HIV in My Day – Interview 13

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Interviewee: John Dub (JD); Interviewer: Ben Klassen (BK)

Ben Klassen: Just sitting down with John this morning, about to get started. To ease our way into the interview, we like to start by asking how you first came into gay life or started engaging in the gay community.

John Dub: That would have been, um… gosh. [laughs] Probably right after high school, back in Calgary, so, late-'70s. Yeah, and in Calgary it was a difficult challenge, obviously, as you can well imagine, in a city like that. So, it was – yeah, it was a difficult time, but there was kind of an underground network that you could get yourself into that, you know, you could find where the bars were that were down some dark alley somewhere, and that sort of stuff – in the back. So, you could actually meet people that way. Not the greatest way of meeting people, but if that's all you have… Yeah, so it was probably late-'70s.

BK: Late '70s in Calgary, and it was kind of this subterranean…

JD: It was, it totally was. It was odd. I mean, I kind of knew it would be, but… yeah. And you really had that non-trusting feeling of everybody, right, because you didn't really know. Yeah. And, you know, I probably got bugged in school – I mean, I remember getting bugged in high school and that sort of stuff, about, you know, "You're gay. You're gay." All that kind of stuff. So, you know, yeah – I tried to cover up. I tried to, you know, do the girlfriend thing [laughs] for a couple years and right after high school, I think, and when I started working. You know, right? So, it's like, "Okay, well, I've got to figure out what to do here, so…" Which led me to, obviously, leaving the Prairies and coming to a big city, like Vancouver, where, you know, life for a gay person was something you knew you could do out here, right? And there were lots of places and all that kind of stuff, so… Yeah.

BK: Was it a direct move from Calgary to Vancouver in the '80s?

JD: I started working for the airlines in the late-'80s, so probably – when did I start? '86-ish, I want to say. And of course, being a flight attendant, you came out here a lot, and I tried to – I kind of knew this was where I wanted to be, because I wanted to be by the water, and that kind of stuff. And Calgary, you're locked, you know – you're locked in. The mountains are beautiful and they're still close, but, you know, I wanted to be by the water. And so I tried to do overnights out here and discovered, you know, the thrill of Davie St., and all that kind of stuff, which I never, ever experienced in my life, right, back in Calgary, with bar after bar after bar, and that sort of stuff. And then same thing going to Toronto, which was even bigger, you know – a bigger scale. It's just that it was another big city to me and I didn't – you know, Vancouver just felt like it still had a smaller town feel that I was used to from Calgary, right? Toronto was a bit too crazy and big. [laughs] Yeah, so I think that's when I really decided. It's like, "Oh yeah, that's the place that I got to get to." So, I transferred here – I put in my transfer to come to Vancouver, and it didn't take long, right? So, they always needed people, especially out here, right, because it was getting bigger and bigger out here. So… And it was a little Alberta-based airline that I worked for and they were trying to spread out. So yeah. It worked out – it worked out well. I probably moved here – well, not long afterwards, so maybe mid-'87 or something like that, so… I've been here a while. [laughs] This is home. Haven't been back to Calgary in a long time.

BK: And I'm sure the gay community in Calgary looks a fair bit different from back then.

JD: I'm sure it does, yeah. But I – you know, I hear that it's still kind of – you know, it's probably not as underground as it was before, but yeah. And they actually have a pride parade now, I've heard, so – who would have thunk [sic]?

BK: Probably still not quite like Vancouver.

JD: No. I can't even picture it being like out here.

BK: What did Vancouver's gay community look like when you arrived here in '87?

JD: It was… You have to remember, it was all new to me too, so it was thrilling, it was exciting. It was just like so different than what I was used to. And you know, I'd never really encountered a bar scene, except for the one down the back alley [laughs], you know, and down some stairs in the dungeon. So – and there they were, like five or six of them along Davie. And you know, just off of Davie, there was a couple over here – you know, before – it's all built up now. So, it was just a matter of getting out there and experiencing the lifestyle. And it was busy, right? The bars were packed, full of people. You know, I haven't been to a bar in long time, so I don't know what they're like now, but you know, they – wherever you went, you would always line up, and that sort of stuff, because that was the place to be, right? There was not the Internet. There was not all these other ways of people connecting, and it was much more personal, right, because you actually had conversations and that sort of stuff. Even though you were in a bar, there's always quiet spots, and that sort of stuff, so it was – it was an interesting way to connect with others that, you know, came from other places as well, because Vancouver's a city of transplants, as we talked about before. There's not many Vancouverites. So yeah, it was interesting to hear the stories of, you know, why people moved here, and that sort of stuff. And most of them were the same, right? It's because they needed to get away, they needed to find what they were looking for and what they were feeling inside, so…

BK: You moved from this subterranean gay community in Calgary to this very visible, vibrant community in Vancouver.

JD: Yeah. It was exciting, right? It was exciting. I met tons of people. You know, I was young. [laughs] And much better looking than now. So, you know, that's – it makes a difference, right? And like I said, there was others that were in the same boat, so, you could go out to restaurants and that sort of stuff – not that that doesn't happen now, but it's not the way that people really meet and chat, which is probably one of the things that we may talk about later, that, you know… I like to sit down and chat with people. I'm not one of those ones that – it's just, you know – I don't know if it's old school or what, but it just makes more sense to me to get to know each other or know people first, and then – and find out what they're all about, right? And that way they find out about you too, so – and there was lots of that kind of stuff, so it was fun. It was fun. It was crazy, right? And it was all new. I think that was other exciting part for me, right? I could hardly wait to get home and, you know, race on down to English Bay because you know there'd be a whole group taking over the beach, and you'd just, like, sit there and, again, chat. Yeah, catch up on what went on, what happened while I was away for my few days. Yeah, it was very cool. There was a big sense of community, whereas – just speaking from what I see now, I don't really see as much of that as back then, right? 'Cause again, I think there's just so many other ways that people are meeting each other, and we never had those options before. It was either the bar or, you know, a wander down the street. You know, going out to a restaurant, or whatever. So, it was a different time.

BK: Yeah. And I wonder if it's partially related to technology, but I also wonder if it's partially related to lessening stigma around gayness and…

JD: You know what, Ben, I think that's part of it, for sure. Yeah, stigma is such a huge issue and you know it's still out there, but it's not nearly like it used to be by any means, you know. And it's still something, I think, that we need to spend a lot of time and effort on spreading the word. It's just that you need to get people together in those groups, which was much easier before than it is now – to fight the fight, whatever that may be, whether that's stigma and discrimination, or, you know, getting new drugs, and all that kind of stuff. So, it's – I think it was just easier to rally the troops back then, whereas now I think we still can, I just think it's a little more difficult to get people together to fight for the cause.

BK: Yeah, I think maybe the community is a bit more diffuse now – less cohesive, or something. Like, you can be an openly gay guy living in Coquitlam, whereas in the early-'80s, mid-'80s…

JD: Exactly. Probably not so much. Yeah. Well, I mean look at New West and that sort of stuff, where, you know, there's a huge gay population out there now, which is awesome. You know, the city embraces them, the whole thing, and that's how it should be, right? But it took a while to get there. A long time to get there. Yeah, it's – and I think working together is the big difference, right? It was easier then. And I think that's why we had so many of those fights, even before I came on the scene or, you know, I watched on TV. [laughs] You know, things going on in New York and San Francisco, and all that kind of stuff, before it actually hit home. Yeah, but it was always big groups of people. And I think it was a diverse group back then too, because it was a bunch of people that you wouldn't expect that came and helped out. You know, whether it was lesbians and hospital workers, and all that kind of stuff, right? I think now we could do it, it's just that it takes – I think it would be a little more difficult, right? And that probably is because, as you mentioned, we're so spread out, and there isn't that much of a fight, I think people think, because we've come so far.

BK: Less of a sense of urgency.

JD: Exactly, right? Yeah, there was desperation back then, especially with what was going on.

BK: Well, I think we should definitely circle back to this, because we will probably end up talking about how the epidemic shaped the community or the way that the community is now, because I think it certainly did. But maybe we can shift gears a little bit. When did you first hear about HIV and AIDS? Do you remember where that early information was coming from for you?

