“HIV In My Day” – Interview #94

January 22, 2020
Interviewee: Raymond Koehler (RK). Interviewer: Robert Ablenas (RA). Also present: Ben Klassen (BK)

Ben Klassen: We are now on the record!

Robert Ablenas: Okay, so, thank you for consenting to participate in our project. I’ll be asking you a series of questions, and for the most part just following your lead with respect to the answers. Everything’s inadvertently going to be viewed through the lens of HIV before, during, and then post the epidemic as well. So actually I’d like to begin by recognizing that right now you’re in Kelowna, but you were in Vancouver during the early days of the epidemic. So, if you could just talk a bit about life for you as a gay man in Vancouver before the epidemic.

Raymond Koehler: I moved full time to Vancouver in 1986, so I had – I came from Calgary and I had heard about HIV in Calgary in 1981, and then I remained basically in Vancouver through until about 2003. So that’s the window of time that I can perhaps share with you.

RA: Did you travel a bit to Vancouver before 81 as well though, or not?

RK: No, I was working in the field of Canadian cultural industries and the BC Touring Council hosts, I think still, an annual event called Contact, and so I was travelling into Vancouver from Saskatchewan, from Alberta on a sort of annual basis from the late 70s, through until I eventually relocated to Vancouver in my role as promoter for several cultural organizations. So I was aware that there was lots happening in Vancouver and always looked forward to my chances to visit.

RA: How far back before 81 would those annual events have been going? Because that gives you a cumulative picture of Vancouver.

RK: Yeah, I would say probably about 1977 would be my earliest visits and that continued on a sort of annual basis until… I guess it was actually ‘85, because I was hoping to cash in on employment through Expo 86, and when I got to Vancouver in ‘85 I found that all the hiring had already been done, so I looked for other opportunities.

RA: Going back to like each year starting around 77, you had a one-year time-lapse, snapshot of each time in Vancouver. Was it all just business with the conferences or did you actually go out and explore …?

RK: It was mostly based in the conferences

RA: Okay

RK: But I was aware that, where Vancouver was at in Western Canada in terms of gay culture.

RA: By the time you got to Vancouver, could you compare what it was like in ’85, say compared to where you had been growing up otherwise or living?

RK: Well I was born and raised in Toronto. I don't usually confess that west of the Manitoba border. But so I came out actually in Toronto, and that was what I could compare it to. And Vancouver at that time, to my outside eyes, appeared to be a place that I could fit in culturally with my uniquely gifted sub-community, the LGBTQI2S friends and family. So it struck me as a diverse and accepting urban area that I would enjoy relocating to, which I eventually did.

RA: Okay, when you did relocate, can you describe the community a bit in Vancouver, just a bit more detail?

RK: Well my first employment in Vancouver was a contract with what was then the Vancouver Gay and Lesbian Centre, now known as QMUNITY. And that was and still is at Bute and Davie, 1170 Bute. I understand there's big plans for the future, for what was then the only facility, and that's exciting for me to see that things are growing and developing. So what can I say, I think I probably put the down payment, or covered the mortgage payments for Hamburger Mary's. At that point it was all in pennies. Although my contract at the Gay and Lesbian Centre was only for a limited number of hours and a limited number of months. I practically lived there at Bute and Davie for the next several years.

RA: Working, correct?

RK: Well, at first working the contract with the Gay and Lesbian Centre, and then I stayed pretty actively involved there as a volunteer, particularly working with the gay and lesbian food bank, and took telephone counselling training there and did some time on the phone lines. And also during that same period of time got involved with volunteering for AIDS Vancouver in their community phone work.

RA: When you were – before people were talking about AIDS, part of your initial days in Vancouver, was AIDS not prevalent? And just what did life seem like with respect to people being not aware of or not strongly aware of AIDS at the time?

RK: The first person that I came in contact with—and I feel really badly that I can't remember his name—but he was an accountant bookkeeper that I retained to help me with my consulting business at that time. And he was the first person in Vancouver that I was aware of that was dealing with AIDS/HIV. Eventually he became the first person that I went and visited in St. Paul's Hospital getting close to his end times, and in those days folks who were living with AIDS didn't live very long with AIDS. And I remember visiting St. Paul's hospital and being aware that all the medical staff were in space suits if I can say that. They were—I think the problem was that it still wasn't known what the mode of transmission was and so there was a lot of fear amongst the medical staff, the nursing staff, and among some of the doctors about even sharing space with folks who had an HIV/AIDS diagnosis.

RA: When you were on contract with the GLC and also eventually as a volunteer, you're interacting with members of the community, is that correct?

