HIV In My Day, Interview 95

Interviewee: Kim Kinakin (KK); Interviewer: Ben Klassen (BK), William Flett (WF)
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Ben Klassen: Alright, well thanks so much for being here, Kim, and agreeing to share your story with William and I today. Really looking forward to hearing a bit about your story. Just to get started, could you tell me a little bit about your connection to Vancouver?

Kim Kinakin: I grew up in Vancouver, so born and raised Vancouver and lived in East Vancouver, North Delta, Surrey, Burnaby, East Vancouver, West Side, West End, yeah, anyway, Vancouver. Except for a couple years that I've lived in Los Angeles and a few years that I've lived in the interior of BC. I'm 49 and 40 years of those were spent in Vancouver, the first 40 years.

BK: Wow. And how about your connection to the gay community? How did you first start getting involved in the gay community or in gay life?

KK: You know, to tell you the truth, I think that I was very … I wasn't really involved in the gay life as a young person that much. I was very involved in the music community, the punk rock music community of Vancouver. Which, I mean, maybe historically it was very queer positive or had a lot of crossovers but by the time I was in that it was still *not* the most queer positive scene to be a part of. Of course, I always knew about what was going on that was gay in Vancouver because you'd go downtown to see shows and a lot of the shows would be sometimes at gay bars and some of [inaudible] that crossed over would have, you know, gay content. So I knew about gay culture as I was kind of curious about … but I never really got to be involved in the gay community as such until I started—well first volunteering at YouthCO AIDS Society when I first started, and that's cause the AIDS activism really hit my politics. I was very politically active in the punk community, and that I liked. As you possibly might imagine, the gay community was very dance music oriented, and I was very punk music oriented, and it just didn't attract me.

Having said that, I think I came out when I was about 23 and by the time I was 24 I already had HIV. So, I quickly was way more involved in the HIV/AIDS community and I really liked the HIV/AIDS community because I was meeting people who were politically active and creating a real sense of community rather than just going to a club or a bar. Having said that, going to my first gay bar when I was 23 or 22 was, you know, it was Celebrities and I was shocked to be in a room with that many people who were gay, cause otherwise it was very secretive for me. I did go to GAB youth services at the time, which is now QMUNITY, and stuff like that. You know, walked around the block a couple times before I walked in because I was like, 'I don't know if I belong here. Everyone's going to see me,' type of thing. And again, while I went and did those things, it wasn't like I met gay punk rockers.

So I quickly got involved in YouthCO AIDS society and for myself it was about how could I queer the punk rock community by being a very vocal person in the scene that was out and talking about being gay. So that was kind of my channeling, of like okay, if I don't see myself in the gay world, then how do I bring the gay world to my world and say that we can take up this space. Yeah, I looked at it that way, sort of like what can you be inspired by one part of the community and bring it to another part of your community and build something new.

I think that involvement I had in the punk rock community was a lot around all ages shows and making sure that—not making sure, but being really involved in organizing youth-oriented events that were all ages shows. Not a lot of punk rockers thought … 'Oh, well we'll just play bar shows.' So I started this co-op called the Just Quest [?] co-op which put on all ages shows in Vancouver that were not racist, not sexist, not homophobic. And that was a big part of the music community of the early 90s. And I think that's why YouthCO really liked when I started volunteering and working with them. That was one of the things they were really attracted to, that I had such involvement in youth activism.

BK: That's really interesting. I think that a lot of the folks that we've talked to, their initial community connection was with the gay community. And it sounds like that was a bigger connection for you, that music was really that first community that you found yourself really immersed in.

KK: Oh yeah, definitely. I was like 14 so that's what I did. Historically the punk community actually was very gay. It had lots of … It just, when it got very popular it became very white, suburban, male, macho kind of stuff. But early punk rock scenes were actually very, 'We're those freaks and geeks and queers' and everything. There really was an interesting history there, it just over time, voices kind of got sided. But I think there's probably a lot of gay community who came out of the gay community, but they're like, I don't really identify with the gay community. I always say there's a difference between gay actions and gay identity. And there's a lot of people who love gay sex—I'm talking as a cis man—that like to have sex with other guys and see themselves as being gay but don't actually identify with what is seen as the gay identity, of what the gay community is, which might be about what kind of music you wear, what kind of fashion you wear, and what social circles you are. I don't think my story is actually unique, I just think often when people say the word gay, they just assume that means that you're a part of the gay community, as opposed to … you sort of come at it sideways. You're a part of the gay culture but not necessarily always a part of the gay community. We all have different communities. We're not all one community, we're all multifaceted community members.

BK: Of course. Yeah, and it's partially about where we draw the boundaries of those communities. If the gay community is just this little bubble in the West End, then a lot of us aren't part of that community, right?

KK: I remember early on in the, I was very research-minded … Anyways, when I was questioning my identity there was this book, what was the book I read. I think it was called "I Thought People Like That Killed Themselves," and it was this history of different people who were gay throughout history that, their stories have gone untold. And the quote was from, I don't know, one of the kings who found out that his jester was gay. But the point of the matter was, there was some interviews in there, and there was one guy in there I totally identified with who thought, oh I'm going to come out to this gay community, and everyone else is going to be understanding all the different oppressions of the world. Just like I see racism and sexism and classism and homophobia all together intertwined. And then I got to this gay-- GAB youth services and found out that a lot of the kids there wanted to have all their same privileges and issues, and they didn't want to look at them, they just wanted to be gay and do that. And I was like, 'Oh, I have a much larger political agenda than this.' So, that's just where people are sometimes. [pause] I'm glad I found the AIDS community.

BK: Yes, because that was a very politically focused community especially back in this earlier period of the epidemic.

KK: Yeah. I mean, I wasn't positive until, what was it, 95? But, ACT UP was already existing and there was a lot of activism around, you know, whether it be trying to do more research for clinical trials or trying to get more access to medication. And it was fun and really interesting. So, people that were involved in HIV/AIDS activism, it wasn't just a desk job. It was, like, 'What are we going to do to shake the foundations of this world who is absolutely ignoring us and we're dying. So what are we going to do?' That was cool. I mean, cool not that people were dying, but cool that people were taking that action.

BK: Yeah. And it sounds like ACT UP was very much an organization that was very much focused on these intersectional levels of oppression and that would have jived with your politics.

KK: Yeah.

BK: So, do you remember when you first heard about HIV?

KK: Oh yeah, I was like a young kid. I was probably 11 or 12 or something like that. It was kind of through the media. You knew it was some kind of gay disease, it had come out as being as such. And then, of course, when I was really young, people kind of – it was a derogatory joke that gay people were dying. That homophobia was just so pervasive, myself included. I mean, I didn't think I was gay when I was a kid. There was just this whole … I wasn't so politically aware as a young child [laughs]. I was just as much of a jerk as anyone else could be. And I could totally remember, ironically, being at the pharmacy with one of my sisters and my dad, and there used to be a diet pill called AYDS, A – Y – D – S, and I remember going, 'Oh, I've got AIDS!' Like making a joke. And my sister was like, 'What is AIDS?' to my dad, or something like that, and I remember me being snarky and saying something like, 'Oh that's just a disease that gay people get and die.' I remember that, totally. And like 12 years later, it hits harder home. But over time, it became very aware that this was preventable.

God, I even did AIDS Vancouver taught a course at – I was part of this thing called Youth Core. It was a job creation program to environmentally work and built paths in some of the parks in Vancouver. And part of it was we had to get education, stuff like that, and AIDS Vancouver did a workshop on HIV and stuff. Never had it in high school, that's for sure. I don't remember anything about that. But, you know, when Rock Hudson found out that he had HIV, and later on, Freddie Mercury, and Easy E, like oh my god! Things like that really hit people at home. And then it was like, 'Why aren't we doing anything about it!' And by that point I was getting bouldered. I remember I was watching the Oscars, and everyone had these little ribbons, and I was like 'Everyone is wearing these red ribbons but no one is even saying the word AIDS!' No one would risk saying the word AIDS, and I was so upset that people were silently—that was their protest, was wearing a ribbon on stage. And that seemed like a monumental moment. Yet I was like, 'That's not enough!' I was just like, 'That's crazy!' That was probably like late 80s. It wasn't like the dialogue was when I was young and I was 12, it was new and we didn't know much. This was years later and there was still no movement. It was so ridiculous. As a person who didn't identify with the gay community, and still hadn't figured out his sexuality, even I could see how ridiculous it was. It was just homophobia. This is just homophobia, classphobia against drug addicts and people of colour as well. Like, these are the people we don't care about. The Reaganomics, the Reagan era, was such a parallel to what we see going on right now, where you just see absolute bigotry, unrestrained, and it seems like it doesn't get a mark on these people for saying those things. Punk rock music did very well because there was so much to rally against in the 80s, because of all this shit. And the punk rock community was very aware of these politics. And again, I may not have been out, but I was quite aware.