JD: Well for me, again, being on the Prairies, it was on TV, right? You know, I watched that kind of stuff secretly, you know, when people weren't around. Finding out – until, you know, my mom and dad would see things happening on the news, and that sort of stuff. And then I would talk about it a bit more. It's like, "Oh my god. Like, look what's happening in New York. Look what's happening in San Francisco." So, it probably would have been around the time of the Stonewall Riots, which – well, no, probably later, because I would have only been, like, ten or eleven then. But I do remember watching some of that on TV and thinking, "Oh, what's happening." You know, it didn't really click, but – because I was too young then, but… So, it was probably when Rock Hudson and that sort of stuff – like, when it really hit home, when it was people who everyone knew, I think. And it came across, you know, TVs and newspapers, and that sort of stuff, and it's like this is happening. And it's happening everywhere, right? We of course hear more from the U.S. than anywhere else, but, I mean, it's happening around the world – we had to have known that, it's just that I think we didn't think that. Gosh, I don't remember what year Rock Hudson died, but it would be around that timeline I would think.

BK: I think it might have been '85.

JD: Yeah, that sounds – right, which would have made me early-teens, mid-teens, so not long after Stonewall Riots and that sort of stuff, so I connected a whole lot of things even though I was young during some of that early stuff. I think it really connected all together, right?

BK: I mean, it's kind of an obvious place to be learning about the epidemic in one sense, but it's also maybe a scary place to be learning about the epidemic because of the sensationalism that went on in some of those forms of media. But do you remember what your initial reaction was when you were hearing this news? Was it a sense of this happening here now or a sense of it happening somewhere else, or just a general sense of…?

JD: For me, I think it was – I think I knew that it was happening now. Like, I just – I probably read some things about it as well, which again can be, you know [laughs] – leans all kinds of directions. But I think that – I kind of did a bit more digging in, and that sort of stuff. You know, travel obviously interested me, so I would see if I could find stuff from other places in the world, which, you know – if it is this worldwide thing and it's not this U.S., you know, made-up something, then there's got to be something about this. Is there a connection? I don't know. Like, it's not close enough to me, or it wasn't at that time. Yeah, so it was – it probably wasn't the best way, but I think it got me digging more into, "Oh my god, this can happen, like, right here. We probably have people right here, and we just don't know it," right? And I'm sure we did back in Calgary, it's just, you know, who would want to admit or be out in the one bar, you know? It would be horrific. I can't even imagine the feelings that people must have had back then.

BK: Not the best in terms of the way it was being discussed, but I think that's the way that a lot of people learned about the epidemic initially, because unless you were really tied into an out, visible gay community, that's probably where you were going to hear about it.

JD: Yeah, and I didn't really think about out here – you know, I didn't think about Vancouver or Toronto, that sort of stuff. Obviously, I knew that they were big cities for us – Montreal, all that kind of stuff – but I didn't really connect it to our cities as well. It's like, okay – New York and San Francisco were kind of the thing, you know, the ones that really stood out, I think, for me. And maybe for a lot of people, as you say, because you saw the whole diverse group of people that were, like, "Okay, something needs to be done. And this is real and it's not going to go away on its own. We've got to act now." Which opened up all kinds of ways for people to get involved.

BK: In Calgary, in the gay bar, you're not hearing about HIV and AIDS particularly, because, like you said, who's going to be the one to bring that topic up in a one-bar city where there's already all this stigma?

JD: In Redneckville, exactly, and so much stigma. When you think you have to be dropped off a block away and walk down a back alley to get to a bar, that's the last thing you're going to be talking about to anyone. Which, when you look back on it is kind of sad, because that was our group, you know. That was the group of people and there could have been someone there that needed support and that sort of stuff, it's just that it's not conducive – that was not the kind of place conducive to, "Hey, I'm one of them," right? I can't even imagine how that must have been, if potentially there was – and I'm sure there was. I mean, I'm guessing totally, but it was everywhere. We know it was, so… And maybe they didn't know either, but you know, at least it would open up the opportunity for a supportive group. But then, would they have been supportive? Who knows, right? Because back then everyone was afraid, so, would you rally around someone who had the guts to tell you? Um… Maybe, maybe not. I think that depends on your personality, right?

BK: When you get to Vancouver and you're embracing the bar scene here and spending a lot of time immersed in the community, was HIV and AIDS something that was being talked about in those types of environments, or not so much still?

JD: I think – I think more so here. Not a whole ton though. I think we knew it was happening around us, especially at that time – like, early-'80s, right – or, you know, mid-'80s, sorry. But again, I don't think people talked about it a whole ton. We did definitely talk about it much more than I would have on the Prairies for sure, right, because, you know, I lived in the West End and we knew St. Paul's was right here and that they were actively involved in that – in trying to… enlist people and all that kind of stuff. So, you definitely knew it was around you more. You saw people that were sick, especially at that time, with the symptoms that we all knew – you know, the wasting and the, you know, locking – if you hadn't seen someone in a while, you know, you would ask a friend, "Hey, what's happening?" You know, so, you definitely – it was definitely more talked about out here. And I think it's only because it was much more visible than it was for me back home.

BK: Continuing with that information and education piece, in that initial period after coming to Vancouver and prior to finding out that you were HIV positive, did you encounter any good forms of information? Was there anybody that was taking that up that you were aware of at the time?

JD: Not that I was aware of, because I think, again, it didn't affect me personally, so I wasn't out there looking for support, and all that kind of stuff, because it hadn't hit home for me yet. Like, it wasn't me. [laughs] It was people around me, right, and people that I knew, you know, whether they were close friends or acquaintances from the bar, or a friend's friend, or their partner, or whatever. I didn't really go looking for anything like that, because it didn't have a personal effect other than the people around me, which is personal but it's not – like, I don't have the feeling that I need to, like, "Oh my god, now it's me. So, now what do I do?" Which happened later.

BK: As you were seeing the epidemic manifesting in the community here in Vancouver, did it shift your behaviour in any way, or was it – as you said, it wasn't happening to you, so why would it impact you?

JD: Yeah. You know, Ben, I can't honestly say that it really did affect my behaviour. I mean, it probably – looking back, it probably should have, but that's… You know, I don't know if that would have made a difference, because sooner or later it was going to happen anyway. Yeah, I don't know that I shifted behaviour even though I knew the risk was there. I might have been a bit more selective and might not have been so risqué doing some of the things, like… you know, a little wander through the park with some friends and all that kind of stuff. So, I may have cut back on all that kind of stuff, because, you know, that opens up a different can of worms, and I probably looked at that a little bit more. But it could be anywhere, right? And I – I don't know if I thought about that then or if it was actually something I was contemplating. So, behaviour-wise, I can't honestly say it changed a whole lot. I might have adapted a few things.

BK: And that's not supposed to be a super leading question to say that you should have or anything like that…

JD: No, no, no…

BK: … because we realize for some people that was absolutely what they did…

JD: Oh, totally.

BK: … and then other people – I mean, you were also for the first time in your life encountering a visible, exciting, vibrant gay community, and…

JD: So new.

BK: … having sex was part of that. It's a huge part of that.

JD: So new, right?

BK: So, it makes a lot of sense.

JD: Yeah. I mean, I have no regrets over the stuff I did when I got here, because I had a great time, right? It was so different. It was so much fun. The people were so welcoming, and yeah, I mean, I don't regret any of it. None of it. [laughs]

BK: That's great. From what you and some other folks have said, it does sound like such a fantastic time to be in the gay community in Vancouver.

JD: Yeah, it was a different time, right? And it was fun. And people were so much more connected. I'd always heard, I think, the little – or heard rumour of the little cliquey group. "Oh my god. You're going to Vancouver? How are you going to fit in there? They're so cliquey." And I was like, "Well, you know, I'm a pretty social guy. Always have been. It's worth a shot." I never found that at all. I know some people still say that. Like, "Oh my god, you've got to know people there." But back then, I didn't think that at all. Maybe it was, but again, it was also exciting. I could talk to anyone in a bar – it didn't matter. Yeah.

BK: Still thinking about this early period in Vancouver, were you aware of some of the community responses that were going on in terms of the epidemic? You said you were involved in supporting or caregiving in some capacity with some friends, but were you aware of anything else like that that was going on?