RK: Um, sure. The organization had just taken over the entire second floor of 1170 Bute. Before they had only had a quarter of that space and before they were somewhere else in the community that I wasn't familiar with, but when I arrived was the moment that they went through a big expansion from one quarter of the space, second floor 1170 Bute, to the entire second floor. So actually, we were sharing space with the Angles newspaper, if anybody remembers that, and also it was the home at that time of the PWA organization, Persons Living With AIDS organization. So it was a shared space, and certainly we were sharing many of the same issues, observations and fears about what was then developing into the pandemic.

RA: Okay. It seems an interesting vantage point to be with the Centre as well with PWA society set up there and Angles set up there, and just wondering in that environment, aside from all your other actions in the community, if there were any unique insights regarding any kind of changes? Any differences as the epidemic became more pronounced or certain discoveries were made, just anything within your being associated with the Centre as maybe a unique vantage point for what's going on.

RK: Hard for me to know where to dig in here, but I was fortunate through one of the only people that I knew coming into Vancouver to mention a name, his GP was Dr. Phil Sestak who at that point had his own family practice at Davie and Burrard. Dr. Sestak eventually moved over and joined the Spectrum health group, but he was my doctor for I think about 17 years. And I was sort of in an interesting position there, I think, because I was and still am HIV-negative and most of his clientele were HIV-positive. So it was good for me to have his medical expertise. I know I was also working with organizations in the community like Dignity which is the gay Catholic folks and Integrity which is the gay Anglican group. And I was able to call on Dr. Sestak's expertise. I remember once in particular when he came to talk to the gay Catholic group, Dignity, about issues around health care and HIV and keeping well, and issues around how do you care for a loved one who has HIV? And the risks and the dangers. And at that point I think there was more fear going around than was perhaps helpful, and it was good to have a medical person who could advise us on those kinds of issues.

If I mention two individuals, certainly from Angles and the PWA organization, and I don't know if this person is still with us or not, but John Kozachenko was a personality all through that period, with the ACT UP organization and taking on our premier of the day, who was Bill Vander Zalm in a very proactive kind of way. So I think John inspired a lot of my activism that came along later. I believe he was also working with Angles, so we saw quite a bit of each other. The other person that was tremendously influential on my understanding and development in living with folks who were living with HIV and AIDS was, there was a young man named [name]. And he had come from Toronto as well, similar to me. And had come out to his family and it had not been a good experience at all. Particularly, as I understood it, that his father was so upset with him coming out that he chose at that point to leave home and travel west. He was the manager for a Pizza Hut and he was about 20 I think, and in '86 I would have been 36, so it was really more a father-son kind of relationship. But [name] became our first volunteer coordinator for what became the youth group at The Gay and Lesbian Centre. And he eventually grew that position into being our volunteer coordinator for the whole organization. Excuse me [coughing], volunteer coordinator for the whole organization, and was just the most amazing, bright, energetic, enthusiastic, good-humoured young person that I'd ever met before. And so, I guess I kind of adopted him as gay daddy in the best sense.

And one issue that [name] was having was he had a persistent cough and he couldn't shake that, and he didn't have a doctor in town. So I took him to my doctor, Dr. Sestak, and they ran blood tests and all that sort of thing. And [name] was living with some students out on Arbutus towards the university, the West Side, and I don't know he had a room, I guess. He was renting upstairs in a house that was shared with boys and girls, mostly very young, and an interesting group of college-age youth. And well, the long and short of it was having got him in contact with Dr. Sestak and Dr. Sestak having run the blood work on him, Dr. … It was a rainy rainy stormy night and I got a phone call, I was home, from Dr. Sestak. And he wanted to get [name]'s phone number, and [name] didn't have a phone so that wasn't possible. And so Dr. Sestak asked me if I could get a message to [name], and let him know that he needed to get to St. Paul's hospital just as soon as possible. And so my long term companion of the day and I drove off from the West End off into the West Side to Arbutus St. to find the house where we knew he was living. And we found [name] in the second story sleeping area, he was on the mat on the floor, and he could hardly breathe. And I was amazed at how much weight he had lost, just since I had known him. And so I ended up carrying him in my arms down the stairs and out to our car through the rain and we took him to St. Paul's Hospital. And it turned out that he was suffering from pneumocystic pneumonia, which was the tell-tale sign that probably it was an AIDS/HIV infection and, well, it was just a night I'll never forget. And once they had him stabilized I took him from the hospital to my home where I was living with, at that point, my long-time companion. And what I experienced there was, although I had enough information to know that it was not an easily transmittable virus, my long term companion and my long term companion's mother who was living in Calgary both freaked out, as it were, that I had brought this person to our home. And so he was there for a few days and then my companion announced that either [name] went or he was going, because he would not stay in the house with someone who was diagnosed—as he was at that point—with fairly advanced HIV disease. And so then, on one of the worst nights of my life, I again took [name] by car downtown into the West End and booked him in for—I guess I gave a month's payment in advance for him to stay at the YMCA and I just felt terrible about it. I also at that point contacted his family in Toronto, and maybe one of the benefits that came out of the situation was that the father who he'd been estranged with flew out eventually to Vancouver and took [name] home. I think it was [inaudible city name] or some community just north of Toronto, where within the next few months he, you know, just continued to decline very quickly. And I was hearing bits and snatches from his mom, and then he was gone.

