

“HIV in My Day” – Victoria Interview 5

January 30, 2019

Interviewee: David Hillman (DH); Interviewer: Bruce Budden (BB); Also present: Art Holbrook

Bruce Budden: Alright. This is Bruce Budden recording an interview on January 30th, 2019 with David Hillman at Vancouver Island Persons with HIV/AIDS Society. Welcome, thank you for coming in... and I'm going to ask you some questions. Actually, I already know the icebreaker. So, where are you from? Where did you grow up?

David Hillman: In Ontario, in Chatham. Small town, between Windsor and London.

BB: And when did you come to Victoria?

DH: In '78.

BB: Wow, okay, that was a year after I was born.

DD: Oh, [laughs] I didn't know you then.

BB: No, no, I was in Port MacNeill. So, you came here in '78. When did you first start to hear about HIV?

DH: It was actually in the early eighties. I can remember where I worked, we got a journal called *Science* – it's a big international publication that comes out every week – and there was a letter to the editor that I remember reading about. And it was just a point of interest that the CDC in Atlanta had been recording unusually high numbers for a very rare pneumonia, of which there would've been maybe twenty-five cases a year in the whole U.S., and the number had like, quadrupled. But they were being clustered in Los Angeles, New York, and San Francisco, and they were mostly among gay men in their late twenties, early thirties, and they really, well, the letter was written as just a point of curiosity as to “I wonder what's going on here?” And then it wasn't until – well, with time we found out what was going on here. But I still remember reading that letter in the magazine.

BB: Wow.

DH: And then it was in the news constantly as they found out more and more about what was going on. So, it was in... 1988, I was so – well, it was just inundating the news so much, I thought, oh, I should just go get a test, get it over with. I never ever thought that I would be a candidate, because I knew my own history, better than anybody else. So, I went to the STI clinic, and in those days, the test, I think it had to be sent to Ottawa, so it took a long time to get the results back. So, I went in, and the doctor said, “Well, you're positive.” And I thought, really? “There must be a mistake.” And he said, “Well, I don't think so.” And I just like, you know, I couldn't wrap my head around it. And he said to me “Well, I guess if you smoke you should quit smoking, and if you drink you should quit drinking.” And that was his only advice. And I went

home, and I was just kind of stunned, thinking I can't believe this, you know? And so, I went home and ignoring his advice, I think I chain smoked a whole pack of cigarettes from that, until I went to bed that night. It just... I couldn't grasp the meaning of it. So, I got a book and started reading about it, and I thought well, I mean, from what I had read in the newspaper and in this introductory book I got, most of the cases in the U.S., these men were like walking pharmaceuticals. I mean they were on massive amounts of recreational drugs every weekend; they were having thousands of sexual partners. I thought geez, in Victoria you couldn't even do that if you were a professional. And I know my own history, I wasn't anywhere close to a thousand or even a tiny fraction of that. And you know, these were the days when there was still a lot of judgement – there were the innocent victims and those who deserved it. So, there was a lot of stigma, even in those days.

And then when I was reading this book, and it started talking about the seroconversion illness, and I do distinctly remember having that, because it was on—I didn't know what it was at the time, but this is kind of back dating—it happened on New Year's Day in 1985. It was such an unusual illness, I think I was out of work for three weeks. And I phoned up work the next day and I just said, "I'm not coming in, I'm really, really sick," and everybody laughed and thought, oh, you just partied too hard on New Year's Eve, and I said, "I didn't even go out." And they characterized it as a flu-like illness, and I thought, well, I've had the flu, and this wasn't anything like the flu. I don't even know how to describe it, but for three weeks I just wanted to crawl under a pillow and just wait for it all to go away. And I went to the doctor after and we just had a regular blood test and he said, "Well, your white blood cell count is very low, so you've had a viral infection." And by that time, I was better, so I just thought, okay, no problem, I'm better now. And then, it was – yeah, it was after I had the diagnosis, and reading this book, and I just, I kinda—by that time I had met a few people who had HIV, and, in those days...