BK: And most of that awareness was, as you said, coming through the mainstream media at the time?

KK: The punk rock community had a lot of awareness about politics. So I read a lot in alternative punk magazines about some of the issues going on. And questioning that. But the mainstream, you could just see how hypocritical it was.

BK: And you said that in terms of sex education in school, that was just not part of the equation for HIV?

KK: I do not even know. Like I never saw any HIV education in my youth, no. That didn't exist. There was talk maybe when I was, when they do the sex education course in probably elementary school, Grade 7 or something like that. I would have been 12 years old, so that was '83. Nothing about HIV was really known then to be able to bring that up, and there wasn't that many follow up sex ed classes. I don't think there ever was in my school. I'm just trying to think. I don't think I learned anything about HIV until I graduated.

BK: And then in terms of, was there information out there about safe sex for example?

KK: Again, the sex education I would have got when I was a kid was just about really preliminary, like this is how a guy and a girl can have a baby. And I don't even know if it touched on birth control. It was really preliminary. It definitely did not talk about STIs. I mean HIV wasn't even on the table then in the early 80s for them to talk about, they didn't know what that was. But yeah, there was no such thing as sex ed when I grew up. By that time, I moved around a lot, I grew up in North Delta, and I didn't have any sex education that talked about STIS, or actual mentioning things besides abstinence and how to not get someone pregnant. It was definitely very puritanical or Christian-based. Don't talk about sex otherwise you're promoting sex, that type of thing. So yeah, you got education from your friends.

BK: And how about into the late 80s and 90s? Was there more information available to you, not necessarily through school but elsewhere at the time?

KK: I mean, I knew YouthCO was doing some stuff, and that's why I got involved with them. And then we basically would do shows, like punk rock shows where there would be tables with information from YouthCO and stuff like that. But other than making that space available … the band I was in was called Sparkmarker and we did a lot of all ages shows. We did a benefit show for BC PWA, and it didn't raise money, because they were trying to run it like a big gay gala and they didn't understand that punk rock kids didn't want to pay $30 at the door to see an event, they wanted to pay like 6 bucks. So they lost money. But that was the first time—I can't remember his name—one of the guys from BC PWA was like, 'Oh its cool that you're doing that! Have you ever met someone whose living with HIV?' And I was like, 'No, actually, I just thought I'd do this.' And then he's like, 'Well you know, I am!' And I remember being like 'Woah, this is the first person I've met with HIV.'

Having said that, interestingly enough, in time, going on later, one of my best friends wrote music for an AIDS song in Vancouver. This is like late 80s. And I don't know how he got involved, but it was in the paper or something. So I was like, 'Dude what was this?' And it was so interesting because he was so secretive about it, and I was putting out a record for his band, because I had a record label when I was in high school. And he didn't—he was so vague about it. I couldn't figure it out. Years later, of course, being a member of YouthCO and being positive, there was this girl named [name], and [name] was the sister of my friend [other name]. And so, I then realized that he knew that she was positive back in the day, and was trying to maintain her anonymity. And so he didn't tell me about it and here it comes full circle, where we actually hired her brother to teach at one of our YouthCO Christmas events. And I'm talking to [friend's name] like, you know, what a weird irony that that happened back in the day. Well not back in the day, it wasn't that long ago to tell you the truth. Probably 6 or 7 years earlier. And our lives come full circle in this really weird way.

But people were still not wanting to disclose people's HIV status because there was so much discrimination and fear. Death marketing around HIV and AIDS got everyone scared and so there was a lot of misinformation around being around someone who was HIV positive. Even though I was, let's say, cool with that, when I met that guy from BC PWA, I was like 'Woah, I've never met someone.' I mean the only time I'd seen that was people on TV. Or Princess Diana holding a [inaudible] with HIV, and you're like, that was risk taking because there was so much unknown in the beginning. And even though we got more information going on, you still carried that fear of the unknown with you. Because it was just so scary in the mid 80s. No one knew what it was. No one knew how you got it and all you knew was you died. It was just so bizarre; I can't quite explain how in the dark we were. Even when information came out, how hard it was to get the information out because there were so many roadblocks about talking about sex or talking about drugs. You just couldn't talk about those subjects, so how can we talk about it.

BK: And of course, even when information does start getting out it doesn't necessarily eliminate all of the fear, like you said.

KK: I think, yeah, once you've already learned the message of fear, what I call death marketing—marketing death to people and giving them fear—even though they get information, they're still at their core having to erase that message that's in their brain that they first received, which was fear-based. And fear-based marketing is just so strong, it's really hard to record over it. Because even though people know it's not right, it's still—instinctually, they're afraid. And it takes a while for people to change.

BK: So how did you first start getting involved with YouthCO?

KK: They did some show, I can't remember which one it was, and they did an outreach table and they had like a free snowboard or something like that that they were giving out at their table to get people to come to their table to get information. And, like I said, I was in a band and so very politically active and I was, by that time … It was a very small window of me coming out publicly as being gay, I was like 23, and by the time I'm 24 I have HIV. So things changed in a really small window. I was very quickly out of the closet and then back into an HIV closet. And I say back into an HIV closet because you legally couldn't cross the border as a person with HIV up until 2008. So I was a very vocal advocate for being a gay man in my music community, and that was shocking for a lot of people because bands just didn't do that. People in bands didn't do that in the 90s. And to come out about being positive, while I really liked the idea of it, I spent most of my time when I was in the band, we were touring the States all the time. So the idea of me having anything on record saying I was living with HIV that could be used against me to cross the border? I was like 'No, absolutely not' that just cannot … I could talk about it with my friends, people knew, but I wouldn't be public about that. I mean, I did some public stuff to tell you the truth. Photos are out there. But you wouldn't see my name saying I'm living with HIV, that type of thing. I was very cautious. I felt like I had to be.

When I moved to Los Angeles—I didn't move to Los Angeles until 2007, and I was like fuck, I'm going to be working done there, how is this going to happen for me to get a work visa and them not to find out. I was paranoid the while time until I got my work visa, and I was happy that they didn't do a blood test. But then I was looking at being a citizen in the states and that change didn't happen until 2008/2009. And I'd already decided to leave in 2009, but I was already looking up lawyers about how to become a permanent resident in the States. And there was no way to do it without paying somebody else to do my blood work. And I was like, 'I'm just not that type of person, man.' I can only lie so much. I really like being who I am and not having to watch what I say because I don't want to be duplicit, it just takes energy. And I was just like, 'Wow I have to fake marry a girl and then I have to have someone fake doing my blood work. And pay somebody.' I was like 'That's fucked up.' I just came from a country where it's okay for me to be positive and its okay for me to be gay and married to someone at the same time. And living in the States was like travelling back in time. I didn't like it

But anyways, your question. Sorry, I just went off on a tangent. I do this very well, I talk a lot. Your question was YouthCO, like how did I find out about YouthCO. So they were doing an event at an all-ages show and I started talking to them. And at that time YouthCO, I don't even know if they had a staff member, Chris Buchner was the first staff member, the first Chris Buchner they hired, and in the beginning, it was just run by volunteers. It was absolutely just all volunteer run and all the board members were volunteers who were doing the workshops. Then when they got funding to hire people and Christopher Buchner and Josephine were hired, I think in September of '95 they got their funding. And that's actually when I found out I was positive. And by December, Christopher decided he didn't want to do it actually, so he worked for like 3 months and they were just getting started and he was like, 'Yeah, actually, I don't want to do this.' And so I was like, 'You're hiring? I'm going to apply for this job.' It was a part time job. And boom! I had to get interviewed by every single member of the board. It was hilarious; I walked into the room, had no idea, and every single member of their board was there, and each single person had an interview question. I mean, they were completely non-hierarchical at that point. I know YouthCO's changed, but at that point is was completely non-hierarchical, completely peer-driven, youth-driven. I loved their politics, 100%, I thrived in it. But it was funny to walk into an interview and realize there was a room of people and every single one of them was asking me a question, taking turns. So that started that part of the journey for me. And Chris Buckner was ED, Josephine Stebbings was the other peer outreach worker, that's what I was in the beginning, a peer outreach worker. And then (name) was our education person, and then Ian, what's Ian's last name … Gardner, was … Ian Gardner was our education person, Todd was our volunteer coordinator. Got to remember the original … that was the original group there. So that was very interesting. We worked with the board very closely because they were basically training the staff, and so we had a really close relationship. And we know the family members of YouthCO because they were youth, so that was like Leighton Schneller, Bray Eeegs and Patrick Macintyre. Those are the ones who thought of the idea of YouthCO. They trained us for some of the stuff we needed to do, with other board members. So that was when we were on Hastings St., and then they began to move and we moved to Pender St. But that was really – we did everything together, it was a really interesting time. It was really focused that of course all the youth who had been hired wouldn't have experience working at a non-profit because we were all youth, so we were all getting trained as much as we could get trained by other youth or any other workshops. And then the dynamic changed, for all of a sudden, the staff had more knowledge than the board and then that changed the dynamics of how the organization ran, because the board felt they weren't needed. It was a really weird shift, because they were really needed because we had the staff and they were needed to train the staff, and then within a couple years the staff were the experts, and the board were doing more policy stuff, and they were kind of bored. There was this shift in the board that …

BK: I mean, that sounds like they successfully kick started an organization. Like, they trained people to such an extent that they had more expertise than they did.