And I don't think I've ever really recovered from that loss. I took myself to grief and trauma recovery groups at the Cathedral, the Anglican Cathedral in Vancouver Christ Church Cathedral I think it is. [name] had sung in the choir there. And so I went through their grief management group twice before I felt any kind of ability to deal with what had happened. And yeah, so to me it was, he was so brilliant, and he was so, he had sparkle, and I loved him a lot. And I don't think I've ever really recovered from that loss. Yeah. So that was my, that was [name]. That was the story of [name]. And you know, it started there at Bute and Davie at the Gay and Lesbian Centre and has affected me for the rest of my life, I think. Anyways. I don't think I can say much more about that.

RA: You mentioned the grief management group. So, I mean, in the process of you providing support or being a caregiver for someone else, you mentioned the grief management group, were there some other resources or supports available to you, to help you out? Because you're dealing with a lot with this.

RK: I guess my coping strategy for life is to throw myself into volunteer community organizations and share what I can with others and that becomes sort of… for me that's my therapy. Years later, after I had left Vancouver, I was instrumental in launching and keeping going our senior gay men's group here in Kelowna, and I found the same thing there that there was so much fear and loss and pain that those folks were carrying with them that just having the opportunity to facilitate their getting together, and to get them to come out to a group was just like pulling teeth. Because they were so afraid about acknowledging the gay experience. Many of them had been married, many of them had children, many of them had grandchildren. And it seemed to be a whole slice of the community that had been traumatized by the HIV/AIDS pandemic. Many of them had lost lovers, long-time partners to HIV and that pain, and then because of the stigma, the trauma, that they were carrying with them, was just amazing. And one of our mantras became 'you are not alone.' And so, this is years later, after Vancouver, but what we did was we developed a network of community organizations that in their mandate said that they were safe and accepting and inclusive, and that everybody was welcome and there was no stigma. And encouraging our guys to get out and deal with that trauma from the 80s and 90s that they had never been able to deal with before. And just by the—the first organization here in the Interior that said, 'Hey come on down!' was the public library system, and that was a very interesting connection because they were very public about the fact that they were a safe space and everybody was welcome. So that was one of the things we learned and shared. Another West End--

RA: Can I just check-

RK: -HIV story, and I may be losing my phone and I have some back up phones so I may have to switch, maybe I should do that. If you can just hang on, I'm just going to put on a different phone

RA: Sure, okay.

RK: Hello! Okay, that means I've got a new battery in the phone I'm in right now.

RA: Loud and clear.

RK: Good. So let me tell you, because I had this non-HIV condition, neurological condition based on hydrocephalus which is the build-up of fluid in the brain stem, Dr. Sestak was constantly trying to get to the bottom of it. I don't know, I've … Hello? I seem to have an echo on the line and I'm not sure why.

RA: You sound fine here though

RK: Oh okay. Well anyways, Dr. Sestak was just trying everything to figure out why I was doing things like falling down and forgetting things and what not. And so he referred me to the person at St. Paul's Hospital who was, at that time, the apparently the leading expert in the province on neurological issues. His name was Dr. [name], but I've forgiven him for what happened, so maybe that should be deleted out of the record. But anyways, Dr. [name] had me walk across his office and he said, 'Oh yes, you have a stumbling gait.' He said 'It's probably AIDS related brain cancer.' Well. For a guy who thought he was up on health issues and safe practices and all of that kind of thing, to be told that I might have AIDS related brain cancer, for me, was hugely traumatic. And I can remember running down Burrard in the West End and running into 1200 Burrard which is where Dr. Sestak was, and bursting in the door and demanding to know why he hadn't told me I was HIV-positive, and of course, the fast answer back was, 'Well you're not HIV positive, you're HIV negative.' But it was an interesting, I guess, glitch in the medical system that because most of Dr. Sestak's patients were HIV positive, when Dr. Sestak made the referral to Dr. [name], the expert on neurology, for some reason, maybe logically, the neurologist leapt to the conclusion that I was a person who was HIV positive, not HIV negative, and therefore put out this possible diagnosis that I had AIDS related brain cancer. So that was really, really traumatic for me, to get what I heard as being a diagnosis completely out of the blue impossibility. It turned out that wasn't the reason for my stumbling gait, it was neurologically connected. So just a word of warning there, the medical profession can sometimes stumble into an incorrect diagnosis just based on circumstances.

