

“HIV in My Day” – Interview 37

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Interviewee: anonymous (P); Interviewer: Ben Klassen (BK)

Interview anonymized at participant's request

Ben Klassen: Thanks so much for being here and agreeing to share your story with us. We like to start by asking folks how they first became involved in the gay community or started engaging in gay life.

Participant: I personally came out kind of late. I was about twenty-nine, and how I came out, I was just curious about my sexuality all my life, but I didn't do anything about it because I was preoccupied with other things, some of them that prevented me from exploring it, mostly mental. Pressure from the way I grew up, was more like guilt, and finally I started to explore it when I was about twenty-nine-years-old in Vancouver. I would, my first sort of break, or gateway into experiencing relations with men, I just met somebody by accident in the city and we started to talk, and we had sexual relations over a short period of time and it was what got me out and confirmed that I knew what I was doing, and I went from there. And at that time, the ways to meet people would be to – there's lots of ways you could meet people but I started visiting night clubs and bars in Vancouver in the Davie Village.

BK: And when was that approximately?

P: 1989.

BK: What did the community look like at the time?

P: It was on the cusp of Gay Games in 1990, so that sort of followed my – confirmed me coming out because it was a sporty environment, it was actually really healthy. I look back, and it was probably gay Vancouver's healthiest time ever – I think it was the apex of a pretty liberated and healthy gay community particularly because the gay guys were looking forward to this event. It was a big sporting event that summer, so that's what I, what made me feel comfortable coming out. I had a relationship with someone after I dabbled a bit with my first encounter, I met a guy at the Odyssey, which was on Seymour St, a guy ten years younger than me. He had just become an adult, so I had this person who was on the same page as me but a ten-year difference, so I had this partner. I am a west coast guy, so we went on camping trips and road trips, we travelled to a couple international cities too, and then after about a year we went our separate ways, and he moved back to Montreal and I was a free man and I was fresh meat. So, that summer was really exciting for me because Gay Games had started, and I just started to meet all kinds of people around the sports realm. And one of the things that got me kind of more face-to-face with people was I landed getting some work for Gay Games – I worked in the graphic design field, so they hired me and I did this big side project for them and I started to meet people through that. And then when that – so Gay Games overlapped pride that year as well, so that was a big component, so I was exposed to that. It is a big party in the city, both of them together, so it made it a pretty exciting time for me, so I ended up joining the gay volleyball league in Vancouver, VGVA, and that was a springboard for me and my sporty gay lifestyle. It was good.

BK: I guess Gay Games was a big event because people were coming from all over the world.

P: It was massive – BC Place opening ceremonies, it was crazy.

BK: And interesting that your way of latching onto the community was through athletics, which is a little different than some of the other stories.

P: Oh yeah?

BK: So, thanks. Any thoughts on what Vancouver looked like at the time?

P: So, I am from BC, and I have lived – so, I was living on the west side of the city, just across the bridge in Kitsilano, so I would come down to the West End because this was the village. It was safer, not that I had any real concerns – I wasn't, I had never got criticized, I never was criticized or had a hard time about being gay in the coming out years. Since then, a lot of people – I have had people say things to me in heated moments, you know, faggot and stuff, but who cares? As far as coming out or what Vancouver looked like at the time, it was the west, I am thinking of the West End, so that's mid '90s, it wasn't the coveted destination neighbourhood it is now. It was just full of rental apartment buildings, which is what I did, I rented in a couple different rental situations, I was involved in, never anticipated the crisis and crunch that is going on now, but following all that I made some choices that solidified my homes, so I am in a pretty good situation now. As far as what the city looked like, Vancouver in the '90s, it was before, after Expo, which kind of put it on the map. It was still pretty compared to now though it was a pretty benign neighbourhood. The way to socialize was going to the clubs – if you wanted to meet people, that would be one way that you socialized and I did that lots, I would even go out during the week, and I worked for myself. But a big social component was going out if you wanted to meet people, you would go out and buy a beer, and then when I finished that I would go to the washroom and fill the bottle with water because I didn't want to be drinking all night.

And the other ways you would meet – Little Sister's bookstore was on Thurlow St. and it was kind of a place to cruise, and it was kind of atticy anyways, so it had a couple different corridors in it. There wasn't any action, but I remember I met someone there, and we hung out there for a while over a short period of time. Other ways to meet guys – you, because we didn't have modern technology, we weren't connecting through the internet, even the chat phone lines hadn't even come into use yet. So, people would meet – like it was important, in my eyes, for gay men, if you wanted to socialize or get out, you would go out. So, Monday, people would go to Numbers – there were certain nights for certain things that were going on. And other ways to meet, down on the beach area, Sunset Beach, that was a kind of a cruisy area, so guys would meet to meet or to have sex or whatever – you would meet somebody and take them home or do it in the bushes, all that fun stuff. I knew about going to Stanley Park – I never went, I have gone since. And I am trying to think... it was important to be involved in sports or clubs or events, because you met people that way. There was the gay volleyball league, and during pride they had a big sports day that was hugely popular. I know they have it still, but I don't think it is quite as popular as it used to be. In my exposure, as far as vices went, men drank alcohol, used marijuana, I knew of people who would use a bit of cocaine, because cocaine became

internationally popular just before that. I didn't, I tried it. Sexual behaviour, AIDS had just sort of started to ravage the community, so, you know it was on your mind to be safe. Any other questions in that realm?

