

**“HIV in My Day” – Interview 69**

**February 20, 2019**

**Interviewee: John Cameron (JC); Interviewer: Ben Klassen (BK)**

**Ben Klassen:** Sitting down with John this afternoon. Thank you so much for being here. We’re really looking forward to hearing your story. Just to get started, can you tell me about how you got involved in the gay community and started engaging in gay life?

**John Cameron:** Initially with the gay community? Yeah, well I’m part of, a product of the 1950s where if they thought you were gay and they caught you, you went to jail for sexual perversion, so you had to hide in the closet. And there wasn’t any bars down here at all or anything really. And then along came the 1960s, which was a wonderful period of flower children and Vietnam and all kinds of changes to society. And then Trudeau was instrumental because he changed the law, where we have no business in the bedroom of the nation, and that changed. And then all these gay people, the party was on – it really was. And all these silly gay people who had gotten married – they’re really flaming, you know, and they get married and have children, and then suddenly they’re leaving their wives. And then the ones like me came out of their closets, and the party was on. And the bars opened – there was all kinds of bars here, opened up. The first one was at the foot of – and I can never remember the name of it, and it was a mixed bar, and it was like the first, it was at the foot of Granville – I can’t think of the name of it, it doesn’t matter. Then there was the Castle Hotel, which was piss elegant, I call it. It had little fire places where you could sit. And then there was The Ambassador right across the driveway, and it was really sleazy, so you’d go from piss elegant to sleazy in about 100 feet.

I remember one of the guys that worked there, he worked there almost his whole life until they closed it, and he would pull a nasty stunt. Initially, it was half gay and half straight sort of, and he’d wet the bottom of his beer tray, so when he’d set it down, your money would be stuck on it, right? But he got into an argument with the management there, and he always used to wear kind of a formal waistcoat, like waiters would wear. What would you call that? A nice coat and high stockings, and was elegantly dressed. He got in an argument with them one day, so he served everybody with no pants on. [Laughs] Anyhow, and then we had the Playpen North and the Playpen South, and all these different bars, and the Gandy Dancer opened up in Yaletown – there was all these different places. So, the party was on. And that actually complicated AIDS, because you went from starvation if you were gay, you’d go down the street and look to see if anybody saw you because Vancouver was a small city, and then you’d dart in. And now, all of a sudden, the party’s on and everyone is going crazy, and that made AIDS worse because the party was on, and everybody went from starvation to a smorgasbord. As a piece of it, you’d see all these people hitchhiking all over. Well, they got rid of hitchhiking, so if you left the gay bars, people would be hitchhiking at strategic corners like Burrard and Granville, and just down here over on this corner, and on Granville just over here, but they weren’t hitchhiking – they were hitchhiking to get home but to have sex as well. So, you’d drive along and say, oh, that one looks nice. [Laughs] And then we had the Fruit Loop down the hill here, and I remember a drag queen picked somebody up and threw them down the hill.

So, that was the change, that aggravated the AIDS thing because the party was on, so you had all this sex going on, left, right, and centre. Anyhow, that's that piece about that. And I'm an engineer, so you couldn't come out and be gay – a field engineer, you're gone. They'd find a legitimate reason to get rid of you, so you had to hide in the closet. And then I met my partner in 1980 – no, before that – it's been forty-years, so before that. Anyhow, it's been forty-two years, and I moved to Richmond, and then they found out I was gay, and there were no rights at work for gay people, so I ended up – I left because it wasn't pleasant working there, and then they blacklisted me because I was gay, so I had to go back and get re-educated and do other things. Plus, I was drinking heavily too, so part of it was my fault, because the party was on, as I said. I was drinking and that aggravated things. If I wasn't drinking, I would have worked somewhere else instead of – I won't say where – for engineering for twenty years. So anyhow, that's kind of the gay history piece of it.

**BK:** Lots of cruising, lots of sex. I guess there were sex workers in the West End at the time too.

**JC:** Yes, just down the street here, before they put – there were houses with picket fences, and that's where the boys were at the beginning. And then they moved over this way and into Yaletown sort of, and it was pretty wild. And kind of crazy. And I was pretty well-built, so I used to get in some horrendous fights because they'd pick on the gay people. So, one in particular, at Numbers – do you know where Numbers is? Some skinhead came in and talked about how they were going to murder the fags, and he took out the bouncer doorman who worked there and ended up in the washroom upstairs, and I went up and there was one little cubicle and I was looking in the mirror, and I could hear the fight going on inside of the cubicle there. And then a friend of mine who's – I call him big lips, because he has giant lips – he said, "Johnny, you have to do something about that," because I was really well-built. And I said, "Nope, it's not my problem." And then I said, okay, and when we were finished, the cubicle was disassembled. And I carried him out by his head. But you don't win all of them, that's why I work in the East End, but now I'm too old, I can't look after myself the same – thirty years of working down there, "Go get John."

Because I used to box when I was young – my old man taught me. And at school, they'd pick on you. But I changed fag bashing to faggots do the bashing – they wouldn't pick on me, they'd just leave me alone. But my old man, he taught hand-to-hand combat – Scotsmen, that's what they're like, they fight and drink. And when I was ten, he said, "John, I bought you a football." And I told him, "I don't want a football, I want a fondue set." And he got very upset. But my whole family is stunned, including myself, he never figured out I was gay until I met my partner, and then he walked in on us in our house, where he was living. And we were doing things on the couch, and I told him we were looking for change under the cushions – he doesn't have my sense of humour. And then he threw me out, and then when I got to the corner, I thought, why am I being thrown out? This is my fucking house, right? [Laughs] So, I went back. And then he said, another time, "I should have put you in the army." And I said gay people don't like the army because you have to get up early and you have to wear the same outfit every day. [Laughs] I've always had a strange sense of humour. That's on the reasons why I'm still alive. Anyhow, the whole gay thing, yes. So yeah...

**BK:** Thank you, that's a great description of what the community looked like in those early years. It sounds exciting but also a little frightening in some ways still in terms of your employment situation...

**JC:** It really was. We're seeing a repeat of it in Richmond with SOGI [sexual orientation and gender identity inclusive education], you know?

**BK:** Oh yeah.

**JC:** I was at that thing, because I was the first person in Richmond to say I'm gay and I've got AIDS. And so, I went to that, and it was horrible. It was in the gym, the bleachers, whatever it is, and there was one part – about a third of the people, about seventy-five people that were supporting the SOGI program, and then you had 150 people, and they eventually called the police that evening, because it was getting really rowdy. It was horrible. And of course, you had people supporting gay kids, and you had half a dozen gay kids there, and the ones that are there are the ones that have come out and are obvious. It was so cruel. And then the district health officer, Richmond health officer tried to speak, and they were booing, and then they called the police. It proved why you need SOGI – it really did. It proved it, because they were being bullied, and I went out and yelled at all of them, told them what they could do – nobody else would, because I had spoken about going through all of that before and how stupid it is, and the big fuss over, oh my god, what about the washrooms, with transsexuals [sic], drag queens and things. Well, what about the washrooms? They're there already aren't they, so they're using washrooms, aren't they? So, they're already there. What's the fuss?

**BK:** It is a little baffling to think that forty years later...

**JC:** It's because they're homophobic and it doesn't agree with their religions and that, and it was all Chinese. It wasn't nice. Anyhow, that policy got passed, so that's okay. It's such a shame to move back to that, because it's so stupid – really stupid, you know? To have all of these gay men running around getting married and having children, and then they're getting – and then their wife finds out that they're gay. I always tell people now, I'm bisexual – I have sex twice a year. So, that is a piece of that story, you know, and it complicates the AIDS thing. People automatically, the moment you tell someone you've got AIDS, you can see their heads going to work trying to figure out about what category you're in, and are you a drug addict or are you gay, and that's kind of distressing. And sometimes they ask you quite bluntly, and I have answers that I give. My doctor, Dr. Montaner, I went to see him, and one of his first questions was how did you get AIDS? And I told him it was a climbing accident. He said, "A climbing accident?" Yeah, I said, "I climbed into bed with too many people." [Laughs] And I had another I developed was that it was – what do you call it? Immaculate infection. You've got to have a sense of humour to survive all of this. Actually, that whole journey has been very, very interesting. Instead of being – I'd be living, if I didn't have AIDS and I wasn't gay, I'd be living some middle-class boring lifestyle. [Snores] This is much more interesting, though kind of scary at times.