RA: You convey the impression that you were very much in the loop regarding safe and unsafe practices, risk for infection, transmission. And therefore, you're telling us about an event where despite all the smarts that you have and believe you have, suddenly you're told that you have an HIV positive diagnosis, regardless of everything that you'd thought otherwise.

RK: Yeah

RA: So that's a very interesting moment, thanks for sharing it

RK: [laughing] Interesting is an interesting word. It was hugely traumatic for me. And I hope it's a diagnostic error that has not been repeated with anybody else, but interesting that it could have happened that way.

RA: You conveyed that you, by whatever means, had an understanding of what's safe, what's not. And maybe a fair bit about the latest developments. So if you could just maybe say something, please, about how you got the information that you got regarding HIV, its effects, prevention, protection, anything that you were finding out earlier on.

RK: Okay, let me go back a bit and put it in some context. I came out, I began coming out when I was probably, well let's go back further: I knew I was gay when I was like 5 or 6 years old, I just didn't know what the word was. I didn't know what I was experiencing, I didn't have any of the background or understanding, no way to describe what it was, but I knew that something was fishy when I was 5 or 6 years old. When I got to the point years later when doctors were trying to figure out how I arrived at the neurological step that I was at, they were trying to connect it to the fact that I was gay, which turned out not to be the case. They would ask me things like if I was promiscuous when I was young. And my response to that, and in fact I had been pretty frisky from the time I was 18 to the time I was 30, but when the doctors would ask me if I had been promiscuous, I wouldn't say promiscuous I would say 'serially affectionate,' and I said I think there's a word for this, I was unable to engage in sex without falling in love and having a romantic emotional attachment to the partner of the day or the evening or whatever it was. And this was apparently something of an anomaly in the gay male community, there was a lot of sed going on without any emotional attachment. I always had an emotional attachment. As a result of that, I spent a great deal of my time being heartbroken, because I was in theatre school which meant I was in a fairly supportive, friendly environment. But weekends were weekends and I was in Edmonton and I was a pretty, well, when you're 18 years old and tall blonde and stunningly good looking, ha ha ha, you get a certain amount of notoriety and popularity. But for me it was always this serial affectionate quality that I would always fall in love, and I would always get heartbroken. And that was just the pattern of my existence. So in '81 in Calgary, when I was with the gay Catholic organization, I heard about HIV/AIDS and that was the first I knew about it and I could sense that I was at risk for that, and so yes, I was getting all the information I could about safe sex and condoms and all that sort of thing. but the truth of the matter is that I just stopped having sex with other people, and I would say from '81 until I had long-term companions, but I wasn't very sexually active outside of my partners for the next 20 years. If I was to go to a bathhouse, which I really enjoyed going to bathhouses, I wouldn't actually be having sex with anybody else other than myself. And so that was a big change in my behaviour that resulted from my growing knowledge about HIV and the transmission of HIV and all of those safe sex messages. My choice was to just stop having that kind of sex and having the long-term companions, who we always shared doctors with and we always got regular testing through our doctor and that kind of thing. But it was a huge change in my behaviour, and maybe not a very constructive one, but if having sex was dangerous then, okay, I won't have sex with other people. And so I guess that was a response to getting the information about AIDS/HIV. Not a very happy or emotionally satisfying choice, but that's just what it was.

RA: Well thank you for sharing that, and I think also in there you actually have given, at least from your point of view, a little more detail or picture of the community, in talking about yourself being a 'serial faller in lover' when that was very much not the norm, so that's an interesting perception

RK: Well certainly, no, the norm in the community I think was just anonymous sex or [inaudible]. When I made it out onto the internet—I've never done this Grindr dating kind of option—but if I was contacting somebody with the idea of having a sexual connection, I would say things like 'I want you to stay all night and we'll have breakfast in the morning.' And that was a huge turn off for many guys who thought that was just weird, like why would you do that? They were looking for a hit and run sexual contact, and I wasn't.

RA: Do you have any observations about mainstream responses to the epidemic? You had your own responses and members of the community, maybe especially in context of the GLC. Outside of all of that, say mainstream: any observations or thoughts about the mainstream responses to the epidemic?