BK: No, I think we are just edging into the HIV-oriented questions, so that seems like a natural transition point. No, thank you so much for all that background. When did you first hear about HIV or AIDS?

P: I knew about it before I came out, and I remember I had one random experience about five years before I came out, and I went to this guy's place and it was – I wanted to have sex with a guy, this guy, and I knew that he was out, and so I remember I questioned him, even then. I was really mindful of how clean he might be – I remember I even used that word. I knew about it, and I didn't know much about it. There was a really – AIDS, it seemed like people would be diagnosed and find out they were positive, and they would get really – they were obviously not well. You could tell by looking at them or also by, you know, they knew, their bodies weren't handling the virus and so there was this crap shoot of medicines that were being used, and so I just was watching all this in a sense. It was a big concern and I think – so, you had the Gay Games thing was a huge plus in the environment here and in that moment and it carried on for the next year or two, but also the AIDS crisis, in my mind at that time was at a sort of, at its inception. Conversely, that was a big deal, a big negative in the community. People were paranoid and it was talked about. I had a new group of friends and none of us at that time had been exposed, or at least we were all safe, or we weren't – we were all still in an HIV negative existence, but things change.

BK: How did you respond on a personal level to that early news around HIV and AIDS?

P: It just made me be really mindful of safety. I was puzzled about the disease itself, because I am curious, always exploring personal health and wellness, so I found it to be a really strange new thing – it wasn't like any diseases I had heard about. It was scary, because it seemed like it was a death sentence if you were diagnosed, and it pretty much was, but not necessarily. And there were people, I remember when I was playing volleyball for the couple of years that I did, I remember that there were two or three guys in the whole league that we knew were positive, and they were pretty open about it which was pretty cool, and they were also really respectable and accomplished people. The great thing is it put a human face on it for my experience.

BK: And as the epidemic progressed, where were you getting information from? How were you continuing to learn about the epidemic?

P: I didn't learn a ton about it, because it didn't concern me in a personal sense, because I wasn't HIV positive, but all I knew was that the guys that I mentioned, when I had conversations with them, they were on medications, they were doing okay though. And then I would see other people around that I met eventually through however you meet people that would tell me that they were doing okay on the meds, or some weren't, and you could see side effects too. But educating me on it was through the community – the bars had posters and advertisements about it, the media was always talking about it, but obviously, organizations weren't set up. I don't even know if AIDS Vancouver and other organizations were set up – I guess they were built,

assembling those at the time. I remember when Friends for Life Society, the house in the West End, I learned about that, because they would have a big party in the park every summer and it was a big open house for that and the other facilities down there, so I knew that there were these places became somewhere people could go, people that had, we called it AIDS at the time. So, I knew of that organization, but I don't as far as the province and the medical industry, they weren't really saying a lot of – as far as personal care and safety and all. That, that was more of the community generating that advice.

BK: And by the time you had come out and were engaging in the community, that message around safe sex, was that out there and prevalent?

P: It was

BK: And that was mostly through seeing posters in bars?

P: Yes, and it was a given – you would talk, if you were going to have sex with somebody. It was typical on the weekend to go to Numbers or Celebrities – it was huge because it was a dance club. You would have a few drinks, find someone to get together with for the night kind of thing, and you would, if you went home together, you used condoms – it was pretty standard to do that. And you would stay the night. It is so different now.

BK: What a novel concept.

P: I know, it is interesting. I was telling someone the other day about how it worked.

BK: With condoms, there was a kind of a consensus that condoms would be used.

P: It would be kind of surprising if you didn't, yeah.

BK: So, there weren't a lot of difficulties negotiating that.

P: And people, because of AIDS, people weren't having anal sex a lot because they were concerned that it was risky even with condoms, so yeah. Like nowadays, it depends on who you are and what you do, but nowadays, it's like some people, it's not sex if you are not fucking. It is just different, and everyone has their own standards and values around their sexual behaviour.

BK: It seems like the consensus might not be there in the way there was consensus around condom use in the late '80s and '90s.

P: It is completely different now with PrEP and PEP and everything out there – it is interesting, it has gone full circle. Like, I am positive and I am sexually active and I've – to be honest, I hardly ever use condoms again. It is interesting.