**BK:** Yes. When did you first hear about AIDS? Do you remember when that was?

**JC:** In 1980, I started getting sick. I quit drinking in 1980, and then I got sick, but my partner, he quit drinking as well, and he moved out, so he was living just over here, and I was in Richmond. He was going out with some people and so was I, and then we had big arguments, because we weren't drinking, and then he moved back, and I moved out... Anyhow, there was a big period there of very bad timing where we were living apart. And in 1981, I went down to Texas to see a friend of mine that went to the University of Washington, and he phoned and said, "John, I'm really scared." And he took a degree in commerce. He was running his own private escort system where he would escort this small contingency of gay men, oil men actually, in fact. He was their arm candy or whatever you call it, and he was well-educated and very good-looking. And I knew something was wrong, so I went down to see him, and when I got there, he said, "John, something's happening. Everybody is getting sick." That was the start. And then I got sick – I had gotten sick just before that in 1980 when I was sick the whole year, but I went to see a doctor in Kitsilano, and he said, "Oh, we don't know what's wrong here." But I had an ongoing sinus infection that wouldn't clear, and then I had my lymph nodes blew up, one like a balloon here on this side, and I got some infections that wouldn't heal. And in retrospect, they didn't know what was wrong. It's quite clear that was a seroconversion.

But I was working, I didn't want to lose my job, so I kept it all under the table. So, I was doing AIDS work, but it was quiet, it was very quiet – it wasn't out in the open, because otherwise I wouldn't have employment. If people knew you were sick or you might have AIDS, you were gone. And then in 1994, that's when I went and got diagnosed, and I went into wasting syndrome, severe – down to 137 pounds. And at that point, the diagnosis was full-blown, but my partner and I said we probably got AIDS – this was way back at the beginning, 1981. We were both working, we had to keep it under wraps, but we were able to do a lot of stuff, and we were still working, so we had other things to do. And then in 19- – when I went to see the doctor in 1980, they couldn't figure out what was wrong, but then they diagnosed me as Hep B, and usually you get that from sex and that, but I got it from a car accident in 1969 – it was a blood transfusion, and I remember all of that. Anyhow... And that was supposed to go away, but it didn't – I was a carrier and I've still got it. Thank god the AIDS drugs help treat that. That's one of the good things about the AIDS world is that it created antiretrovirals that work for other things – opened the door. Anyhow, that was the start of it all.

And then I'd quit drinking, so I was a member of AA, and the AA groups – there was one just down the street at the YMCA, and there was a big one at 16<sup>th</sup> and Burrard, and they were decimated with people with AIDS. You see, if you're an alcoholic or a drug addict, you're much more likely to get AIDS and other things, because you make bad decisions, go to bed with the wrong people. So, that was the start for me. And then my partner and I, we were fine, and then in 1984, everything collapsed, and then my partner, about the same time, in 1985. Then we fooled ourselves, we thought, oh well, maybe we escaped or something. Initially, they thought if you were HIV positive that it was in your lymph system so it would only emerge in a small percentage of people – so a small percentage of people would get full-blown AIDS. And that started out at like 10% and then it got bigger and bigger and bigger until it was ninety something. There's a small group who can't get AIDS. So, that's how you ended up – initially, if you had full-blown AIDS, you were reportable, but if you were HIV positive, you weren't, and now I think it's entirely reportable for both. That's how that category happened, or that division, right? And in Canada, if your count was, eventually – because they didn't have viral load counts – if

your CD count was below 250 and you had a primary infection – there’s a list of them – then you had full-blown AIDS. So, I went into that category in 1994, and my partner shortly after that.

**BK:** A list of AIDS-defining illnesses or something like that.

**JC:** Yes, there’s about thirty of them. I wrote some of them – here’s some of them. Wasting syndrome is one. PCP pneumonia – that killed 60% of the people during the first fourteen years – 60% of people died of PCP. MAC – mycobacterium avium complex was one. KS. CMV retinitis. Toxo[plasmosis]. And there’s some other ones. TB is kind of included in there. Now, a lot of those diseases, you don’t see – you don’t see anybody with KS. They used to send us – at the beginning, you had to go over to St. Paul’s to the ophthalmology department there and they would dilate your eyes once a month to see if you had CMV retinitis, so you had to go there once every month and they’d check on it, because you could go blind in one eye in like twenty-four hours, and then the other one, another twenty-four. I know somebody that that happened to, a Native person I worked with in the East End. And then you had to drive home and you can’t see because your eyes are... [Laughs] And my partner is Native, so he’s got really dark eyes, and the darker your eyes, the harder they are to dilate for some reason. That’s gone now, that whole CMV thing doesn’t happen. So yeah, the AIDS-defining illnesses.

That’s how, initially – so the first test, and it was the ELISA test, about 1983 or something, in that period. And then there was the Western blot test, and then they put the two together, I think. But before that, it was GRID, gay-related immune disorder, so when it was GRID, they defined whether you had AIDS by your illnesses. I was wondering about that, because when I looked it up one time, I thought, well, how did they know you had AIDS? Number one, I guess because you were gay, and then you had KS and PCP and all these certain diseases that gay people would get – and thrush. And then they’d say, oh, you’ve got GRID. And the test was – the initial test, I think in 1985, wasn’t very good, because you could be positive – it had a 7% false positive and 7% false negative. So, we had a friend whose results came back and said he was positive, but he wasn’t, and he had a really nice job with the city and an apartment and everything, and they told him, “You’re going to die,” because that’s what they would tell you... It’s always the same: you got two years to live. And so, he got rid of everything and he moved back east to be with his relatives to die, but two years later, he hadn’t died, and he wasn’t very happy, so he came to stay with us for a while, for a few months – he was a member of AA. And then he did get AIDS later on. Anyhow...

**BK:** So, you didn’t get tested until ’94 you said, right?

**JC:** That’s when it was confirmed, because we pretty well knew. My partner and I sat down and said, look, if people find out, we’re fucked basically as far as employment, and I ran a private business as well, so you wouldn’t have customers. So, we cut a deal, but then we kind of thought, well maybe we got away with it or something, which was stupid, but then we both were getting ill. So, that was the first fourteen years was helping people under the radar, moving people in. There was a huge amount of – what would you call it? Disturbance isn’t the right word – I wrote down a bunch of... [Long pause] People just became totally unsettled, and they got sick, and they had to move home to live with their relatives because they were dying and the partner died, and then they couldn’t work, so they had no income, and all of these health

problems. They'd move you to be close to St. Paul's basically, and that's what I railed against in Richmond. I said, why should I live in my community all my life, I've contributed, paid my taxes here, and I'm not going to move – why should I? This is just silly. But I understood the rationale, because I didn't want to deal with AIDS – why would anybody else? So, when I came out in front of city council and told them...

**BK:** When was that?

**JC:** That was about 1994 when I came out publicly in Richmond, and then I got involved with Richmond Disability, and I was like a token person with AIDS. I started an AIDS support group, and then a little later on, a couple of years later, I filed a class action suit against the hospital – I didn't file it, I threatened them with it, because now there's people with AIDS and they're not getting treated properly. One was a kid, an adopted Native kid that had AIDS, and in emergency they said, oh, we've got one with AIDS over here. That's stupid. And other people would have to have a drip – I remember a guy had to have a drip for toxo or whatever it was, and you'd come to St. Paul's and they'd do it in twenty minutes, and he's left sitting there, a guy that's dying, for three hours. Not entirely their fault, they just didn't know, and nobody wanted to deal with it, because what are you dealing with? Gay people and addicts, and who wants to deal with something that's unpleasant? So, I phoned – I started with a – hospitals have a board and a constitution, a board of directors, and the constitution says that they must provide basic services to everybody with every illness, and they weren't doing that. They were saying you have to move to the West End to be close to St. Paul's. And they also had a policy that the NDP put in called closer to home, and that meant they wanted you to live in your community, which is good for you and society, because you can still go to work, and your relatives can...

So, there's a fine line there where if you need specialized services, you go to other hospitals, but each hospital is funded to provide certain services in their catchment area, and Richmond wasn't doing that. And to their credit – I got very lucky. I phoned – no, it wasn't class action – a human rights complaint – there's the two pieces, class action suit and... And I phoned and I got this very gay voice on the line – what are the odds of that? And very interesting. But a week later, they had a meeting and that opened the door for Gilwest Clinic at Richmond Hospital. And then they were making people in Steveston, there's two welfare offices, they were making people on disability lineup, and that was wrong. If you had breast cancer, you'd go to the front of the line, but if you had AIDS, you could sit there all day, first come, first served basis, people dying. So, I went to the ombudsman and filed a complaint, and we had a meeting – that was when I got sick. I filed a complaint, and it was dealt with – the ombudsman came over and did an interview, and that was corrected. You can't make people that are dying just line up like that, so it wasn't nice – a lot of it too is people who don't know any better, so making all those changes.