KK: Yeah, they did a great job. And for myself, I was just such a … what do you call it … a working-class guy. I worked in factories and warehouses and stuff like that. So for me that really jumpstarted me to be able to work in an office space and to be advocating for youth. And I loved it because we had very strict parameters of what the policies were of the organization. It was like, if a member of our group didn't feel inspired by a project that someone proposed to us—because everyone would be like, 'Oh we want to get youth on board!' and it would be like, 'Does anyone in this room want to do this project?' And if someone did, then we would do it. But if no one was interested in a project, we would just say, 'Wow that's really nice. Thanks for the offer, but we are a youth-driven organization and that idea is not youth driven, that's an idea that came from an adult. And it's maybe a good idea, but for us where we are at, we're growing at the pace we need to grow at, and sadly we're going to say no.' Because, God, everybody wanted youth to do everything and wanted the youth voice everywhere so they could say they were representing youth. And it was like, well, we want to make sure we're taking care of our youth and we're not just overexploiting our youth unnecessarily. It had to be driven by that. I, again, flourished well in that environment. I mean, we're non-hierarchical so we all got paid the same, and there was no one that was higher or more better than any other person. And that became a challenge for people, I think, over time. And later on, these people came into the organization who didn't like that idea that an executive director should get paid the same as an average worker, something like that. I don't know. I guess I'm quite the socialist and I do well in that. And I love consensus–it was consensus-based decision making, everything was consensus-based. So if we can get consensus, we can do it. For a lot of people, that was a very frustrating organization to work with. I loved it.

BK: And what did your role look like there, in terms of the work that you were doing?

KK: It was building a youth organization for youth living with HIV, because none of that existed. So in the beginning, it was just like, 'We know of some people who are living with HIV that we're friends with,' because some of the people volunteering there were youth, but it was like, 'How do we reach the other youth who aren't here?' And they're not going anywhere else and they may not know that we exist. So my background through the punk rock world was doing graphic design and putting out records and putting out posters and putting out shows and promoting things and marketing things. So what I brought to the table, I guess, was marketing our group. And the Georgia Straight at that time was a very free newspaper; it was thick and everyone read it. And so we would advertise in the Georgia Straight, because that was a real general free magazine that went everywhere throughout the city. And then we would also advertise in Xtra! West. And then if there were youth groups that had some kind of publication, sometimes, or a pamphlet, something that they would do, we would try to … we had a budget to … so if Urban Native Youth was doing some sort of brochure thing and we would say, 'Oh, can we do a page in that to promote our thing?' Or we would also do outreach at their events, so that people … if youth were coming there, let's say, that was on Hastings and Main area at the time, like Josephine would be there and just be involved in their activities. But if one of the workers there said, 'Oh, I know this person is positive,' then they'd refer them to you, and they can have a confidential conversation somewhere else. And if that's all they did, that's all they did, but if they want to, they can come to our organization, which was kind of in the middle of the Downtown Eastside and West End. We were at like Hastings and Richards area. And then, so what we were doing was just creating a little database where we had everyone's name, and if we had a phone number for them, we had a phone number for them. Not many people had emails back then, it was pretty much phones. And then as we would have an event -- we would basically have a once a month dinner, I think it was on a Thursday or something like that, and then we would try to do a day time movie watching thing, I think on Fridays, and then we'd have retreats. Retreats were the big one; once a year we had a retreat. And so, with that database that we collected we would – If we had a phone number, then I would phone them once a week and say, 'Hey, how's it going?' In the beginning there was like 20; by the end when I left we had about 120 youth that were on that database. So it took a while to find everybody, but it was very personal and it was like, 'Hey these events are going on!' And even if they didn't come, it didn't matter, we were just checking in with them. At least once a month, ideally once a week, if there was stuff going on and depending on how busy we were with other things. And selling the retreat and I ended up telephone soliciting. You're just like, 'Hey we have this great event! It's free, you're going to go away for three days, and it's all expenses paid. You'd be able to stay there, you'd be with the youth … it was selling youth this opportunity to go away.

It was very specifically, like, we had a woman and a guy working as the outreach workers so that we at least had some gender representation. We were just very conscious of … and then we made a pamphlet that was our first pamphlet for our Positive Youth Outreach Program, which tried to aim at diversity in the photos so that people who were either comfortable having their faces in it or it was just their hands or what not. The first brochure, I'm not going to say it was the most beautiful brochure, but it was just trying to promote diversity of what positive youth looked like. And so we did as much outreach … we had our dinner events, I mean we would have guys and girls, straight and gay, from the street or privileged, all coming to our dinners. We wouldn't have more than 12 people. At the end we had 120 people in that database by the time I'd been there for 5 years. But you wouldn't get more than 12 people at an event. I'd say 8 would be our average, and if you were lucky maybe 14 or something like that. But it was a very mixed group. And looking back at it, it was a place for people to meet their partners. Whether you're gay or straight, or male or female, you're just looking for somebody you can date. So it ended up being a place where youth can meet other youth who are living with HIV and start relationships, and you kind of keep hanging out. We used to joke that we were creating a dating site was all we were doing. But having food was what we needed to do to bring people together.

We'd have retreats which would really bring people together. The retreats we did at the beginning were out in the interior at … there was a First Nations circle, it was like a First Nations healing retreat is what I would call it. I'm forgetting the name, they only lasted for a couple of years. So we did that for a couple years, and we had elders teach us interior First Nations way of healing, and they were also open to having HIV positive youth come out there. And then we did a couple on the Sunshine Coast, where we were able to find a space and still maintain a connection with a sweat lodge on the Sunshine Coast. So we were always able to maintain being able to be aware of our First Nations youth and our ability to see if we could foster that knowledge and creating that space. So that was really unique. We lucked out with that. Even finding that first healing retreat space, it was by Falkland. Now I think it's a retreat center; I think it got sold by the same people that run it. I've driven by there and I know that that's what it is now. I don't know whose involved it in. But yeah, I was a punk rock kid, I was used to like getting a van load of kids and travelling across North America and sleeping on people's floors and going to New York City. So getting a bunch of kids in a van and going to the interior for a healing retreat? Sure, we had a lot of different needs of people that were at different places in their lives. But overall, we would always stand back and say everyone was taking care of everybody. It wasn't just like the gay guys were here and the street people, you know, divided into two groups. The folks in the Downtown Eastside, and the gay guys in the West End; it wasn't like they were two separate groups. Everyone really tried, and had a really big heart for helping each other out.

And at the time, too, drugs hadn't been available like they are today. It was a crazy transition. We started and, I mean, I have clients who—when I say clients, I mean members of YouthCO and their positive youth outreach program—who they were gone. Like their families had written everything, signed off, and then these new protease inhibitors came out and they came back to life. It was insane. Not that that happened with everybody, but that happened. And it was like, 'Holy fuck man!' It was bizarre. And people still died and overdosed and everything else. I'm just saying it was a really interesting mix.

I was a part of a lot of different studies, because when I seroconverted, I actually wasn't HIV positive I was actually HIV negative. And I was seroconverting and my doctors figured that out. So I became like a lab … you know, 'We have this one kid who is in the window of conversion,' and so we're going to basically put me through every test that they possibly could. I was jumped onto every study really quickly. So I was one of the first people of that YouthCO crowd that started taking protease inhibitors. Because people were like, 'What are these things?' And I was like, 'I'm in a study for it,' because I was like, 'Wow, If I'm going to die anyways, I might as well do something for science. So I'll try these drugs.' And I dealt with them fine. So a lot of people were like, 'They're okay, Kim?' And I was like, 'Yeah, I've been taking them for 4 months now and my numbers dropped and I feel fine. There's no side effects.' Because I'd done AZT and I hated them. I was like, 'I'll never do those.' I was like, 'Fuck any of those drugs.' I did them for two weeks and was like no way. I was one of the … what do you call it … when the big AIDS conference of I think it was '95 or '96 came out, and they were presenting in Vancouver all the work about protease inhibitors, I was one of the people that was in one of those studies that was like, 'Look at the great results we're getting!'

