“HIV in My Day” – Interview 38

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Interviewee: Bart Reid (BR); Interviewer: Ben Klassen (BK); also present: William Flett (WF)

Ben Klassen: Great, thank you for being here and agreeing to share your story with us. When did you first become involved in the gay community or start engaging in gay life?

Bart Reid: Well, it was touch and go. It was basically hitch hiking, I kind of knew I liked guys and I was an introvert reading a lot of books, and one of the goals was how was I going to become more extroverted, and one way was to make myself completely dependent upon strangers, and what better way to do that than to hitch hike. And I was a student at SFU and hitchhiking was in, so I decided to hitch hike to Los Angeles. I was in Oregon and this guy picked me up. There was this guy in the back who said, “I’m gay,” and he was really verbose about this, a PhD student in Literature. “Oh, are you gay?” “Uh-huh.” And he said, “Have you ever been to a gay bar before?” I said, “No, I haven’t,” and he said, “Would you like to go to one?” And I said yes, and with some trepidation, rather than continue on down south, we got out in Eugene, and went to his place. And I was getting all excited, I haven’t been to a gay bar before, and I was kind of interested in guys, and he started to wear this denim jacket, and I was getting more excited. Then he started to read, being an English PhD student, he started to read this poem, “The Blacksmith” by Rimbaud, and I lost control and pounced on him so to speak, and we never made it to the gay bar. We had some, I guess you could call it sex, but it was curious, and I was confused and elated, and he dropped me off at the corner, and then the next day I continued hitch hiking down to LA.

The next day, it is just the guilt operating, I slept overlooking Berkeley Stadium in a patch of, what do you call it? A cousin of poison ivy, I slept in it and I went to pee and touched my genitals, and everything swelled up. I looked like the elephant man and I thought this is my punishment for sleeping with a gay man, and I panicked. So, I rushed down to SF airport and flew back home to St. Paul’s, and I went to emergency and pulled down my pants ‘cause my genitals had swollen up so much, and I had a slit, ‘cause I didn’t know, poison oak, I didn’t know that any part of your body you touch it swells up. I looked like a monster, and I remember after I got on the plane and going to St. Paul’s and pulling down my pants, is this what I have because I am gay and this is what happened? And the nurse said, “Nah, that is just poison oak, here is some ointment.” So, I went home to my parents who lived at Maple Ridge. Then the second time happened when I was in grad school in Winnipeg, where I came out with all my friends, my two roommates, and that was really remarkable event, because we all came out at the same time. And all the girlfriends were astonished by what had happened. Some were upset – oh, he’s gay and he’s gay and he’s gay, and that sort of thing, and it was all very distracting, I have to admit. So, that is when it happened. Nothing happened until my mid-twenties, although you know, I saw guys and all that oppression oozing, I knew what Victoria spinsters felt like when any touch you would swoon. A guy would touch, just his elbow or wrist would just breeze against me, and I would swoon like this.

And so, that is how it happened, but then it took place rather quickly again, being in Winnipeg, not necessarily gay friendly, and I hung around with artists more than I did with the gay people, so we were sort of our own separate group. And my other roommate, he was a med student, and the other guy was in the planning department with me, and I had also run out of money and I was living under a table at the time, and that allowed me to overcome my other inhibition which was being naked in front of other people. This girl who fell in love with me, she says, "You know, you can make some money if you posed for art class." Really? I thought if she can do it, I can do it, 'cause I was tired of living under the table, a scholarship was two months away, another scholarship to get me through grad school, so I decided to do that and I started getting naked in front of strangers, which was very traumatic thing to do. Then this lady kind of fell in love with me and I became a project of hers – this was a time when people were moving from, if you were in visual arts, from abstract to figurative art, and I was part of that transformation, because in her sculpture classes, people were doing slabs of stuff and I was going to be her model, and she did this hero statue of me like this, and as tall as I was in clay, which scandalized the planning department, because bureaucrats don't get naked and they don't do these things. Then there was the whole gay issue, because people – my other friend who had come out was a bit more flamboyant than me. He was wearing clothes from Milan and all the rural types were offended by his attire and would hiss things like fag.

So, we had to fight back and created quite a commotion and got into the student newspapers and on and on and on, and we became a sort of controversial people in the planning department in Winnipeg, which is a very, very, very conservative place in terms of gay things. But I had a good advisor, and that was my entry point into the gay world. It was initially Winnipeg and then also by my contacts in Toronto, 'cause I knew a lot of artists in Toronto, so I would be moving back and forth quite a bit with people that I knew. And also, my academic advisor became a serious alcoholic, so I had to suspend my studies for a year, and that caused me to move to Toronto where I ended up working at the Clarke Institute of Psychiatry, working on and off on my master's degree but going very slowly. That was my entry to the Toronto arts scene, and also to the gay scene. Then I returned to Winnipeg when he got over his alcoholism, we became the best of friends, and I completed my studies there. It was sort of a late entry into the scene, but an interesting one because it was done in a number of different cities. So, I was sort of an outsider in the gay community in a way, being in academia, also being more interested in the arts than the gay community, which I found boring in a way. I found the artists more interesting in a way and many of them were gay.

Then summer – well, anyway then I came back to a summer job with the department of public works and I couldn't tell my parents I was gay and I had to lie. I got a job in a gay bar on Pender where they had these remarkable drag shows – it was a really neat community. BJ's, it was called, on Pender, a real sense of community. I met this guy who thought I was a remarkable person. He said, I have got to get you a job, and he was from Detroit, and he was an actor and he got me a job at BJ's, and I worked there on the weekends as a bar porter, and then on the rest of the days as a bureaucrat in waiting at public works Canada doing research and office decentralization in Vancouver. So, it was kind of interesting, that year in Vancouver. Then I would go back to Winnipeg and continue my studies, and again when the trouble with my academic advisor, I lived in Toronto for three years where I did academic work until they asked me to come back, but I made a lot of connections there, and it was a great time to be in Toronto and gay. I guess that provides you a bit of a back drop, and I met a lot of gay artists, and most are – well, one is still alive, and then it was a very exuberant time, as it was in Vancouver as well at the time, and it is really interesting how that has changed. If you are interested in how the community evolved, how it developed and how it has changed since then, it has been a really remarkable change if you are interested in space, which I was. Primarily, I was involved in mostly academic studies, reading books and writing papers, doing that kind of stuff right into grad school, and then when I was doing post-grad stuff that occupied a lot of my attention, as that was proceeding…

If we are talking about the advent of HIV and all this and that, it is really interesting how that, in my own mind, how that gradually made its presence known. There is almost an apocryphal story for me: I was in a bar in the Castro and it was the washroom, and there was a rose in the washroom, and this is the day they shot John Lennon. Why is this rose here? And it always stuck in my mind, this is the day the guy picked me up and really, on Castro St., we drove all the way down to the Silicon Valley, past San Jose, just to have sex with me, all the way down there, 60 miles. And we kind of had sex, and then I was just amazed, he showed me this long list of all the people he had slept with, about sixty people, it was like I was just some totem. I was number 250 – there was an amazing sense of pride, I have accomplished this, I was this number. I was kind of, wow, it is just someone, a scalp that you put on your belt. This is really kind of weird. I didn't know what to think of it, but it always stuck in the back of my mind later on, and my exposure to HIV, and he showed me this list of people San Francisco. And I always wondered, was this perhaps the time I was initially infected? I can't say, but I always come back to that point, just the fact that he showed me all these contacts, all these people he had slept with. And at that time, 1980, San Francisco was the epicentre of the epidemic, so there was a high probability that I could have been exposed to the virus, but I may not have been infected by that one contact.