JD: No, I really wasn't. Again, I think it's because it didn't impact me. I think when it – you know, that all changed of course later on after my diagnosis, and my partner and that sort of stuff, which is coming up. I'm sure that we're talking…

BK: We can go there now if you want.

JD: Okay. So, that was '88. My – I had a wonderful partner. Met him in – not long after I got here, actually. So, we did a ton of things together obviously as a fun-loving couple in their late-twenties do. Yeah, we always had fun – like I said, going out and that sort of stuff. And then I noticed that he was not doing very well and we made some doctors' appointments, and they were like, "Oh, you know, it could be anything." You know, there wasn't anything in particular that would trigger them down the road, which was kind of strange, but – because he had a sex life before I came along. So, '88 I guess it was, and he didn't actually get tested ever. And he kept on going – he kept on declining – so, you know I was… We started not going out very much and that sort of stuff, because he didn't have the energy, and that was okay. I mean, we hung out at home and did the usual things you'd do, and yeah. He started getting the… Things started happening upstairs, you know, in the brain and that sort of stuff, and you could tell that it really wasn't him. And I'm like, "Hm, are you sure that we don't need to do something?" You know, I could have been more pushy, I'm sure, but you know, he's a grown-up. I mean, I'm not going to force him to do something he doesn't what to do, and that sort of thing. I – it ended up that he was so weak that he couldn't get in and out of bed and off the couch, and that sort of stuff, so I called his best friend and I said, "We have to take him in to the hospital. Something is wrong." So, we did and that is when they did the testing and figured out that, yes, he was beyond HIV positive – obviously had AIDS. And the – you know, AIDS-related dementia and that sort of stuff, which was very difficult to watch. Thank goodness it didn't last for long, because it was too late to really do anything, but it was very painful. And I think that really was the turning point for me, right? Like, I realized that, "Wow, this is really close to home." And you know, it really – it really changed where my motivation went from that point on, and some of it still, you know. Here we are thirty years later and some of it – my motivation is still in that, and it's because of that. So, he ended up passing away. It was a beautiful thing to watch, but – it was so peaceful and calm, and I knew he was in a better place. It was traumatic as heck.

And of course, the docs then wanted – you know, suggested I get tested. There was no – back then, they really didn't force you to do any of that kind of stuff. It's not like now where you can go in and, you know, if it's the rapid access and all that kind of stuff. Back then, you know, "It's going to take a bit to get your test back, and we should know in… You know, you could be totally fine, but it's better to…" And I knew that. It was still really raw, and that sort of stuff. So, I did the test, kind of thinking in the back of my mind that, yeah, you know, with what's happened, there's probably a pretty good chance. And sure enough, it was probably a week before my twenty-ninth birthday, and – yeah, it was a week before my twenty-ninth birthday, and I went in and they weren't nearly that compassionate back then. He sat me down and he said, "You're test came back." And I said, "I'm kind of guessing I know the answer." And he said, "Yes, you are HIV positive." He said, "You know, there's not a whole lot out there. We have those awful drugs that – but you know, you're not going to make it to your fortieth birthday." And I was like, "Forty. Holy crap. I'm just gonna turn twenty-nine. Like, you can't tell me I'm not going to make it another eleven years, right?" Like, it just doesn't seem – doesn't seem right, you know? It's like… So, it was a real challenge for me, wrapping my head around that.

And then something clicked. I don't know what it was, but it was like, "Okay, I know it's only those awful drugs" – you know, AZT, DDI, DDC, which I read about. There was [sic] horrific stories about the toxicity of them and all that kind of stuff. And I thought, "You know what, if they don't help me, the research they get from this kind of stuff could help somewhere down the line." So, I went in and told them, "I want to do it. I need to do it for me, for my sake, and I'm willing to do other tests when they come up." So, I started on all those awful drugs [laughs] and had some awful, awful side effects. And then ended up taking some other trial drugs too, which of course, you know – like, I imagine trials now that are done, you know, it's all secretive with your little coded… Then, I think they used our initials or something like that with a number – something like that. So, some of it I have no idea what even was, because I just kept thinking in my mind, "Take it. They'll get something out of it that may not help me, but sooner or later down the road, it's gotta help someone," right? We have to figure out what we can do. So, there was all kinds of weird ones. I remember sitting in St. Paul's and having an IV of this stuff every – I think it was every three days. What it was – who knows, right? Because they were grasping at straws, trying to figure out something other than these awful toxic drugs that was their only real option back then.

So, it was at that time that I made – it changed everything for me. Losing my partner, getting the diagnosis – it all happened so quickly for me. It's like my life was flipped upside down. But yeah, I mean, I'm happy to say twenty-eight years later that, you know, I'm still here, and look how far we've come. You know, I wish I could take one pill a day like lots of people do. I don't. But that's, you know – I'm lucky enough to be stable on the ones that I am taking that, you know – there's a few of them that aren't the greatest, but that's… You know, people can take one – like, one pill a day. Who would have thought? I would have never dreamt of that when I was turning thirty – ever. So, I'm not sure if you want me to continue more down the lines of that – what happened to me and that sort of stuff – mid-'90s and that or…

BK: Yeah, we definitely want to leave some space for you to frame your story, so if you want to continue, feel free to. I can jump back in later with some further prods.

JD: Okay. I think the next defining moment would have been the mid-'90s for me where I ended up with two AIDS-related illnesses. First of all, I came down with the PCP pneumonia, which was awful. I swear I thought I was going to die. I was – I had a new partner by then – I had met another partner who was also HIV positive, so we were in the fight together. He did not go as far as I did on, you know, taking that kind of stuff, but that was his decision. I was totally fine with that. He knew what I decided, and yeah, he was so supportive. I thought then they were right – "I'm not going to make it to my fortieth birthday," because of course I'm thirty-five now. I was lucky to make it six years, so awesome. But I fought on through. It was awful. I was in St. Paul's and yeah. I mean, people were dying around me from that PCP pneumonia. It was a horrible, horrible thing. When I walked out of there, I was like, "Oh my god. I can't believe it. I've beat something else." Like, I don't what it is, but Johnny has some kind of thing going on. And then I ended up with KS of the lymph nodes, so I didn't have any of the awful purple blotches. You know, I saw lots of people with those purple blotches, which of course, you know, sent them underground at first, because no one wanted to be seen, but then you would see some people out there that were like, "This is me. This what's gonna potentially kill me in the end," right? So, I don't know if I want to say lucky enough or not, but I was – it was in the nymph nodes, which…

BK: That doesn't sound lucky.

JD: They were not – yeah. They were not very happy about it, because of course in the lymph nodes, it can spread anywhere. Luckily enough, I caught it soon and did some radiation treatments and that sort of stuff. And I don't think I did any chemo treatments at that time. And did tons of biopsies on those poor lymph nodes. But ended up beating that as well. So, I was like, "I don't know what it is." I've got a horseshoe [laughs] or something's going on. The good prairie blood or something – I don't know what it was. So, I'm like, "Okay, maybe I will see forty. I might see my fortieth birthday."

So, those again, probably did a bit more of the turning point for me. It's like, "Okay, I need to get more involved in the community." That time in between my partner passing away and me being – getting sick. You know, like I said, I found another partner in that time. We were getting to know each other, and that sort of stuff, and sharing our story on how, you know – becoming positive and all that kind of stuff. And he was from out in Surrey, so you know, as you mentioned before we even started, sometimes in the 'burbs of our very own Greater Vancouver, it was not an easy task, right? So, it changed my perspective again and it was, "I need to get much more involved in the community and give back." Because I'd been – I guess lucky is not the right word, but I had been fortunate enough to fight a couple battles and make it on through. So, I can share with people, you know, that it's worth the fight. It's worth fighting for because you just never know, right? I mean it may seem like it's over and that sort of stuff, with how sick you're feeling and, you know, not wanting to get out of bed and all that kind of stuff, but that's okay. If you fight through it, it's worth it.