So it was a really weird changing time. I went from being on waiting lists when I found out I was positive or found out that we did the p24 antigen test, my doctor did it because my white blood cells were so low. My test came back negative, and my doctor was like, 'Well I did the p24 antigen test because I'm concerned you had risky sex and your white blood cells are low.' And so I said, 'Yeah, okay, great, I did that. What are the results of that?' He's like, 'I can phone and find out.' And so I phone and they say it's reactive. And I was like, 'Reactive, so that's definitive?' And they're like, 'Yes.' And I'm like, 'So what's this p24 antigen test?' Because I knew they had HIV antibody tests. And he's like, 'You have HIV. Your body hasn't created the antibodies yet. You're seroconverting as we speak.' And I was floored of course. But then I was flown into all these tests and what not. And I was in waiting rooms with people who were at deaths door. So when I had to do my blood work at the IDC Centre in St Paul's, which was in the basement at the time, I remember just being in shock. Because I sat there right away and was like, 'Yeah I'm 24 and I just found out that I have HIV, 'and I'm just in shock. And the nurse just broke down and left. She just started crying and another nurse had to come and do my bloodwork because … I wasn't even that emotional, I was just in shock, because it was a death sentence. It was like … I told you, I wasn't working at YouthCO at the time. It wasn't until 3 months later I was working at YouthCO. My job at the time, they were like 'We've got to put you on long-term disability. We've got to get this for you.' I worked at this workers' co-op which was this very socialist, hippy-dippy, gay-friendly place. It was called Horizons Distributors. It's a big company now, but it used to be co-op. And they were as helpful as they can be, because they lost a lot of their friends, and they were like, 'Holy shit, this kid's positive. Wow, well what can we do for him?' And then quickly for me it just turned into, alright I'm going to work for YouthCO, and that's too bad, and see what we can do to change the world. That kind of shifted. But yeah, going to appointments and being young and 24, and my health was still fine because I was just seroconverting, but being in a room with 10 or 12 other people who were really really frail and really really sick. Because they wanted to get my tests started off so I have a baseline for everything from checking my eyes to my lungs, you name and it and we did it. I'm not pissed off about it, I was just saying it was scary. That's all.

BK: Because seeing people that were farther along in the virus' progression was like a glimpse into the future.

KK: Yeah. This is where I'm heading. It was just like, 'What? Holy, this is where I'm going to be. And then actually the first thing I did after [inaudible] was I went to the Pacific AIDS Resource Centre and I went into the library. I was a very knowledge, information kind of guy, want knowledge. I was like 'Alright, I just found out I'm HIV. I want to know what drugs are available to me and I want to know what the typical life—what the typical longevity someone could expect living with HIV with the current state of things, what kind of a lifespan could I expect for my outlook.' And at the time, for the research that I could find out, there was a few people who did … they didn't know why but the longest person at that time living with HIV documented had lived 17 years. And I was like well, I was a vegan vegetarian real health nut and I was like well if I'm good at this, maybe 15 years. Because 17 was obviously doing pretty well, but who knows what's going on with that guy genetically. So I'm just going to optimistically say 15 years. And I just held on to that 15 years, I've got 15 years to do everything I want to do. So that's how I dealt with that trauma. I just needed a timeline and I held on to it. It didn't work out so well when I hit 15 years later, actually, I had a meltdown and a bit of a personal breakdown, because I was wrong and I kept living, and didn't know how to live my life past 15 years. But that's another story.

BK: And where did you find support initially when you found out about your HIV status?

KK: I just jumped into YouthCO [laughing]. Coincidentally I found out I was positive in September and I think it was October there was the BC HIV conference, or something like that. Not the world international conference but the BC conference. And so, like I said, that would be '95, and I went to that. I wanted information, I was just like I need information I need to absorb as much information as I … I just started dating this guy and he was very supportive. And I was like, 'I need to get as much information as I can if I'm going to survive this,' that was it. And I'm not saying that that was the best way of doing it. I just jumped in with both feet and was like, 'Alright, what can we do to change this and make this better?' YouthCO had a dinner in November, I think, because I went to that conference and someone was like, 'Oh yeah, we now have this positive youth group, you should come to our dinner.' So I went to that second dinner that the Positive Youth Outreach Program ran, and then from that meeting found out that Christopher quit afterwards, and then I applied for the job. So they had two dinners and then I would help conduct the third dinner. So from September 25th, which is when I found out I was positive, by the time January 15th showed up, it was January of the next year I was working at YouthCO.

BK: That's crazy. Wow

KK: Yeah. I think that's very common. A lot of people that were hired that worked at YouthCO were just like, 'Alright, let's do it, let's change the world, man. I want to make the world a better place.' Either prevent other people from getting positive or how can we have empowering… I just didn't like the stigma, I hated that aspect of it. Other people were like I need to prevent everyone else from becoming positive and they wanted to go to schools and teach everybody. I wasn't so big on that. I really felt it was very ... I get it, why the message is powerful from someone living with HIV to do a workshop like that, but I also felt it was very exploitative of youth living with HIV. And we as a non-hierarchical organization, we all had the same amount of support systems, and that was why people who were positive who were doing this workshop deserve more support than someone who is negative doing that workshop. Because when we leave that table, we're vulnerable because we've shared something very personal to a room of at least 30 people. When we walk out, we don't have control over whether or not they're going to maintain our confidentiality or not. And that just is not cool with me.

While I started off at YouthCO as a peer outreach worker, I left after a couple years because my bang was going on tour, and we were going to Europe and stuff like that. So I quit the job, and then when I came back they had hired somebody else. And then they got more funding and I started working at AIDS Vancouver for a while with Phillip Banks. And they got that new funding, the guy that replaced me quit, and I was like, 'Okay, yeah, I'll apply for that.' And the new job was full time and it was being a program coordinator and I was like, 'Oh yeah, that's more what – I'm burnt out being a counsellor for youth, but I can do the organizational stuff.' So the last two and a half years of me working at YouthCO was me being the program coordinator and then I had two other youth that were the outreach workers. That was our team. I enjoyed being more of that keeping home base and making sure that that was held the fort. Because as expected, as I just said, both of my coworkers ended up going on stress leave because they were burnt out. We were the only youth in the whole fucking city who were identified as being positive who were going out to places, outing ourselves as being positive, to meet other youth. Which is powerful, but is also very vulnerable, and they burnt out. And so for months I was the only person working in that program, maintaining our dinners and our in-house activities because the outreach work was just too much to be out all the time, I think, and exposing yourself and being by yourself going to other organizations. It was still … it held ongoing stress. That's just my critique, that's how I looked at it.

BK: And, of course, the stigma at the time would have been pervasive, and that would have magnified that stress immensely, presumably.

KK: Oh yeah. I mean everyone wanted that story, because it had a bit of a punch to it. Like we were always being asked, 'Do you have a positive youth that will go on TV and talk about their experience?' God, everyone wanted that, and our whole thing was like, 'How do we create a safe space for our youth and not exploit them? If somebody wants to do that, we will let them know, but we will not exploit them in any way.' Having to say no was a big part of the job.

BK: So how did YouthCO change or develop over those years that you were there? It sounds like they grew a lot, for one thing.

KK: I mean it grew immensely when we got that funding, that's for sure. And then even more funding for the youth program was seen as a success, and so hence we were able to go from 2 outreach workers to 2 outreach workers and a full-time program manager. So that was great. We did a lot of advocacy work too. So again, I was a graphic designer, so I brought in, we had a graphic design team, but I brought in aspects of advertising. We would put out in different papers; we would also do a little newsletter type of thing to keep people up to date on what's going on. We did, I actually found these things, we did these zines. So in the punk rock world, we do zines all the time so we did like, anonymous or not, but our members would write stuff and come up with photos or promote… This was Bloodlines, was a documentary of positive youth in Portland, so we would screen that film. People would write things, we would photocopy them. And this was at, oh, our retreat in 2000. People would make mock-up funny advertisements from magazines that were promoting some of our drugs, and we'd be critical of them and say, 'Oh my god, that's crazy' or 'dream hospice Barbie'. It was just silly irreverent stuff. And then you know we did this one as well, that's number two. So we did things to let people document themselves and have something documenting themselves that they were a part of. So things that were empowering, like we did workshops sometimes, whatever their interests were. We had support groups as well. We would do a talking circle, that would happen. We would have the dinners; the dinners were separate, they were just food and socializing. The workshops would have a focus. We would bring a professional in to talk about a subject people were interested in and then we would have a discussion or question and answer period. Or we would do the zines, or we would do the retreats. We also had a big billboard that we did at Virgin Records, which is where Victoria's Secret is now. It used to be a Virgin Records, huge, and that's how big records were back then. We had a big display that we painted together and put up and had a campaign saying 'Am I HIV positive?' on t-shirts to bring up the question for advocacy and what not. So we still tried to make some of that activism and raising the voice in advocacy. That was good.