Well, also, I should back up, and say when I found out, when I had the seroconversion illness, I was also involved in a long-distance affair with somebody in Vancouver for about six months, who had lived in San Francisco in 1982. But nobody was connecting the dots. So. But he did complain that he was not feeling well, a lot, although he looked fine. In those days, in Vancouver anyway, the only way that you knew if anybody had AIDS was they either had Kaposi's sarcoma all over their body, which was a big visual clue, or they had wasting. But otherwise, you had hundreds of people with HIV who looked perfectly normal and healthy. There was no test in those days. Tests didn't come out until later. So, people just carried on. And then, yeah, so when I was reading this book and I just thought, well, maybe some people just do better than others, maybe I've, for whatever reason—because by that time I had recovered and I was doing fine, so I didn't really give it another thought. And then the year later, this was about 1989, I came down with shingles. And by that time, I was like thirty-six.

[conversation about adjusting the microphone]

So, 1989, I came down with shingles. And I went to my doctor and he was out of town, so he had a locum, fresh out of med school, and I don't think she ever had seen a case of shingles, certainly not in somebody so young. And she thought it was a bacterial infection and sent me home with a bottle of pHisoHex, which that was a popular antibiotic wash. And the things just got worse, so I went back the next day and the blisters were out of control, and she sent me down to see a

dermatologist in the same building, and he knew instantly, “Oh, you’ve got shingles,” which is unusual for someone in their mid-thirties to have shingles, it’s usually among seniors. And he said, “Oh, it’ll go away on it’s own or you can take Zovirax, and I just thought, okay, if it’s going to go away on it’s own, it will. And then reading this book that I got, it did mention that shingles was one of the most common manifestations of HIV. So, at that point I thought, oh well, ‘cause I had not told my doc—my general practitioner, about any of this. It was just done at the STI clinic, the records are confidential. I thought, well, I’m okay, I don’t need to tell my GP. But at that point I tell him and then he said, “Well, I need a record of it, so you’ll have to go back and have another test so that the records will go into my files,” because he couldn’t access anything at the STI clinic ‘cause it was all private. So, then I did that again. And he was on the verge of retirement, so he had no clue what to do. And then he sent me to an infectious disease doctor who I think at the time was the only one in Victoria, who mostly dealt with tuberculosis. But he was getting the HIV cases because—

BB: What year was that in?

DH: ‘Bout eighty... ‘89. ‘89.

BB: Oh, okay.

DH: And that experience was – you know, I thought, oh, he’ll know what to do, he’ll fix me up. And I don’t know what I was expecting, but his attitude was – he was so clinical, you know, and I’m coming in as a traumatized patient thinking I’m doing to die at any minute. And he was looking at me like a disease that needed to be dealt with, a medical problem on two legs. you know, rather than this traumatized patient. [Laughs] Who I guess was looking for a little bit of, not sympathy, but just some kind of understanding. But... and anyway, there wasn’t much he could do anyway, because there wasn’t much to do. And then I remember that I think it was about 1990, AZT became available as an experimental drug, and it wasn’t even a clinical trial. There was so much pressure, certainly in the United States and Canada, for anything. And so, I guess, what was it at the time, the company, GlaxoSmithKline had it—no, [unclear]—they’ve changed so many times, anyway, they made it available to anybody who wanted it. So, we were all... Anybody who wanted it, we were all volunteered to be guinea pigs. And I thought, well, I’m not quite sure, because I’d read good and bad things. So, I phoned up AVI, and I wanted to talk to a couple of people who’ve been on this so I could make a decision. And I talked to two people who had completely contradictory experiences. You know, one’s “Oh, it saved my life,” and the other was, “Oh, I’ve never been so sick in my life on this.” So, I thought, well, how am I supposed to make a decision on this? I thought, well, I’ll try it. So, at that point they were – they had a – there was a clinic, an outpatient clinic at the old St. Joseph’s Hospital. You know where the – you’re too young to know where that was—

BB: Probably.