BK: And undetectability, that has changed so much for so many people.

P: Exactly, yeah.

BK: At the time – you talked about some of these early community responses. Were you aware of some of these organizations or how the community was responding?

P: I am trying to think what sort of things were going on. I don't recall any organized media to push for safe sex, it was just a given that you would do that – it just made sense. Within Vancouver, I knew that AIDS Vancouver was getting organized and Friends for Life was doing care for people. What else was out there at the time? That was about it. I don't remember any big campaigns for safe sex, I don't remember any... yeah.

BK: It is interesting, because it would have been a big adjustment at first for some guys to use a condom, because before the epidemic it wasn't a thing most gay guys did. I wonder how that became common practice.

P: I guess you just start doing it, and I think compared to now, in order to avoid condoms, they are – that's another topic, a lot of people just didn't have anal sex, they had the type of sex where they felt they could have sex, where they didn't need a condom. So, it would be, you know blow jobs, oral sex, but there were even people, there were even a significant people that wouldn't even do that without using a condom. I meet people nowadays that have that policy. It is rare but no oral, and if we are going to have it it is with a condom, but we are probably not going to have it. Which is fine, everyone has got their choice and their level of comfort.

BK: How visible was the epidemic as you were coming out. Was that something that was showing up in Vancouver already, or just emerging?

P: In my experience, it was just emerging as I came out. As each year went by after 1990, it became more obvious because of statistics, and also because of what I saw around the community, because people were physically ravaged by the disease and the medications, so it was a visual thing too. You could see it in certain people. In my experience, I would think, is it just because I am coming out and getting to know this that I am realizing how prevalent it is, but I think it was on the upswing.

BK: What was it like, seeing that as a guy who had just come out, seeing this visceral image of HIV?

P: It was an eye opener, and it made you think safety, and you were thankful that you didn't have it, so, that is kind of how I looked at it.

BK: From what you recall, what was being said about HIV in the mainstream media, or just mainstream, outside the gay community?

P: I felt that there was quite a stigma attached to it – you didn't want to be one of those people, and there was quite a bit of judgement around it too, even from people within the community, but obviously more from people in the outside world. There was the extreme of “it is god's wrath from the religious,” but even from within and without, it is like, silly you, you should have used a condom, that was what I observed.

BK: Some of that stigma infiltrated the community, too.

P: Yeah, out of fear, people judge. It is sort of a mechanism you use to keep themselves away from it, keep themselves safe by saying I am not part of that, and I think at the time, the researchers weren't 100% sure on how people were getting it. They had already learned a lot about it in the years prior to me coming out but there was still uncertainty around how the disease was passed in unsafe anal sex. I wasn't 100% convinced that that was how it got around, but I am kind of skeptical – I am not a conspiracy theorist, but I really wondered what was really going on. Like anything, I like to question it and wonder if there are many sides to this story, and what really could be going on. People were talking about how it started, you know patient zero, did it come from Monkeys, and how was it getting around. There were some questions still, people weren't convinced by what – not all of us anyway, that what we were being told were the only side of it.

BK: And there were some questions around did HIV always develop into AIDS – the connection between HIV and AIDS was being questioned by some people. From your position, what did the early medical response look like?

P: Before I was diagnosed, the information I had about the medical treatment was that it was working for some people but not for others. There were side effects that people had to deal with, and in my opinion, when I would see people who were sick especially if you could be visibly sick, I would think, wow this disease was really ravaging their bodies. But following that, there was a huge concern that it was the medications that were doing the damage.

BK: Medications like AZT?

P: Yes, I heard about AZT a lot. But I didn't – I wasn't too concerned technically about what the meds were and what they did because I wasn't using them, I wasn't HIV positive.

BK: And were you at all aware of what the government response looked like in the early days as well?

P: Yeah, it seemed like worldwide governments were – this was a big thing to grapple with and they didn't realize how bad it was going to get and so there was – you heard about lots of activism. There was an organization called ACT UP and I remember they would do, periodically, they would do demonstrations, things to really get attention, so they – I recall things like they would show up and disrupt where events would be going on, and lay on the ground covered in blood, mimicking death. And come on governments, wake up, this is a crisis and we need you to help us and steer us through this. And it seemed like the government was not responding very much at all.

BK: And the activism, what did you think about that?

P: I thought go for it, I am glad you are fighting for something. It was pretty desperate time for a lot of people.

BK: How did all this change with your own diagnosis?

P: Oh, okay, so...

BK: Change your relationship to the epidemic, the community, maybe?