That stuck with me for years before I began to notice symptoms of the infection, which were hidden because I was dealing with a number of other issues. But I always wondered at the same time, in New York, when I lived in Toronto, those trips to New York, another epicentre, later on, when I became sick, were those the times I was infected, because I think I was infected for a very, very long time. I was really sick, near death when the diagnosis was carried out, and that is basically self-diagnosed, but when I saw the lesions, I thought this is it, I don't need a blood test for this. And I went back to my doctor, who was very sweet, who said he didn't want to ruin my Christmas. Well, it was kind of messed up anyway. "No, you don't want these results between Christmas and New Year's." I said, no, so that is how it happened with me. The interesting thing about this, the level of anxiety over all those years began to build because there was always the possibility that I was infected, and it was a background concern, and then these approaching clouds as time progressed, more and more people I knew were infected. I guess the first significant impact was this artist in Toronto, Robert Flack. He did a video, it was really sad. He was a really vivacious young guy involved with the Avant-garde artists in Toronto, and he became really sick in the early '80s, and he did a video of himself, and it was a kind of memorium to himself. It was very solemn and almost like a dirge. In the video he said, and he looked haggard, and he was this bubbly, frisky, bushy tail guy, and then the sadness and regret that basically his life was over, and that was disturbing.

But then it was happening to other people, and then in grad school, I was in Winnipeg, I was – we were again… That is when a lot of the activism occurred all across North America. Even in Winnipeg, the quilt came which was quite moving, and it was interesting the impact that had on people in Winnipeg at that time. I had moved back and what was more interesting was this really nice guy became deathly sick from HIV in Winnipeg, and my other friend ex-planner, he was involved in the alternative magazine in Winnipeg, and these people who were taking care of – this was just a spontaneous expression of community impulse to take care of this fellow, and it was remarkable to watch what happened in Winnipeg, involving the parents and women and lesbians and straight people and it was really interesting. They documented because they did a diary every day, they would jot down what would happen. My friend incorporated that into an article in ‘86 or ‘87, it was really quite moving, so I went to after the fellow had died. I had read the journals and it was really quite gripping, particularly the father, what he did lifting up his son to drain the fluid from his lungs, because he couldn’t stand the pain, because they didn’t have very many palliative remedies to deal with the infections which were occurring at that time and it was just amazing what people were doing. It was 24-hour care for this one fellow, and so I went to the event afterwards, and what I was struck was how – and this is Winnipeg, it is a curious place. Not the so-called liberal bastion, but a very interesting city, and what really struck me was the level of care and empathy with the straight people that were taking care of this fellow and his parents.

What I found even more remarkable was the selfless efforts of the lesbians that were caring for this fellow. What does this say about community? This is a good, this means to me that there are these community impulses which exist beneath the surface that motivate people not only – far beyond self-interest. Lesbians were the last people to be affected in terms of their own well-being. And what I found, not disturbing, but I was confused by the reaction of the gay guys that were caring for this person in question, how – and I still recall how needy they were. And I was truly struck, here these straight people that were helping this poor guy, this nice guy and these lesbians, and then I saw these gay guys, and some of their care was genuine, but there was another agenda and it is probably too harsh of a word to say a bit of a self-serving selfishness in what they were doing. The way they were wanting all these other people to pat them, poor, poor you. Well, you know, you didn’t die, so they were actually – I don’t know if I can have the words – it was an attempt to beg for sympathy and consolation which I found jarring. And it is not to denigrate what they did, but there was something self-serving in what they were doing, and they were mourning for themselves, and I thought a rather selfish way, rather than for the selflessness amongst the lesbians and straight people.

And that really did strike me, and it is something I have kept in mind ever since, not only in regard to HIV but in how do people approach death, whether it is you or people you are caring for. And people react in different ways and it can bring in the works, it can bring out things, good things which people weren’t aware of in themselves, or it can be a neutral influence. And I have kept this in mind as I became involved in care groups, people who were caring for people who were sick whether it be from HIV or not. What is going on here? Should you be caring for this person that is sick or is this for you? It is something that I have always been attuned to, because later on through Friends for Life and other gay people or not gay people who were caring for people who were terminally ill, I did see a very disturbing sub-group that, for a lack of a better word, had a ghoulish – they sort of got off on the suffering of others, and it wasn't really to care for themselves, it was to care for themselves.

Which leads me to think of a prominent gay activist like Larry Kramer, who I view as an abomination and an expression of that if you have every… And it came to mind when I got a free ticket to see *The Normal Heart*, it was put on here, and all the things that I had seen of these people, I saw in this playwright and actually, he did cover the tone of the times, but it was completely overwhelmed by this maniacal ego-seeking redemption, seeking love, seeking attention, and it was as if the whole HIV thing was a platform for his ego to bleed all over you, which I was exposed to for three hours at the play, and it just literally gave me a headache. And then I talked to other people in New York, this guy I think was booted out of the organization, because I have seen people like that who can exercise a demonic influence on organizations. They break things apart because they overwhelm, it becomes me, me, me, me, and I wonder those poor people in New York with ACT UP, they had to deal with him, and I guess there is a story to be written about him. And again, we go back to history as myth and mythology, reporters allegedly document people who do documentaries, they constantly come back to this one fellow, not that he should be consulted. But actually, I don't think he embodies the best of the activist strain of altruism. I view him as a demonic megalomaniac with a god complex and I have seen people, I have seen people – he is the worst case, but I have seen other people in the HIV care realm and other realms like that, and so those people spook me. And I have seen how they can do damage to people, particularly vulnerable people who are dying.

And I was caring for people and one of my chief duties was to keep people like that away from the person who was dying because the dying person didn't want to hurt the feelings of this awful person who dished. The person that was dying, their needs weren't being taken care of first and it was this person, their needs, how I feel about you dying. And I have seen this strain in myself, caring for my parents and also people who are sick, and I didn't know how one deals with this, how you get rid of people like that out of the caring professions, people who volunteer to care for people who have terminal illnesses, because they can do an immense amount of damage and harm. And they aren't necessarily aware of it because they are emotionally stunted or their egos are so expansive that their feelings define the universe other than… As I always say, if you are caring for someone that is dying, your feelings, you always have to park them in the back if you are actually going to be caring for people. Not caring for strangers, any loved one, it is really something that I think people have to be aware of, in no matter what you do. It is something I see over and over again and it is something that astonished me when the HIV community, the really remarkable things people did and the really shabby things that I saw at the same time. And again the mixture of good and bad, within organizations itself.

I guess I should go back because as I was finishing my degree, I have come back again. Vancouver, my parents lived in Vancouver, but I had made friends with a guy in Vancouver, he had actually done his PhD on gay stuff in Edmonton, but he didn't like academia and he just finished his law degree. And he didn't like doing family law, so he ended up doing some work for the human rights commission, and he was quite interesting because we had become real pals and he had told me he was HIV positive. I probably was, too, but was bubbly and healthy. Every Christmas I would visit him and come here and we would talk about the community and who was doing this and that, and we talked about the West End, because he lived in the West End, and the changes. When I knew him, there was prostitution, it was a significant issue in the West End, male and female prostitution – they did a movie about it, *Hookers on Davie*, I think. It was interesting, I remember walking the streets and seeing male escorts on the street. It was almost like a carnival-like atmosphere. We would say we don't like Gordon Price, he's going down on defenceless prostitutes, that was our schtick being good liberals, we talked about that. I maintain this contact with him in Vancouver and then when a good friend of mine in Toronto was diagnosed with HIV, what do I do, because he was really kind of messed up about it. I will tell him to fly to Toronto and see my friend in the West End and maybe they can give him some moral support and get him to buck up.