As we grew what happened was all the staff started becoming 30, and we all became very conscious that we were getting to be 30 and we needed to move on. And most of us, not all of us, but some of us, we were there because that's what was affecting our lives, but that wasn't necessarily our dreams. It wasn't like, 'When I grow up, I want to be HIV positive and work at a youth organization around HIV/AIDS. That's just what happened. And this is my critique: I don't know if the trips got carried out well. I don't know if we mentored well enough for new people to come in and carry on that same course. Some of those skills, to tell you the truth, aren't skills, they're personality. So you had to remember, except for the first two dinners, I was a consistent voice and so was Josephine. Josephine was there from day one, from the first dinner. So we were two stable voices for 5 years in that organization. The people that came to the organization, they might even have only come 3 or 4 times some of them. Some of them came way more than that, but I'm saying some of them might have only come 3 or 4 times in that 5 years, but when they came there, they saw the same face. There was personality, there was community that you built.

So when we aged out and moved on and did other things, and people were living with HIV now and so they didn't really need to get support because they weren't concerned about dying. They just were like, 'I will take my pills now and I'm not worried about dying, I'm just going to take my pills and everything's going to be okay,' that type of thing. It was a really big shift from '95 to 2000 in those 5 years that I worked there. Not just me aging out, there were just so many other things changing. We went from incredible need for activism and voices and education and what not to, 'I'm exhausted, I now have pills that I can take, and I just want to step back for a while. I'm going to live a bit longer now.' And I think some of that changed what people's needs were, or maybe the attitudes around it changed. I mean, that was a huge revolution, to all of a sudden have drugs available. That were working! There were drugs the whole time, and they were horrible, and they weren't working and they had crazy side effects. And then we had drugs that had weird side effects like the protease inhibitors, and then drugs got better. And it was like wow, like this is really easy, you can take a couple pills a day. And then they were talking about drug vacations, which wasn't a good idea, but at the time it was like, 'Let's see what that's like.' All of a sudden it wasn't such a big deal. Everyone started taking drug cocktails. Before that, not everyone would take a drug cocktail. It was like, 'Why would I want to get sick and take these pills? They make you feel gross all the time.' The drugs were horrible. I took AZT for 2 weeks and I was like, never again, that was horrible.

A lot of things changed, and our executive director left. I left. We had a couple changes in the education department over the years. So I think its dynamic changed. And then oddly enough, I don't think there was that many gay men that were working there. It was kind of fun for a while there. It was like everyone that worked there seemed to be real political lesbians, which is not a diss to political lesbians, but the diversity of the organization became a very different aspect. And I'm not too sure if some of the guys were like, 'Is this organization for me?' Because it was shifting to reflect the staff hiring and who they could hire. They had trouble finding gay men that wanted to work in the positive youth outreach program. Like completely, they just couldn't find people that wanted to do it. They asked me to come back years later. They're like, 'You want to come back?' and I was like 'No.' They just had trouble. They could find gay guys, but finding gay positive men that wanted to do that job, for some reason, it wasn't as easy as they thought, I guess. I don't know. I don't know what the dynamic was. It absolutely changed, some things for better and some things – it's a completely different ball now. It changed so many times since I left. I can't even critique—I can only critique what it was like to leave and what it would have looked like when I left. I mean, I don't know, everyone's trying their best and doing the best they can. So that's cool. I'm not a youth anymore, I can't critique it.

BK: I'm a little bit curious about, you mentioned the diversity of folks from different backgrounds and walks of life and different moments in their life, and how YouthCO in those early years navigated that. Because I'm just thinking, like, early ASOs that started off much earlier in the 80s typically were working with a much less diverse community initially. You know, mostly with gay men. So, yeah, I'm just curious about any thoughts you have around how you navigated that.

KK: Part of the portfolio at the time, I don't know what happened to it after, was diversity. It was like, 'How diverse is our organization and what are we doing to maintain diversity? How is hiring looking at being diverse?' So that was always our subject, it was like, 'How un-diverse are we and how much better diverse could we be? Where can we hire people in positions of power so that we create—it was non-hierarchical—a sense that everyone could be present and give them the skills to bring them up there. So we had a lot of, I would say, when I worked there a lot of male-female equilibrium. A lot of people of colour working in the organization and volunteering with the organization. I can't say that we always had as great a representation of people with street experience. That was a mandate, believe me that was in there, we knew that, but maintaining that was always a struggle. And I think that was a harder position to fill. And understandably, people's life circumstances are a lot more challenging than just volunteering on a board when you're trying to figure out where the roof over your head is and where the food on the table is. So we tried to make sure that we weren't being too happy about ourselves, but at the same time, people have to be open to taking on that criticism and sitting in that uncomfortable position of saying, ‘Wow, we’d like to think we’re diverse but are we? So how can we network with all these different organizations?’ I mean, we were all about networking and partnering with the Block AIDS Network, whether that was with doing stuff with Urban Native Youth, or Healing Our Spirit, or there was a group called ASIA at the time. We were partnering as much as we could with organizations. So that was critical for us to be looking at diversity, like, ‘If we can’t reflect it how can we support those who are meeting those needs so we can better collectively meet those challenges?’ I think there was effort. I’m not one to say whether or not we succeeded, I’m a white middle class kind of guy. But I think we definitely had that on our radar. We weren’t blind to it when we looked at our group and said this is too many gay white men, or something like that. It was ironic later on, 5 years, there were very few gay men and it was all white lesbians and I was like, this is the funniest turnover, it went from one to another. So I don’t know how that shift happened or how that goes on but it shifted. It happens.

BK: And what was your experience with the medical system during those earlier years? Like you talked a little bit about volunteering in different trials, but also just your interactions with doctors more specifically, or health care providers?

KK: Yeah, I mean, right away I was in the Centre for Excellence because, I told you, I was in that window of opportunity. So I was thrown into that really quickly. So I just did that. My doctor was a specialist, Dr. Conway, he worked with Julio Montaner and then they had some disagreement and left. But in the beginning, it was like Julio and Dr. Conway. And he did lots of bloodwork with me. Man, I can’t even tell you, they just wanted samples of my blood all the time, because they wanted to be able to monitor this period of me seroconverting and what not. I don’t know. I was working part time, I lived downtown, I was able to do all that stuff because I worked a good job, or I was paid to be HIV positive so that was kind of easy to do. Because that was my job. If I worked in a different organization where I was in the closet about my status, that would have been a lot harder to do. I probably have a weird experience with that. It was easy, it was convenient, and it was very well supported. Working at YouthCO was the first organization I worked at where I was fully embraced as a person living with HIV, fully embraced as a person who identified as a sexual minority. And not just supported but nurtured. That was a very empowering … again as a working-class kid who worked in factories and warehouses, that was a very empowering process. And so to have to go through this really scary thing around HIV, and then not only am I going through these tests and doing all this stuff, I’m becoming a very experienced advocate for folks living with HIV while I’m doing this. Like this is my job. It normalized it a lot for me.

I mean, it got to a good point where I was good with being vocal and strong about … sometimes my specialists would have interns from other places around the world who were coming in to train at the Centre For Excellence to get some of their experience and stuff like that. Sometimes I would be very vocal about that I didn’t like some of their prejudices or stigmas that they brought to the table from wherever they came from. God, I remember one doctor who was having to see me before Dr Conway saw me who started grilling me about my safe sex practices and if I was having safe sex with everybody. And I was just like, ‘I didn’t come here for you to lecture me about safe sex, I came here for you to actually give me my test results around how my HIV and my viral load is doing. And I would really like if you kept your moralization about what my sexual habits are and whether or not I’m using a condom to yourself right now. Because I don’t need that, that's not why I'm here.' So I was able to be a vocal person that way because I already had that background in support. Like, this is my job, I get to do this. And then I would just tell Dr. Conway, like, that person never again. They don't get to see me, they are … they're not an asshole, I'm not mad, I'm not crazy mad, I'm just like, 'yeah, that's not cool.' And that's their learning process, right? To have me stand up and say, 'That's not your job right now.' But I recognized in that journey of having to go through as a patient and an advocate that sometimes you see a doctor and they're really homophobic and they might be a professional and they might be working in HIV and AIDS, but they still have their own fucking issues of discriminating against you based on their own moral beliefs, or something like that, that they haven't gotten over. And so sometimes you have to have a bit of a standoff with the doctor that you're seeing and say, 'I'm going to see another doctor. You're not the person for me.' Yeah, you had to be ... again, I think I was already political so back in that time it just fell in my comfort zone to be able to speak up around that stuff. But I'm happy that I got to speak, and I learned a lot about the value of people with lived experience being at the table and having their voices heard. I think that's a really really unique thing in the HIV world. I mentioned to you I think maybe briefly in passing – now living with cancer and kidney disease, I have to sit with some of these professionals in that world and they are not used to patients being such advocates for their own health. And I'm shocked sometimes how much I have to advocate for myself because they're so used to people just sitting back and just taking what the doctors give them as law. And I'm like, 'No, this is what I'm comfortable with,' and they're shocked. But for me, again since I was 24, I'm like, 'No, no, I'm an expert on youth living with HIV so you have to listen to me!' So that gave me some confidence.