RK: I think the stigma of being uniquely gifted in any form coloured many people in the mainstream public in sort of leaping immediately to the ‘gay is bad because you’re going to give everybody AIDS’ attitude. Which is, you know, it’s a homophobic attitude. But we’ve made huge strides, I mean, of what I can see, having passed through the AIDS pandemic. I think in the wider world, we’ve made so much progress in human rights, in the public understanding that we’re all people, and human rights should be universal. And the reason we call them human rights is because they shouldn’t be legislated. They’re rights, you don’t just go and change the rules. But what drives the homophobic and negative voices I think still is this fear of HIV/AIDS. Which, you know, it goes back to the old argument about it being God’s punishment for sexual identity and things. What really tends to change the corner I think, is when a homophobic dad finds out that his son is gay. Of course, it’s traumatic for the son, but it’s very traumatic for the parents. Interesting that in my experience, if the parent’s worst thing in the world is when dad says, ‘Well, we’re not having any of that uniquely gifted stuff under my roof, you need to get out into the streets and learn what life is really like.’ Sorry dad, that is the wrong advice because you’ve put a kid out on the street, he’s homeless, he doesn’t have any money. What’s the first thing he’s going to find he can make money at, is hustling. And that’s going to put him at very high risk for HIV/AIDS. And it’s going to put him cheek by jowl with the drug trade, and we all look to find our own medication—mine’s coffee—but if you find something that takes the pain away, you repeat it, and that becomes an addiction. So why folks would do that … when older people had said to me, ‘Little Susie is gay, what should I do?’ My response is ‘Well, how about love her?’ And also, I tend to find that grandparents tend to be more accepting and more inclusive than parents do, which is sort of an ironic thing, but a lot of it depends on how we’re raised and that sort of thing. Yeah, I forgot where we were going with that, that’s my cognitive –

RA: Well I was asking a bit about the mainstream, and maybe you’re pointing out even just you know, families. That can play out in different ways within families

RK: Yeah

RA: You’ve mentioned some institutions, for example, that I don’t consider queer necessarily, but mainstream. Let’s say the YMCA where you brought [name] to get a room. I have no idea what their response was, but you got the room. You mentioned church.

RK: It was never a question there, but interesting you mention the YMCA, because here in the interior, the YMCA is actually total on side-- Are you familiar with the term SOGI? Sexual orientation and gender identity issues. I mean YMCA is right onside there. They’ve helped our youth group; we have an open access street level medical psychological social services program for young people, which is called the Foundry, and I’m not sure if there’s a Foundry in Vancouver, but there are several of them across the province, wonderful organizations. Our Foundry has set up a youth support organization which the young people name themselves, taking the whole alphabet soup of previous acronyms and boiling it down to Etcetera. So it’s the Etcetera group. And they found allies certainly at the YMCA, and they know about the library as a safe space. And while we were still operating as senior gay men, we had 30 or 40 community organizations that said they were accepting. I don’t know how many churches I visited to find out who was ready to do gay marriages, and some are and some are vehemently not, but that’s the way things go. But certainly community organizations in the fields of recreation and all sorts of social service organizations claim to be open and accepting, and so what we do was we went around and challenged them on that, and listed the ones that we felt we were satisfied were, in fact, going to be celebrating diversity, rather than exercising exclusion and those more negative things.

RA: Regarding church, you mentioned the church that had the grief management group that you attended.

RK: Yes yes.

RA: And presumably they would have been aware of why you were attending, so you've mentioned some mainstream institutions that were-

RK: Yeah unfortunately the Anglican Church is tearing itself apart about inclusion. We know that the United Church is onside, and we have some Evangelical Protestant groups that are supportive and some that are vehemently opposed. So that was why we were doing some of that work on investigating and testing organizations to see how onside they were. And I was quite surprised to find out that there were as many inclusive organizations around us in the community. I think that something that has really changed since 1995 or so, whenever we got the cocktail for HIV. I think people became less fearful and the quest for zero transmittability is now being understood. We're seeing mainstream and cable and media advertising for pharmaceutical products, I guess mostly south of the border, that they seem to be able to take HIV patients to zero detectability and zero or very near zero chance of transmission, so I think those are all good signs.

RA: Could you … thinking of yourself as a caregiver, you describe the instance of you taking … going to the Arbutus residence and taking this kid down the stairs in the rain. Can you share some observations about different aspects of caregiving? Maybe in general terms or as specific as you like.