DH: You know where that was? The old, what used to be the old General, and after the new General had moved out, the old building was used for just, I don’t know, supplementary stuff. So, they put like an HIV clinic in there, because practically nobody ever used that building, so that’s where I picked it up. And after two weeks of this stuff—and like I said, we were all guinea

pigs, nobody knew the correct dose or whether it would even work—and after two weeks, I was so sick and nauseous all the time. I said to the nurse, “If this is the cure, I’ll take my chances.” And I stopped taking it, and within forty-eight hours, I just felt so much better. And I guess the upshot was, after this kind of experiment had finished, they discovered that the dose they were recommending was double of what it was later dosed at, that’s why so many people got so sick on it. So, I thought, okay, well, that’s that, I’m not going on that again. And at that time, it was around that time that I was dealing with a lot of like, health issues, mostly, primarily just this crushing fatigue, that was the big manifestation with me. I had terrible sleep disorders, you know, not being able to get to sleep until like two or three in the morning and then having to get up and go to work, and sleeping in often, and working late. And it was just, I—I got to the point where I thought, I’m going to kill myself if I’m going to just force myself into going to work. So, I quit in – when was it? August of 1990, I think. Yeah, I just couldn’t handle it anymore, and it took me almost ten months to just recover, in the sense of getting my strength back. To me the biggest hurdle was just this crushing fatigue all the time. I could hardly get through the day without having three or four naps.

And then when I got on my feet I acc—well not accidentally, maybe it was fate—I ran into an old acquaintance who was coming out of the building where my infectious doctor worked. And I knew him from years ago in Calgary. And anyway, he phoned me up that night, because I guess—I didn’t even know he lived in Victoria—but my name was in the phone book, so, he said, “Well, what were you doing in that building? What doctor were you seeing?” And I told him, and he said, “Oh, so you’ve got it too.” And at that point I hadn’t told anybody, but he figured it out – two gay men going into a clinic where the only infectious disease doctor in town worked. Putting two and two together, that’s probably why I was there too. At that point he was doing some work at AVI, but trying to get up a little support group of just positive people to meet on their own for, you know... I guess, what was the buzz word in those days, was empowerment. And AVI was more like... a group of social workers looking after people, and I thought, well, I can look after myself, thank you, I don’t need that. But he managed to get a room at the YMCA once a week, and there was a small group of people who regularly showed up, and we’d just talk about you know, what we were doing to stay healthy, what pills we were taking.

I think by that time DDI had come out and I was on that, and in these days, everything was monotherapy. And most things worked for a while, you know, you don’t know how long, and they had a variety of side effects that some... DDI was a drug that I did quite well on, and I had no real issues, no issues that I was aware of. It did have—it was pretty heavy on the pancreas but that was not something that I was aware of. Anyway, I did quite well on it for a few years and then like most of the drugs in those days, they kind of seem to wear off, and then you’d be right back at square one. So anyway, we would meet every Friday at the Y, and just talk about how we were doing, and we would have socials after, and it was just a nice little way to connect with other positive people.

Art Holbrook: May I asked who it was who organized that?

DH: Oh, it was a fellow... he went by the pseudonym of Windy Earthworm. [Laughs] Very few people knew his real name and I—I didn’t either. But he was kind of a member of a group called the Radical Faeries, he was a gender bender way back in the ‘80s. He was kind of a – he was

quite a character, quite the character. But he was also a real social activist and a rabble rouser, and he was kind of the organizer behind all of this. And unfortunately, he died in, geez, what was it? '93. But he was really the one that who really got the PWA society here off the ground, and unfortunately died so early that almost nobody except me and maybe two or three other people actually remember him. There's not that many of us around from the early '90s. So, he got it off the ground, and he managed to get a twenty-thousand-dollar grant which seems like peanuts today, from the Ministry of Health, so we could open up a little office, which we did. And it was all volunteer. And the rent was cheap, because the house was owned by, well the CRD, but they told us that it was at some point in the future, it will be torn down for a social housing development, which it was. But we had it for I think a couple of years. And it was, it was built as a duplex, but it had been empty for years. And we took the main floor, and then VARCS—which you were with—and VARCS was starting up almost at the same time, the Victoria AIDS Respite Care Society. So, we said, well, why don't you move upstairs, and we'll just share the rent, which made it even cheaper. So, we had money for our telephones and mail, and I think we even got a computer, when computers were just coming in, and we had a nice little set up. And you know, the rest is history for that.