P: I remember when I was diagnosed, by surprise. I was going to be going away on a big trip and I had felt really crappy that winter, and mostly because I was sexually active, and I was single, not that that may or not have influenced different people. When I got the diagnosis, I remember the response was from a fill-in doctor, 'cause my doctor wasn't around at that time, but they gave me the results in December of that year, and I was really shocked. I actually was concerned that I had Hepatitis or something, 'cause I felt really lousy, and the reason I thought of Hep because I had a friend who got it somehow, and I can't remember what hepatitis he had – A, B, C, D. And I remember the doctor, a stranger, a fill-in, telling me that news. I sat in her office on West Broadway in the Fairmont medical building, and I remember her telling me this, going through the results, and divulging the results. "You are HIV positive." So, I was in complete shock when I think back. I was sitting there absorbing this and I remember her telling me that, "There are medications for this as you probably know, and you have probably got about seven years left." I remember her telling me that. And I thought, oh, wow, and I kind of existed in a sort of fog about that topic, and I know that it really influenced my personal life too. I didn't tell any of my friends for – some of them I didn't tell for years, and these were people that were part of my daily and weekly life. Because I had come out just prior to that and late in life – part of the reason behind all that was due to a very traditional and judgemental family background, so I didn't tell family members like for – at first they saw that I was coming out as a gay man, they observed that I was up to something because my social behaviour, my social life had changed. I was always with guys and I had, I am from a pretty large family, so over time, at least one sibling was super supportive, and I knew I could come out to her. She is a highly educated person and she gets it.

So then, oh, here I go again – I am going to be coming out all over again in a different sense. Even with my group of friends, it was rare to have somebody in your realm that was HIV positive, and so because of that I just never said much to anybody, which is fine. Do you have to tell everybody, so they tell everybody? Telling them or not didn't make any difference to my health, but when I look back, it was a different time, but I think in human behaviour, it is best to tell people that you are close to, because why not, it helps you. You don't internalize as much, and they are there to support you so – but it wasn't until there was more and more diagnosis and more options of facilities to help you in various ways either mentally, physically, medically, it wasn't till that became more prevalent, that you became more comfortable about coming out about your status. So, I didn't go on any medications for years. I was hell bent on finding natural ways to maintain my health. I was intact, I was fine, but in the – within a few years, I finally took the doctor's advice. They were regularly marketing that you should go on some medications, yeah, so I finally caved in and did that.

BK: When roughly was that?

P: Around the diagnosis time, '94, '95 – I can't recall the year exactly – a few years after that, so late '90s. I remember the first round of meds I went on. I had a doctor who had an office on Davie St. – they are still around, they are part of Spectrum now – it was Carol Murphy and Joss De Wet, and they got me on a medication called Crixivan. And so my numbers, I would get results back and, "Oh, it is working, your numbers are better." But I have always questioned how they establish these numbers and what they meant. The word undetectable wasn't around then, but as long as your numbers were down to certain ranges, they would say obviously the medications are working, so I just stayed on it. And then with Crixivan I started hearing all these experiences of people that were having side effects and some were humps and growths, not deformities, but it would be hard on your body in different ways. You could see in in people's faces too, and so I got really wary of it and I started to think that I was not feeling great physically, because maybe the medications were too toxic. So, it wasn't uncommon, like people were still experimenting with their own care, so it wasn't uncommon to take a drug holiday, and they weren't recommending – some medics were recommending, but most were not. Doctors don't want to be advising their patients to take a drug holiday in case they pass away, and I remember people at that time were still dying even though they were on medications. Then this big question came up in the community of, you know, a lot of the sustainability of people wasn't working because these medications were not really the right dosage and maybe they weren't the right thing to be using. But you know, this whole journey was a huge public experiment, and understandably. Researchers were challenged, it was a whole new thing, so yeah.

BK: Sounds like you took a very active role in determining your own health care.

P: Yeah.

BK: In terms of deciding when to go on medication.

P: And I went through periods, since then, so then my numbers looked not great and maybe I wasn't feeling as great as maybe I did prior, so I would go back on medications. But then there would be a whole new artillery that came out from medical labs, so I was hopeful, no more Crixivan. You would go on, I am trying to think of the name of the new drug I went on, so then and I did that for a few years, and then I took another drug holiday. And my lifestyle, I live a pretty clean lifestyle, I stayed sporty and active, I went to the gym and took all my supplements and hoped that all these things would help me or assist me through, besides being on or not on the medications. So, I never got really like sick like a lot of people did, but there were, whether side effects of medications or not, I would definitely go through periods where I never felt – where I wouldn't feel great all the time.

BK: In those early years, following your diagnosis, you mentioned that you didn't tell a lot of people that were close to you. Where did you find support?