This was in the late '80s. And still a death sentence, the medication was toxic, the presumption was that it was somewhat hopeless situation – there was real terror there. At the same time, my other friend I had gone to school with, his first boyfriend had died of AIDS, and we only found out because we looked at the AIDS memorial, oh, there is his name. He went through his whole family, he got the HIV test with a great sense of relief, he found out that he was HIV free. The ironic thing being, as years followed, his two other boyfriends became HIV positive, one virtually from Bulgaria that lived in Toronto, accusing him of infecting him, but again when they did the test, he was negative. The Bulgarian guy lied and said to his parents, I got it from hookers in Cuba, so that relationship ended, and then in Columbia of all things, he ended up becoming boyfriend with a Columbian guy for two years, and the same thing happened, and the boyfriend accused him of giving him HIV, but again the tests were done, and he was negative and the guy was positive. His friends in Toronto, what is wrong with you, all the people, including his other friends – why are all your friends HIV positive? And that was not said in a very complimentary fashion, it was sort of a measure of saying, why are you being with these polluted people? He couldn't say that because he was too good of a liberal, and his mother was a professor at U of T. You can't say things like that, but the intent and expression was there, and that didn't surprise me. But my other friend did, and it really riled him up, and I told him not to worry too much about it or be too hateful towards these people, and it is part of what humans do for a variety of reasons.

It is not only being clean or unclean, but also it is a status marker and gay guys can be pretty nasty and can have to do with looks or anything. But to mark oneself off and more or less desirable, and infection in addition to penis size and other things all go along with these markers that can be used to make yourself more or less desirable in the jungle market of finding a mate or a sex partner, so I told him not to be too offended by this. Which goes to the other thing about, you know, the stigma, and it is truly interesting, the stigma within the gay community I would have to say as significant as the stigma with – from outside the gay community, I would have to say. And I primarily became associated with that when I was diagnosed here and I saw the reaction of gay guys – oh, uh, oh – really irrational, nasty stuff. But the most ironic thing was the response from people who were already HIV positive, how really nasty some of them were to each other. I thought, wow, this is really kind of incredible, what kind of a dysfunctional culture have I been submerged into? Not to say that all people, but a really significant number of people. There is something not so good going on in this HIV community that I have been involved with. Those were other things which I always thought about. As I mentioned, I am really interested in is there a gay community? Does it exist?

Organizational capacity, for a community we should have institutions which engage in social things and we should be able to generate funds and look out for ourselves if this community does exist. And in Winnipeg, there was evidence of it on an implicit level with the lesbians, what they did. Just suddenly this tremendous huge effort just, this organization emerged, and eventually it resulted in the formation of the Kali Shiva organization which was the first AIDS hospice. So that actually led to a real institution, but then I thought in Vancouver, what has happened here? Because when I was diagnosed, it was really a weird thing because part of it was – what can I say? It was protective mechanism, because I knew I was very likely infected, but things were so unstable that I was fearful that I wouldn't be able to handle the diagnosis and I would fall apart. The other thing, it would completely foreclose any possibility of doing any academic work, because America was the most probable place for me to do any research. There was that working on me, so I just kept that stuff, I fragmented stuff, and I was watching people around me getting stuff. And at the same time, my studies were on hold because I was taking care of my parents because my mother was diagnosed with cancer, that was quite horrifying. I was teaching in Winnipeg, and she had six months to live so I was a wreck. All gays are mamas' boys – even if you are kind of independent, you kind of fall apart, and my advisor, he was willing to get me a job teaching an urban history class in Winnipeg, and I was blubbering the whole time. Listening to all the dirges and reading all the cancer books, you know, and I am flying every two weeks to see my mother because I thought she only had two weeks to live. And eventually I had to move back after I taught the courses because my father was not able – he loved her, but he was not aware of the fact that he was probably clinically depressed, and he could not handle caring for my mother. I had to ask her, "Do you need any help?" And she said, "I am lonely at night." But it really did surprise me that I decided everything, I packed everything up after I did my teaching courses, and I moved back here, and I became the primary caregiver in Vancouver for my mother.

So meanwhile, I was getting all these rashes – I don't know what they called them, but you get all these lesions all over your body, many HIV people get them. But my – I was going to the clinic at SFU, because I didn't have a regular doctor and I didn't want to see my mother's doctor, and the nurses set me up with a psychiatrist. He was actually quite useful and, also, he supplied me with medication – I don't know what it was, my whole torso became infected with this viral thing. It was very painful, lesions all over, but it was quite commonplace with people with advanced HIV infection to get this. My doctor thought it was the stress from my parents, so who knows what was going on there at that time, but meanwhile I was juggling all this. And my friend in the West End was getting very sick with AIDS, so I was kind of juggling, finishing my degree, taking care of my mother. And so eventually she died, and that was really traumatic, and then my father became ill and I had to take care of him. And my advisor died and so I had to reconstitute my – I became a doctoral orphan. Eventually, I got a new advisor and the head of my committee became a person at SFU, so full circle from my undergrad years, and he became the lead person on my committee. Meanwhile I had to care for my father who did not handle his death too well. I was becoming more drained and my friend, an only son, he was getting upset – "Why are you giving all this attention to your father? What about me?" Again, only son, they can be – you know, it is my father. You are dying and you are really sick – he actually has to come first, although I am not ignoring you, and so on and so forth. That led to a mad scramble to finish the dissertation, then Canada student loans were after me because I had spent so long, and rather than ask my parents for money, which I thought was unethical, and I couldn't tell them that I needed money, so I just got out student loans, so then they started to chase me and they were phone calls, and we are going to do this to you. And so, I ended up in the guerilla warfare with the Canada student loans people.

Meanwhile, I was desperately trying to find work all over the place, and I suddenly became very, very sick. And I was living with a gay couple and getting sicker and sicker and sicker, and people were shocked because I had reached a stage where you gradually decline, and then you enter this steep, radical, cataclysmic decline, which I was in and wasn't aware of it. I had become emaciated. It would take me two or three hours to get out of bed, and I guess I looked very eccentric, because I was doing revisions to my dissertations because they do a final electronic copy in Ottawa, and I was just trying to fix that up and hopefully, even though it was completely delusional, get some work. But that was my goal in mind, and so I would shuffle off to the library with a toque and mitts on, because I was so cold, I had no flesh, eating this horrible chocolate cake to try and put on weight, and nothing worked. And then really amazing, because people must have looked in horror but wouldn't say anything. One person said I looked grey. Really? Do I look grey? I knew I couldn't wear pants and I would go into these horrible coughing fits, and people would think I was drunk, and I was losing motor control, and stagger on the street – oh, he's a drunk or a drug addict. I guess the infection was proceeding so far that I couldn't control my motor functions.

Meanwhile, a friend said, "You know, you might have…" He told this in front of my two roommates – 'You might have HIV." And I just exploded and said – not if he had said that in silence to me, that would have been okay, but the fact that he had actually made that declaration in front of other people, I thought was an appalling breach of privacy, so I was very irritated. "This was completely unacceptable for you to do this in front of other people," this was my response. Things were testy for a couple months, and three months later I noticed the lesions, the KS – well, that is it, I cannot delude myself anymore. So, I told my doctor, "I got AIDS." He might have still given me the test, and that is how it proceeded. And I entered the HIV netherworld of organizations, which was really interesting for me, and some of them were really helpful, some less so. I got to see a lot of interesting things, and the medical system, because I had been healthy most of my life, maybe saw a doctor every two or three years, but suddenly my whole system became immersed in doctors, and it was really interesting the way they talked about doctors. And they would talk about Montaner, these people, like they were hokey superstars, because I had never thought of doctors that way. This one is good, this one is bad, this one is good for that. It was an amazing culture revolving around doctor care and who is on the pyramid of virtue and who is – and I never experienced this before. People wrapped up in what kind of medication are you taking, what are you taking? This and that, and this is how you get this, and this is how you get that. It just amazed me because I would – I was never exposed to this stuff.