And for me, I found a niche there where I could be useful. And so, after my health had somewhat recovered, I kind of threw myself into that and took it on almost as a part-time job. I have to tell you, I grew up in a family that had really strong work ethic, and going on, like, disability, I had nightmares for months about, well basically not working myself into the grave, because that's what it would've been. And people said, "Well, that's the whole point of insurance, you know disability insurance: if you get disabled, you don't get left out in the cold." I just had a hard time, you know, wrapping my mind about that and being comfortable. And I threw myself into this volunteer position to the point where it's – well, I'm earning my disability pension, as if I had to earn it, or justify it in my own mind. But that's what I did in those days. Anyway, I found my niche and I really enjoyed doing what I did. And you know, over the years, things just got more complicated. It started out as a volunteer organization where it – very small, but in most of these groups, as soon as you get more people coming in, you get more ideas, and then things don't always operate on consensus, and you know, other opinions conflict with the people who were there first. And then you see all this – this hierarchy building up, and conflict. Well, I look back on that now, and you know, could we have done it differently? Yeah. But you know, I think the fact that we're still here after, god knows what, twenty-six or -seven years, I think is... You know, we were persistent and we made it despite a lot of struggles along the way. Mostly internal struggles with just, personalities and things. And I think all those conflicts from the '90s that now just – they don't exist for a lot of reasons.

AH: May I ask what your niche was? I think I know what it is but...

DH: Oh, well, I started up the treatment library, because in those days, well, there wasn't hardly anything. As I said before, there were like two drugs on the market when we started up. So, it was mostly trying to get a hold of newsletters from other agencies, mostly in the US. These were agencies that were started up by positive for positive people, who had newsletters written by positive people on, you know, the research, their research agenda and what we could be doing to look after ourselves. So, I was trying to—you know this is before the Internet was what it was today—subscribing to all these newsletters, and then photocopying the articles and filing them

by subject matter, on what you could do with, you know ‘cause people had a lot of like, skin disorders, and just a lot of little things that went along in the package with HIV. I mean, this stuff you don’t see at all today because the meds take care of that, and you just don’t have all these continual set of minor problems. And nobody knew what to do with it. So anyway, I had amassed this huge file of information, and then all the new drugs that were in development, and yeah, people accessed it. And we had a newsletter, and I would kind of summarize you know, the monthly news that came out of all these sources, mostly New York and San Francisco. This was even before CATIE started up, and then CATIE too, and so, just sort of little snippets of... My intention was always to keep it positive, which was different than a lot of people, especially HIV negative people. I don’t know why they always emphasized how horrible the drugs were – side effects, you know, these drugs are going to kill you. And just the negativity. And I was trying to be, every month, to be upbeat. You know, like, we’re making progress, just hang in there, things will get better. So, in spite of the fact of this other element was, you know, the sky is falling, but it did often feel like life was like standing on the edge of a cliff, waiting for the bottom to drop at any moment. ‘Cause there wasn’t that certainty until, maybe about 1996, the big international conference in Vancouver, which I did go to, the first and only one. But in that one, we had two, two things that happened that completely turned the course of AIDS around. And that was the viral load test, which could actually measure how effective your drugs were and the introduction of the protease inhibitors. And that was the game changer. That changed everything.

And you know, I’d lost a lot of friends at that time. And I just, you know, it was sad, the ones that couldn’t hang on until the protease inhibitors, because they’d probably still be here too. I mean, even the first protease inhibitors that came out, they were like the equivalent of AZT back in the late eighties; they were horrible, they came with a lot of side effects. I’m thinking of Saquinavir, and you know, multiple times a day with all sorts of restrictions. And then it was in ‘96 when I think Saquinavir—uh, Crixivan and Indinavir came out, and that was just as complicated but it had a better track record. And that was the drug that almost everybody went on in ‘96, ‘97, ‘98, everybody was on Crixivan. But that wasn’t an easy drug either, it was three times a day on an empty stomach, your whole life had to be regulated around the pill schedule. The company was giving out free docketts and beepers, you know, it was—in one sense, you were grateful to be alive, and in another sense everyday was determined around your pill schedule. If I went out for lunch, it has to be structured so that I would be, I would have my two-hour period before three-thirty, ‘cause it would, there wasn’t a lot of wiggle room. First thing in the morning, as soon as I got out of bed: pills. Middle of the afternoon: pills. Last thing I did before I went to sleep: pills.