But you know, still, the stigma still hasn't changed. I mean, in Richmond, I can only think of four people who have ever come out and said that they have AIDS – me, my partner, my friend, [name], who's positive, and [name] – four people. Other people go in the newspaper or something, but it's all anonymous, and I'm difficult, so I always like – like, fuck you, this is the truth. Get used to it. I guess that's the way I am. [Laughs] My partner won't ride on the bus with me because I have neuropathy from AZT – I had to go on AZT and they had to double the dose because it wasn't working, and I got lucky, I was one that it worked for – it kept me alive until...

But I have no feeling in my feet, so I have to be really careful, and you go on a bus, you know how it lurches, and you really don't want me sitting in your lap, do you? [Laughs] So, my partner won't ride on the bus, because what I would do is I would say, "Can someone please give me a seat because I have no feeling in my feet." And then you got all these people, especially young students and that, that just sit there, just pretend – and then I'd yell out on the bus, "I've got AIDS and I want a seat!" [Laughs] And usually that gets some action, right? That tells you what I'm like.

**BK:** [Laughs] I love it. That's great.

**JC:** Like, I won't shut up. If you go into a restaurant on a Friday night and the service is slow, just say, "Can I have a table for two with AIDS?" You get it right away and they can't get rid of you fast enough.

**BK:** It sounds like you've done a lot of advocacy in your time.

**JC:** Yes. The first piece with AIDS was at Numbers. We had one of the first people I think, if not the first person here, he came in, and I was with all my friends standing there, and he said – nobody had – this would be about 1982 or 1981 – I think it was '82. And he came in and he said, "I just found out I got GRID, AIDS, and nobody has to touch me," he said. It was a death sentence. And then you could hear the – it was like dominoes, because then the friend I was staying with, he said, "Oh my god, I went to bed with him." And then somebody else said, "Oh my god, I went to bed with his partner." And it was like dominoes, it went out in all directions. That was the beginning of it. And the first was the steam bath crowd. I remember one friend of mine was a member of AA – he's long-since dead – he said, "Oh, I went to bed with eighteen people last night. I had sex with eighteen people." Well, of course, AIDS spread like mad. And then we had the controversy during the '80s about the steam baths – they shut them down in 'Frisco, and here, they didn't. But there was one right around the corner here on Howe or Hornby. I went a few times and I was always envious, because you have these queens that wander around with their nice little towel – it's so pretty and everything – and I have to hold mine, because I'm a big slob, right? They had it nicely folded and everything.

**BK:** I'm sure you got lots of attention too back then.

**JC:** Yes, but I really didn't care for steam baths. It's just sex and that's about the size of it. Anyhow, they tore it down, didn't they? It was just over here. It's gone.

**BK:** I think there's still one down the street...

**JC:** Is there?

**BK:** But there's not as many as there used to be, that's for sure.

**JC:** So, that was a controversy, wasn't it, during – about 1985 – what do we do with the steam baths? Because they're a source of infection. What else happened? So, we were putting up quite a number of people. But there was a huge upheaval and displacement, people with no place to

go, gotta go home to die. I had a friend, he was twenty-two – twenty-one when he got diagnosed. He was going down and having sex with all the black dudes in the steam baths in Seattle, and he phoned me one day and he said, “John, I’ve got...” He was a member of AA, and our sponsor – he said, “I just found out I got AIDS.” When you’re young, your immune system isn’t set because it hasn’t been through trials, and that’s one of the sad parts is that if you’re in your thirties or forties, you do better because your immune system has faced a whole bunch of different diseases. He got ill and he was dead within a year, and he had to phone his parents to tell them, “I’ve got AIDS and I’m gay.” And I made arrangements – my partner and I made arrangements with Air Canada and – what was it called? Greyhound, but it wasn’t called that – doesn’t matter. There was a different name for it. We made arrangements to get him home, because he had KS and PCP – he got ill very, very quickly – very, very quickly. And made arrangements, and they were really nice, both the bus service and – they waved the fares and they both gave him attendants to get him home. And he never complained, but he was dead – he went in Spring and by the Fall he was dead. But he never complained about any of it.

But I was lucky – in both cases, I got on the telephone and they put me on hold, and then they went and got women – motherly women. They said, “This will be looked after,” and it was. I remember putting him on the bus, and it was down – oh, what is that? A hotel down on Hastings there. And they said, “Now he’s in our jurisdiction,” because they had an attendant, “You guys go away.” He looked so disconsolate – he’s going home to die. He’s sitting there and he’s ill and he kept coughing, and my partner has a nice way with people, and went to sit with him until the bus went. He said, “Can I please sit with him?” And then I phoned – eight months later, he was dead. I phoned his mother and she said, “Please don’t phone again. I can’t handle any more of it.” That’s what it was like. And then going to the hospital, we were visiting people in the hospital, and you had the problem with healthcare, some of them still weren’t sure how the disease was spread, so they really didn’t want to deal with them. So, during the ‘80s, there was a lot of people coming in and taking care of them, right? And that changed. So, that kind of diverged from the first person.

But you know what’s funny about all of this is we were all scared, because things started when the guy said – so, there were these twisted jokes from other people who were at-risk. Like, “What’s GAY? Got AIDS Yet.” And it was an expression of fear, because we were all sitting there – it was like a bunch of sheep in a pen waiting to be slaughtered. There’s a good part of it all that all those first years in particular, there’s a real purity in all of it because you’re sitting there in the same boat as other people, and you were able to help people – it was all about helping people, because you’re all... Sort of like the Holocaust, you’re all sitting there and one by one everybody’s getting ill and dying, and then you’re sitting there wondering when’s my turn? Which is bad, because it’s kind of sad, I know a woman, she was Native and she had three boys, and two of them died of AIDS, one about 1981, about 1982, and the other one about 1994 just before the meds came out. Pretty shocking. But people helped one another. My job was to move people. I had a truck. Especially people in AA, moving all these different people, somebody every week almost. I think I moved every queen in the West End, and they all had hide-a-beds – have you ever moved hide-a-beds?

**BK:** No.



**JC:** You don't want to. They're gone now, thank God. They weigh a ton, and you get them in the elevator and then you tie them together with a belt or a rope, but then the thing will fall apart and hit you in the nuts. They're horrible, horrible. I don't ever want to see a hide-a-bed again. And then I recall moving this one – I'm really rambling here – one friend of mine who ran the best hair salon in Canada, and we were moving him down, a procession coming up the hill and along Davie Street, and he's screaming orders, and he had all his furniture that looked like Liberace – the prisms. And he had all these idiots carrying it who wouldn't know what it was and would destroy it. He had to move, because he'd fallen from grace because of the upheaval and that – his partner I guess had gotten ill and had to move him to the West End. And visiting people in St. Paul's. I remember going to visit somebody and he was right in the beginning, he was about 1983, and I went to visit him a number of times. And the last time I went up – he was there for almost a year – and he went blind, and I went to see him, he was screaming, "Would somebody please kill me!" I didn't go in that day. He had gotten shingles from head to toe and internally, he'd gone blind, so... That would be about – oh, that was about 1985.

So, I'm an engineer, so I always look at stats – every year I read the stats – this is diverging again, but in 19-... You can guess when it peaked in different communities or different groups, and the mortality rate in gay men peaked about 1991 – in there, '92 – between '91 and '94, there was a peak in deaths. So, what you do is you go back – because if you had AIDS and there was no treatment at the time, you subtract ten years and that tells you when it peaks. It's like a bell curve – one gets infected, then it's two, then it's four, then it's sixteen, and on and on, and then you run out of people and then it goes down to a trickle. So, I'm guessing from extrapolation, it would be about 1984 I think the infection peaked. Then – I do all this work in the East End – then it moved into the East End and peaked there in about 1995, '96. That's not absolutely clear, but there was one year in the gay community where it was 96% gay people in the '80s in Vancouver, and then it moved of course, because you got gay people doing drugs, and then it moved into that community. And then, and because addicts – gay men are having sex with men, right, so it kind of stayed, but then it moved and it started, then the next infection was from addicts having sex with women, so now it's moving into the suburbs, and that's when they declared a health emergency in the East End – it was going nutty.