The other thing was my doctor was really helpful, because I told him how much money I had, and he said, "Oh, you got to go on disability." Oh, how do you do that? Which is quite an experience, because it was like, in a way, somewhat humiliating. I had to empty out my pockets, and all this stuff that I wasn't aware of – I guess someone should have informed me about that. The lesbian at AIDS Vancouver was fantastic – you have to do this, this, this, and we are going to get you on this disability. And my doctor, well, we are going to have to – you have got this and this, and oh, that is pretty horrible, you are that sick. And so, they managed to process me and things turned out rather well, because at that time I was – the gay couple I was living with, I did not tell them I was HIV, and they saw how sick I was, but they were quarrelling amongst themselves, and they told me I had to leave. I ended up living at the YMCA and then an SRO on Granville. And that was really weird because I met this one gay teacher, he was a high maintenance guy, and I told him I live in this skid row hotel on Granville St. at this gay pride event. Just this – well, he was a hypocritical evangelical Christian, so it didn't surprise him, the look of disdain and mock pity on his face, how far have you fallen. Oh well, go to hell, and then the other remark when I was homeless was with these people I was involved in community planning. They thought, oh, he has had a nervous breakdown, and I guess his advisor died, his parents died and so that's why he is living in a skid row hotel. And I didn't tell them, and they still don't know that I had HIV, I didn't think it was appropriate.

So, I remember this guy who drove me up to see this guy's doctoral defense at SFU – well, how does it feel? I felt really irritated because he was a reporter for *The Vancouver Sun* and he did all this stuff on the Downtown Eastside, and he was giving me this – like I had got my comeuppance, which I thought was really quite distasteful, because he assumed for one thing I was middle class. Even though I have an advanced degree, my background was working class, and that was another assumption. Now you know what it is like, now you know what suffering is like. You asshole. That was the only time I was slightly demoralized for two or three hours in this hovel I was in. Then there was a housing society, which actually, that was one time having a degree helped me, because we can't have – a person of your stature can't be living like this. I fully agreed with them – it was really awful, there was shit all over the place, and there was this lady looking at me and looking at my crotch at the communal cooking space we had, and it was driving me crazy. I have always had a hard time sleeping, and they had this policy, maybe because I think they assume most of these people are mentally defective, that they needed to be checked every morning to make sure they didn't kill themselves. Someone would come into my hotel room, just barge in if I didn't respond to them, and it made me neurotic because I would stay up all night until they did the morning check, and then I would fall asleep. And fortunately, I was rescued by them.

Then I started to do volunteer work with a number of the AIDS organizations, but I had also at the same time established, helped to establish a community economic development corporation in the Downtown Eastside, and that actually – a lot of my volunteer energy went into that. But initially I did some stuff with PWA and that was disheartening, I would have to say. My first experience, they had this well-paid gay guy who was responsible, they wanted to set up a computer lab, so I volunteered twice. He had set an appointment and I would come, and he failed to show up, and to me this is the most insulting thing you can do to a human being or a volunteer. It means you are worthless if someone does not show up – you set an appointment. That ended any warm feelings I had for PWA, which were cemented by other things. I remember going to some conclave in, and there was this one fellow who – they had this weird culture of peer group interaction, which kind of took me aback because, even before I was diagnosed, there was this one guy who was diagnosed HIV, he was a wing nut, and he was telling me he was a peer counsellor. Oh god, you are going to give guidance to people? "Yes, I am going to give guidance to people." Oh god, I didn't say anything. And when I got involved with the organization, this other guy that I knew who was HIV positive, we were at this gathering and there was this other fellow who I have actually been the head person for the HIV organization in New Brunswick, but my friend said he was a thief and a fraudster, and what is he doing here. I guess he had collected all the funds from the HIV organizations and zipped of with his boyfriend to party in Boston, this sort of stuff. My friend confronted the people, and the people in Vancouver did nothing, which appalled me. You have elevated this fellow as a peer counsellor, someone to be looked up to and provide guidance, and the guy is obviously a thief and a fraudster, so that made me a bit jittery about the organization and its competence.

So, I didn't have very much to do with it except the retreats, which I have to say are, were phenomenal, and the only saving grace of PWA are those retreats, without question. And it is the only thing that I thought was really – there were real professional people at work, people who had the capacity to self-correct, to look at what is wrong, what is right. I decided to work with them, and they would carefully examine, how can we make this better, and I went to a number of them, and I was amazed at the transformative impact of those specific retreat. Here, in this organizational swamp, there was this one beacon of light. I don't know what it is like now, but I was really impressed with that and the only good thing I can say about that organization would be that one specific service. That is not to denigrate PWA – I think there were real challenges because I even talked with some board members a year ago, what is going on with the organization? I actually think it should fold. It has served its purpose and we are in a qualitatively different situation.

And because of my involvement in this other community non-profit, I am – governance is really important to me, and integrity and ethics are important to me. I said, you know in my organization, if an organization was in crisis, our CEO would be put to the test, would have deliverable, if you are going to be paid, this is what you have to do. So, I talked with this guy, and I don't know very much about your CEO, but he has been around forever, and your organization is floundering – what are you going to do about it? I think maybe you should maybe change the person, because it is a normal practice when an organization is in crisis, you get someone new who can push in a new direction. And he was a well-meaning guy, but he had to tell me, well yea,h he is getting a lot of money and uh… we are going to wait until he retires next year, which absolutely floored me. Because what he told me was that PWA exists to serve the CEO, to supply him with a wage, that is the primary function of the board. He wasn't aware of what he told me, what that really meant, but that is what it really meant. And I guess the other issue, because I always had an issue, this is a well-managed organization, and I never thought it was, as I began to talk to people who were in administration for verification of my hypothesis and said that there may have been sour grapes. The guy may not be competent.

Leaving that aside, the other issue with PWA was the rebranding of PWA as Positive Living, which simply appalled me. I read – if you are going to market yourself, if you are going to try to get donor dollars to market yourself in terms of lifestyle is absolutely grotesque, to a viral disease. I am – this is my – I remember reading – was it in that magazine they wrote or another publication? – "I am proud with my HIV lifestyle." And it appalled me. How can you be? And I'm really happy and I am proud and I am living my life, and all this. I thought, well how on earth are you ever going to get – the general public is not going to give you money to support your lifestyle. This fatuous marketing which I saw, which to me is another indication of their incompetence, really I thought was somewhat revolting, and it also told me that they are probably off-key. The other problem that I had, and again, these people were well-meaning, but some of the outreach people that they had I thought were not competent to do what they were doing, and it was just sort of a make-work project. And that came to my mind when I went to one of these – the last event was an HIV conclave and – which really, I found disturbing because I am a secularist, and it began with basically an Aboriginal introduction, which to me was inappropriate, because it isn't an Aboriginal organization, it is a secular organization. No group is given specific reference, and then they had a prayer, which appalled me in light of HIV activism, because to me it was one of the supreme examples of secular activism and medical science combining to produce something remarkable, a cure, basically a medical – not a cure, but a way to deal with this epidemic and it had produced real results.