And then that went on for several years and then finally I got a drug failure, because I had been on – after I had been on DDI for quite a while, and I was failing that, so my doctor put me back on AZT, now that we knew the proper dose, which was half of what I had been on before, plus a new drug that had just come out called 3TC. And they were being combined, I guess at the point, the Centre for Excellence was moving towards this theory that, “I wonder if two drugs work better than one?” And yeah, they did, but again, not forever. So, I went back on AZT with the 3TC, and when I had—I think I was on that for about two years—and then it was at that conference, when I came back to Victoria, the viral load test was now available at St. Paul’s. And I had my first viral load test and it was 27,000, so I knew well these drugs aren’t even working anymore. Everybody else was getting undetectable, which that was the whole goal of

treatment, and now we can show whether you had achieved that goal. So, at 27,000 I thought, well, these aren't working, but I had--there was nothing left for me to do, other than this new drug—Indinavir or Crixivan—so at that time we just added it on to a failing regime. And I think Crixivan carried me on its back for about four years, until 2001 when I had drug failure. So, it was a good drug for me in spite of the burden it carried with it. So then, yeah, I can remember that time I came back from a – I had a workshop to go in Vancouver, I came back and, what was it...? Oh yeah, I should say that while I was on the AZT, 3TC, and Crixivan, I did manage to go undetectable – after my first test of 27,000 on two drugs, I became undetectable after we added the Crixivan.

Then in 2001, I came back from Vancouver, and I can't – as soon as I got back, I came down with a norovirus, so if you've ever had it, it's pretty horrible, like the stomach flu, awful. The next day, I broke out in cold sores, herpes, and then the day after that I came down with a cold. So, I had like three viral assaults all at the same time. My next viral load test, it had gone from undetectable for about four years to 7,000 in about three months. So, I thought my immune system had simply been overwhelmed with these three viral assaults in a manner of two or three days and my immune system must've collapsed. So anyway, I had drug failure, and my doctor, my ID specialist said to me "Well, what do you think we should do?" And I thought, well, you're the doctor, not me! I said, "I think you should send me over to Vancouver and let them figure it out, because you obviously don't know." So, I went to Vancouver, and at that time they threw everything but the kitchen sink at you, you know, having to go on five drugs, and I thought, "Oh my god." But you know, I didn't have much choice in the matter. Anyway. I did. Over, since 2001, yeah, we have tweaked my meds, over time. I'm still on more than three, which is the standard. But you know, over that time period I've—it's just part of my life, I don't even think about it anymore. Pills at breakfast... pills at nine-thirty am and nine-thirty pm, and that's my life.

Just one more thing. There is a new, I know that there's a new drug – oh, it's not a new drug, Health Canada approved a new formulation of old drugs, piled into a single tablet, which I'm waiting for, to be put on the BC formulary, because I would qualify for that. I'm already on two of these drugs, but to have everything combined into one single tablet once a day would make my life easier. So, it's just a matter of, I mean, every province decides what it will and won't – I could get it right now if I decided to pay for it myself, but I'll wait. So anyway, I'm looking forward to this when it does it come on the formulary, I'll probably get that and my pill burd—I'll still be on the same number of drugs but far less pills. So, that's my life in a nutshell.

BB: I wonder more about how you were affected personally by the initial diagnosis, how your family reacted to it, how your love life changed over time, between being diagnosed and going through all the different periods of time.

DH: Oh, I was traumatized originally. As I said before, I just couldn't wrap my head around this whole thing of being positive. My reaction was I just went celibate, for several years. I just didn't know what to do. I thought, well, I should just avoid – I mean this is how I got it, so I should just avoid this whole area for a while until I can figure out what to do. And I was very selective in who I told. I mean, I did tell my supervisor at work, and she was very, very sympathetic. And I think after I left on short-term disability and then long-term, I think they all figured it out, I just