So, it peaked in the drug community about '95, in the gay infections, in the gay community, about '91, '92, in there, and in the Native community in B.C. it peaked about 1999. Kind of logistics to all of it, because it moved from the big cities – like when I went to Houston, moved from 'Frisco to Houston, and then up the coast to Vancouver, and then from Vancouver eastward, and then into the province. So, there's a physical piece there. And another friend of mine – this is diverging again. This would be in the late – this would be about 19- – before 1990. We had a friend of ours, this was in the mid '80s, he went home to die – this would be about '87 – he went home to die, he was Native, and he went home to his reserve and they wouldn't let him on the reserve. So, he got all the way back to – he wanted to get back to Vancouver, and he got to Calgary, and he phoned a number of people and said, "I'm dying. Could somebody come and be with me?" And there was no way anybody could, he was dead the next – that's always haunted me, that he died alone. But then another Native friend that I knew decided that's not good enough, so he went out and fought, railed against the reserves not allowing people in, and he was able to help change that. Anyhow. A disproportionate number of Native people of course got AIDS.

**BK:** Even within the gay community?

**JC:** Oh yes. Native people – well, there was a stat – if you were a Native woman, you were ten times more likely to get AIDS, and the men, same thing. Do you know what was the biggest group with the highest rate? Drag queens and transsexuals [sic], because people wouldn't hire them – most of them didn't have jobs, so what do you do when you don't have jobs? You go and work on the street, right? And I knew one of them really well, she started one of the first – I can't think of her name now – she started one of the first AIDS organizations, All My Transgender Friends, but it was called something else before that.

**BK:** So, that community, the drag community was really hard hit as well?

**JC:** Very hard hit. See, I've always followed the stats because that's what engineers do, because they tell more truth. And immigrants, and we brought a lot of immigrants in that were carrying AIDS, so that was another high-risk group. So, there was this spread from the cities to... So, you can kind of divide the AIDS – I kind of divide the AIDS thing into different periods. There was the period up to '95, '96 when the protease inhibitors came, and that was like a line in the sand – '95, and then by '96 everybody's on them and everybody's surviving. And I looked up the mortality rate in the two years when the protease inhibitors came up, the mortality rate dropped by sixty percent – huge change, huge shift. Prior to that, there was a period where you just died – you just got in the lineup and waited to die, basically. And then you've got a second period of treatment, and now you're kind of in a third period in the last few years where you can't go on disability – very different. All the young people just take their pills and go to work. And the infection rate is one-tenth of what it was, and you've got PrEP now, so for me, there's the three different periods. So, all you've got left now basically is a bunch of worn-out old queens. I'm part of a study on old people with AIDS, people over fifty, at St. Paul's. I think when I came, there was seventy-nine people in the study, long-term survivors, and the guy doing the study said – I said, "Well, who's had AIDS the longest in your study?" And he said, "You have." "And who's the oldest?" "You are." Now, there are older people living with AIDS, but in the study – he said, "You must be really pleased having survived." And I said, "Yes, isn't it wonderful?" And then I thought you have seventy-nine people lined up going over a cliff, and I'm at the front of the line. [Laughs]

**BK:** Does it still feel that way?

**JC:** No, it is what it is. I've done tons of workshops – like, I did a workshop years ago in Winnipeg about who gets to survive, and I did a lot of research – who survives? What were the elements of survival? Before – and there's some differences before you had AIDS treatment, absolutely crucial is – in Africa they would give people a multivitamin, no treatment, but give them a multivitamin and it would buy them two years on average. Isn't that amazing? What else? A good doctor is really important. So, I have Julio – absolutely wonderful. He's really good at diagnosis, really brilliant – he'll walk back and forth, "What do we do? What's happening?" Or, "It doesn't matter what's happening – what do we do?" And other things – if you've got a partner, you do better, because you eat better, and you got one to care for the other. All the victims are dead, or most of them. If you're a victim, it's like with anything in life, it's self-

fulfilling, right? You just sit there and expect people to give you a hand out and it's like self-fulfilling – you've got to work to survive, it doesn't just happen. Other bits and pieces... A good doctor is really important. If you went to an AIDS support group, that was good – that made a difference because you had advice and support from other people. Take your pills – when the pills came out, take your pills and don't ever miss a dose – just don't. That's what they're there for. I can't believe people won't take them. When you survive a period where they don't have any treatment and you get it – there was a period where I was taking 43 pills a day at the beginning – seven times a day, 43 pills, and if I got other infections, I had to take more. So, seven times a day, and you'd have to get up at 2:00 to take this one, and you can't take this one with food. So, they gave me the little blister packs – what are those things called? They've got little compartments and you put pills in them, and I said, "How do I get 43 pills in one of them?" Now we're so lucky – I take three pills.

**BK:** I imagine with those 43 pills, you probably had side effects too, right?

**JC:** Yes, terrible. We went through – there was liquid ritonavir was one of the first protease inhibitors, and something went wrong with the manufacturing plant, so they gave us liquid ritonavir, and it was like swallowing turpentine or something – you'd throw up. And if you wanted to survive, you did it anyhow. The good thing about it is that you remembered to take your pills because it was so awful, you wouldn't miss it, and then you'd throw up in the sink and do it again. But that was necessary to survive. I did a workshop at the Carnegie with nurses from UBC at 9:00 in the morning – this is about 1994, '95. Early in the morning, and at that point I couldn't leave the house until 11:00 because you didn't know if you were going to throw up or need a washroom, so you're really not capable of working, even if you want. So, I was doing a workshop and I had all these student nurses, and then I threw up on the table, because they wanted – the workshop was what's it like living with AIDS – well, that's it. [Laughs] But you know what's horrible is that you throw up and all your pills are there, and you want to reach over, but that doesn't look too good, and pull the pills out and take them. But that's how you survived. My partner, I'd be surprised if he misses two pills in a year – that's one of the reasons he's alive, right? And all pills cause side effects, so you had to endure all of that, and permanent problems. In his case, he has lipodystrophy. That's because the early pills especially – what was it? It started with a C – white pill. It effects your mitochondria, the factories that metabolize everything, and so, he has no fat on him, so he's really skin thin. And I have lipodystrophy, where you get fat here and skinny there.

**BK:** Nowadays, with the current medications you're on, are the side effects a lot better, or are there side effects? What does that look like now?

**JC:** Well, GI problems for me – I've always had them – and the neuropathy has never gone away, so trying to negotiate in the snow and that is really dangerous. There's lots of things people don't understand – why do they put marble floors in malls, because they're really slippery. And in Gastown, where our needle exchange was before it moved, they have all these brick roads and they're really slippery as well. And I can't use escalators. Yeah, there's a lot of medical problems that go with AIDS. And then when you get old, it just accentuates everything, compounds them. So, a few years ago, I got – what do you call it? Where you lose all your pigment, like Michael Jackson – oh, what's called. Doesn't matter. And that was an autoimmune

problem related to AIDS, because your immune system... So, now they sent me in because I'm getting other problems, and I'm gaining a lot of weight, and what happens is – it's called a thyroid problem, so this causes thyroid problems, and I didn't know that until I saw the dietitian, so he's put me on a program. He asked, "What's your most favourite meal?" And I said, "A 20-piece KFC dinner." [Laughs]

**BK:** Good answer.

**JC:** But everybody that survived goes through all of these... And one of the reasons people survive, a very basic one is luck – you didn't get the diseases that killed people – and genetics. But I think it's important for everybody to realize, all the people that act like victims end up dead, and if you do drugs and alcohol – especially alcohol. So, running – like, I started one of the first needle exchanges in Vancouver, the Consumer's Board – peer-driven, most of the people had AIDS. And almost everybody's dead now – a few of us left out of maybe a hundred people, maybe five or six.

**BK:** When did you start that?

**JC:** '95.

**BK:** And whereabouts in town was that?

**JC:** It was at the Washington Hotel. Oh, and in '94 I started the AIDS support group that's still run every Thursday at the Carnegie. And then I started the Heart of Richmond AIDS Group in '94, and I don't work with them. I wanted it to be run by people – the first few years were fine, but we had some people who wanted it to be run by professionals, and I wanted people with AIDS to run the board, and so they won, I guess. It's a good thing, because I was able to go into the East End and do a ton of stuff.

**BK:** How did you get involved working with that community initially?

**JC:** Well, I was furious in 1994 when I got diagnosed, I was furious – with full-blown at that point – I was livid. I was just finishing a degree in advanced engineering and waste management, and I had my business, I'm working full-time – I was working at a 7/11 because I was doing my university as well and running my business. And now all of a sudden, it's all blown up and everything's collapsed. I went down to 135 pounds and I got shingles in my eyes, and I was livid. And then a woman at the Carnegie, coordinator that's now long-since dead – well, she died about three years ago – she conned me into – she was retiring in a couple years. She said, "John, you're really good at organization. Can you come down and run an AIDS support group?" So, I did – I started it, I still run it. And then she conned me into doing World AIDS Day – I've been doing that for twenty-five years with a couple of thousand people wandering through every year, and I do that on \$2400, all the donations and little bits and pieces. So, that's how – I got conned into it. Flattery will get you anything. It's good – it's good, because I wanted to try to go back to work, but I couldn't, because initially at the beginning you might have six good hours in the day. And I was on AZT, and that six good hours worked for maybe two days, and then on the third day, you'd have to go and lie down to buy you two more days.

