. And I think more of that needs to be brought into the medical side of the field, because I don't know if they're – I think the research side of things is stepping up to the plate and dealing with that, but I don't think the people that are working out there in the medical field are looking at that piece, 'cause I think…

JH: Do they think it's over? They think that it's…

P: Well, this is it. You've got your newly diagnosed, you've got the ones that are kind of in the middle, and then you've got your long-term survivors, so I think now we have to look at the different demographics now, when the person was infected, how long they've been on medications, 'cause I think that's where your different concerns are coming up. And when it comes to a medical – not even just the medical field, but your mainstream population out there, education, education, education. And I don't know how to reach these people all the time but I'm still very disturbed and upset when there might be a conference going on about the criminal piece – something positive happened about the criminal piece and it's gone up, it might be a news article. And I'm thinking great, something positive in the field, and people put comments – I read one or two of those comments and then I shut it all down, I can't read them because of the stigma and the ignorance that is still out there is appalling. And that was just recently with World AIDS Day, the criminalization piece came out, this was all positive and everything, and I know one guy, I think from the post he was maybe a little bit older, but still that shouldn't matter, he says, "So, these HIV people can just walk around and murder people." And to hear that in 2019, 2018…

JH: Wow.

P: … is disturbing. Yeah, and you're always going to have those rednecks out there, whatever you want to call them, however you want to label them. But it's still, like it's shocking how the stigma piece is still very much out there. Yes, has it moved, has it shifted – yes, some. To the place we'd like it to be? No. But due to the fact that maybe other organizations are coming forward now, mental health is more out there now, I think when those other pieces come out and they're talking about stigma too, I think that can only help the HIV piece too. They're different because it's not like you can catch mental health from someone.

JH: But we learn from each other, our allies, on how to fight better, or how to present better, or work it, whatever. Our allies are important. They're dealing with the same issues, like stigma.

P: Yes, and I think mental health is definitely an ally. The cancer piece, it rubs me the wrong way, because that's a whole business now, and they have so much publicity out there and they've got so much money and backing behind all that piece, so much more well-recepted [sic] I guess within the mainstream community, which is kind of…

JH: So, in wrapping up, is there something else that you would like to get on the record, get out, tell us? I've learned a lot a lot listening to you, [name].

P: Hm, thanks Jackie. It's important to be true to yourself, advocate for yourself, I feel, and pick your battles. I know it's not easy when you're dealing with health stuff, but there were some things I just could not let go of, you know? And especially that piece the confidentiality piece and my workplace, and that was just – I was horrified thinking that my whole workplace was going to find out about my HIV status, because when I was in that workplace, it came up in our training about first date and HIV, and some of the comments that came out, it was a bit – going okay, can they tell? They can't tell, I don't have it tattooed on my forehead, okay, they don't know. I'm okay, we can get through this, just ignore the comments, they're just ignorant people, they don't know anything. It's kind of nerve-wracking, but when that piece happened, I felt I had to step up, even though everyone told me, oh, you don't sue for that, lawyers don't sue for that, that's not a common case, they do that in the States, that confidentiality clause and law is fairly new within Canada, you won't make any money on it, you won't get anything out of it. It wasn't so much about the money piece, it was just about you people really – excuse my French – really fucked me over here, and I was getting no support with trying to go on disability in my workplace, it was all complicated there, and micromanaging. And it was just a horrible, toxic place to work. And then I've got the insurance company that I'm dealing with here that's supposed to be supporting me, helping me with getting the support, denying me and putting up hoops to jump through and lying about things that I supposedly had or hadn't done. And then when I voiced it to them, them coming back and saying, no we never did that. I was like, no, that's incorrect, you broke the law there, and you guys are an insurance company that's supposed to be protecting people's medical records.

JH: So, this is the be true to yourself piece, or stand up.

P: Yes, so with the HIV piece, because there are so many places where it can be disclosed against your will, where you have no control out of it, where the doctor disclosed it and I knew nothing about it, or a relationship you've been in where they disclosed it to someone else you didn't give authorization to, so many of those different pieces that have happened, I feel that I've had to voice and I just couldn't let go, because they eat at you. So, I think where you feel comfortable, what you can do with yourself, where you feel you need to speak up and voice yourself, voice it, no matter how many people say, no, don't do it, or, oh, that's not the right thing to do, or whatever. And I'm speaking to all these legal lawyers and everything and I'm like, well, I need to do this for me. Even if I didn't win, even if I got nothing out of it, I knew I did what I needed to do for me to be able to move forward and stand up for my rights and that. So yeah, just pick your battles where you can, and lots of self-love – lots and lots of self-love. And get a good therapist.

JH: Thank you, [name].

P: Thank you, [name].