said I had chronic fatigue syndrome, which basically, that is what I had, I was chronically fatigued all the time, I just didn't go any deeper than that. And I told a few select friends here, you know, and I said, "Could you keep it to yourself?" And of course, who could keep that to their self, it's such a major piece of gossip. But what annoyed me a lot was that a few people that I told, these were gay men, ended up dying of AIDS. They never, and I shared my journey with them for years, and I found out later, none of them ever went for testing. And I just, I couldn't, until they ended up in the hospital flat on their back, with a diagnosis of AIDS, 'cause they had a major opportunistic infection, and I thought, what the hell's in your head? You know, it's everywhere, you've heard my journey, why didn't you go get tested? I guess they thought, oh, well it doesn't affect me—well, that's what I thought too, about me. But I just assumed that everybody would be getting tested. But no, everybody wasn't getting tested. There were a lot of gay men just saying don't get tested because, well, there's nothing you can do about it, which was true. So, you're gonna be totally traumatized, and why put yourself through all this 'cause you're gonna die anyway? You know, and the attitude in those days, well, why should I clean up my act, and some people said, well I'm going to die anyways so I might as well just party-hardy—and that's exactly what they did! They partied 'till they dropped dead.

And there was no... I mean, my attitude was, is there anything that I can do, you know on my own, to clean up my life, improve my health? I guess I just had a very different attitude. And I do remember picking up a book, I can't remember the author, it was by a doctor called *The Will To Live*. And he had been dealing with cancer patients and people with devastating diseases. It wasn't a mind over matter, but it was like, having a really intense will to live really contributed a lot to his patients' survival, as opposed to those who just, you know, it's my fate, I'm going to die anyway. And they did, like a self-fulfilling prophesy. That wasn't my attitude. But anyway, back to these friends that I just, I felt so angry at. You know, I went to their funerals and I thought, why the hell did you not do what I did? You know, after observing me sharing my journey with you. Anyway, that was the attitude. There was a lot of attitude about, you know, they didn't want the stigma, and there was a lot of stigma too. And a lot of judgement. So, I just kind of, you know, isolated myself from that aspect. I wasn't really involved in the greater gay community; my community was the small group of positive people that we had collected at the centre. Our first office was on Superior Street. That was my social group right there. I couldn't be bothered with, you know, the judgment and all the other stuff that went on in the larger gay community. And there was a lot of it – really bad. So...

BB: Well you're obviously still aware of it though.

DH: Hmmm?

BB: You were obviously still aware of it though.

DH: Aware of?

BB: Aware of the fact that, you may not have been involved with them, but you were aware of what was going on.

DH: Oh yeah, oh yeah. And I told my parents, and I don't know, their reaction was very strange. Um, I can still remember. I don't have a very close relationship with my parents, and my mother seemed to be more traumatized than I was. She was—she was—almost hoping that I had been using injection drugs. That was her first question. And she didn't want to know.

BB: Because that would be better than being gay?

DH: Yeah, yeah, I said no. And 'cause I hadn't – see, since I was eighteen, I'd always lived thousands of kilometres away. And did go back once in a while for a visit, but you know, I never talked about myself or my life, and they didn't ask questions either. So, you know, I'm pretty open sharing with people, but like you gotta ask me questions, I'm not one to just dump my life in your lap without you asking questions. So, there was just this – I was always called “tight-lipped.” And it's also because they never seemed to take much interest in my life anyway, so that's why I never mentioned anything. But I really thought it's not fair to them to not tell them, because at that time, I thought at some point I'm going to get really sick and die, so they should know now. And so, yeah, they were upset, but it was like, all the sympathy went towards my mother, not to me, because of how she couldn't handle it. Anyway, I got them, I introduced them to a group of – there was a support group, I think it was an offshoot of VARCS for parents and friends of people. It was like a HIV-positive equivalent of PFLAG. It was sort of parents and friends and others dealing with a friend or a child who had HIV, so I got them into that. They were very good about it, they were fine, they adjusted. They told my sisters, and all my nephews and nieces. And even the relig—I have one sister who's very religious, and they were all, I mean, they were all fine. Even my nephews and nieces were with everything: with the diagnosis—well I mean that was a different generation of people too—and the fact that I had HIV. So, there was no problem there.