I used to just – there was a period, I'd just walk across from my house at the corner in Richmond, and in the mall, there's a little mall shopping centre across the street – all I could do is walk over, have a cup of coffee, sit on the bus stop at the corner, and go have coffee and go home for a period. And when I got shingles really badly, on a day like this, you had to put blankets on the window, because it's like being stung by millions of bees, and that went on for about a year, and I had different outbreaks. And that goes back to stigma, because the people I used to sit with at the – what do you call it? At the coffee shop, one day, I came out in the newspaper, and when I did that, now they knew – I thought they knew anyhow that I had AIDS, but two of them – they're middle aged men – they wouldn't sit with me, because they were going to get it. Whatever. I found that out this year, I found out that's what was going on, so I'm sitting there by myself. It was really very cruel. Just stupidity. You can't educate stupid people who've made up their mind already about something like that, but one still went there – Starbucks – the one I went to, and he still won't sit with me. So, I stay away from him – the other one is dead now. That's the way stupid people are with AIDS, and that stigma still exists. It got such a bad rap at the beginning, it's never left.

**BK:** The information is out there now. By 1994, people obviously knew that you couldn't get HIV from sitting next to someone.

**JC:** No, a lot of people don't. I go to AA meetings with people, and I cook all the time, and there's people there who won't eat the food I cook. One in particular, he'll eat everybody else's food but not mine, and he won't hold your hand at the end of the meeting because they all hold hands. But you can't educate stupid people – it's hopeless, because they've already made up their minds. And sometimes we're all like that sometimes, right? Like, I thought what kind of an idiot eats alfredo fettucine – fettucine alfredo – and then I made it and I love it. I thought, who eats this, just stupid Italians or what? And then when I ate it, it was absolutely wonderful, and I thought don't have such a closed mind. Older people, their minds get closed. That stigma still exists. And my step-mother – my dad had all these wives, and when I first got AIDS, he found out, and she'd come over to the house and she actually showed up with a mask and gloves on, and looted the refrigerator, because she didn't want to get infected. My dog used to hump her leg, and I would give the dog cookies for doing it. Good pooch. [Laughs] What a stupid woman she was. But trying to educate dumb people...

**BK:** Obviously, in 1981, there wouldn't have been a lot of information out there – HIV hadn't been defined yet. When did there start to be more information out there in the community about HIV and how to prevent HIV?

**JC:** Well, I opened the door by getting involved with Richmond Disability, and then we put the first World AIDS Day on, and that would have been '94 or something in Richmond, and that opened the door. And a friend of mine is a nurse at Vancouver Coastal, and she put me in touch with another guy who had AIDS, and then we were putting collection things out, started the Heart of Richmond a couple years later, and one person to another and another, and suddenly you've got a group, and that all materialized. In the West End, it was already here, so AIDS Vancouver was first, and then Positive Living – I know the founder of Positive Living, one of

them – there were two. They wanted something run by people with AIDS, and they still run the board. Both good organizations.

**BK:** Did you get involved with those organizations at all?

**JC:** Yeah, I was vice-president of AIDS Vancouver for a while years ago. Yes, I've had different involvements with them, with AIDS Walks – twenty-five years with AIDS Walks or something – the Gathering Conference, all sorts of things. I was on the PAN board, Pacific AIDS Network, advisor to the Minister of Health when the NDP were in the previous time, from the street level. So, I wrote some things down. What have I got here? The first – a particular incident – the first few years, AIDS was horrible, because in terms of pets. Dogs, you can't get anything from. Birds are really dangerous, because you can get diseases, so you couldn't have birds, or you shouldn't have birds. And then cats, indoor cats are fine, outdoor cats, no, because you get toxo, and you're not supposed to change their litterbox. And one of my friends, he got AIDS early on – I haven't seen him for years, I presume he's still around – this little quiet Jewish fellow who taught school, had a kid, his wife had left him. And I went into the library – they used to have a library at Positive Living when it was here, or downstairs – they moved back, but before that in the old building. And I said, "What are you doing?" He didn't know they had a library. "Oh, I've got toxo," and he had to go in and they'd do an IV for like three hours all the time, and then it gets infected, because they put it here and then they move it into your heart directly. And he said, "But I've been looking it up. I'm not going to go for that. I'm going to go see my doctor shortly. I'm going to get them to inject straight into my eyeball." Was it toxo or CMV? It doesn't matter what it was. "Oh, I'll get them to inject straight into my eyeball, and that's really good because it's instant, and then I can get other things done, and it's more effective anyhow." Now, is that tough or...?

**BK:** That's crazy. Wow. And also showing how people were seeking out information for themselves.

**JC:** Well, we had a support group at the old building, at AIDS Vancouver, run by Positive Living when they were PWA, and Colin Stewart ran that for about sixteen years, and that helped keep us alive – a lot of information from one another, especially before there was really effective treatment, and what do you do about this or that? Very informative and supportive. I really appreciated that. I got – and then I started mine to share information. My crowd is different, an awful lot of Native people and addicts and that, so you had to treat them a bit differently. One time, I got a yeast infection, so that's when your immune system is really down – women usually get it, but I got it, and I got it where the sun doesn't shine. And then they had a discussion over yeast infections, and some silly – I won't say who it was – said – or somebody said, if you put cloves of garlic and shove them up your ass, [laughs] they work as an antifungal. And then some other twisted person said, "Yeah, and I'll bring olives and tomatoes and we'll have a Greek salad." [Laughs] Never forgot that. That was twisted.

One thing though, I think that for me, with all the work I've done in the AIDS community, the thing that pleases me the most about everything I've done is I was able to help bring two communities together. The gay community, the drug addicts would refer to – in the East End – refer to – I was the first person with AIDS to come out. They were having a meeting and they

were talking about the homos on the hill, and then at the end of the meeting, I said, “This old queen,” and they didn’t know, and they all looked at me, right? And they didn’t like gay people in that part. There was like a dividing line on Cambie Street or something. And then the people here, some of them, didn’t like the addicts because they built all this infrastructure, and now you got all these people coming to take advantage of it and starting fights and things. So, I think if I did anything, it was to help to build, with AIDS Day and my group and being very vocal, helping to build bridges so people recognized we’re all the same, whether you’re straight and you have AIDS, or gay or a woman, right? Same thing. So, I think that’s what – making that change. Anyhow. I did some wild things in my time. I had a guy come to my AIDS support group and he wanted to take information to North Korea on AIDS, and I gave him all kinds of brochures and things – I don’t know what he did with them, but he was going to take it there and get it interpreted and distributed – I never heard. And then I helped, along with somebody else – I can’t remember who it was – I helped them take all the swear stuff out of brochures and change them – they were going to get them interpreted and hand them out in Egypt. So, some interesting stuff going on – that was different. All kinds of stuff from the beginning. There was the Vanguard study – have you heard of that?

**BK:** A little bit.

**JC:** It was with AIDS Vancouver, and that interested me. They wanted to find out who was getting AIDS. There were twelve determinants of health – which ones dictated whether you had AIDS or not? And you know what the two were that made the difference? If you had ever been institutionalized, like in a mental institution or a prison, you were much more likely to get it. And the other one is – what was the second one? Oh, if you had poor housing. And all the other ones really didn’t matter. So, I found that interesting. Then they did the VIDUS [Vancouver Injection Drug Users Study] study that’s still ongoing in the East End, they’re looking at addicts. Initially, a big piece of it was AIDS, now it’s just tracking addicts, and I took that early on and translated some of it. Because they had all of this information, but it wasn’t telling anybody anything except them, and I wanted to know about AIDS. So, they had a mortality thing there, and I translated it, the stats, and I wanted to look at different things. This is interesting – if you’re HIV – this was back quite a long time ago – if you were HIV positive and were a drug addict, your average survival time was fourteen years or something. No, pardon me, I’ve got that wrong here. How did that work? If you had a hundred addicts and you came back ten years later and looked at them, the death rate among addicts that were HIV positive was like 30% to 40%, and the mortality rate among people who were addicts and maybe had Hep and that but weren’t positive was 14%, so AIDS was very defining as to survival. And then I broke down mortality into different, and the two highest things were wasting syndrome, because people don’t take care of their AIDS and themselves, and the other one was liver failure, because most of them had Hep. So, that was interesting. That’s changed now of course, because we have better treatment and everything. Yeah, I’m jumping all over the place.