BK: Yeah, just trying to get a picture of some of the larger context here. How was the government responding in the mid 90s?

KK: Well it made a slight shift. I mean, in the early mid-90s, there was still lots of advocacy about making it so that we can have access to drugs and have access to ... Pushing forward for drugs that were in stage 3 clinical trials and getting people who needed them now to have access to them now. There were still, like, when you had an AIDS conference there were all these advocates that would come in and shame the Prime Minister or shame the Health Minister for the lack of action. Again, that was just kind of expected. It was expected that there would be this big… A part of YouthCO organizations were, 'Oh, we do education to theatre too.' So there was a lot of creative people who were like, 'Alright were going do this big protest. It was very fun and cool that way and it worked. And then there wasn't anything to get so upset about anymore because all of a sudden, people had access to drugs and the drugs were working. Before, when the drugs weren't working, it was like, 'No, not enough! Not enough! Not enough! Not enough! Not enough!' How lucky we were that there were these advancements in HIV to be able to manage that. Going back to cancer again, holy fuck, man chemotherapy is horrible! It absolutely is like all the horribleness of AZT that I only did for 2 weeks, that I had to do for 10 months. And I was like this is horrible. And cancers been around a lot longer. Wow, how lucky we were with HIV that we had all these advancements. In the beginning, it was like, 'Oh you have all these drugs available? Well that doesn't really make sense. You just made us 3 drugs, so we had to take 6 – oh my god, protease inhibitors, in the beginning they were so big they were much better than AZT, but I'd have to take 18 pills of one drug a day. And they were refrigerated. So 6 in the morning, 6 in the afternoon, 6 at night. They had to be refrigerated. They'd last about your day, your pocket or sitting out somewhere. The rest were in bottles, a huge bag of drugs in your fridge. Then that was only one of three drugs. So then you have the other drugs you needed to take, so I was taking like 24 pills a day. It was a crazy amount of drugs. Refrigerated the ones I was taking because it was a soft gel cap, that was the study I was on.

So when my band went on tour and we were going in Europe, I was like, ‘I am not taking all these drugs. Definitely not across the American border, and two, I’m not going to Europe with all these drugs. We’re going for two months, I can’t possibly refrigerate this in a small shitty band. Like punk rocks shows, it’s just not going to happen. But this gives you an idea of how important it was, in that time frame, that the testing of drugs worked, because it was still so new. Dr. Conway said to me, he would organize it that any major city I wanted to tour with, I could go to the hospital and pick up my drugs until I got to the next hospital. So he could organize it for me to get my drugs in London or Rome or Munich, whatever the big cities were. He could organize that for me to pick up what I needed to get to the next one. And I was like, ‘I’m going on tour and the focus is just getting to the next show, and I really do not need to find the hospital and pick up the drugs. That sounds nice in science, but in the real-world terms of what I’m going to be doing, I’m not going to have the time to do that. This is a punk rock band not making any money. I just want to see the world before I die, tour and travel Europe with this band I’m in. And nothing’s going to stop that.’ I’d rather do that than just be taking my drugs, because that was my dream. So I’m glad I did it, but I was very honoured to be given that option. Going, ‘Okay wow, this is really important to these researchers that I stay on this pill. They’ll do anything to make me stay on this trial.’ But, you know, I didn’t. I took some other drugs I ended up doing well for a while. They were kind of substandard drugs, they worked for a while, so it was okay.

BK: And you didn’t have any major side effects on any of those early protease inhibitors?

KK: When my boyfriend ate my ass, he said it tasted like a gasoline tank. So yeah, there was some weird funny side effects like that. And I would burp up a lot of chemicals and stuff like that. But I didn’t have of side effects like … I mean, I ended up getting some lipodystrophy but it wasn’t actually from the protease inhibitors, it ended up being from the d4t, I think it was, that I was taking. They ended up finding out it was a combination of the drugs that started creating some of that stuff. It wasn’t so pronounced with me at the time. I mean, it was hard to know because I was also 24, very baby-faced, and by the time I was 30, I was taking all these drugs. And it was hard to know, is this me just aging and becoming an older person who’s in a mature body, and losing the baby face? Or are these the side effects of the drugs? You don’t have that perspective. When you’re an adult you’re just like, ‘This is what I look like. I’ve changed.’ But when you’re young and your body is still changing, you don’t know if it’s genetically changing or if it’s changing because of the drugs. So there’s a lot more questions when you’re young and taking all these drugs, that’s for sure. And for that matter, I’m 49 years old and I found out I was positive when I was 24. So I’ve spent half my life living with HIV now, and the drugs haven’t been around long enough for us to know what is it like for somebody to be actually, in real life, taking these drugs, and what kind of impact does it have on your system? And so we know people are living longer, but we really don’t know the long-term effects of these drugs on people. And so, in a way I’m always a guinea pig. My life on HIV is a guinea pig.

BK: You mentioned some aspects of HIV activism. And I guess a lot of the work you were doing at YouthCO can be conceived as activist in nature in a lot of different ways. But were you involved explicitly in any kind of HIV activism work beyond what you already alluded to?

KK: There was some really preliminary stuff that happened at the events. We got to hold placards for Jean Chrétien about acting on making drugs more available. But I think the more fun activism probably happened before that. And I had this weird role where I just started working at YouthCO, and then we had the international AIDS conference and this was my opportunity to be networking with a lot of interesting people, and trying to get an idea of what it is that my job is. So I felt very overwhelmed to quickly be in a position where I'm supposed to be gleaning all this information. There was activism happening, again, we did some simple parts. They were easy. But I never did anything radical, not that I would say. I think I was really trying to fill in my new shoes and trying to figure out what it is that I'm supposed to be doing as a new hire for a new organization. What are youth living with HIV supposed to be doing at a conference like this, to bring back to our youth talking about what came out of that workshop? So I think I was a bit overwhelmed with all the different … being pulled in a lot of different directions at that time. And again, after that there really wasn't much activism because drugs were available. And so all of a sudden, it didn't have that edge to it anymore.

BK: Yeah, it makes sense. So we have some questions that we ask closer to the end of interviews, but William, did you want to jump in and ask anything at this point?

William Flett: Well, I don't have the interview questions handy, so that's all on you. But the one thing that is sticking out, and I'm not sure how useful it would be, but earlier when you were mentioning zines, did you flash an actual zines back from old YouthCO days?

KK: Yeah, that's what I have, I have two of them.

WF: Because that seems like it would be useful in some way or another to be on some level of record.

KK: Oh totally. You're more than welcome to have me scan those or what not, because that's definitely a part of the history.

WF: Yeah, because for all effects and purposes, if I were not to out the history of this project too much, a lot of this project started basically from a small magazine that then found us ---. There's not enough of this existing in record. Also that seems like, I can't remember what the… Angles, I think it was called, the magazine was called.

KK: That was the gay magazine at the time before Xtra! West came out.

WF: Yeah, and that reminded me of that. So I think it'd be useful to have some level of documentation. Although I'm not sure how it would become useful, other than like we'll --- the documentation and then think of what to do with it later, which is possibly also questionable on the ethics standpoint. But I think it would be a waste to have that just be another thing that disappears.