P: Yeah, I went to AIDS Vancouver in their original location on Seymour St. and became a member and I went – I am trying to think why I went there. I went there to get information, and I kept in touch with that organization. They seemed to be, if anybody, they would be cutting edge with gathering information for people, but that was really subjective information too at the time. It was all new, but they were printing a magazine which you could read to learn about things,

they had created the AIDS Walk, so that was a huge public awareness campaign, and I volunteered with them a little bit too. So, I got a little bit community involved, just to keep in touch, and they had lots of printed material in the facility, so you could read about what they were saying or not saying, and they were challenging a lot of things. So nowadays, we are more convinced that the medications make a difference. Back then it wasn't – you weren't convinced, you were even wondering if it was a bunch of marketing for a pharmaceutical, so people really questioned that. So again, there was this thought that the meds were doing a lot of the damage, so it was a big question mark.

BK: AIDS Vancouver for you was a source of information. Was there any other elements of social support or...?

P: Well, you know, if I would physically hang out at their place that there would be other people there who were in the same situation as me. But what I did, because of the setting I would go to Friends for Life Society. It is in a house and it was a lot more – you know, it is a beautiful place, a relaxed environment, and I would go there for social reasons. They had lunches and stuff like that and they had the physical therapies and the mental therapies, so if you wanted to go and talk to a counsellor, which I did a couple times, and I would take advantage of their massages and different things that they offered. It just made you feel better. I don't think the massages were helping with the HIV, but massages are good for you, they help your body, and I think there is an element of comfort that comes from going there for that.

BK: Any other sources of support for you in those early years?

P: I can't think of anything else, nothing that I accessed. I would do research, I would do a little bit of – I would go to the library to read up on things. Even when the internet came out, I didn't jump on it, I didn't get a computer until years later. I just gathered information by what I saw on posters and print around town in the newspapers, different opinions, expressions on HIV and AIDS were out there because it was a going concern.

BK: So, you sought out a lot of information for yourself.

P: Yeah, but it was pretty available. You would read the newspaper and you could read a research paper, an aspect of it, so you kind of kept in touch with it.

BK: Any other thoughts on how the community responded to the epidemic?

P: I think it galvanised them in many ways. It was kind of a shock at first, just like anything, everyone is freaking out and not knowing what to do, but I think whether you were HIV positive or not, the community started to get together, and say people need support and we want help too, especially medically. So, I think people banded together and any organization that had an event or fundraiser that had anything to do with AIDS support was hugely supported. For example, when I was going to Friends for Life, I got involved with them on various levels. I volunteered with them, and I guess the apex of my association with them was one year I was on a committee, with them. They were wealthy, they had money, people were supporting them really well, anything to do with AIDS, so anyway, I suggested that we throw a party for the people that had

been supporting them for the last – I think they had been around for ten years at that point. I spearheaded it, and we had this big successful – I always wanted to throw a party, and so we had this really great party at a house, and it was like this is the way, and this is how well supported anything to do with AIDS was. I would go to, because I was self-employed, I had the initiative and I remember walking in the daytime, I would take time out of my job and I would go to Robson St., or up in Kerrisdale, different areas, in part because my job was mobile. So, I tied in with work, but I would literally went to store owners and I would say, this organization is having this big support party for their donors, and I was soliciting door prizes, and gifts and people were like, “Sure, of course.” It was phenomenal, and the party was hugely successful, because I learned in sales, you always go out and look for new business, but you have to say thank you to what you already have, and I still think people forget to do that.

Since that organization, in recent years went through a big financial crisis, it taught you a lesson, to not sit on your laurels, and number two, there is always new competition. And I think the AIDS fundraisers were the shining example of how to put together a successful support for any kind of disease, so you know, this community came out with the AIDS Walk and all kinds of galas and fundraisers, which were very well supported because there weren’t a ton of other diseases that were – I mean cancers and things have been around, but you didn’t have that community, innovative community that went out of its way to support it, and now everyone has looked to that model and built on it. When I look back – so, I kind of disengaged with Friends for Life, some drama and politics, and I was a lot more stable and healthier and I felt that I didn’t need to, like AIDS didn’t define me, and I had my own life. Carried on, lived my life, travelled and did different things, but I was kind of shocked when I came back, which was only a few years ago, into accessing – I am not sure why, but I just started to access more, the AIDS community. And so, I went back to Friends for Life, I had made some new friends and they were members there, and I said, oh, I had a history with them, and they started telling me about the new Friends for Life and how it was having some challenges. And I was shocked, because I remember how wealthy they were and how everyone was donating to AIDS organizations, it was the thing to do.