RK: Sort of on that point, I mentioned to you that I have probably helped pay the mortgage payment at Hamburger Mary's at Davie and Bute for a number of years. I had a huge crush on one of the waiters there, and he's passed away now. He was a German boy, and again, just the sunniest disposition. Always a smile, always 'how are you doing?' And so on the personal level dealing with this fear factor—and it's not a story I'm proud of--[name] invited me to his apartment for tea or coffee or something one afternoon. And of course hot to trot Ray, as soon as he was finally going to get to get it on with this handsome German boy, and as I got invited into his apartment, he shared with me that he thought he needed to let me know that he was HIV positive. And I didn't respond well at the time. I regret that for me when he announced that, it was sort of the end of my plan that we were going to finish the afternoon by getting it on and so as diplomatically and as quickly as I could, I left. And somewhat later, I learned that [name] had passed away. And I was more proud of him for his integrity in disclosing his status to me than I am of myself for my response. My response was not a good one. And again, it was based on the fear thing. Anyway, that's a sad little story from me. I forget, where were we on, we were talking about caregivers. Certainly--

RK: Well caregiving

RA: I think St. Paul's is now closed out the HIV ward, as I understand it. And so I guess that means no more nurses and doctors walking around in space suits. Certainly I think the progress that's being made in the response to HIV/AIDS disease sort of goes hand in hand with the growing awareness and acknowledgement that there are gay people out here, and some of them are your kids, and maybe your father was gay, what!? You know, it's a difficult learning curve for all of the community but I really think we're making progress. I am not too thrilled with any Canadian politicians right now, but I am so inspired and moved by the candidates coming forward for the US presidential campaign. So I'm out there on social media now, doing everything I can to support Mayor Pete Buttigieg, apparently the first openly gay Democratic candidate for the US presidency. I think this is an indicator of just the huge change in public perception and attitudes and acceptance of the fact that there's gay people out there, and once we get past that then the HIV/AIDS issue comes up and then it's getting folks who are positive onto the current cocktail of medication which apparently, as a I understand it, can indicate a normal lifespan. And then for those of us who are negative, in BC in particular it's so important that we get everyone onto the PrEP protocol. We didn't have that in 1986. We didn't have that in 1995. And now we've got it and now it's available for GPs for free, for goodness sake. Why wouldn't any person get on to the PrEP protocol? The numbers are growing, but I'm amazed that there hasn't been more uptake for the PrEP protocol than there has been.

On that subject, I'll just mention to you that my current partner—25 years thank you very much, no applause, just throw money—had to have some urology work done. And so there were two appointments, one was the intake appointment at our general hospital and one was the surgical date. The surgical folks were fantastic, our urologist is just an amazing guy and very inclusive and very welcoming and very supportive and just wonderful in all respects. His nursing team fabulous. The aftercare remarkable. This urologist came in to the intensive care department to check on my partner in the middle of the night after the surgery just to make sure he was doing okay, and was there first thing in the morning because they had to remove a catheter or something. And you know, fabulous non-judgemental inclusive care. On the intake procedure, however, when he listed his medications, he mentioned Truvada because that was one of the meds that was part of the PrEP protocol, and the nurse who was doing the intake visibly freaked out, as did the anesthesiologist. Their reaction was visible, and they were horrified to see that he was on Truvada. And it turned out they didn't have any clue about what the difference was between HIV positive and HIV negative. Well, I filed a complaint with the hospital that this was unacceptable.

RA: What year is this?

RK: I beg your pardon?

RA: What year would that be?

RK: That was just last year. And actually, I'm—on part of my activist umbrella here is we have what's called the Patient Voices Network which is patients inputting with medical folks in Interior Health on various issues. And I go in there with my rainbow flag every time and I'll tell that story as many times as it needs to be told that they need to do some education work with their front line people, and they need to understand that maybe 40% of their demographic are uniquely gifted in one way or another. And anyways, it was very disturbing, but I did get a phone call back from the hospital after we filed our concern. The good stuff, and I'd say the urologist was great, his people were great, the care was great, the intake procedure was so wrong. And so I think those of us who survived that period that you guys are particularly looking at have an obligation to make sure that the organizations and the institutions are up to speed. I also want to mention that after my theatrical career, and after my brain—once I realized I have a brain situation on the go, I actually did a switch and was working in what we call Community Living which is working to support folks with cognitive and physical disabilities. And the first organization I worked for in Vancouver was called Mainstream, and actually their original executive director had also passed away with HIV/AID, o that was a working team that was pretty up to speed on the issues

RA: You mentioned putting on your activist hat, okay so--

RK: Yeah

RA: Aside from Patient Voice Network, which is more recent, and say the senior gay men's group recently, just going back to 1985 in Vancouver through the 90s, were you wearing your activist hat back then?