**BK:** That’s fine. We’re getting a lot of really great pieces of your story, so thank you.

**JC:** Yeah, I think now, going back and watching all of this develop, Vander Zalm – did they tell you, he wanted to put us on an island? And I’m sure it wasn’t the Bahamas, it was probably some island in the Arctic. I remember that.

**BK:** How was the government responding at that time beyond the island and quarantine?

**JC:** Well, that didn't happen, but he's a devout Catholic. So, I thought we could do a survivor program, like on TV, and we call it AIDS Survival – they stick us on an island and nobody gets to survive. What an idiot. Do you know who corrected him who came to town around that time? Mother Theresa. So, we're watching all of this, because we've got AIDS and we're watching this because of what's going on in the world, and Mother Theresa said we need to look after them, they're our brothers and sisters. He got corrected. So, that's kind of a weird thing. And then we had "Patient Zero" – remember him? What's his name? Dumont?

**BK:** Dugas.

**JC:** Dugas, yes. Boy, he got blamed. It wasn't him at all. Oh, and the origins of AIDS interested me – how do we get it? It's pretty clear to me that it came from monkeys, because viruses are species-specific but it jumped species somehow, but they used to, in the old days, if you were dying of AIDS or something and you got a severe illness, they would just quarantine you in your hut. They did it in England during the black plague – they wouldn't go near your house, and then it died out. And then along comes airplanes and everything, and it spread like mad. So, I firmly believe – and it looks like it may have been – it went to Haiti, that's where it looks like it jumped from Haiti to North America because of the social conditions there. And I had a very interesting workshop with a guy – I went to listen to him – where he said, "I know that AIDS developed in Africa, but I wanted to find out how it got to the United States." So, he said, "I pretty well conclusively figured it jumped to Haiti and that's how it managed to spread because of the living conditions." And he said, "And then I thought my theory was entirely wrong. I interviewed people, because this Japanese person in Japan was one of the first people, and so I talked to him, and he said he lived in Haiti for a while." So, there you are. You still hear people talking about conspiracy theories about – no, I don't think so. I do think it was quite possible it got in the polio vaccine, because I talk to people in Africa, and they said they blame all the people in the villages for eating monkeys, but some of the people in the cities got infected first, so they disputed it. So, was it in the polio vaccine maybe early on, because they were using monkey tissue for that – like, in vaccines, you use agar – agar, they were using monkey tissue. That's a possibility. It doesn't matter anyhow. What else have we got here? [Long pause] ACT UP – you want to talk to John Kozachenko. You heard of him?

**BK:** Oh yeah. We haven't interviewed him, but we know who he is.

**JC:** Well, talk to him by all means. He was there at the beginning. He was out and the rest of us were hiding.

**BK:** Do you remember seeing ACT UP in Vancouver or what they were doing at the time?

**JC:** The demonstrating. He tied himself up in a – what is it that babies wear? Diapers or something, chained himself to the police station. And then he laid down at the Orpheum and Lillian Vander Zalm trod over him.



**BK:** And fell. I think she tripped, right?

**JC:** Yeah. So, you want to talk to him because he was there from the beginning. He's a rather interesting piece of work, John. I like him. [Long pause] I think what's interesting, like I talked about the three periods – the modern period, the infection rate is one-tenth of what it was. I won't be popular that I've said this, but I helped build the infrastructure, because I mean, at one time there was just AIDS Vancouver when I came along and Positive Living, and then they decided that, oh, there's AIDS on Vancouver Island and in Prince George. And that's rather interesting. It's a different mindset building infrastructure as opposed to managing things – two different worlds. Oh, the Dr. Peter Centre – Maxine, I remember when she started that. I would say of all the executive directors, she's the smartest – she managed to hustle ten million dollars – four, she collected. I mean, this is for addicts with AIDS, and she hustled four million from the community, and then she got BC Housing to carry the mortgage for the other part and built that building, and then the people live there and pay for everything else, comes out of their rent money – really smart. And I remember when she started that, when it was in the building behind part of St. Paul's, the off building there, it was just running a few hours a week, and then she had one board to run things and then another board to build all the new stuff – really smart. But she's retired now.

**BK:** Did you have a hand in setting up some of those AIDS organizations outside of Vancouver? Like, you talked about Prince George, setting up the AIDS organizations there – were you involved in...?

**JC:** No, not much. But the first, and you want to get a hold of this guy, the first hospice was The Lotus Hotel – it's at the corner of Abbott and Pender, that was the first AIDS hospice, because there was no place it could be. And that was run by, that was set up by [name] and [name], with [name] Antiques, and I would go and visit people there. It was a place for people to go and die with AIDS at that time. So, that was the first hospice – there was no place to put people. And then after that we had May Gutteridge and whatever. And then we had – I can't think of his name – he was Native, and a lot of Native people would go and stay with him in Kelowna to die. One thing I didn't talk about was the suicides. We just had the suicide study – they just did the suicide study – they did an art exhibit and that. So, during the 1980s, people would find out they had AIDS and they were positive and commit suicide, so either they just couldn't handle the diagnosis, or they got ill, and they knew they were going to die a horrible death. So, it was one suicide after another. I had one friend, just over here, he hung himself – I won't say what house, I always look at it – he hung himself in the closet when he found out he was positive. And then I had another friend, a Musqueam, hung himself in his basement. People overdosed, and then you had people would come and say goodbye – say their goodbyes and then do themselves in. One friend shot himself – he said he was going to do it properly.

They initially had AA groups at St. Paul's and I helped with a friend of mine at Vancouver General because there were so many gay people with AA. The halls were lined up in the early '80s for a period, and they had people stacked in the hallway. So, I was involved in that. Back to what it was like living at the beginning, you had to boil all your water, because you'd get chlorosporidium or whatever it was – there were different things you could get. Not so much for me, but my partner, we had to boil all the water. And tea kettles last about six months maximum,

buying one after the other. And then you couldn't eat – you had to avoid anything, like salads and that, where there was a lot of surface area that could have different – because your immune system is fractured. So, you couldn't eat salads, don't eat sushi, because raw fish – so there were dietary restrictions, there were a lot of restrictions. I'm jumping all over the place.

**BK:** It's okay.

**JC:** So, doing AIDS work all these years, I reduced it two things – what's our mandate if you do AIDS work? Help people who have AIDS and stop other people from getting it. It's simple – it doesn't matter what you're doing, it fits in those two. And that simplifies what you're doing. So, maybe what you're doing here is helping both groups, right?

**BK:** We sure hope so.

**JC:** Sometimes it gets lost in little things, but that's really what you're doing. I'm trying to see what else I've got here. I think early on during the '80s, watching all the people who got sick, stars, and you know it was kind of a lesson there not to let people know. I mean, you had one of the first guys infected was a guy called Klaus Nomi – have you ever heard of him? He hung around with Bowie, and he got infected really, really early on, but he kept it a secret. He had KS and he changed his outfit – he was a singer – he changed his outfit to cover the KS. And then you had Miss Kitty from *Gunsmoke*, she died of AIDS and she kept it hidden. And then who else died? And then you had Walter [sic, Arthur] Ashe, tennis star – I think he came out though. And then you had Magic Johnson, the great hero who told everybody about it, and then Rock Hudson. So, we had all these people, but most of them wouldn't come out of the closet. Oh, you had Sylvester, the singer – he came out and he helped with AIDS work in San Francisco. But the vast majority kept it hidden or would keep it hidden until the last minute, so that was a lesson to all of us, don't come out. And then you had the – he kept it hidden – oh, what's his name? On *Psycho*. I can't remember his name now. The star of *Psycho*, the movie *Psycho*. He went to bed with everybody – Anthony Perkins – he went to bed with everybody under the sun, from – was it Nureyev who got sick, the ballet dancer, and they all kept it hidden.

And we went through that here locally, because sometimes you'd go to a funeral, and we'd know the person died of AIDS, but they'd say that he died of something else, and the richer the person, the less likely they died of AIDS, because they didn't want the reputation that went with it. So, you'd be sitting there – not that many times – saying I know they died of AIDS. I guess that's changed now. And then you had – oh, you know who you need to talk to here is Dr. Conway – the IDC on the second floor. He was in that right at the beginning – he was like – Dr. Montaner and then Dr. Conway. He's been involved since square one.