Yeah, and I just kind of felt here, I only needed to disclose to people who I thought needed to know. I wasn't one of the people – like I had a friend on one of the Gulf Islands that had a shirt, “Nobody knows I'm HIV positive.” Or they'd have tattoos saying “HIV positive” with one of those biohazard icons on it. And I just thought, I don't need to tell the whole world, I'll tell the people who I think need to know, but not casual acquaintances. They don't need to know any of that stuff. And I'm kind of – I'm glad I did, because you know, gossip and judgment and all of that stuff. Anyway I'm, I've got to the point where I'm quite fine with it, I mean now in 2018 having HIV is like... you know, it's like diabetes. Well, not really, but it's a manageable thing. You just live with it, you do what you gotta do and life goes on, and you're gonna die – well, at least people with HIV will die with it, but not because of it. So, that's my attitude now, is just, I have the rest of my life to live and so I'm going to live it. I'm not really involved with – well, if there is an HIV community, I don't even know if there is one, as such – not the same way there was in the '90s. I think a lot of us older, old-time survivors have just decided, well, okay, we're not going to die of that, so we might as well just get on with living the rest of our life. So, that's what I've been doing. Although, I still have a connection here. I come in once a month just to do my own little thing in the library. I don't know if anybody uses it, but it's more for me because I like to keep in the loop of what's going on. I sat on the Canadian HIV Trials Network for ten years as a member of the community, where we, you know, would look at trials that were seeking funding and we would give our input as potential patients entering the trial. That was

one way I could keep in the loop and know what was going on. That was fun, but after ten years I thought, okay, I've done my thing here now, I wanna move onto the next stage of my life.

BB: Sounds reasonable.

DH: Yeah, well, HIV is not a career. I mean, especially if you have it. It might be a career if you make your living in it – I wasn't making my living in it. So, it's just like, it's not a career, it's a step on the journey.

BB: Yeah, pretty much all these have been answered. Do you have any advice for health professionals?

DH: Well, you know, I would say I'm not really in the system as an HIV positive person that much. I see my – well, not the ID specialist I talked about before, he's retired. All of my doctors are retiring, and I seem to be outliving everybody. But my GP's fine, and the person who looks after my HIV stuff, I only check in with him every sixteen to eighteen months to tell him I'm still alive, in case you forgot, because there's nothing wrong with me that's HIV-related. I see my GP maybe once a year, and that's for, I call it self-induced mechanical injuries from the gym. It's not... I don't have any HIV-related problems anymore. I still get my bloodwork done maybe every six months. When I go to see my HIV doctor, he does a full physical every two years, and I get a gold star, everything is right where it's supposed to be. But you know, I've also – I mean, I've found things that work for me. I'm very much into approaching any health issues with let me do lifestyle management first before I look at drugs. And so far, in most cases, it's worked. I had a doctor in Vancouver that wanted to put me on statins – I mean, he put everybody on statins. And I said, "Look, I know how to read a blood test, you know, and I know that I'm not going to have a heart attack in the next six months. Let me see what I can do." And I got all my numbers back into a nice comfortable position...

One thing I didn't say was that I had been, during this course, I'd come down with a serious clinical depression. I'd been dealing with this since I was in my twenties, you know, mild episodes. But it was back in the '90s when I had probably my first serious one, and the funny thing is it had nothing to do with HIV. It was just one of those things where, I don't know, life just seems to be overwhelming. I managed to get through that by myself, and then it was in 2001, it was right around the time of 9/11, it had started about a month before that. That was the first serious episode where I had to go on medication, and I did that for about a year, yep, I came out of that and stopped the meds. Then about nine years later, I had another episode. And none of this stuff was related to anything going on with HIV, and that episode, I was on, I don't know, about three different meds before I found one that worked. And then I just stopped those meds, almost accidentally, about six months ago. I had gone on a half-dose for, I think almost two years, and then I went on holiday, and I had my psychiatric, my anti-depressants with me and I forgot to take them. And I didn't realize that for about four days, and I thought whoops, I should maybe just take one every other day. And then I did that, and then I forgot again, I thought, "Oh, to hell with it, I'll just stop." And I'm fine. But I just found it curious, because they say clinical depression is one of those things that is part and parcel of HIV. But I often wonder, is it *because* of the HIV? I mean in my case I wasn't obsessing on that, it was just one of those things where

everything just seems to fall apart and there's no rhyme or reason, and no triggering event. There's never been a triggering event. It's just one of those things.