RK: I was trying to. And the name that I remember from AIDS Vancouver was Bob Tivey, and I don't know if Bob is still with us in one form or another but certainly I was trying to help AIDS Vancouver with fundraising projects and various activities. One glitch that came up during that period was, I also tried to volunteer with the PWA organization and then that was going along swimmingly until they found out that I was HIV negative. And then I experienced what seemed to me to be reverse discrimination, in that I was uninvited to participate because of my HIV status being negative rather than positive. And so that, I mean, I respected their decision but I was a little… I didn't think it was handled well. But things like the Gay and Lesbian Centre, now QMUNITY, I think we were very keenly aware that in programs like the food bank that it was important to include our friends who were dealing with HIV/AIDS. And certainly the food banks have been, especially since my cancer diagnosis, have been keeping my partner and I alive. And we do anything we can to support them, but I always make sure that I'm wearing a rainbow something when I go in there and sharing the fact that we need to be celebrating diversity not shying away from it. And keeping on top of the new and very exciting information about HIV and getting folks to a zero chance of sharing. And I think I have to change phones here again--

RA: Okay

RK: --Making noises at me. Let me just see where my next phone is … Let me try this one … Hello

RA: Yes, we're here.

RK: Ah good. We're here and we're queer! It's my mantra. So yes, I think the progress that's being made in dealing with HIV since the pandemic is the very helpful thing, and it's really contributing to a better public understanding and acceptance that this could happen to anybody, and we need to be welcoming and supporting diversity and HIV infections are not – doesn't have anything to do with really being gay or not, it has to do with the mode of transmission and the steps we take to ensure safe sex.

RA: Okay, do you have any advice for the younger generation of gay men?

RK: One thing that I've found in all age groups, at least from my point of view, I think it's really important that people have a general practitioner, a GP doctor working with them. I'm not sure what the situation is in Vancouver, but here in the Interior there's a lot of people who don't have a doctor. And I think that needs to get addressed because, you know, in terms of access to lab work and all that sort of thing, you can get it done hit and miss at walk in clinics or whatever, but somebody needs to be on top of your situation and able to make the kinds of referrals that we all need to stay healthy. Certainly the young people in my work with homelessness, I mean, we know that 30 to 40% of the homeless youth will self-identify as being uniquely gifted in one form or another. And they need more information earlier. And it upsets me when I hear folks saying, you know,' you're putting youth in danger by giving them too much information too soon.' Information about HIV and AIDS and sexuality I think always needs to be presented in an age appropriate format. I mean, it starts with a baby getting hugged for goodness sake. So I don't think there's such a thing as too early, there may be such a thing as age-appropriate guidelines that everyone should be following, but certainly for the youth on the streets I just think it's a huge risk and a huge danger.

RA: Okay, so you mentioned two things. One is everybody should have a GP, and then access to information … from your point of view, how do they get the information that's reliable and useful.

RK: One of the things that we learned through our Journey homelessness initiative this year is that among the adults, probably 10% of adults have no digital communications at all. No smartphones, no computers, no iPad, no email. So whatever information channels we're using, I think we always have to allow for, in budgets or whatever, printed material for folks that just may not have the smartphone. I have a smartphone I'm just not smart enough to use it yet. I don't think we can rely solely on digital … I mean, it's great and it's very expensive but I think it misses 10% of the population. There's a literacy problem and there's a technology gap. I think it may include 10% of the population--

RA: By literacy you mean what?

RK: I mean people who can't read.

RA: Okay that literacy, got it.

RK: But also digital literacy. You know, I have a smartphone but I don't know how to use it yet. [laughing].

RA: You demonstrated being able to operate three phones in this interview!

RK: [laughing] I'm juggling them all over the … Fortunately my partner, his name is [name], is just a technical whiz, and he keeps me connected, but without him I'd be lost. I don't know if you're in touch with Robert Berringer and the research he's doing out of … oh he lives on Saltspring and he works at SFU and with, used to be the RCMP university, Mount … anyways, near Victoria. He has been doing a lot of work on the end of life issues and things like that. Well, one of the expressions I like is we should never regret going older because there are so many that are denied that opportunity. Certainly getting our end of life ducks in a row is important. One of the things I remember from the time period you guys are working on is there used to be a… I don't know if you'd call it a tradition or something that happened more often than not, would be for a person who was dealing with HIV/AIDS, an evening celebration of life party followed by a morning suicide. And I hope that that doesn't need to be happening anymore, but it was ironic, I guess, that that would be a format for the final exit. Just talking about it makes me very sad. Thinking of the many many many folks that we've all lost.

RK: Just a question about … you found a particular GP and you've emphasized how important it is to have a GP and especially a good one

RA: Yes.

RK: So you're not .. there are many who were lucky to have that particular GP and others who were equally amazing through all of this and just how did. Are you able to comment on how you actually got connected to that GP in the first place?