KK: I don’t know how much you’ve known about—I’ve already had this conversation with Ben—I’m actually creating an archive of my personal archive at SFU Libraries Special Collections that’s basically documenting my life as a teenager until now. With all my creative work in music but also as a queer person and obviously living with HIV. So I’m going to be donating all my materials to SFU, so it will always be available through SFU as well, under a stream of my collection of stuff. Whether it be those zines or some of the other old paperwork I’ve kept. Oddly enough, I have my original drug request for AZT, I have my original HPC [?] station study patient, the consent form that I had to … I don’t know why I kept all this shit, but I do. This is my favourite—because at the time you had to prove you were HIV positive to get a lot of services, I still have a doctor’s note from my doctor (name) it says, ‘Mr. Kinakin is HIV positive. Please assist him as best as necessary.’ So I can use that when I was going to organizations to prove that I was living with HIV. So you were talking about activism. This was one of the postcards, it was like ‘killing times, killing people, AIDS action now.’ And it was a little postcard and stuff like that. So I have a bunch of these weird little things that I will be donating. Even the 1994 Positive Living manual and their bylaws and constitution of ‘91. They created a Living Positive magazine early on, before they changed their name. And there’s a bunch of photos of myself and other youth, we wanted to make sure youth were represented in it. So that stuff will all be donated to SFU and you guys will be able to have access to it once it’s there.

So yeah, I like collecting stuff. I’ve always, as a punk rocker kid, learned that if you don’t document your own scene, no one else will. Because punk rock music in the 80s was really not cool, so people weren’t documenting it and preserving it in libraries. Now people want to do that, but a lot of it got thrown away. If you ever find this magazine, though, this is from San Francisco. It’s called Diseased Pariah News, and this is the funniest magazine in the world. They did this whole thing on Barbie on the back covers with KS Ken and AIDS Barbie’s Dream Hospice. And no one would ever sue them because they were a bunch of people living with HIV. And they were so scandalous and irreverent, and they were just hilarious. They inspired our zines because we’re like, ‘this is what we can do.’ It’s like, no one is going to sue a bunch of youth living with HIV because they’re going look horrible if they do. So we can do whatever we want, because an organization that’s going to sue a bunch of HIV positive youth for critiquing their protease inhibitors is going to look like a real asshole in the end. So one of our ads and -- I don’t know if I have all the zines we created, I know we created at least 2. But there’s one hilarious one that was like, the drug, it was one of the protease inhibitors, and they had an ad with people climbing rocks out in, I don’t know, the Grand Canyon or something like that. And there’s a guy helping another guy out and it’s like, whatever the drug name is, ‘Enjoy the freedom.’ And one of our members added these little thought bubbles like, ‘Hey Frank, how’s it going?’ And then the guy below says, ‘I just shit my pants.’ Because it was making a joke that these drugs have lots of crazy side effects. It wasn’t all freedom, like some of these drugs were keeping people alive but they had really crazy side effects. The drugs we’re using now are way better. But you weren’t supposed to critique them because they were giving you them, but we were like, ‘Fuck it, we can do that. Are they going to sue a bunch of youth living with HIV? I don’t think.’ So they didn’t [laughing]. So that’s an aside from what we were talking about.

BK: No, I mean, I think it's such interesting … so many interesting historical pieces there and the historian in me is so so happy to see that that's all going into a collection somewhere. It's so so valuable.

KK: I'm really happy I reached out to them and they were interested, and to take part in this as well.

BK: Of course. William, if other questions come up, don't hesitate to jump in, but I'm going to just move on to the last couple questions here. So I guess, since '95, how has your perspective on HIV changed looking towards the present?

KK: Well, presently, it's had a huge transition, and that is that obviously being diagnosed with multiple myeloma, which is a blood cancer. One of the things that I have learnt in my new journey is that in our speciality aspect of researching and studying health issues, is that we compartmentalize them and we don't integrate the research on them. So in my journey with cancer, which is a blood cancer, and of course I have a blood virus. There's no research to say whether or not there's a correlation between me being positive or my drugs that I take having any effect on the fact that my cancer has been really—even though it's not considered an aggressive strain, it has been aggressively attacking me. So that information we have around other health issues in HIV just doesn't exist, because everyone is focused on their specific vision and viewpoint. Once in a while there's a crossover and the only research that I've been able to find about the effects of HIV and multiple myeloma is a study that has 3 cases. And the study says there's not enough data for us to actually do this, we need more research, because these three people all progressed really quickly with this cancer, but we don't know if there is a correlation between HIV or if there is correlation between the dugs they're taking or not. You know, we just don't know, because people with HIV are excluded from cancer trials and people with cancer are excluded from HIV trials. And so I'm in this crazy situation where my cancer is quite progressed and its harshly affecting my kidney, but my kidney only operates at 20%. And 20 years ago, I wouldn't be able to get a new kidney because I have HIV. I'm allowed to get a kidney now with HIV, but I'm not allowed to get a kidney now because of this cancer. And so my progress with this cancer is limited because it's already taken out my kidney. When I say taken out, I still have 20% left, but almost taken out my kidney.

And so my biggest focus around HIV now is it's not just getting old with HIV in the sense of just what aging looks like, it's more like, what's the complications of other health issues and how are they magnified by HIV and/or the drugs that we've been taking for 25 years? That information no one can give me, because there's just no data on it. And that frustrates me. I expect that to be falling mostly on the world of HIV, because HIV has had so many progresses that they have space to focus on it. Whereas cancer is overwhelmed, their advancements have – I mean, there's money in cancer, but they haven't made as many advancements that are nearly as close to the advancements we've had in HIV. It is so archaic, chemotherapy. I'm not doing it again, that's why I'm doing all this stuff because they're going to recommend it one more time, and I'm saying no. I'm not going do it because it's just too horrible. I just don't see my quality of life being well. So doing this archive project for SFU or even doing this interview with you guys, part of this is like, 'Alright, it's time to share my voie, because there's not much time left on my clock. There could be if we had different insights, but there isn't. And much the same, there was at one point with Hepatitis C that people couldn't get a new liver because they had hepatitis. And if they had a new liver, maybe they could live longer. It's getting me the treatments that are going to make the biggest changes, because the organ transplants aren't going to be available. So the new treatments for cancer aren't enough around the corner to make a change on my life, because the treatments that they need for my cancer require me to have a good kidney, and my kidney has to be above 40%, and it's at like 23%.

I mean, I'm happy. When I was 24, I thought I was going to live 14 years, so I've already lived 10 more years than that. On that perspective, I'm grateful, I'm lucky. But having said that, we still have a lot of work to do around what does HIV look like for people who are living with HIV and taking these drugs? Now we have a lot of things to prevent people from getting HIV, which is awesome I'm really happy that people can take PrEP and prevent themselves from HIV. But we still don't know what the long-term effects are of a person who is negative taking PrEP for 20 years. Will they, I mean, they'll probably just stop taking them if they have problems. But when it comes to HIV, people living with HIV, and having this, it's not just that, 'oh I have cancer and now it's affecting my kidneys.' It's like, I have 3 illnesses and I can only take certain drugs because each drug interacts with the other drugs for the other issues that I take. And so I am so precarious in what drugs I can even take to begin with. Because I have such a complex case that I have to have a cancer specialist, a kidney specialist, and an HIV specialist, and they're all like, 'We don't know, just looks like on paper what we think would be the best.' But there's not much research or evidence for them to go by. We're just kind of … and if I'm lucky, I'll get some more time, but I have to be realistic. It could change really quickly. And if the cancer comes back, it's just going to go up to my kidney. It's not that it's a kidney cancer, by the way, it's just a blood cancer, and it toxified my blood and my kidney can't keep up with all the toxins in my blood, so it toxified my kidney. So once the cancer gets back again it's going to affect my kidney and or affect my bones.

It's crazy, the doctors who were looking at the problems with my kidney were like, 'Oh it's probably because of your HIV drugs. We'll change your HIV drugs.' And in the 6 months before I got diagnosed with cancer everyone just went, 'Oh, it's your HIV drugs. We just need to figure out what's going on with your HIV drugs.' No one thought to think it could be something beyond HIV because they were so blinded by the fact that I was living with HIV. This must be about my HIV drugs. It's like, wow, what a difference it would have made, possibly, who knows maybe not, if we had 6 months ago also said, 'Oh, I don't fit the age bracket of someone who would be considered a target for this cancer.' Normally it would be someone who's 65. But who's to say that because of me taking these HIV drugs that the target needs to be actually lower for people living with HIV, so that we're looking for this cancer for people at a younger age. Because I got lost in the blind spot, everyone's looking here and looking here but there's these two blind spots, and I totally fell through the cracks. And I work in the HIV/AIDS world! It's crazy, not only was I working in HIV/AIDS, I knew all the specialists that were HIV specialists that were being consulted but no one was thinking cancer. And I think that's what we need to start doing, is not just thinking cancer but thinking what else can it be besides HIV? Like if someone's been living with HIV for this long and that's going to become the new norm what are the other health issues we need to be looking at that are going to be compounding their health? And being able to look at that and be a bit aware of it ahead of time. Because I'm not the only one, and I won't be the last one either. So that's definitely a new insight I have had. Also the fact that I worked for two HIV/AIDS organizations and neither of them had long term disability plans for me. So I didn't even get to go on the long term disability. I had to go and apply for disability through the Canadian Pension Plan. And when you're dealing with a cancer diagnosis and having to go through chemo and jump through those hoops, I really fucking would have loved to have had my work, as HIV/AIDS organizations, to have had long-term disability so that I didn't have to do that. And so that was sort of my two insights or critiques about the HIV/AIDS world. Having people living with HIV falling through the cracks.