Anyway, my take on it was they were complacent and maybe some financial mismanagement, I am not sure, but it is nice to see. I am involved with them in a small way and it is nice to see that they are on the upswing, there are new people, and new blood and it seems like they are doing better. So, that was my – that organization was the one I kind of took on as the one I liked being involved with, and then I took a break from all of it, and I think it was kind of good. You can get too entrenched in – you sort of live in this ghetto, we are already geographically in a very unique neighbourhood, so I kind of had to get out in many ways, and so I just decided that my life outside of these organizations was important and I didn’t have much to do with them. So, when I started to hear about things, like Positive Living, like they have this thing, it is called a Positive Gathering. I had friends that were positive that went to it – “Aren’t you going to go to it?” Nah, that is not for me, but I did finally start going to these. I finally got more involved in the AIDS community again, so I have kind of gone full circle.

BK: Did HIV as a whole change your relationship to any community? To the gay community? Maybe there is an HIV community as well?

P: I think there – you are part of an HIV community if you have HIV, but how much you are part of it is up to you. You could be at the low end, you identify as someone that is HIV, so to me you are part of that community whether you like it or not. Whether you physically or mentally or otherwise participate in that community is another thing, and how much you do that is another thing. I know some people that it is, especially nowadays, it is just your own personal status and it doesn't really affect who they are – they don't talk about it, it is just private information, they see no need to. And then there are other people who are much more vocal and open about it and want to share, and for them participating is really important.

BK: How have your perspectives on HIV and prevention changed over time, thinking back and looking toward the present? How has the meaning of HIV changed to you?

P: It seemed like back then, if you were diagnosed, you were told that HIV led to getting something called AIDS. I think at the very beginning you just had AIDS. Now there is a big divide. I never – because of the progress in health care, in medicine, the AIDS word is almost never used anymore. You've had bloodwork done and you have tested positive to being exposed to HIV, like a lot of things you have been exposed to. It is really not a big deal. I don't go around telling people about it either. I don't think it is that – I think part of it is because there is still a stigma – naturally, it is sex related, bad behaviour. Not bad behaviour, but sex is still a big topic on its own in our world whether to do with the religious influences, that is not that big of a deal with me. But I don't go around throwing it in people's faces, my sexual activity or my status. I actually have another health challenge that I discovered a few years ago and that is way more of issue than HIV. I have iron overload – I have way, way, way too much iron in my blood, my body just hoards it. It is called hereditary hemochromatosis, so I have a sibling that has it and cousins that have it, and my cousins had told me that they had it fifteen years ago, when they were diagnosed. I probably wouldn't have the challenges I have with it – I feel okay. Sorry, I am going on a bit of sidetrack.

BK: It's okay.

P: I am one of those patients that they don't quite know how to treat because it is a pretty astronomical number. They have tried the traditional treatments, and it is only something that has been diagnosed since the '90s. A million Americans have it, so I am experimenting with trying to get my body to stop hoarding iron, so the first thing you think of is don't eat foods that have iron, which is in iron, but that may not be the answer, because it isn't being exposed to food containing iron, it is about stopping the imbalance of how your body handles it when it gets it. So, I am trying some new things but I am not really sure what is happening with that. So, what it gets down to, is any heavy metal in your body, your liver has to process it, and we live in the land of rich food and drink, so your whole body is processing all these things, so it could become this overwhelming thing that could do me in. I don't really know where it is going to go. My father died at sixty-five, my mother just a couple of months ago at ninety-five. My sister thinks that because it comes through his bloodline, that maybe he had it and didn't even know. Men have a bigger challenge with it because women bleed, so they get rid of stuff. Most women are anemic actually, whereas I am the opposite, that is my challenge you know. I feel pretty stable with mentally and physically thinking that the meds I am on are making a big difference with because of... For my HIV treatment, as far as that goes, I am pretty comfortable with that, and

now I am almost sixty, so I think that I have a had a pretty good kick at it, considering I had a doctor who told me a had seven years left in the mid '90s. It is all bonus time, it is all bonus now.

BK: Well, hopefully there is a lot more left. It does put things in perspective if HIV isn't the thing you are worried about anymore.

P: That comment I made is pretty standard for me, that challenge for me is the iron overload. It is just another challenge in life, right? There are people who pass away that don't get the number of years I have got out of life, and considering things, I am pretty lucky, and I feel I have a good ways to go. But who knows, I could be affected by this. I know I was off topic, so managing this thing that I have known about for about four years now, the system was a bit negligent to be honest. They saw this high number and they thought it was a typo and it got ignored, and it was suggested by a doctor, whose waiting room I am looking into right now...

BK: Oh no.