And so, we are drifting off into a magical world of superstition and sectarianism, which really appalled me. And then I went to their meetings and there was this guy who had dyed hair and he told me he could heal people from a distance, he just had to touch them, and he could heal animals too. And people were falling for this stuff, and I can heal people from a distance with my magical healing powers, and PWA was sponsoring this quack. And I thought – I was thinking of Jim Jones, and I am in some kind of cult. Then they had a leadership group, I knew the guy, well-meaning, but this wasn't leadership, this was, I think it was ego-building, because the leadership, these are going to be our leadership guys. And I looked at this and I thought, these are not leadership, and then they had people like, I don't know whether they had him under duress, they had the former Princess Diana as a leader. I just couldn't imagine that this was the most successful gold digger in the world – she got all this money form the royal family, she is an absolute bubble brain, how can you even talk to her in terms of being a leader? Just brought all these other people up which had nothing to do with leadership but had more to do with celebrity, which is different than leadership. And I thought, you folks are making these folks dumber, not smarter, less resilient instead of more resilient. And if that was my last interaction with PWA, and I don't think it has any real purpose now the disease has changed.

And what really impressed me was YouthCO and their transformation, because I talked to people, changing circumstances, they had basically reconfigured their mandate to deal with gay men's health rather than simply focusing on HIV, and I thing that is the direction PWA or Positive Vancouver, that is the direction they should move in. It is too late, there is too much heavy weight for them to do that, but I was really impressed with their ability to adapt to new circumstance. Friends for Life is an amazing organization, and I did a lot of work with them, but again they pretty well folded. They have risen again, but it is a qualitatively a different organization now. They have a remarkable volunteer infrastructure, and it has mostly evaporated. There are still vestiges of that, which is really a story to be told, it is one of the – I think there, in the 1980s, a remarkable period of institution building, and some remarkable institutions came about – housing societies, Friends for Life, the Dr. Peter Centre. I didn't like Dr. Peter much and even PWA, all these organizations appeared, and thirty years later, I look and I just see a puddle – they have more or less melted away in terms of their functioning as gay organizations. They may still function, but not really necessarily as gay organizations dealing with gay men's issues, which is the angle that I look at with many of these things.

And I am rather astonished, thirty years later in Vancouver, the medical establishment has produced – I would give it a bronze medal in terms of North America and in terms of innovation.

And epidemiology or virology, they have really done stuff in terms of health, preventing, stuff like this, and the gay activists played a role in that because, I am sure, because in the early ‘80s there was a shift over to the NDP administration. And prior to that, a lot of the gay activists, the nasty Social Credit party and Bill Vander Zalm, and when the NDP came, one of the best things that they could do was actually distinguish themselves form the nasty right wing, blah, blah, blah, is actually support gay organizations. So, I haven’t don’t the research, but I think under that regime, there was a lot of money that came in support of gay organizations in Vancouver, and they weren’t necessarily NDP. Mayencourt was a Liberal, a primary founding figure for Friends for Life, and I think that affected the medical establishment and produced a pace to produce the Centre of Excellence [sic], and I don’t think that would have come about. However, I may have denigrate the gay activist from here, but that gay activism provided a political foundation and a social space for the Centre of Excellence [sic] to come into existence. That is a speculation I have, and I think ultimately that will be the key legacy of that eruption in institution-building in Vancouver, it will be the Centre for Excellence, not the gay organizations, which are basically melting away, which is really interesting to look at. Which is not necessarily bad either, because organizations come and go. When they cease to serve a need, why should they not disappear?

But at least an issue of what you do with gay men’s health, because I think HIV has to be incorporated into a spectrum of health care, it doesn’t really stand-alone anymore. But nor should it exist in an organization like PWA, where you got a lot of straight people, you have drug, heterosexual drug population that is involved in that constituency and their needs are a bit different than gay HIV men. And I think it is time for that organization to fold and something new to come about to – a new spectrum of care to deal with gay HIV issues, because they are qualitatively different from heterosexual drug dealers in terms of what is going on, and how the infections occur. The same with other populations, and so I don’t know what is going to come out of that. But the most remarkable thing I can say about the explosion of community building across North America, and the HIV communities that arose out of gay activism is that it played a key role in triggering, on the medical establishment, to change and metamorphosis itself to deal with a virulent deadly infection in ten years, from its first identification to effective therapies. Ten years, an amazing short period of time. Without that gay activism I don’t think that would have happened. So, I think gay people can be happy, even though the gay organizations have faltered. The end result was a gift to the rest of humanity because most of the people being rescued from death from HIV are heterosexuals, not homosexuals, and that is an interesting thing to look at. Even if gay organizations come and go, what the end result, what came out of all this suffering, all this mobilization – and something quite remarkable in the medical establishment, to produce in such a short time these medications and protocols for people to address this killer viral infection.

And this is really quite remarkable, and I am one of the beneficiaries. When I came on the scene, the drug regimens were quite benign, but originally the regimes were as toxic as chemotherapy. Because I tasted some of them from the people that I knew – they said, “Taste this,” and I just spat it out. It was the most foul, wretched-tasting stuff you could imagine, this green fluid I don’t know what it was. But so, you know, no matter what criticism I have to make of the heroic community-building in gay activism, and there were heroic aspect to it, it led to a real shift in a real contribution culturally in terms of gay activism, in terms of branding diseases – the AIDS quilt, the red ribbon, all these marketing stuff, which all the other organizations are copying. And if you – cultural diffusion, what has come about, but now that is part of the past and what we are talking about is a period that is going to recede into history. There should never – people should never get as sick as I did through PrEP or whatever, and people should not have to go on disability, they should be able to work and prosper from here on in. We have entered a different period, but a challenging period for gay people. Getting back to how do gay organizations adapt or disappear, and I think it is an interesting time, I think that organization should fold. YouthCO I don't think should – they have found a very useful place in the organizational ecology. I think there is a challenge for gay culture or this thing we call this gay community, because you know in Vancouver, there is just a puddle, all these great organizations and potential leaders who may have existed, but they don't exist anymore, nor are there any great organizations. Friends for Life has morphed into a West End community centre – it still does good work. The Dr. Peter Centre, I think it deals as much if not more with heterosexual people who suffer from drug addiction rather than having this gay-centric focus, which originally, when it came into existence, that was its focus. The food services…

BK: Loving Spoonful…

BR: Yeah, that was a great organization and I knew the woman who led that and had fascinating conversations with them. Is that necessary anymore as this cohort dies off? Is that service required anymore because people shouldn't be getting this sick. Maybe, I don't know, but to me it involves a whole re-examination of this stuff. But I see no gay leaders. It is really interesting, there are gay people who are influential, but none of them identify formally with the gay community in terms of taking a leadership role, which is really dubious. I can't think of anyone in Vancouver or even in Toronto, although there are really successful entrepreneurs and people doing this and that, but it is really interesting when it comes to this so-called community, there is nothing. The gay and lesbian centre [Qmunity] is a shabby structure on the second floor of a commercial structure on Davie, and I told my doctor, what does this mean? And the city is putting away money for them to build a community centre, but I have changed my mind – should they really do that? This community can't raise funds by itself, why should the city? These are the thoughts going in my mind, or is it a community if it can't raise funds for itself, because you have all these gay people, all this money actually, and yet it cannot bring itself together in a common purpose to actually produce or create a physical space for itself. And I notice some friends at Friends for Life, for a variety of reasons, a gradual loss of interest in supporting that structure from the gay community. Did it have to do with the diluting of its mandate? They were taking care of cancer patients and on and on and on.