So, that's when I got much more involved in the community. So, getting involved in Friends for Life and – Friends for Life was probably a saving grace for me at that time as well, because they offered not only… You know, the support that I thought I needed at that time. And I kind of wanted to get involved with them, because I knew they had a homecare team in case something happened, because I saw what happened, you know, to my first partner and how dreadful that was, and how nice it would have been to have someone help. I mean, I had a couple friends that helped, but they were scared too, right? It was a scary, scary time in, you know, '89. So, it's – it really opened my eyes to, "Okay, I can give back to this community and share my story, and we can sit down, and I can be supportive to other people," and all that sort of stuff. So, I got really involved at Friends for Life and then that opened other doors to, you know – like, PWA back then or Positive Living now.

And of course, my looks had changed over the time and, I mean, I see people look at me on the bus lots of times, even now, right? And I'm like, "This is me," right? Yeah so – yeah. Not long ago, actually, I was sitting at a bus stop and someone sat down beside me and he goes, "Are you a tweaker?" And I said, "Pardon me?" He said, "I'm really sorry, but…" he said "…That's a stupid thing to ask. Please forgive me for asking you that," he said, "It's just that you look so thin." And I said, "I have some health issues going on," and that sort of stuff. But it happens, right? And it's just interesting – I think it's all in how you deal with it, right? I could have been a whole lot more [laughs] – I could have been different to him, but why? Like it's – you know, he apologized. I'm sure he felt awful and that sort of stuff, not that I want to make someone feel awful, but if you're… Go ahead – look stare – I don't really – this is me. Take it or leave it. And that's kind of always been my thing. I kind of went and jumped a little ahead there.

BK: That's okay. There will be lots of time to circle back to lots of these things.

JD: Okay.

BK: But that's such a great example of the persistence of some forms of stigma around HIV. Or not even necessarily around HIV in that instance, because the guy wasn't associating you with HIV actually. You were talking about people with KS and people going underground in the '80s and into the '90s, because they didn't want to be seen with these lesions. We can be a very visually-focused group – gay men. Maybe a little bit vain in some ways. I think that must have been so challenging for a lot of gay guys.

JD: Yeah, and I agree, Ben. I think that sometimes we're our own worst enemy, which is kind of sad, right? Because we should be together and fighting a fight together, and that sort of stuff. But I think that that's partly why you guys are doing something like this is to share that there is a past that got us this far, and some of us are still [laughs] fighting on – you know, fewer and fewer of us, but there's a lot of us. Yeah, I mean I don't see – or it's probably more so that I don't notice stigma, because I really don't care what people think. [laughs] You know, and I don't usually get called stuff. I mean, I've seen people and I'm like, "Are you kidding me? You're actually saying that? You realize this is 2017?" But that's just, you know – we can be really cruel to each other, and not just in the community but as human beings as a whole, I think. It's like – yeah. So, just go back to what's happening now, I think, in my own personal health is that – which is again something I never thought of, but those old drugs – those toxic drugs that we took originally because that's all that was out there… And many people chose not to take them, which is totally their decision, right? That was a decision I made right away as I mentioned. So, they're taking their toll, I must say. The liver is – yeah, the liver is probably the biggest issue right now. I've – yeah, I've seen the transplant specialist and, you know, I mentioned I have my gastro guy that I see probably three times a year, easy, and we do all kinds of scopes and stuff, just making sure. Transplant isn't really an option for me because there – there's no guarantees that it will actually help, and I kind of decided that it just adds more – it adds more pain to the suffering because then it's all these anti-rejection drugs and all that kind of stuff, which at this point I'm not really… You know, I've had – if that's what happens, I've had a good life. I'm fine with that. Yeah, and with the liver shutting down, of course it causes all these other complications, which were the build-up of, you know, water and that sort of stuff, because you can't filter stuff properly.

So, I spent a lot of time in hospital the last couple years. It's been good this year – touch wood. I haven't had to go in there once aside from the tests of course. But I was being drained of, like, four liters of fluid once a week. Yeah, which for a tiny guy like me – that's a lot of liquid. But there's no place for it to go, right? Like it just cannot process it fast enough. Yeah, I've had – I've had lots of surgeries – hernia surgeries, mostly, and that's because of me being so thin and the muscle walls pushing on through, right? So, I've had – one, two, three – I think three different hernia surgeries, and the latest one was the abdomen, which was frightening, I must say, because I was two days away from a booked day for it and it decided that it needed fixing now. So yeah, at three in the morning, I ended up at St. Paul's. Good thing I know the surgeon. [laughs] He was not surprised. And it happened to be him on call, which was hilarious. Anyway… So yeah, it's those kind of things – it's impossible for me to gain weight. I will probably never see above 135 or something like that. If I get to 135, it's a big thing – yeah, I haven't seen that in a little while either. But you know what, that's – and it's just because, you know, the body doesn't feel like eating, and I know I have to eat, so I do. And I try to eat properly, but – and again, being alone – I live by myself now – it's tough. I have great support from friends and that sort of stuff. I mean, I'm very fortunate. I have some amazing chosen family around me, and without them I don't know what I'd do. So, I'm a very – I'm a lucky guy, if you want to call it lucky. [laughs]

BK: Lucky in certain ways. Fortunate in lots of ways. I think it's a really important thing for us to touch on, and this is why we can't just say, "1996, firm cut-off. Let's not talk about anything else." Because we do have this idea that after 1996, HIV is no longer something that's going to kill you – it's a treatable illness now, it's a chronic condition. But that's not always the case, right? Especially if you're someone who's been on certain types of drug regimens for a very long time, there's all sorts of health issues that are ongoing in the present too.

JD: Yeah. And I think a lot more of these ongoing health issues, and you're probably finding that as you're doing various interviews for this project – that you're finding that there's this common thing where we just need some time, you know. Yeah, I feel bad when I've signed up to do something that I really want to do, whatever it is – you know, whether it's a little talk somewhere or a training course somewhere, and that sort of stuff. And you're just – you can't do it, right? Because that's never been me, but people understand, I think. Not everyone in the community understands, but I think some people get it, that it did take a lot to get to where we are and we're dealing with those health issues. And some people, it's – some people, even though they know some of those amazing treatments are out there now, they wait too. So, they're probably dealing with stuff that, you know – or they have other issues, whether it's – whatever that may be. That's second to them, right? They're dealing with whatever is in front of them, whether it's – you know, it could be anything. It could be anything, so maybe they're waiting it out and maybe they're getting sick too. You don't see it nearly as much as you did when – back then, but yeah. I think more so now and even when I was in St. Paul's, it's all – it's all related to the side effects of the old – you know, the other drugs. I mean, I probably lost more friends, again, this year than I have in a long time. And most of them were heart issues and that's one of the things that's just been cropping up. And some of it has to do with age – I mean, I realize that at fifty-seven. You know, I'm not getting any younger. Yeah, approaching the six-oh. [laughs] I just said fifty-seven out loud. [laughs]

BK: But when you're told you're not going to make it past forty, every year must feel like a huge victory.

JD: Every year's a victory, Ben. Yeah, it really is, and I really think that way, too. Like, I've been so fortunate in that aspect of it. It's like, "Oh my god." For the first few years it's like, "Haha, proved you wrong, proved you wrong." And that lasted until the mid-forties. And then it's like, "Okay, don't get over-confident Johnny." And now here we are. Like you say, this is seventeen years past when I was supposed to, so it could have been any time before forty. They said I wouldn't see my fortieth birthday, so it could have been any time in there. But yeah, it's all these side-issues, and liver issues is another one I saw a couple people this year, unfortunately. And that scares me a bit, right? Because that's close to home again and I think that that brings, you know – that brings it really to light. It's like, "Oh my god, that – I've had some of those symptoms." You know, I've managed to fight on through, but you can't fight forever and the body is not going to fight forever. So yeah, there's all kinds of weird things happening, and it was a very interesting year – very interesting but sad year, too, to see that we are losing people. And it's not because of the epidemic itself, it's the side-effects of the epidemic. So, it's like a round two for us older guys that – and gals – that are still around to see it, because we've lost so many in-between that they're not here to see that things worked and how well they turned out, which is another thing I'm grateful for as I might imagine before. Yeah, I know some of it's age, some it's side-effects and that sort of stuff, and then together, probably makes it more difficult for us to fight. If it was some of this stuff and you were relatively healthy beforehand, it may be a little easier for, you know… It's just a guess – it's maybe a little easier for you to fight on through. It's tougher now, I must say.