P: Downplayed it, and especially someone in this community who was my caregiver, I thought it was a little bit negligent, really. I don't know how much of a difference it would have made. I am at a point now where I have tried their treatments, which won't work, they aren't working for me. So anecdotally, I have found that there are certain foods that absorb iron absorption, and one of them are brazil nuts, and they are a great food otherwise, they are great at making your body produce testosterone, like a lot of nuts are – macadamia nuts are the best. Brazil nuts also are iron blockers, maybe because they are high in selenium. Selenium and iron compete, so anyway, I tried this experiment and I am still doing it, and it worked, or something worked because my number dropped pretty significantly, not to where they want it. And I was really proud, like wow, I found something, that is working, but then prior to going on a trip recently, I thought I better get tested for everything, and it skyrocketed again, so we aren't really sure what is going on. That is where I am at. But I feel all right, I am kind of doing all right. I worked for myself for most of my working years, and my last stint of work I did, 'cause I don't work now, I was an employee, and at the end of the term of that job, which was four years ago, I realized that if I play it smart, I probably don't have to work anymore, pardon me. So, so far so good, and the thing that has made that easy for me is I have my housing figured out. I don't pay rent, I bought and paid out my place earlier in the game, and it wasn't financially unreachable like it is now for so many people. No, I am living a pretty easy life, really. That freedom 55 thing people used to talk about way back then, I actually attained it, but most people, forget it – you got big bills to pay, big mortgage to pay.

BK: That has changed since the '80s.

P: That is a big topic, that is the big topic now, your housing. It is not HIV.

BK: I was going to ask about Friends for Life and AIDS Vancouver. It sounds like there was a difference in the kinds of services those organizations were offering, but was there also a difference in the clientele?

P: Yes, well I think AIDS Vancouver was foundation grassroots, they were for the guy on the street. You would go to their facility and they offered different services. They offered – I mean, you could get groceries there, and its array of services is broader, whereas Friends for Life was more of a – you would go there for a couple times a week, you could go there and eat a meal because it was community. And I would participate in that because I like that, and I met – I made some friends through going to that organization. They have massage and different treatments too but not the broad spectrum that AIDS Vancouver offered, so I could see how AIDS Vancouver would appeal to people who were more desperate, but they also offered advocacy. Friends for Life doesn't offer that. And that was really important, people really needed people to fight for their life.

BK: Was AIDS Vancouver serving a more diverse group of people? My impression is that Friends for Life was mostly West End gay men.

P: It was, that is what I saw it as too, and it was founded by someone who did it to help the AIDS community, but there – officially they were there for anyone that is dealing with a terminal illness. What happened with Friends for Life during my – I think I was involved with them for maybe ten years, I saw it go from this very cohesive group of regulars – they were a big part of it, the facility meant a lot to them. It was funny, we had very little to do with AIDS Vancouver, how many community organizations do I need, and there is community there, it is social. And what started – what happened during that time was, recreationally, drug use changed dramatically, so I observed – when I first started going to Friends for Life, I met, if you smoked cigarettes, you could go out in the patio and smoke. Like, where do you get to smoke now, which I am happy about because I don't like it, but that was the norm. People were influenced by things over time. What I am getting at is recreational drug use really changed, so when, during that time, people were hooking up with the phone line, you didn't have to leave the house much, and now we are in a different realm where you use your app, and you are walking around, so it is even different again. So, that is how people were hooking up, and I remember when I was participating in that, I would be on the phone line trying to hook up with a guy, and he would ask me if I was partying. Yeah, it is Friday night, I am partying. I didn't even know what they were talking about, but I noticed when I would have an encounter with someone, something was different. And I even remember the first time, it was in the daytime, a young guy came over to my place, and he was really odd, and I thought maybe he had Tourette's, or had a mental condition, his behaviour was really strange, and it was my first exposure to guys who were high on drugs. I didn't really know a lot about, but I thought the behaviour was cause for concern.

And so, Friends for Life had a whole – what really affected it on that level, people were becoming – their lives became unmanageable because of the drug use and abuse, and they were showing up there as somewhere to hang out and they were messy when they would show up. People would be high, disruptive, it was a whole new challenge, and they had new staff, and I talked to some of the staff and I said, you don't have to handle this. It was a challenge, so the house became – they changed policy with a lot of things. You couldn't even show up to have a cup of coffee, they were discouraging you from showing up outside of lunches and programming because they were overwhelmed with a population of people who were showing up to hang out and being disruptive. And theft was going on, of personal property and property of the house, so it just gave me a really bad taste. For some of the political reasons with staff and also with what

was going on there, I disengaged with it, I had nothing to do with it for almost ten years, and I just recently, in the last couple of years, I started getting involved with them again. But it is more stable and it seems like that portion of the population for the most part, the ones that are poorly behaving, they don't show up there. I see them more – I go down to Positive Living once in a while and I see more of that there. I think that because there has been such an upswing with use, that they have their one community that they hang out with more or less in various ways, whether it is just getting together and being high together, or whatever you are up to, they are elsewhere now. I remember that it would be really unusual to me doing party drugs and now it's the norm. I am single and I am sexually active, and my frustration now is meeting people who aren't doing that because it isn't what I like. I can stand it a little bit, but to be honest, it's – there is more of them than there is of me, so they are all hooking up and doing their thing, but I don't want anything to do with it, so that has really changed.