RK: So Dr. Sestak. And one of the gay contacts that I had from Saskatoon, and then later from Edmonton and then I connected with when I got here to Vancouver was also a patient, HIV negative, of Dr Phil's. And so he took me there and introduced me and asked Phil to take me on as patient and Phil agreed.

RA: Okay

RK: So it was through a personal contact. But most GPs in this area just let it be known that they're not taking on new patients.

RA: Well we've been asking you questions about before and during and after the AIDS epidemic in Vancouver, and I think at this point would there be anything that we didn't lead you to or ask about that you would like to mention or discuss?

RK: I'm just buzzing through my notes here and seeing if there's anything that leaps out at me.

BK: Did you find yourself –this is Ben here--

RK: Yup, hi Ben.

BK: --like looking after other friends or visiting other friends in the hospital, like was this a common occurrence during these years for you?

RK: I had both experiences, which we've detailed of the major St. Paul Hospital experience that I recall was right near the beginning of the pandemic, and it seemed like all the nurses were travelling up and down in space suits because they didn't know the mode of transmission for the virus. And in terms of caregiving at home, again the issue was with my long-term companion and his family who at that point didn't have any information, but freaked out about the fact that I had a kid who'd been diagnosed with HIV in our home dying, you know. So for everybody, I think palliative care is also a really important issue. It's going to affect everybody, HIV negative or positive, sooner or later. But failing that, people are being cared for at home, and just based on my own experience, I take my hat off to folks and caregivers that need support too, that's really important. But I think in terms of knowledge about HIV and about knowledge of the treatments available for folks who are positive and knowledge about treatments available for folks who are negative, I'm very hopeful that some of this pain will end, and that folks will get to live full and happy lives, and hopefully we'll all find ways to contribute to the community and to the wellbeing of everybody.

BK: And I feel like you've provided some little pieces of this other question that I have, but just like taking a step back, this was obviously a gigantic calamity for the community. So how was the community as a whole kind of responding?

RK: Well, what I'm seeing particularly among partners who've lost the love of their lives to HIV/AIDS, there's a whole lot of aftercare that the survivors need that maybe isn't happening. And maybe that's also because of the stigma and the fear. So I don't know what the best way to combat that is, but I do think there needs to be a focus on dealing with the fear and the stigma that's still continuing to affect the survivors. Maybe there was a high suicide rate amongst folks who were dealing with HIV/AIDS, but there's also a high suicide rate amongst those who survived. And I don't know what the answer is. I continue to think that finding out that 'I'm not alone' is a really important message, but it's hard to get that message through to people who are still fearful and really shackled, really bound by the stigma, which leads hand in glove with the fear. So I think we're on the right track but I'm just not sure how to get that. I think there's lots of good news out there and I think we need to make sure that folks who are still suffering emotionally or physically or medically are kept up to date and fully informed as much as possible about the good news that is there … Hello?

BK: Yes, we're still here.

RA: Yes.

BK: And this will be my last question, but you've also mentioned like a few different organizational responses that were occurring in the 80s and 90s, so AIDS Vancouver, PWA, ACT UP … Did you want to say anything more about what those organizations were doing at the time?

RK: I think that they're all doing good work and certainly, you know, in any society, any community there's always going to be a range of responses of activism. And certainly, you know, I applaud ACT UP for embracing the pandemic and getting that message out there because a lot of that spilled over into the mainstream media. And whether people responded positively or not, at least they were made aware that there was an issue that needed to be dealt with. PWA … I think its critically important that you know we say nothing about us without us and certainly to get leadership and initiatives from folks who are actually on the leading edge of the issue is really important. And in terms of what I see AIDS Vancouver's mission broader mission was again kudos to them I think certainly from my experience they were doing good work my laughing my volunteer work with AIDS Vancouver kind of hit the rocks because of my growing cognitive glitches that I was unable to continue at that time to do what I wanted to do with AIDS Vancouver but I know they were doing good work and was happy to help when I could.

RA: Well Raymond, unless there's anything else that we haven't covered, this is a chance--

BK: Yeah, feel free to take a moment to think about anything else you might want to add.

RA: Oh, I don't think I mentioned the name of Kevin Brown. I don't know if you folks would know of, but I believe he was heading up PWA, I think, during that time period. And I know that I went to a celebration of life for Kevin at the Unitarian Church on Oak Street. And so we didn't know each other well but I was well aware of the good work he was doing. At the same time as Bob Tizzy was at AIDS Vancouver also doing good work. And now you fellas doing good work too, thank you for what you're doing!

RA: Thank you Raymond. Okay.

RK: I think I'm tapped out

RA: I don't know how many more phones you have up your sleeve but unless there's more of that to add then I think we will wrap this and …

BK: So I'm going to stop the recording.