BK: Thank you for sharing that with me. And I guess these are issues that get missed in a lot of the end of AIDS or end of HIV messaging that we see out there. There's a lot of issues that still need addressing, in terms of the long-term survivors especially.

KK: Yeah, and that voice will get a lot smaller as people … not saying that people say this or that I think this, but there's a part where you're like, 'I'm just happy to be alive. I'm alive longer than I expected to be. I'm not going to complain.' No, no we still need to advocate for ourselves for sure.

BK: Absolutely. And I guess just in terms of any words of wisdom to impart to folks who maybe didn't live through this period of the epidemic, do you have any advice for people who might be newly diagnosed today or younger folks in our communities who just didn't live through this time?

KK: Oh, I guess a part of me … I'm just trying to think of how some of the issues that I have seen, some of the advancements that we had in HIV happened with people who were dying. They were raising their voice and being activists because these were the last months of life that they had left. And to, I guess, value that some of the changes that we take for granted now are because people's lives were at risk. And they didn't want to be on the front lines and be screaming, they had no choice. This is how dire that was and that's hard to imagine how … I really can't think of any other … I mean, I know that there's talks about discrimination around the pandemic going on now, but people really didn't give a shit about gay people and drug users and people of colour from other countries or from Haiti. It was so not important until it started affecting other people. And this comment that I'm making isn't me making this up, this was a term that was: when innocent victims were being affected by HIV. That was the term that was used. Innocent victims. And that other people with HIV, by default then, weren't innocent and that they deserved it. But it was the innocent victims, the person that wasn't gay, wasn't a drug user, was white middle-class went for a blood transfusion, they were an innocent victim. And how powerful words are when we forget how we talk about things like that. Whether that be people saying, 'Oh, they're HIV.' Rather than saying 'They're living with HIV.' And not identifying with disease so that you are the disease, but that it's something that you're living with. The power of our language and our words is still very—we still hold these words. And, 'Oh, are they HIV?' And it's like, no, no one is the fucking virus, they just have the virus and they're living with it. And having humour with it as well.

But with all the advancements that we did have, for me I was always very aware when that happened that the drug companies, they were happy to have their drugs be pushed through quicker so that they could have HIV drugs accessible at an earlier time. They didn't have to wait an extra 20 years of research before it went public. We advocated to have it now, and the government said, ‘Okay, let’s make it available.’ And those drug companies, as far as I’m concerned, are still responsible with all the money they fucking make to be doing the research to be able to affect why someone like me living with HIV has other health complications. And why aren’t they footing the bill for that? Because they would have had to foot the bill if we didn’t actually make it available, that they could jump the queue and make those drugs available for us. Sure, we got something out of it. People are living longer. But we also lost something out of it, and that is a responsibility for the drug companies to be able to have more research and maintain the research once those drugs became public to be able to still study and find out what are the long term effects of people living with these drugs. Because I’m still a guinea pig and they’re not responsible for anything. I’m not saying I want to sue them, but I’d like to at least have some research, that would be nice. I’m not forgetting about that piece

BK: Yeah, I think that the HIV activist movement was at times aligned with pharmaceutical companies in terms of getting these drugs approved, but also very much—think of ACT UP in New York, especially, how vocal they were about making treatments affordable and about ensuring there was access to universal health care in the States. The tension between activists and pharmaceuticals, it’s been going on for a long time. But yeah, your point about, they should be doing this research, I agree

KK: Yeah, they got the money. They’re making well but we have to advocate for it, and we have to push for it and so hopefully we don’t … I know there’s a lot of battles that we need to fight, and we just got through a huge battle getting Truvada being able to be available for people who are HIV negative to prevent themselves from getting HIV positive. And I’m really happy about that, but that doesn’t mean that we forget about the people who are living with HIV. I feel, I worry now HIV/AIDS organizations are just—its pushing Canada more so than my experience in the States—are so focused on following where the government funding is going that they follow the funding around harm reduction. And harm reduction is a part of how we look at education around HIV and AIDS, but it’s been, I think, re-appropriated to just mean needles and pipes and around drug use, and it to me is only one part of the education aspect of it. And there’s so much money obviously with fentanyl going on that AIDS organization are just being focused on harm reduction aspects, as that’s where all the funding comes from. And we’re forgetting that people are still living with HIV and aren’t getting the support needs or the research needs. There’s so many aspects of what people living with HIV still need. There’s education, there’s support, there’s testing obviously, and there’s advocacy. And we focus so much not just on education and harm reduction, but harm reduction *only* of education. That’s still where all the money is being channelled into, one branch of one of the pillars of how we’re supposed to be approaching HIV. That we don’t realize the table is so tilted on harm reduction. I love harm reduction! I’m a drug user! I’ve utilized harm reduction. I have no problem with harm reduction, but it can’t all just be harm reduction. I really am worried that AIDS service organizations are just following the funding and not actually looking to see how they can be more better at reaching out to the people who need those other services around support, around testing, around advocacy that have been lost, because we’ve just been so focused on harm reduction. And again, not belittling harm reduction, but not forgetting about the other needs in that journey.

BK: And simultaneously, we've also seen organizations that cater more to some of those support needs disappear in recent months, so I think that just speaks to the necessity of other organizations existing, organizations filling that gap.

KK: And in Canada, a critique I've heard other people say too is we rely so much on government funding. Well that's why organizations do fundraising, so that you can do the work that the government isn't giving you money for and focus on getting money to do what you need to do as an organization. Not just the numbers that the government's always going to focus on, what's the crisis of the moment. But we know there's more needs than just the crisis. We have multiple crises. So how do we look at other ways of cultivating money? To be able to do the work that we want to do rather than chasing the funder's needs. How do we start meeting where we want our money coming in and where we want it to go? And fundraising is one of those ways to do it. It's interesting, because you go to the States and HIV/AIDS organizations are HIV/AIDS organization, and Hepatitis C organizations are Hepatitis C organizations. They didn't have to meld, because our government actually said you have to meld, this is how we will fund you. YouthCO had to change our mandate if we wanted to maintain getting funding, because we were changing to meet the funders needs rather than …

I'm not saying that was a mistake, it's that when we're doing that, we're missing out on opportunities where we could be getting money to do what we want to do, not just following the lead. I think there's a bunch of things that got lost in that. And Positive Living, they just shut down. They focused just on HIV. They didn't do that. And in the end they folded, and I think that's sad. And I don't think it's that they did something wrong, I just think there's something else wrong with the system and how we fund what is the disease or the health issue of the day. There is always a disease or health issues of the day. And for a while there, HIV was it and there was lots of money for it, and then it want away and then it was the next health issue. It goes through these marketing cycles of – everything's going to COVID right now, we know that without a doubt. But what I'm saying is there's always something like that happening, but it doesn't mean the issues go away. People are still living with cancer in COVID. People are still living with HIV and a plethora of other health issues during COVID. It's just another thing on top of what you already have. So how do we maintain that? Not forgetting. When there's a big wave of whatever issue there is, how do we not forget about the other waves that still exist before and after that? Did I talk enough?

BK: This is great. We definitely appreciate people that are verbose and share their experiences, and that's what these interviews are really about. I'm kind of out my formal questions. I feel like there's probably aspects of your story that we didn't cover, potentially, so I guess if there's anything that you want to add or clarify at this point, please feel free to do so.

KK: I know I'm a very fluid talker so I get off topic a lot, and I don't expect me to be able to say everything in one interview. But what we captured here, it's cool. And I'm sure there'll be things I wish I said, but that's just a part of life and doing an interview. You try to do more.

BK: Yeah and like I said, if there's things you think of afterwards that are really essential to your story, we can always find time to chat about those things and document them in a follow up interview.

KK: Totally

BK: So that’s definitely an option

KK: What was the last bit, sorry?

BK: Oh, that’s definitely just an option

KK: Thank you, this is great. I feel satisfied and I’m excited to be able to participate in your project. It sounds like perfect timing for me, so glad we could do it

BK: Yeah thank you so much, Kim, we really really appreciate it. William, did you want to add anything else?

WF: I can’t think of anything else at the moment, no.

BK: Great. Then we’ll just leave it there. I’m going to stop the recording, and again, thanks so much, Kim.