BK: I think it's an important piece for us to capture a bit of because we can't just talk about HIV as if it's in the past. People are still getting HIV on one hand, but people are also still dealing with health issues as a result of treatment regimens. And it should still very much be a present health concern.

JD: Very much so, yeah. Very much so. And I think that some people, going along with some of what you just said – people are still getting it because they think, "Oh, it's a one pill a day thing and I'm going to be fine," right? But there's no guarantee with that, right? So, you're still playing that game that we played twenty-some years ago. There's never any guarantees with that kind of stuff, so just because we've come this far and treatments are so much better, I think there's not as much of a – there's a not as much of a – worry is the wrong word, but there's not as much of a, "Okay, well, I know it's still out there, but I can take a pill and totally be fine. I know other people that have…" Yeah. Or, you know, "I can take pill after I know that I've been exposed to someone." And I'm just not sure that we know all of the effects of those drugs either. They're still early and look how long it's taken these ones, right? Sure, they may be working now and let's hope they continue to work, but you're still kind of playing a game and it's probably not such a smart game to play. So, I agree. I think that, you know, we still need to fight on because it's still happening. And we need to take that complacency part out of it because I think that's taking away from it. I mean, I'm grateful that those things are out there – that's part of what someone like me fought for, but I don't know that I would have thought back then that this was how it would be used later on. Had I not been here, it wouldn't have mattered, but to see it – it's like, okay, I'm so grateful that we've come this far, but you know, taking that kind of stuff – not for granted, that's the wrong word – but it's there, it's available… It's still fairly new and I don't know that people think about that, because it's not as in-your-face as it was for us back then.

BK: Of course. And now with PrEP emerging as the new thing that pretty much everyone in the community is talking about, which is amazing in a lot of ways… But yeah, if you're talking about long-term effects, then maybe there should still be some questions around some of that.

JD: Right. But I don't know that people are willing to ask that question – those questions, right? So, we need to get them onside first – the people that are, you know – because that's another one... Like, PrEP and the one pill a day treatment are things that are – we dreamed of but now we need to get these people onside, whether they're on it or not. That, "Hey, we don't have all the info still, really. We're early on in this sort of stuff." It's great that they work but, you know, I think there's lots of education around it that needs to be done. And I don't know that people are as committed as they were back then to finding the solutions, because there's – it just doesn't seem like it's high on the list now, because it's there, we're good. And I think we need to get rid of that complacency or attempt to anyway, you know, and get more support on side, whether it's agencies or, you know, people. We just need people. [laughs] You know, you can't fight anything without a group of people. Strength in numbers – the old saying, right? [laughs]

BK: Absolutely. So, maybe jumping back just a little bit, you talked about this very conscious decision to be involved in all these clinical trials. Did you see that as a form of activism or advocacy or…? When we talk about community responses to the epidemic, there's a few things that come to my mind at least – street activism, like ACT UP, and then caregivers and AIDS Vancouver, and Positive Living – all these organizations that gathered around and provided support to people with HIV. Is that another type of community response?

JD: For me, personally, it was, I think. As I mentioned, some people decided not to take those, because reading all that stuff of how awful they were. It was like, "Screw that, I'll take my chances and see what happens." And I came at it from the other side thinking, "Okay, well, we're all taking our chances. [laughs] We know that this isn't going away and the only way to find something better than this awful stuff that we're taking is to try." And I think that I just wrapped my head around that was going to be my form of potentially giving back, right? And I think that there was a lot of people in that – there were a lot of people on both sides, because lots of people were scared of those drugs, but then I think there was a lot less that knew that the game's over anyway, so we thought, so why not try something else, right? It may end up helping me. It may end up prolonging, you know. Did they? Potentially. I mean, I don't – that's something I'll never really know because some of those – I'm sure that some of those drugs were some of those protease inhibitors and all that kind of stuff that were the blocking of the – some of those toxic effects and all that kind of stuff. But we didn't get those without people trying stuff that was available. I mean, I was a little worried about some of the stuff that they had no idea about, but I was committed at that point, right? So, new trial, they'd be on the phone to me. It's like, "Okay, we've got something new. We don't know a whole lot about it, but…"

BK: This is a very specific question, but were they testing multiple things at once or was it a one-at-a-time trial?

JD: Um… It was a whole variety, Ben. It was – you know. And obviously, like any trial, some of them had the little placebo, so you never knew what you were on. It could have just been mister fake or missus fake. [laughs] You know, and two others, right? And those two would have been the ones, but then again you never knew. And then sometimes it would just be the two and they were comparing which one worked better. And I think probably the reason for that is that we're all different and the virus as we know affects us all differently, so we might need more than those, and that's how they ended up with that huge doctors' list on the back of doors that you'd go on and "You need one of these, and one of those. And you need to take one of those, and they'll counteract each other…" [laughs] Right? It was such a… And it was tough for the docs too and I think it's tough for them now. I mean, I know my doc. You know, he's a great guy, but they didn't expect these things, because we weren't supposed to be here. So, all these weird things that are happening, they're like, "Oh my gosh. What do we do?" They – yeah, they weren't prepared, and I don't know that any of us were, really, because I think – again, speaking for myself – I didn't think I'd make it this long. So, did I expect to get this – to this age and have all of these complications? I think deep down, I probably didn't.

BK: No. I only asked that particular question because the big intervention that comes through in '96 is this combination of – the cocktail, right? I was just curious about that. But I really love the idea of advocating for the common good or for the community's health by – that is pretty incredible to put your body through some of those – some of those drugs would have been…

JD: I can't even imagine. You know, I think back and that sort of stuff, and I can't even imagine. But you know what, that's – again, it was conscious decision. It's not like someone tricked me into doing it or anything like that. It was something I decided right then, and it was probably because everything happened so quickly for me – losing a partner, being diagnosed – "Holy crap, I'm not going to see ten years or eleven years from now. Okay, we have to make the best of these eleven years, right? So, what can I do to hopefully prolong mine but potentially help others?" Yeah, and as you mentioned, I think that's how we ended up with all of that – you know, the big chart on the back of the wall. Like, I remember, right? [laughs] Going into a pharmacy and seeing those and on the back of doctors' walls so that they knew what they were supposed to give. Yeah, it's – but I don't know that any of that would have happened without people trying it, because you'd just be guessing that, "Hey, this might work." And we were guessing before too, but without having, you know – trying it on people that it was actually affecting. I think you get a – obviously, a better result, so…

BK: It's pretty amazing.

JD: Thank you.

BK: Thank you. Really, thank you. That's an incredible contribution. When you actually started volunteering for these trials, you weren't actually sick, right? I mean, you got your positive… Which makes it even more incredible…

JD: Yeah, I was diagnosed as HIV positive, but it still – yeah, I started before – like, early-'90s on stuff and then I got sick in the mid-'90s there with those two AIDS-related illnesses, so it was before I ended up… Which maybe potentially helped with – I mean, I don't know. There's a whole bunch of guessing that goes all the way back to the beginning, so… No, I started right away and – because that was – it was still – it was early on in the fight here. I know it had been around in the '80's, you know, which I wasn't really involved in. So, you know, I was familiar with it through some of the things we talked about, but it didn't really affect me. I think when it affected me is when I really got much more proactive about it.

BK: Thinking along these lines still, did becoming positive change your relationship to the gay community in an identifiable manner? Did that shift in any way?

JD: I honestly don't remember it shifting very much. I mean, I still went out to the bar. Yeah, I just went with friends. I mean, I met my second partner at the bar. So yeah, I don't know that it really changed that. Yeah, I can't honestly say it really made a huge difference for me. I mean, it might have for others, again, but for me I just kind of kept on doing the same thing, just knowing in the back of my mind that I had a fight to – that I needed to do as well, which was also happening. And, you know, I had a couple friends that were not very keen that I decided to do that kind of stuff because they were like, "Oh my god, what are you doing?" And I'm like… But like I said, we all make conscious decisions and that's – we just – yeah, I'd talk it through with them. It's like, "Okay, you know, if this happened to you, you may choose not to. You know, if it's actually staring you in the face, you might choose differently." So, changing me and the community – probably not so much. Yeah. I mean I – yeah, my partner and I still – you know, maybe we didn't go out as much, but I think that's like any – you know, when you're in a relationship and you go out it's like one or two times a week, it's not like every night. So yeah, and of course I'm getting older then too, so it's not – the draw for the bar isn't quite as much as it was, because I'd experienced it, and especially coming from small town to total craziness, right? So, it's like, "Okay, the bar is there. It's no… I know it's there. I can go for a drink and someone's going to be there that I know and I can chat with if I need to." So…

BK: That's an important thing to touch on too – just staying involved and immersed in the community. But it sounds like in some respects you became involved in a different way – in a different capacity. But I'm not sure if that's in terms of the gay community – is that in terms of a positive…? Positive Living at the time was probably still – was the clientele largely still gay men at the time?