**BK:** We'll see if we can talk to him. That would be great.

**JC:** Yes, he's really a nice guy. We got – oh, the testing. In the old days you had to wait a week and then they'd say come back and you'd get your results, and there was a period where you could use a pseudonym, so my partner was – I was Jimmy Swaggart, the preacher [laughs], and he was – what was her name? She sang "Paper Roses" and she hated gay people – Anita Bryant. That was our false name – he was Anita Bryant and I was Jimmy Swaggart, but it was okay for

Jimmy Swaggart to pick up hookers and chase them around the car, and they'd want \$20 and he'd argue and only give them ten – that's okay. [Laughs] All that fuss that went on – I mean AIDS really has a bad rap. Stigma hasn't changed, people aren't... This last AIDS Day, there was nothing in the paper, so people need to get out there and say U = U. I see the World Health Organization has changed, has recognized...

**BK:** That message needs to get out there.

**JC:** It really does. I bet 90% of people don't know that. Oh, and then I wrote down AIDS dementia, so that's one of the things that happened when we didn't have treatment. I got really ill and what happens is that the virus goes through body-brain barrier, and then you lose it, do silly things. Like, I put the telephone in the fridge and I put the milk way in the cupboard, and then weeks later you could smell the milk. And then I got dressed and went shopping at Safeway but I put my pants on and my underwear over top of it. That didn't catch on, that dress fad. And we had a friend of ours who had dementia, and he dressed up like Ronald McDonald with a parrot on his shoulder, but the seagulls got the parrot one day down here on Davie Street. Oh, Queen – here I am jumping again – Queen, he didn't come out until the last minute either. And there were other ones. You really had to give Magic Johnson credit, because he's still alive. What else have I got here? And he had to quit the Lakers because he might infect somebody. [Long pause] I don't know. What other questions have you got?

**BK:** I think we've covered a lot. I probably have a couple more questions. Where did you find your support system?

**JC:** Initially, I would say that was Colin Stewart's support group at Positive Living. There'd be twenty people with AIDS, no treatment, sharing information. And then later there'd be...

**BK:** Do you remember what that group was called?

**JC:** It was just BCPWA support group. Wonderful. Colin really needs some kind of an award for doing that as a volunteer for years and years. It mostly gay people. And from my involvements in the system, and doctors. You know, if you've got AIDS and you want to live any place in the world, where you're best looked after is British Columbia – Canada, but British Columbia in particular. We get spectacular treatment. So, I've never complained about the health system. I got shingles – oh, here's a piece. I got shingles and I have to have a drug and it wouldn't be covered, and then I had to have another drug because I was losing all this weight. In order to get – that drug cost me \$100 and change every day, so I went through with that and the other drugs that weren't covered. And everybody's under the illusion that everything's covered in Canada. I had to cash RRSPs in, 40-something grand worth – so it's always smart to have money.

**BK:** That's awful that that wouldn't have been covered.

**JC:** Well yeah, but then you don't have to worry about how much interest you get – that's how I look at it. I'm grateful I had the money. I really am.

**BK:** And your partner, was that a source of support as well?

**JC:** Oh, absolutely. He's an artist and taught art to handicapped people and people with mental and physical problems. Yes. And he's really good at dealing with them intuitively. So, at the Gathering Place, people would come and talk to him, they'd send people with AIDS to him and street people and that – he's really good at dealing with people. I'm better at pragmatic stuff.

**BK:** You talked about what the gay community looked like in the '70s and into the early '80s. How did HIV change the way the gay community looked?

**JC:** Well, the party was over – and I don't know, because I don't go to the bars, so I really can't answer that. I think they did a study, a survey at Numbers at one point, and 60% of the people there at that time were positive, they figured. How did it change it? I don't know. You tell me, if you go to gay bars. Last time I went, somebody said to me, "You must have been nice-looking at one time." I said, "Oh, thank you very much." [Laughs]

**BK:** Well, it certainly sounds less vibrant than it was back then, or it looks less vibrant to me than it sounds like it was back then.

**JC:** It was wild and crazy. There was sex all over the place.

**BK:** There's still a lot of sex happening, but it's on your phone, right? Using your phone and apps.

**JC:** Is it? I don't even have a cellphone.

**BK:** That's what a lot of young folks are using their phones for. [Laughs]

**JC:** Oh, I know, because I've got friends. Yeah, I had a young friend, he said, "John, why don't you get a cellphone and then we can do FaceTime?" One of my friend's son, and he wouldn't shut up. You gotta get a cellphone, we can do FaceTime. I said, "What's FaceTime? The only time I want with your face is it stuck on my crotch for a couple of hours." [Laughs] He hasn't bothered me since. Isn't that amazing? I don't have any of that stuff. I thought a blog was a piece of furniture from IKEA. I do have a computer though, because I get all these AIDS – not just AIDS but harm reduction, there's always stuff on that. People you should talk to – John Kozanchenko, absolutely. Get a hold of – if you look up, you should be able to track down [name] from the Lotus Hotel – that was really important in the early days. He ran [name] Antiques, and they still run, but not locally, and he's retired now. He ran that, and I think I asked him how many people are alive from that, and he figured two out of the whole hotel full. Who else? [Name] from Positive Living, absolutely – he'll put you in touch with all the other people. And that's a good start for people. And Dr. Conway, Dr. Montaner, and then that will feed off into a whole mess of other people.

Yeah, I guess sex is all on the Internet – that's what I tell them, because I do stand-up, so I told them I phoned a sex chatline and they put me on hold, and they said we'll put your call in priority sequence, and I said and I'm still waiting. Well, it was so crazy during the '70s. If you wanted to have sex with somebody, you wouldn't even get their names – just totally wild, you

didn't even bother finding out their names. And now, you don't see that and you don't see the big crowd of people after the bar, or do you? I don't know. The leftovers after the club closes, and they're all outside – sifting through the leftovers to find someone to go home with.

**BK:** It must still happen sometimes, but I don't think it's as prominent.

**JC:** No, not as obvious. I used to sit in front of the – close to the washroom, because then you don't have to get up, because it's a high traffic area. Anyhow.

**BK:** Part of what we're trying to do with this project is to generate some intergenerational dialogue between long-term survivors...

**JC:** Let them know that this disease is not –  $U = U$ , so what does that tell you? It means it's really important to get people on treatment. And one thing that's a problem too – and I forget the stats but – there's a lot of people out there... When you're really infectious is when you're first infected. There's a lot of people out there that are infected, and they spread it, so it's really important to have testing and to get those people. As Dr. Montaner said, if we did what we're supposed to do, it would just be gone. We have the potential to eliminate it. It's kind of died now. It's not even on the agenda. So, stigma needs to be dealt with – hasn't changed. People need to know they must do their pills – that's the key to survival. Yeah, stigma, testing – those are the important pieces. I'm really pleased to see, in Africa, if you follow Africa, it went up like this, and now it's gone [down] with treatment in Africa, now we're able to get the pills there – it's really crucial. It's really crucial, because there were some countries there, one of them had a 27% infection rate – I can't think of which one. Sometimes I wonder though if I would have gone along with testing everybody at the beginning, mandatory. There was a big kaffuffle over, no, we can't do that, it's – some fancy human rights things are great, but they're too liberal or something. I don't think it worked. Well, the counter-argument is if we test them, they're all going to run into the closets. Why not test everybody and we wouldn't have had this?

I get rather tired with all the harm reduction and the overdoses and all that's going on – I get rather tired of hearing how we're the most progressive place in the world when it comes to addiction. And my question always is, well how – did you know that the East End of Vancouver had the highest AIDS infection rate in the industrialized world in about '95? And the highest – I went to Seattle, I wanted to know because I used to go to Seattle, I wanted to know what's it like in Seattle. They had – their number was a third [compared to] ours, HIV infection rate one-third the number of people infected, Hep C one-third, and I wanted to know why. Now, there was a number of reasons – primarily, they built housing all over the city, right? You could actually take – we took the Vanguard study and actually kind of mapped out where the people with AIDS are coming from at AIDS Vancouver, and wherever there was poor housing, you could see a large pocket, by taking all the clients' names and their location. Along Granville Street was one of them, because there were a bunch of poor hotels there at one point. So, that's kind of interesting, right? Seattle did a much better job.

Plus, in Seattle, you didn't get the infection because, especially among the addicts, because you'd go and buy your drugs in a beer parlour, in a bar, and you'd exchange the money, and then you'd go in the washroom and they'd hand you the drugs, and the police know that was going on

but they kind of had an unwritten deal with take your drugs, go home. So, if you got arrested and you were doing drugs on the street or you had paraphernalia, you'd go to jail for a long time. So, if you went home, did the drugs privately, the police left them alone, and their stats are way better than ours. Coupled with housing all over the city, and they don't hand people large amounts of money to blow on welfare days. But people don't want to hear that, and I'm outspoken about stuff like that. What else?