I also looked at the AIDS Walk, it is a non-entity now, and it is really interesting all these other diseases. In the summer there is usually a disease a week, and the AIDS Walk used to be the most significant on the calendar, and now it is almost invisible. And going to PWA, it might have been able to say at one time that it was a populist organization, it had a bottom up representation that represented the will of a lot of people, but I think if you went to the AGM, you might have twenty-five people show up. If you were a populist organization, you would have hundreds, so even its mandate, how it defines itself has been undermined by changing circumstances. And what you re-recording now is basically something, it is a reality that doesn't exist into the present. There are new conditions, the disease is a chronic disease, it isn't a terminal disease anymore, and so what does that mean in terms of institutions? And myself, I wouldn't – I represented a different era, I could not conceive of anyone, unless they had mental problems becoming that sick that they couldn't work anymore or function normally if you have an HIV diagnosis. It is a pain in the ass, you have to deal with, stuck with dealing medication for the rest of your life, but it is not disfiguring like it was even fifteen years ago. This will – could be a hiccup in our history, or memories of something that may not repeat itself, unless another epidemic occurs. These re the things that come to my mind.

And I did a lot of volunteer work at Friends for Life, and going back to that thing when people deal with death and misfortune, you have that tripartite, some people it brings out the social solidarity, the others, it brings out the worst in people. That is the other issue, I don't know how organizations deal with that, because those more negative people, they almost destroyed Friends for Life – they had a big crisis five years ago. A subset of people who were able to overwhelm the society, and they were stopped, but they could have overwhelmed and ruined this really remarkable institution. But eventually it dissolved anyway, and it was really sad because it really was something special, and that one house, they had so many facilities. And the volunteer aspect was phenomenal, and I was actually – to bring one of the key people into the non-profit, I was involved with to work with volunteers, because they are – if you talk about community value, those people, the benefit they produce, not only to the people they were caring for but to themselves, they became much better people through volunteering and it became a central part of their life. And if you talk about alienation, urban existence, for many of the people, I don't think they realized how important Friends for Life became to their sense of worth, and the sense of accomplishment, their ability to socialize with people. It was phenomenal to witness, so I will never underestimate the value of volunteerism.

PWA did a bit of this as well, and I can't denigrate what they did as well, but they did – I had a shabby experience, so maybe they improved what they did, but I speak out of ignorance on that. But it has been an interesting ride for me, and I don't know what is going to happen now. I think things are in flux, and it is interesting that you are documenting this stuff now because this could – everything, the conditions that created this epidemic and the form it took, the involvement of gay people and the way that they did it, is a part of the past, and it is a completely different reality that people have to face. It requires different approaches, I think, and again I am one of the lucky guys. I suffered a bit but I managed to – I was shocked at how quick my recovery was with medication. Again, going back to that conclave they had at PWA when the superstition that they were faith healing, I found that profoundly disquieting in light of what science had done, what activism had done, what activism and science had done, what remarkable results and improvement in human health that collaboration between activism and science and reason – not the descent into unreason and superstition – produce something really remarkable, and that is what we see now at the Centre of Excellence [sic] which I think is an enduring legacy. My existence is a legacy of that because I am recently fit and I can do things which really shocked me, and the fact that it is not going to kill a lot of people at least in North America of people who have Medicare.

But it is a challenge, how do you deal with gay guys, sexuality and all that stuff, irrational behaviour of men when it comes to sex and reason and those sorts of things? And I have been forced to look at all of that stuff. That is important – you guys worry about isolation and having boyfriends and that kind of stuff, which is interesting because the other thing is that people have

– they are terrified of being alone. So, that may be one thing that the gay community may have to deal with, neurotic gay men worrying about having boyfriends and being alone. And whether you are sick or not, I just see all of them having nervous breakdowns and joining self-help groups. But that is a real issue because – and it goes back to community again and how you define yourself. Are there community supports or does it even really matter, because if you are gay, is it only just one part of your identity? You have family and other people you are dealing with. But I know that a lot of HIV guys that I talk to from Toronto, one of their biggest background concerns is being alone, which is kind of a challenge, but I don't know.

You know, it's – I don't see that from myself as being necessary. If you have got a good imagination, if you have lived well, if you've fallen in love, you are actually never alone because even if the persona that you have loved is gone, you have these fabulous memories and connections which are real actually, and I believe they sustain you for as long as you live. If you are unfortunate and you have never experienced love or your parents hate you, you are really messed up and you don't want to – you certainly don't make boyfriend material if you suffer from those sorts of things. And I think for people in my age cohort, but even younger, it is going to be a real issue, and people looking for, misconstruing sex for intimacy, those kinds of issues present all kinds of health issues for gay guys that can lead into all sorts of problems with infections and bad practices if your primary imperative is to not be alone and the pursuit of sex as your main way of trying to resolve that issue. And I see a lot of gay guys that that is one major means of trying to resolve that issue of the fear of being by one's self, and the destructive forced coupling of gay guys who are not suitable as couples out of the sheer terror of being alone and being by themselves, which I find really interesting. Are there any more questions I guess I am skipping all over the place?

William Flett: I can offer a couple prompts, but I think of all the questions that we have, you at least lightly covered them. Perhaps if you want to go back, possibly to the beginning, just to like add a little bit more detail with the poison oak story. By the sounds of other parts of your story, that wasn't necessarily have an understanding of what HIV was at that time.

BR: No.

WF: So, what led you to believe that this poison oak infection was something specific to you?

BR: It was residual guilt from my mother, even though my mother was an atheist, from her German background. This was residual guilt to do with body functions and sex, and even expressions of affection. Although I liked my mother very much, we did not have a language to communicate, and one of the most embarrassing times in my life was when I was in grade eleven and I blurted out, "I love you mom," and it was absolutely humiliating. Ohhh, I have said the wrong thing. It just wasn't the mode of communication from the uptight German Lutheran background, and it did not mean that love was not present, but it was shameful to talk about sex, bodily functions. I remember asking my mother, "What is a virgin?" And she said, my mother, I became pals with her, I helped write her essays at university when – she was a remarkable person. "Ah, it is a woman who doesn't like men," so and so. And I got into trouble when I did the naked statue thing. Hey mom – I was so proud of my statue, a bit vain too. I sent her a picture and it went into the rubbish bin and never mentioned again. That was the issue, and it was a guilt response. It had to do with being gay which was a forbidden desire because I had always fantasized about growing up in a military base at a young age, looking, you know, and this and that, and knowing that this is forbidden without anyone telling me that this is the wrong thing. And then when it actually happened, the fact that it was forbidden and sexual, and the poison oak, even though I didn't really believe in God, this was divine retribution.

It was rather hilarious actually. I really looked like a monster. My testicles where like this, I looked like the elephant man. I touched my whole body, my eyes were slit, people ran away from me at the airport in San Francisco. If you have ever read Nathanial Hawthorne's *The Scarlet Letter*, this was my badge of dishonour, the whole world knows that I have had this sex with this guy. Got off the airport, ran to St. Paul's and pulled down my trousers, showed my shame, just poison oak, that was what was going on in my mind at the time. I was kind of ashamed of my body, so that was a real challenge because I had run out of money. I had to do the modelling thing, that was excruciating, I had to strip in front of strangers, I almost fainted. I am relatively shameless now, not to say that I am an exhibitionist, but if there is a reason to be naked, I am not going to go into a lot of this and that. Part of the issue was a hidden legacy, because my parents were not religious. My father, if anything was a pagan – he believed in Irish faeries. I went to Sunday school twice, I found religious people very depressing, so it wasn't overt religious indoctrination, it was just by osmosis. The sense of shame and bodily functions, those that were shameful, and sex was shameful. And to articulate affections of love – my father was different, he was Irish, but my mother it was really challenging.