JD: Well, I really wasn't involved that much with Positive Living then, it would have been Friends for Life, and it was still mostly gay men. You'd see a few ladies coming through later on, but when I first started there mid-'90s – like, '96ish – after those awful little messes, it was mostly gay men. I want to say it was all gay men, really, because that's who would have been affected the most. And I think that they knew that was a place of community and support and knowing you're not alone – all of those things that you go looking for when something big like that happens to you, whatever it is, right? And you could actually sit there and talk to someone else who was in the same shoes and potentially had PCP and made it through like you did, and all that sort of stuff. So, it was great to see. You know, I volunteered lots at the front, so it would – you know, you'd see lots of people coming in and they're nervous to come in at first and that sort of stuff, but then once they see how open and welcome it is, and that sort of stuff… You know, I could walk around the corner into the living room and it would be packed full and everyone's in there chatting and you could tell by the noise level going up, right? And it's like, oh my god, this is amazing that this community of HIV/AIDS men are willing to talk amongst each other and not be – you know, not have any of that stigma stuff to worry about or… They can be themselves, right? They're not trying to hide anything. And some of them, you could see where they kind of dropped that at the door because they had this other persona out there for whatever reason – and of course stigma probably being a big one. And when they walked through the front door, it's like – you know, the relief of, "Oh my god, there's other gay guys that are in same shoes as I am." Potentially worse, right? And they can be supportive of each other, which is a really special bond, I think.

BK: And life-giving. That would have been so essential for so many people.

JD: Yeah, and I think it leads to something that we're missing now is the social interaction, right? We just don't really have that much anymore. And we're, you know – as humans, we need that. It's a big part of, you know, who we are, and it's a big part of healing and being able to talk, and all that kind of stuff. So, I'm a big talker, as you know, [laughs] but I think it's an important thing, and now we… I think we've – there's lots of people that have turned into the little recluse, because there's no – or they don't feel comfortable going to some place and that. It's good that there still are places. I'm happy that Friends for Life is coming back online, hopefully and supposedly, and I'm glad that, you know, Positive Living has a lounge and they've opened a women's lounge, and all that kind of stuff, which I think is great. I don't know that I'm totally in agreement of separating the men and women, but I see why, because they have different issues, you know, and different ways of handling issues and that sort of stuff. So, I think it's a good thing – we just wouldn't have done that before. And I think it's still just me wrapping my mind set around, you know, "Johnny, have a look at it. That's a good thing that we have an actual women's group," and that there's a lounge there that does the same sort of thing. If you want to sit around and chat, then great, right?

And I'm glad that there's lots of services out there. I know they're getting used, it's just that I think we don't hear much about them. Like, Loving Spoonful, for instance, was a godsend for me, not last year but the year before. Yeah, I mean, 'cause like I said, I wouldn't cook on my own and I knew they're there because they've been connected to the community for so long, and they were amazing. So, everything that I'd heard – I mean, I'd never used them before and that sort of stuff – I never had a need, which again, thank goodness. But when they were there, you know, they came through. So, it's those kinds of places – I'm glad that there is places [sic] like that still around, and I know that they're getting used, because lots of them have waitlists and that sort of stuff – you know, attempting to get services. There is a need. I think we have to remember that.

BK: Continuing on this theme of support, during that period of 1988 and before the present – the mid-'90s – where were you finding support at the time after you were diagnosed, as you were going through all these clinical trials, as you were dealing with your own illnesses? Where did you find support? That's a lot to get through.

JD: Yeah, as I said, Ben, I'm very fortunate to have amazing people as my chosen family, and I did have a partner for twelve years at that time, who was also HIV positive as I mentioned. So, we were supportive of each other. I mean, you know, I had a few more issues than he did to deal with, but he was right there, like… yeah. I mean, I'll never forget, you know, three of them walking me home after they released me from – with the PCP and you're still feeling like crap, but my partner and two friends that walked me back home, to our house. And without these people… yeah, my little support network… they mean a whole lot. And you know, even my partner from that time, we still – how many years later – still talk to each other, probably once week. He lives back in Toronto, and yeah – we're like brothers now and he knows he can talk to me about anything, which is amazing. Yeah. You know, that was probably who I leaned on the most. I did chat with lots of people at Friends for Life as well, because people asked me lots of questions and they know that I'm not afraid to tell them my story, right? Like, I've never really been – I think the more you spread the word about something like that, the better. And getting it out there, I think, makes a difference, so that was probably another good support network for me.

I think my chosen family was probably – and they've all been there. I mean, I'm lucky enough to have friends that have stuck with me that are, you know… I meet one of them for coffee probably a couple times a week and he was actually a friend of my first partner who passed away – it was his best friend. So, he was, you know, obviously quite familiar and seeing what we went through, and yeah. You know, they don't like to talk about things all the time because they know that this is really close to home for them and I don't like to bring up a whole lot of things to them. We do talk about things, but I know how difficult it is and especially for him, because he saw what happened and he can see what I've been through for the last few years. And I think it really – it's bringing it back home to him and he's not – you know, we're a lot older, so he's not as tough and strong as he was back then to be the pillar. But I have lots of other people that – and he still is. I mean, he'll be there in a second for me. It's a little raw for him, again, so… And I think only because things have been happening recently. He was fine before, it's just I think, for the last few years he sees the reality of it. And I think I do too and I'm not afraid of it or anything like that, because I know that it's [laughs] – we all end up there sometime. And I've had – you know, I've been very fortunate, so… I've fought a lot, but I've been very fortunate.

BK: I don't know if this is something you can really answer but it really astounds me – the personal resiliency that so many – well, caregivers too – but long-term survivors, people who were diagnosed in the '80s have. Where did you find that strength?

JD: For me, Ben, I think – I was adopted when I was days old, so I was an only child. I spent, you know, growing up in Calgary, obviously, going to school in Calgary, but I spent every summer on the farm in Saskatchewan where all my relatives were. So, I always considered I had the best of two worlds growing up because I lived in the big city, which they all – you know, some of them craved – but I got to see the other side of what real hard work is and you know what you have to do to keep a farm going and all that kind of stuff. And I think growing up as the only child makes you – personally, it made me a whole lot stronger. Like, did I miss not having siblings? Of course. It's like, "I wish someone else would help me shovel all this damn snow." [laughs] So, in my particular case, it's probably because I was always alone and I knew I needed to be strong, right? So yeah. I lost my dad probably a couple years before I got diagnosed, so I was in my twenties, which is young. Yeah, so you know, I knew I needed to be there for my mom, but then she knew when I moved out here that this was where I needed to be too. She wasn't overly happy or supportive [laughs], but that was the day, right? I mean, it's not something I ever talked about with them or they ever knew about, because that's just not something you did. But yeah, I mean, later on I ended up taking my partner to Saskatchewan and visiting my aunts and uncles and they were all totally – couldn't care less. So, times change.

BK: Times have changed.

JD: Yeah, so I think for me personally, it was just being on my own, knowing decisions are yours, right? You decide what you have to do. And I think we're all on our own, even if you have brothers and sisters, but at least you have someone else to talk to, whereas I didn't really have that. I had cousins that I was close to that were around the same age, but it's not like I'm talking to my cousins in Saskatchewan about any of this kind of stuff, because even more so there, they never really heard much about it – it's just not something that would've affected them, even though it probably was. That was – yeah… So, I think that's what made me so resilient is that I've always been a fighter.

BK: We talked a little bit earlier about stigma. Was stigma – did you experience a lot of stigma as a positive guy, either within the community…? I guess going back to the late-'80s and into the mid-'90s – or outside of the community? Was that something that you experienced much of?