So anyway, back to, you know, I've always been into lifestyle management for me is first and foremost. And when I've told people about my journey, a lot of them will just say, "Well, it's easier to take another pill." And it's like, well, you can do that too. I think I like the challenge of seeing if I can change things on my own. But with depression, it's not one of those things you fool around with. And I've done the six months of doing all sorts of you know, the natural route, and it didn't help the least bit. But I think it's one of those things that, even psychiatrists, in the medical community they don't really understand, what's going on in the brain or anything like that. So, medication worked for me and I wanted that. The lifestyle management for me doesn't work with depression, it's very chemical-bound. But with everything else, with you know, cholesterol, triglycerides, high blood pressure, high blood sugar, I think I can try to work on that without any medication. And so far, it's worked, because with a lot of my meds and the fact that I'm getting older, it's like an uphill battle. But so far, I'm winning. Because most of my contemporaries, whether they have HIV or not—because I'm going to be seventy this year—they're all getting high blood pressure, pre-diabetes, cholesterol, arthritis, you know, one thing after another. And it's just like, well, it's just the package, it's part of the package. And it's like well, not necessarily. I mean you can do things about that. But again, I get this, "Oh, I'd rather take another pill. It's easier." It's like, okay, well, go for it. Anyway.

BB: Do you have any advice for future generations that didn't have to deal with this kind of a thing growing up?

DH: Well, we know how HIV is transmitted – pay attention. You know, I just thought after about, when was it in, when we started up in the early days, 'cause we'd always be getting new people coming in recently diagnosed. And it's like, well, how could you not know? We were just inundated with information in those days, how could you not know? I thought, everybody knows how it's transmitted, and the usual answer was, "Well, I didn't think it would happen to me." And I'd say, well why not? Why are you so special? That's the answer, that's what I said to myself: why me? Well, why not me? It only takes, you know, I don't want to call it a mistake, but when I got infected, there just was not the information there is today. But you know, you're young, you experiment, you're just not thinking, that this isn't going to be my problem. Until it is, and then it is your problem. So, my advice is just to pay attention. I don't know, they don't cover this in high school anymore, but I would think anybody should know you don't share needles, and especially for gay men, you don't practice unprotected sex. Unless you're on PrEP, but that wasn't an option years ago. So... And from what I hear through the grapevine, there needs to be more education, especially aimed at, you know, first generation immigrants and overseas students coming here who seem to be not aware that you know, this disease is still there and they come over with this expectation that there's a cure for everything, or it's not even discussed. They were born at a time when it doesn't exist. That's just... I have a friend in Vancouver who works as an outreach nurse in one of the clinics and he said over fifty percent of the people coming in with an STI are either first generation immigrants or international students who just have no clue, because it's not discussed in the family, it's not discussed in the culture. And they think, oh, I'm gay, I've hit paradise, where you can do anything you want and be out and be free, and then reality hits them in the face. So, yeah.

But you know, from what I hear, the healthcare system is so much more compassionate and educated, for the most part. My only experience in the hospital, I did have pneumonia, but it was just, my doctor said it was garden-variety, whatever that means, it wasn't PCP. And I found all the young nurses were, they were no problem at all. I only had problems with one older nurse who was – kinda kept her distance and only did what she had to do, and was, kind of... I mean it was very visible that she wasn't very friendly, you know I was radioactive. When was this...? In '93. But even then, the young nurses in nursing school were getting educated and they seemed to be – they had no problem dealing with HIV patients, it was the older ones that were still, didn't want to get too close to the subject. But I think that's all gone now. So, unless you have any more questions, I don't think I can think of any...

AH: Is there anything else that you can think of that you would like to say?

DH: Nope, no, not really. I think I've talked myself out. I'm just glad I'm still here after, yeah since when? 1985. I mean, every New Year's Day it's kind of like, oh, this is my anniversary, and I'm still here after all these years. And even with this place, I never thought it would last this long. So, we're still here and we're still doing work. I mean, the work is very different from what it was in the early 1990s, but it's obviously still very necessary work or we wouldn't get funded.

BB: Okay, well, thanks David.