BK: It is an ongoing issue in the community, it seems. Thinking on this grand scale, how do you think the epidemic changed the community as a whole? You talked about it coalescing at some point, but looking toward the present?

P: I think the present, I think what has happened in tandem with the epidemic is we had a federal government that was not really – they didn't really care as much. They could have done more and quicker, but even internationally, you look at money is a big thing now for everybody, so if you aren't wealthy, or if you aren't wealthy in this world, you aren't doing very well in this world. So, care and like housing is such a big deal that I think we are in a time, whether you are HIV positive or not, and whether you are doing recreationally or not, which is a big deal because it is affecting the ways you manage yourself – housing is this huge deal right now that I see right now. I think there was a time you could be an addict, you could pay your rent, you went to work, but I think now communities on all levels are overwhelmed

BK: How has that affected the gay community at all, if it has?

P: I personally see, in various parts of the population, I see people who are very desperate and some of them have become not very hopeful. And I think that on one hand, their health is okay if they are looking after themselves, leading a normal life, getting sleep, eating properly, they are exercising or whatever they do, or not work, 'cause there, I know people that are fine physically, healthy, that have HIV, but they have taken the disability option, right, and that is fine. But I think the big game changer is if you have drugs as a big issue, you are not doing so well in many cases. I see that. I have seen people of really high professions lose their entire life – it isn't the HIV anymore, it is their drug use.

BK: Thinking about HIV in the present, in terms of health care or education, are there any things that we need to be doing better?

P: Well, there's the medications, or something, has made reclaiming your health pretty successful, plus if you are – and also, there isn't this big divide between positive and undetectable and guys on PrEP, or are negative. It is all sort of in what I am seeing and it is happening really quickly, is it doesn't really matter that much anymore, which I think is great. So, I can – I have got more of a pool to play with and I don't have to hook up with a guy, the

classic HIV poz, recreational drug addict. I think what has happened to some people, they have because of being positive, or for whatever reason, they have lost some of their self-respect and self-care, so they are kind of just partying until it is all over, right? But on the other hand, there are people who aren't like that and because you are being respected and acknowledged by people who aren't HIV positive, in a better light now, it's made life in my existence much more – it is just normal, you know? There is not a big divide between positive and negative people anymore. I like that.

BK: That is pretty amazing and hopefully that continues.

P: One of the comments I was building up to is now the big concern is, because protection isn't as required, is STIs, things like syphilis. And I knew as soon as people were using PrEP, I tell people, PrEP is for HIV, it isn't for everything else, so just know that you are exposing yourself to other things. Even before PrEP had become prevalent, there has been big increases in STIs even before PrEP – any big metropolitan centre is having their challenges with STIs.

BK: So, maybe that is an area that we need to focus on more.

P: Yeah, but what are you going to do? What are you going to tell people? You choose to not use a condom. Okay, HIV isn't high risk anymore, but there is still all this, but I think the education is out there. Syphilis and things are talked about.

BK: People maybe just don't – aren't concerned about it?

P: Or I don't think they are concerned, and it is like a lot of people, I'll have sex with guys who are not positive, they are on PrEP and pretty confident. But I think a lot of it is, it isn't going to happen to me, but if it does, I will just get it taken care of. But what they don't understand is that it isn't good to be regularly exposed, but also by doing that it is getting spread around, but that is just the way it goes. And some people, the education element has to improve. A lot of people know that syphilis, know that it is really easy to contact, but a lot of people don't know that. It was shocking to me to learn that you can get it from touching someone who has it. A whole new horizon.

BK: All these new developments, but new challenges as well.

P: If you read historically, syphilis has been around for a very long time. It is a survivor, but there is talk that maybe that is the next one that they get a grip on. As much as the world has bad things going on, but genetics and modern science and medical science is making some really great strides, so there is hope.

BK: I think the last big question I will ask is, if you have any advice for future generations of gay men or for folks who are newly diagnosed based on your years of experience living with HIV.

P: Especially nowadays, it is not a big deal. Live your life, you know, however you choose to do it. Don't let it be the excuse to let go of yourself, just live your life – it is just a tiny facet of who

you are. Don't use it as an excuse to not carry on and fulfill your life in whatever way you want to. You are very lucky and fortunate that there are great treatment options and the future can be pretty hopeful, and you can live life as a normal person.

BK: Anything else I didn't touch on that you wanted to talk about? Or anything you wanted to expand upon that we didn't cover in our questions?

P: Not really, I can't think of anything.

BK: If you do think of anything, we can talk again at a later date. For now, I will just say thank you for sharing your story with us.

P: Thanks, it was a good retrospect. I haven't done that – it is kind of cool.