JD: Luckily enough, not so much. I think, you know, '90s probably was… I mean, my partner and I never held hands or anything like that, right? I mean, it's not like – we wanted to but we knew kind of still that stigma was out there, so why bring it? And I think the only other times would have been from elsewhere, where you're walking down Davie St. and people are heckling or calling you names, and that sort of stuff. Yeah, a boyfriend and I, after my second partner had moved to – we would walk down the street holding hands and we probably got more then, I would think, which was odd because that would have been, you know, early 90s. But still, you know – yeah, early 90s. No, sorry – early 2000s. But I think it's just that people weren't aware of seeing it in your face. [laughs] So, it was becoming much more acceptable – not all the way there by any means, but we'd certainly hear a lot more then. But really, from the community, nothing really that stands out for me. It was mostly external. Yeah, mostly it was from others.

BK: I guess people's experiences vary greatly on that issue too. We still hear people today talk about the prevalence of HIV stigma within the gay community, so that seems like another area in which you may have been somewhat fortunate.

JD: Yeah, I mean I'm not really overly comfortable about going out and stuff now. I can't honestly say why. [laughs] I guess I know that the stigma's out there and that sort of stuff, but for someone like me who doesn't really care, why does it bother me? And I know it exists in the community. As we said before, we're our own worst enemy sometimes, so – but I think it's just lack of understanding, right? It's like – I think it's – lots of people just don't realize what it took to get us where we are. And to see someone straight-on is – especially someone like me who's very skinny and who's got the sunken face and that sort of stuff, people know, right? They don't really say anything, which I appreciate, but I don't really think that if they did say anything that I wouldn't be afraid to educate them on the reasons why. You know, it doesn't – yeah. It wouldn't scare me to talk about it, it's just that I think in the community maybe it's getting – there's a bit of both.

There's a part of the community that's still supportive and knows that we're not nearly – it's not nearly over – the fight isn't nearly over, there's lots to be done. But I think the bigger part of the community is the part that thinks that potentially, you know, we've won the fight, there's not much more we can do. But there is, you know, still consequences that we can – that we still need to look at and fight for and all that kind of stuff. But I don't know that the drive is there as much as it was before. So, I think that that leads to some of the stigma within the community. So, I think poz people are supportive of other poz people, I usually find, but the rest of the community, not overly so because it doesn't – again, it doesn't affect them. And if it does, there's so many opportunities out there that it doesn't affect them nearly as bad, so you know. And they might know that these are some of the symptoms of those old drugs, but they – and they think that this may not happen to them, but we don't really know that. [laughs] You know, we have a pretty good idea that they don't, but I bet you if you ask some of the docs and that sort of stuff, honestly, I bet you they don't know what the long-term results are.

BK: I think they'd certainly be more cautious, yeah.

JD: Much more.

BK: Do you have any advice for the younger generation of gay men? We've talked a little bit about how HIV just means something different now. In terms of thinking about people who are either newly diagnosed or people who haven't been diagnosed – maybe we can think of some ways to prevent HIV still, but any advice based on your experience for this next generation of gay men?

JD: I think that they need to realize that there's a community out there. It's a supportive community, or it can be a supportive community. I mean, we're [laughs] – I think we wish we were taking over, but we know we're not. And you can look around and see that, whether it's – you know, we're fortunate here in Canada to – we still have some things to fight for, but you know, we're very fortunate here. They're not so fortunate in other places. You know, when it comes to the whole gambit of – whether it's HIV or marriage equality, or any of that kind of stuff, right? Like, what an exciting day to be in Australia when I was there – when that was announced, it was unbelievable. But, you know, even though it seems so old to me – like I, you know – I was like, “Oh my god, yeah.” It’s been like 2002 or something for us, so it’s fifteen years later and look how much they went through. But I think a key to that story is they, as a community, fought together, right? And if we have anything to learn, we need to remember those kinds of things – that strength in numbers works. It’s how the – it’s how things began, right? It’s how we got things rolling is, you know, way back at the Stonewall Riots and, you know, the Harvey Milk assassination that brought things to, “Oh my god.” And when you look at the crowds it makes it – the strength in numbers thing really does work. I think we have a bit of a divided community now and we need to work on being more cohesive together, because I think that will bring us closer to the strength in numbers. It’s – I don’t know that it will be easy, but nothing’s easy. [laughs] I think that they just need to remember that there was a past and there’s not a whole lot of people left that can share the past. They – “they,” that sounds like such a wrong word. The community needs to, you know, realize that it took a long way – it took a lot to get to where we are, and to make any advances, that’s how things work. I mean, it’s not just with HIV, it’s with anything. So, I think we just need to not have such a fractured community and work together more as a whole. How to do that is going to be a difficult one, I think, because I think it leads back to “It doesn’t affect me,” right? And “If it does affect me, it’s okay, because there’s things that can help.” So, it’s a real – it’s not going to be an easy task and it won’t be one that I’ll be interested in getting going. I mean, I’m happy to lend a voice too. I don’t know that I’m one of those ones to lead a fight anymore. [laughs]

BK: You’ve done plenty of fighting already, I think.

JD: Yeah, I kind of feel like I’m at the end of that era. [laughs] But that would be my biggest thing then is not have such a fractured community and know that we’re all still one. And I don’t know that that’s realized by some groups and some people, right?

BK: No, absolutely. Switching gears a little bit again, you talked a bit about some of the early medical responses that you saw in Vancouver – I guess maybe the callousness of your diagnosis, for instance. Can you say much about what the early medical response looked like? It probably varied a lot, I imagine.

JD: Yeah, you know, just speaking of mine and a couple other friends’ stories from that time is they were all very similar. It was, you know – it was a death sentence, so… And I think docs knew that, ‘cause they’re the ones doing the research. And I think deep down we knew that from seeing what was going on around us, right? I mean, you don’t lose friends without thinking about, “Holy crap, that could have been me.” And it was – it was callous but I don’t know that they would have had another option. I mean, it was a very – could he have handled that better? Yeah, definitely. I mean, it was kind of – especially something like that, even though, you know, in that time there was lots of people that were getting diagnosed, obviously – you know, late ‘80s is kind of when Vancouver went through a ton of it, right? A ton of the diagnosis and a ton of the going on the or not going on the toxic drugs. I wish it was handled different. I will always remember those words, which is kind of – kind of an impact on your psyche and that sort of stuff, because I don’t need to – I don’t think that you need to be told something like that. [laughs] And – but it did give me the opportunity to say, “Hey, I proved them wrong.” [laughs] So, having a number did give me that, but looking back, how do you give a number on something like that, because it could have happened the next day, right? So, it just depended on how ravished, unfortunately, your body had become by the time you decided to go in.

I mean, as I said, my partner didn't think anything was wrong, and really I kind of knew, but did I push it? No. So, you know, he found out when he was in a hospital and by then it was too late. So, I thought, "Well, I'm not going to – there's no way I'm going to leave it that late. I want to be able to know what my options are." Yeah. I think the docs were much more blunt at that time is probably the way to put it, because there were so few options – they knew, more or less, what the outcome was going to be. But I don't know that they realized that we're all different, so, you know – we're not just another HIV guy or gal, or, you know… We're our own person and you needed to be a bit more personal with that, which I'm hoping now has changed. I mean, I know I can't see my doc ever saying that to someone. Yeah, I think it's just handled so much differently now, but again that's because of all the changes over the years.

BK: Yeah. Thinking about the test in the mid- to late-'80s, I can totally understand why people would say, "Why get tested? If all they're going to tell me is I'm going to die and there's no treatment options, or very few treatment options, what's the good of knowing?"

JD: And especially if you made up your mind that you didn't want to take any of those toxic drugs, because that's all there was. And you know, I guess I just was thinking for myself at that point, obviously, because we are all our own selves. You know, "Toxic drugs might be an option. Why don't I wait and see what the result is." And then I weighed my options after I knew. But I agree. I'm sure some people had no desire. It's like, "No, I'm not taking any of those, even if I do get diagnosed positive." It's like, "…and that's all there is out there, so I'm just going to live life now the way I am." And I'm sure people knew, right? People knew whether – they didn't know for sure, because they hadn't gone through the test that seemed to take forever back then… [laughs] which was another issue. But we've come a long way in testing as well, obviously. I think of the rapid testing now – it's just like unheard of, but it took days back then.