**BK:** I think that's more or less it for my formal questions. You're welcome to take a moment to think about if there's anything want to add.

**JC:** So, how did you get involved in all of this?

**BK:** I'm happy to talk about that, but I might turn off the camera if I'm going to talk for a bit, because we're more interested in hearing your story than hearing me talking.

**JC:** Yeah. [Long pause] The new generation, you don't even see them anymore – they just go to work, take their pills, they can't get disability. Maybe that's a good thing, right?

**BK:** And they're probably not rushing to AIDS service organizations either.

**JC:** No, but the AIDS service organizations want to survive, but they haven't got the clientele, so they're having to branch into other things, do Hep and that. But that's what we wanted at the beginning, that was our two objectives – stop people from getting AIDS and help people to survive, and we've done that, so that's good. I think another piece is the AIDS world, we opened the door for how people deal with diseases, and the AIDS Walk and ribbons, and that was gay men, because they were used to standing out and fighting for gay rights, you know what I mean? So, they were already out and then they just transposed it over to AIDS, used the same things to make a statement, and it changed the whole world with diseases, especially in North America – it's how they're dealt with. Yes. Oh, and I was on the AIDS Candlelight [Vigil] for years – still involved with it indirectly. AIDS Vancouver, Brian Chittock oversees that still, indirectly with that. Yeah, I was on that committee at the beginning, and the pagoda there down by Beach Ave., Alexander Park, we'd put all the names of people who had died around that and update it every year. But then they changed the – you couldn't do that anymore.

**BK:** Oh, probably for...

**JC:** Privacy – they put privacy laws in place. And that was kind of distressing, because you'd see all these people that you knew that died and it upset me for days. At the beginning, I used to sit at the kitchen – my partner's Native and he seemed to be able to handle things, accept things and handle them more easily, and me, I'd be upset – survivor's guilt. I couldn't watch that movie for years, *And the Band Played On* – have you seen that? From the early years.

**BK:** I haven't seen the movie, but I've read the book.

**JC:** Yes, from the AIDS epidemic during the Reagan years. He wasn't very nice. I wouldn't watch it, it was too upsetting. Anyhow, it changes how you think. When you watch everybody

around you die, then – like, I’m a pacifist now, I don’t believe in the death sentence, because one of the most fundamental rights is to survive. When you go through this and you watch everybody – you know, everybody around you died – it’s upsetting, to put it mildly. And then you wonder why do I get to...? It’s very leveling, because you realize you’re no more important or less important than anybody else, no better or worse. So, I find it changed how I think. And you also, when you get sick, you see people with other illnesses and things, and you have some – before they weren’t there, and now all of sudden you have a lot of compassion and will help them. It also makes you more difficult – for me, if I think something’s wrong, I just won’t shut up. I think that’s old age too. Yes. There was something else. Anyhow, it changes who you are and how you think. Oh, you know, sometimes you run across people – like, I know a few people that are left who had AIDS, and there’s a common understanding that’s hard to explain. Anybody with any illness, there’s a common understanding – you don’t even have to say anything, there’s a connection.

**BK:** Like, a sense of having gone through something together or been in the trenches together?

**JC:** Yes. So, I go to AA in Richmond. I’m the only one who comes out and says I’m gay. One other young guy said he was gay, but I haven’t heard from him. I’m the only that will come out and say that, and I’ve got AIDS, so what does that tell you? That tells you about stigma, doesn’t it? And I annoy them because I go on and on about it, and they don’t want to hear about it, a lot of them. Most of them are good – that’s not right. When I came out in Richmond and said to people I’ve got AIDS, I wondered what’s the reaction going to be – is my house going to get firebombed or what? And for the most part, it was really, really good – it really was. I had some of the bikers coming and saying, “Thank you John for coming out because some of our friends have died.” And the guy at Safeway across from me, the produce manager, would give me free dog food. So, for the most part, it was pretty good – there was a few people. I would say 90% positive – I was amazed.

One more thing, I forgot, a particular incident that happened. When they put me on AZT, I was told you got maximum two years left to live – go get your will and make arrangements and everything. And at that point, I’m 137 pounds and I can barely do anything. Then six months later, I’m alive and I put twenty pounds on, and I felt what do I do now? So, I went down to Seattle just to – thank god I listened to somebody who said, “When you’re up to your ass in problems, don’t make major decisions.” Because I was going to get rid of my house and all of this, and I went to Seattle just to sit and think for a day. What I found about making decisions, make them and then go somewhere quiet and let them percolate in your head, and then you don’t make as many mistakes. So, I got down there and I got to this – what do you call it, where you go off the road and take...? It’s spots on the highway where you can stop.

**BK:** Like, a rest stop?

**JC:** Rest stop, and I got really ill and I went – I was just coming into Seattle, you go up the hill and you go to the University of Washington. And I got really ill and I’m pissing blood and I’m deathly ill, so I went down, I got a room at the Commodore Hotel – common odour hotel, I call it – and then I thought, well, if you can find AA in a telephone book, maybe you can find an AIDS [group]. So, I looked up AIDS and there was this AIDS organization, it was in Capitol Hill,

which is the gay district, and I phoned them, and it was a house with maybe six or eight people that were dying of AIDS, and they would have meetings with the AIDS community. And I went there, and they looked after me for two days. And what they said is don't drink any coffee – it doesn't agree with AZT particularly. They kind of held me together until I could drive back to Vancouver, until I felt good enough. Wasn't that nice? I never forgot that.

**BK:** That's incredible.

**JC:** The Capitol district, yeah.

**BK:** It's a nice neighbourhood. I like Capitol Hill a lot.

**JC:** Yeah. Is there still a place there called the Tacky Tavern – it was the Wolf.

**BK:** I don't know, I'd have to look.

**JC:** Tacky Tavern.

**BK:** It's still quite gay.

**JC:** Oh, the bars are much better in the United States. They're more colloquial, they're smaller, the same people come there, some of them for their whole lives, and I used to go there to the 6/11 club – it's gone now – and they'd say, "Oh, that Canadian is here, yay!" But they had the Tacky Tavern on Capitol Hill, mostly with drag queens and that. They would sing their theme song every night, which was "Ooh Baby" by – what's his name? Black singer. Yes, Tacky Tavern. That was when I was young. I went there one time – I was still drinking at that point – I went there and there was this – and Canadians are much more sleazy than Americans – they really are. In the United States, even if you're gay, you have to kind of be introduced by people and their friends, and then you go out with them, and still there was this mix between black people that sat in a group, right?

Anyhow, I went to the Tacky Tavern and there was this group of black dudes sitting, and this one guy kept looking at me, and I looked back at him. And then I had to leave – I think it was family business, it was Christmas, I had to go to see them because I have relatives in the States. And when I left, I looked, and he was staring at me – well, you know that look. And then I went back the next night – guess who's there? This black dude. I ordered a drink and I'm sitting there, and then I went in to take a leak in the washroom, and then I look – guess who's standing at the urinal next to me? This black dude. And suddenly – it's Christmas time – suddenly he turned and he said, "How would you like this for Christmas?" [Laughs] And then I told him I was feeling festive already. [Laughs] That was before the AIDS thing. I had another friend who was Sitting Bull's grandson, and he died of AIDS, and that was really sad. We were friends and I went to see him, and suddenly he wasn't there anymore, and nobody could tell me. And I went into this bar that he frequented, and finally the bartender told me he died of AIDS, of lymphoma. It was really sad. Oh, here's another piece if anybody talks about it is if you wanted to go the United States, what about your pills? So, sometimes you'd have to just cut your pills off and go on a holiday, a pill holiday for whatever amount of time, or you could get them shipped.



**BK:** Because you weren't actually allowed to bring them across the border?

**JC:** Nope. They didn't want people spreading AIDS. And that's one of the reasons that ballet dancer wouldn't disclose, because they wouldn't let him into the United States – which one was it that was infected early on? That was a problem, and I think in 1995, they changed it finally – they finally changed it so you could get in.

**BK:** Crazy.

**JC:** I remember I had to go down there, I bought a Lincoln – antique Lincoln. I had to go down there to pick it up, and it was going to be a couple of days, three days, and I just had to cut my meds for three days, go on a holiday if I wanted to do that. Yes, so anyhow...

**BK:** Unless you have anything else to add, I think we've covered a lot of ground.

**JC:** It's quite a bit, isn't it?

**BK:** Yeah, it's a lot. We've been chatting for a couple hours, which is great.

**JC:** Have we? I'm glad we did this. It got my mind off my partner. We'll see how he's doing.

**BK:** If you're okay with it, I'm going to stop the recording.

**JC:** Yeah.