And when I became her primary caregiver, it became a challenge to express to her that I loved her, because her autonomy was important. I had to be careful – I would say, this is medicine mom. I just picked up these things about massage, because I knew people that had cancer. And I could smell her body rotting, I realized that she probably feels unclean, but being the good gay son, doing everything I could for my mother, hey mom this is a massage and it is medicine, and I picked up the stuff you do with feet and they are attached to organs. So, I picked up this card, showed her, and said hey mom, I found this new solution. I am going to rub your feet, is that okay? I would also rub her and this was my way of – one legitimate way of connecting with her and making the declaration that I love you through touch. She actually reciprocated in a very biblical way. Her way of showing that she really appreciated was to – she saw my feet cracked and it was very difficult because of the cancer, she had lung cancer and it was choking of her esophagus, and it was very difficult for her to bend over, but she found a pail of water and washed my feet, which was very remarkable, and this was her way of showing that she loved me. This was the language I had to employ in her case. This is what I mean when I say I had to respect her autonomy.

And it is something I carried with me when I cared for this woman who died of HIV maybe three or four years ago, a really remarkable woman, a close pal – we would gossip. She was a den mother to the Vancouver Whitecaps, she actually managed one of the apartments, and she was such a delightful lady. This poor guy, he came out to his evangelical mother, and the mother cried, "You are never going to have a child, and what are my relatives going to say?" The cute soccer player, he did a bit of volunteer work at Friends for Life, and he would cry, and so she would have to mediate. "Mother, put your act together. This is your gay son. He really loves you and he is supplying you with all your money too, so you put yourself together and you treat him well." And it is really delightful, how she negotiated with this gay guy and brought the mother and son together. Things like this, really impressive people that I met, but it became really important when caring for her to keep certain people away, when she would tell me, "I really don't want this person around me." And this person didn't really mean to hurt her, he just was – well, he hated his father, so everything he did to help other people had this other narrative dealing with his own dysfunctional family. She didn't want him to be around her too much, but at the same time she didn't want his feeling to be hurt, so it became – part of the caregiving had to do with establishing buffers between certain people and other people and only allowing certain people to come into the immediate realm.

She ended up at St. Paul's and they were really phenomenal. When she realized she only had twenty-four hours to live and death approached with rapidity with her, and she cried with her girlfriend, and her girlfriend said, "There is still hope, but you don't want that thing in your mouth anymore." "No, I don't want that thing in my mouth anymore." It is really… see how animals – she cried, "Who is going to take care of my cat?" And that melted the nurse's heart, and she was a bit of a Prussian at heart, so all the protocol, 'cause usually to take someone from a regular ward to palliative involves process, paperwork, and time. She didn't have time – she didn't realize, but we realized she had about fifteen hours to live, and we were able to get her out of the fourth ward and up to palliative right away to get the respirator out and do the final vigil, and that was really quite beautiful in a way how that was managed. I was impressed with some of the people at St. Paul's, what they did. Some of the people that came to care for my friend and some of the – one of the housing societies – she was really worried about being homeless and her car payments, and I was really impressed. I went to them and asked, "Can you help this person out? It is going to really help her out if she doesn't have to worry about rent." And if anyone deserved help, it was my friend. I am infinitely grateful for the help they provided, and they had the means to do so at that time.

There still is – these organizations, some of them – I am not – they still do useful things, but the generic AIDS, like PWA, need to be rethought. Some of the organizations that provide support for people still need to be around for the time being. Housing issues for people with HIV – I am a recipient of some of that support and you really can't – because it is a specialized disease, and the visits and so on. I thought as I get older, can I actually leave the big city where it is cheaper? Actually, you can't because you need these specialized services, and that means you can't escape a high-rent environment. To me, that is a new pragmatic issue that might be dealt with at a governmental level, because if I lost my rent subsidy, I would be completely screwed. But at the same time, I have limited options because of the specialized disease I have. I have to see the doctor I have to get blood tests every three months, I have to get medications. If you go into the periphery, they don't have the medical expertise and competence to deal with these issues. There is an urban issue here as well as I thought could I move to a cheaper location, and I thought I can't 'cause how do I get my medication, how do I see a specialist who really knows what is going on? And I have heard some horror stories from the hinterland about doctors who are ill-equipped to deal with it because there aren't that many people suffering from this condition, or there aren't the facilities there. So, to me that is a question that still needs to be dealt with in terms of support and something the gay community or the HIV community, if you can call it that, it is something they need to look at in a more systematic way.

I was also thinking in terms of the shift of St. Paul's, what is going to happen if they move to the new site, how that affects the ecology of care, because the downtown south, in this area is an interesting ecosystem of different services you can access on foot. For instance, I walked here by foot. Basically, you can live and die in the West End. As one of the key administrators – I talk to, a few weeks – last year, a doctor, yeah, you can be born here and you can die here, everything you need is in this community. So, it is a question, I understand why St. Paul's has to go there, but all this dense – even HIV-related infrastructure has accumulated here. You have HIV housing in this area, you have got Dr. Peter Centre, you have got the Centre for Excellence housed in this area, so I wonder about that as well, because it really makes a difference for me, because if I need to see a doctor, if I need to have a blood test, I can cycle or walk. And I think that makes a big difference from the horrible years when I was caring for my parents in Maple Ridge, where I was doing the primary caregiving, it was so painfully isolated. Other questions.

BK: Did you get involved with any ASOs earlier in the epidemic, in the '80s or the early '90s? Or were you involved in any caregiving capacities during that early period?

BR: In the 1980s? Just indirectly. Again, when I was at the university, a lot of it was done by these ponderous liberal types – the new head of the department, oh, Bart's a fag, oh, happy AIDS day. Oh god, leave me alone, lady, and I thought that was rather condescending – she was a horrible person. I became involved indirectly because I knew doctors, but my entry into the whole HIV realm was coloured by being transferred to Vancouver to care for my parents, which lasted for six years. Prior to that, I didn't do much, I was an observer – I went to the march, passive stuff, I wasn't really involved. I talked with a lot of people. My quirky roommate who was a med student, he said I am going to discover – "I am going to discover the cure for AIDS," and he was flamboyant in that way. That stuff was going around – no, when I – actually, in 1996, the – when my father died, that is when the protease inhibitors came out. That was the game changer, when you actually had viable therapies, and I remember sitting with – typing the last chapter of my dissertation, and the radio was on, and they had the big AIDS conference was here. And I thought, oh, that is good – if I do get this thing, I might be okay. And I moved onto other issues.

I was aware of the flamboyance, the drama, which really impressed me, because I thought of this in terms of cultural innovation. This was the last gasp of a progressing Avant-garde movement using all this Dadaist, agit prop moves to get attention, and only gay guys firmly entrenched in the entertainment industries, and cultural industries could pull this off. And that flamboyance, the gay activism, and one of the reasons it was so successful, you had these middle-class gay activists and entertainers involved in the arts industries, being able to create these symbols and actually mobilize. And a lot of the stuff you see with ACT UP, it is sheer agitprop stuff from the '60s and Dadaist from the 1920s, and so there is a history to that, and you might well actually say that this was the last progressive flourishing of progressive Avant-garde, because what they were rebelling against was the middle-class establishment, and in this case, the medical establishment and the state. And they did it rather successfully in the very anarchistic fashion and it was productive, it wasn't nihilistic, unlike the shamanistic stuff I was talking about earlier. They were not negating science, they were challenging science to do something better – they were becoming researchers. So, New York, San Francisco and maybe Vancouver – maybe a gold star in New York, silver in San Francisco, a bronze for Vancouver in this AIDS drama. Less of what the AIDS community did, but because I think they were fundamental in establishing the basis for the Centre for Excellence, and if that activism had not existed, would the Centre of Excellence [sic] have come into existence in the way that it has here? And I suspect that it probably wouldn't have, but I don't know, I haven't done the research, talked to people, government people, what prompted them, because there was a lot of money they pushed into the Centre for Excellence which came from the province.