BK: There was a period early, early on before they had viral testing lab in Vancouver where they had to send stuff back to Toronto, I think. It was a three- or four-week process.

JD: Yeah, and that's just the way things were back then.

BK: But getting tested, knowing your health status, knowing what your options were, in a lot of ways – well, you were more able to make decisions about your health as a result.

JD: Which is something that I think I always wanted to do. Like, I wanted control over where it goes from here – or as much control as I could have. Obviously, I had no control over what they were giving me if I signed up for something, but I knew that – I knew that going in. But I think I was much more informed and that's because I wanted to be. And again, I think it leads back to it all happening so quickly for me, right? It's like, "I don't want that to happen to me," you know, although it still might. Some days I feel like I'm losing my mind. [laughs] Again, that's age. [laughs] That's what I'm chalking it up to anyway.

BK: You have that excuse now.

JD: There you go. Thank you. [laughs] I have some people reminding me of that all the time now, though.

BK: Well, fifty-seven isn't so old. It really isn't.

JD: It isn't. It isn't. But again, you know, we hear all the stories of "we age quicker" – those of us who have had the virus for a long time, right? And some of those older age symptoms are things that are happening to us in our fifties and sixties. And I mentioned, you know, heart attacks and all that kind of stuff, and it's – it's a reality. And especially if it's happening to people around you and you see it happening again. It's like, okay, you know? And do they really know? My guess is probably not, but that's just a guess. Maybe they do know that it's a combination of, you know, how long you've been positive, and the heart's just not happy, just like the liver is not happy. Yeah. Did I think of that back then? No. Would it have made a difference? Probably not… No, it wouldn't have – not for me.

BK: So, healthcare provision back then – you mentioned a little bit about healthcare provision now. Is there anything that comes to mind around how we can improve healthcare around HIV in the present or prevention in the present? We talked about the prevention side of things a little bit, but as someone that's been positive for almost thirty years now, you have a lot of expertise on this matter.

JD: Yeah, I think that it's again getting the word out there, right? I think that that's a big – a big part of it. I don't know that you're – if you're looking for the clinical side of stuff or if you're looking for the personal kind of stuff…

BK: Whatever you feel you can speak to, I guess.

JD: Yeah. I mean, I'm not – I must say I'm not nearly as involved in the clinical side of stuff anymore. I mean, I read up – you know, in like Positive Living Magazine which says which trials are going on and that sort of stuff, which I might do a bit a more digging into, but it's not something that I'd rush on over to St. Paul's and sign up for. I'm glad they're still doing stuff and not all of it is just related to HIV, it's related to some of the symptom stuff too, which is good to see. On the personal level, it would be about getting the word and doing things like what you're doing, right? You know, sharing our stories and hopefully it getting out to more and more people, whoever that may be. As I said, I was fortunate enough to take part in another amazing project earlier this year and I've done lots of talks and that sort of stuff at various places. And it's – people are willing to listen and I don't know that they realize, again, how tough it was. And this kind of puts it all in a nutshell because they're not actually hearing about it, they're seeing the person that went through it, and I think it brings it home a lot more. You know, it's like, "Yeah, that's a real person that's telling me that it's okay." And you know, life goes on and never give up, which are some of my key words that I use, because I know that lots of times those are easy ways out for people, but you know, sometimes the fight is worth it and I'm living proof of that. So, I think the more we get the word out there, the better. I'm not sure how that is.

It is projects like this, obviously. And I think that most other long-term survivors that I know are quite willing to share their stories, and you've probably come across that as well, because we're at that point, I think, that we realize that there's not a whole lot of us left that saw the horrors of the late-'80s and early-'90s. So, yeah. That would be probably the key thing on sharing as much as you can with whoever the audience may be, right?

BK: There's so much power in these stories and having these stories told by the person who lived through these things – not just having them on a page, but having them told by someone like you, it's very powerful for me, and I imagine that's the case for most people who are in the viewer's position.

JD: Yeah, I think that it puts the reality in front of them, as I said. It's like, "Oh my gosh, he's the one telling us to be strong," and that sort of stuff, and "Look what he went through." It brings it all into perspective, right? And without actually it being all together, I don't know that it would have as much impact. It has impact, for sure, but it means that someone actually has to read through that transcript or – which some people, that's not something they're interested in doing, right?

BK: No. I think I'm almost out of my questions, so to speak. The one final question I have is about how the community changed as a result of the epidemic and I think we've probably touched on that throughout the interview in some respects, but is there anything else you want to add about that?

JD: Um… I think one of the big things which we did kind of touch on is that there's a lack of, you know, cohesiveness of the HIV community. Like, there's a bunch of side groups but they don't tend to do things together, and that sort of stuff, which I think might make a difference. It might be helpful to all of them and especially in this day where funding is difficult and all those kind of things, because everyone is fighting for the same buck, but we're all kind of fighting the same thing, just in different ways. So, I think that it's not quite as cohesive. I mean, it's – back then, I think it was more supportive but on a personal level. Like, I think that it was much more personal back then only because there was so many people around you or people you knew, or they knew of someone who… So, there was this connection and there wasn't all these distractions of, you know, whether it be social media or, you know, all that kind of stuff. I think that it was much more of a community kind of feel back then. I'm not entirely sure that that's there now. The groups are there but I think if they had a closer relationship with each other it might make a difference. I'm not sure – that's just a guess on my end but being that they're all fighting for the same thing, it leads me back to that strength in numbers again. It's like, if we're all fighting for the same thing and fighting for the same buck, and especially in this day and age where, you know, even the government is pulling back funding and all that kind of stuff, because it's supposedly – or close to being over, when we know it's not because these groups are there and thriving. It's just they don't have the cash to do it. So, if they are not competing for that same buck and they're working together for the same buck, they might get a better bang for that dollar, right? It wouldn't be nearly as personal, I don't think, as before because we're not losing as many people and that sort of stuff, but I think it would bring it around a bit more and make it a bit more easier for people that needed the help to know that there is all these places. Because I'm not sure that everyone knows unless they're told about them, whether it's seeing a poster somewhere – or their healthcare provider, luckily enough now, passes them on to – whether it's counselling that they need, or whatever it is, which we didn't have back then. So, there's definitely differences. Yeah, I do miss – I mean, I don't miss losing people, although this year was not great, but I miss the community aspect of it. We've kind of lost that and I think that's sad because it's mostly people that are involved that still have a connection to it. And I think we need to get those others on board, which opens it up to things like this. It's like, spread the word. It's not – there's still work to be done.

BK: Absolutely. Is there anything that you wanted to discuss that we didn't have a chance to talk about or that you thought we'd bring up that we haven't asked about?

JD: You brought up tons there, Ben. [laughs]

BK: We've covered a lot of ground. [laughs]

JD: And as I said, I'm a big talker. My poor filmmaker from earlier this year had to cut it down to four minutes and she said she had two-and-a-half hours, so I apologize if I've gone over. I always figure more is better. [laughs]

BK: Of course. Absolutely.

JD: You know what, Ben, I think we covered all aspects that I kind of thought we would. Yeah, I knew some points would be difficult. I managed to hold it together. I didn't think I would. Yeah, and I always appreciate sharing my story, so I think that being given this opportunity was – like, I jump at any of these type of opportunities if they became available, because it's – it gives the – it gives people like yourself and others that are doing this work something to work with and to share and help fight the fight. So, I totally appreciate, especially, you know, someone like you taking on something like this, because it makes a big difference 'cause there's getting to be fewer and fewer of us. So, any little bit that you can grab from anybody is one of those things that we'll hang onto a piece of history. And you never know when history repeats itself.

BK: Hopefully not anytime soon around this issue.

JD: And I don't think ever is bad but, you know, I don't know that we know, as I said, enough about some of this stuff, so… No, that was a good array of questions, my friend.

BK: [laughs] Well, I just want to say thank you. We really appreciate you taking the time to share your story with us and ultimately with the community. So, thank you so much for that.

JD: You're very welcome.

[End of interview, 2:21:18]