It didn't come from – it was quite different in Ontario, and if you look at their AIDS infrastructure, and if you look at the – and the PWA organization there is really bad as well, it is faltering, for your information. A lot of people have real problems with that organization, but if you look at the care and what they have done in BC and compare that to Ontario, it is night and day in terms of officially allocating resources, and dealing with the epidemic and controlling the epidemic in terms of PrEP and other things. This is the really phenomenal – I don't want to do the hero worship, but the people in the Centre for Excellence have to be commended. But again, giants rest on the shoulders of many other people and if that activism had not existed, would those people have been able to do what they did in the past and what they are doing now? That to me is an interesting question, and I can only speculate, but I think that activism was foundational for them being able to access resources to do what they were able to do. At the same time, I was doing my other non-profit, was involved in the Downtown Eastside in economic development and dealing with a marginalized population, and there was a crossover in populations in the work I was doing there. So, I was able to see what was going on from a number of different vantage points. They had the Four Pillars project that Mayor Owen had that was too extravagant, but still, it was a really dramatic attempt to address the drug addiction problems in the Downtown Eastside. And that was heavily infected with HIV infection as well, which overwhelmed the gay organizations that arose in this part of town and threatened their – well, threatened their viability to a certain extent from my perspective.

It is fascinating, if you can get the stories or analysis, you might come to some really interesting conclusions about what happened and what might happen in the future. I think that heroic age of institution that occurred in Vancouver, I think all of that has melted away, and it is not necessarily sad, it is the nature of civil society. Institutions arise to deal with crisis, and if they don't adapt, if they don't perform well, they melt away. But I think in terms of the gay community, if you can call it that, there is something troubling by the fact that there aren't any real structures remaining from that huge period of innovation and institution-building. Mayencourt, I am not a Liberal, but it was a phenomenal example of social entrepreneurship to promote Friends for Life and create this astonishing organization, and do so much, and now it has evaporated. PWA deserves to disappear, but all these other organizations, what I see is a puddle after thirty years. I guess a question, what needs to be done, or maybe nothing needs to be done, but in terms of – I suspect if you are a gay male, something needs to be done. I don't think the organization, that organization, is equipped, for a number of reasons, but some other organization, maybe HIM, but I don't know how competent that organization is. But I think there has to be a gay organization focused around men's health issues, because if your gay men's health issues, by their very nature deal very heavily with sexual behaviours and sexuality – that is just the nature of gay existence.

And I think – one would think in America it is different, because they don't have socialized medicine, it is a whole different ball game there. That is something that is a work in progress, something that needs to be created and a new mechanism to address men's health. Then in terms of organization, who is going to lead it? Who can be a legitimate leader? Many of the people who claim to speak or purport to speak for the gay community of gay men, I think they are illegitimate – they don't have the knowledge or the confidence to speak for the community, if you are talking about the community as a whole, and it is a real dilemma. And I have no answer – maybe you have some ideas. Maybe it doesn't really matter, maybe we are a consumer sub-group, we consume sex and that is all we are, a postmodern consumer sub-category. And you just have to look at the Internet – it is quite amazing, that has to deal with the selling of sex and desire and everything else, but is that community? That isn't community, that is consumption. I don't know, I am really torn. I think there is a community, but I think it is invisible, it is incoherent at this point and time.

BK: Anything else? Maybe a bit more about when you first heard about HIV and AIDS?

BR: It would have been when I was in Toronto. I was actually working at the Clarke Institute of Psychiatry as a security guard. I worked the night shift and gradually began to hear about things, and I remember the one time I was reading the magazine, one of the magazine shops in Toronto, and they listed some of the symptoms that indicated infection, and I had had all these symptoms. And I remember this flood of adrenaline completely overwhelming my system, and going into a bit of a panic. I remember Winnipeg, when I moved back to Winnipeg, all the people I knew on an informal basis, dying off one by one. The nurse that I knew, he was very thin and then disappeared. And then the very flamboyant drag queen, the lady in white who used to walk down Portage Avenue, suddenly – used to live wither her old mother – suddenly disappeared. It was an ominous disappearing act – it was like a dark cloud approaching closer and closer, and then eventually engulfing me. But before that dark cloud engulfed me, I had to deal with the stuff that I had to do with my parents, which sort of took me off on this other tangent.

And I guess the other thing was my good friend in Toronto, how he dealt with it. I don't know if they were boyfriends, but his roommate or friend, he died of AIDS, but he was really severely disfigured by KS. You know, when they would go into a restaurant, people would stare – he would try to put some makeup on. He really suffered a lot out of vanity, too, because doctors wanted to – he developed rectal cancer, colorectal cancer and he refused to have himself outfitted with a colostomy bag, so his end years were excruciating because of that, because every time he had a bowel movement, he had excruciating pain. And so, he suffered a lot of – he was a tough guy because he got into arguments with Margaret Atwood, and an antique collector, and I remember him bragging how he bested Margaret Atwood over a sell, over one of her antiques at her yard sale. So, he was a really dynamic guy, but his whole family completely threw him under the – I don't know the metaphor, but had no interest in taking care of him. My friend became his primary caregiver, and so those were my experiences, people caring for other people. I was caring for my parents. Again, I go back to the most phenomenal thing that sticks with me, and it does say that there is a gay community and gay communities involve gay men and lesbians – it does exist. Because what I see erupt out of this need, this sense of altruism was astonishing in Winnipeg and other places. And even in Vancouver, when I became ill, some of the most helpful people turned out to be lesbians, which surprised me – well, not really. Maybe guys are too competitive, I don't know what is going on there.

I was really surprised at how – and when my lover – actually, I did fall in love when I had HIV, and I did care for him at St. Paul's. Actually, I forgot to mention that. He was a really sweet man. When I was diagnosed, they had this – there was a guy that was doing these men's touching sessions, and I was offered a scholarship – body electric, that was it. It is really kind of a scam – basically, it focuses on tantric sex, so they threw all this new age stuff, new age Catholicism. But anyway, I got together with all these naked guys, rubbing each other's genitals, and this is supposed to be community building, and you are looking in each other's eyes. And I was feeling better on my medication, and touching guys, well, that is a good idea to me. Then we had this whole elaborate ritual – we would take each other's clothes off and stare into each other's eyes, and do this and that, and twenty-four ways to manipulate his genitals, round the penis and the testicals, and look into their eyes. And you are not supposed to ejaculate, you are just getting the body gripped up, and this went on for two days, huffing and puffing and this and that, and meanwhile in the background there was this guy that really fell for me. I didn't see him because he was crying, he was kind of overwhelmed by it. And two year later, I saw him at a party – he was drunk and he came up to me. He knew this pharmacist – "I really like you. You may not remember me, but I was at that retreat with all those naked guys." And he was really attractive, and then he insisted, he demanded that I follow him to look at this Christmas tree he had decorated from his pharmacy friend.

So, he took me home and we threw up all over each other, then I basically didn't leave his bedroom for about forty days. And he told me, "I almost killed myself because I lost my job at St. Paul's." This is when they got rid of the unionized labour force – that job was really important to him, it provided stability for him. And then he told me about going to San Francisco and being involved in drug taking with this demonic gay guy, and how his former boyfriend picked him up at the Vancouver airport and brought him home, and I almost died. And then he gave me a special key, "But you are going to be my last boyfriend." Hm, wow, and there was just this phenomenal bond which I could say, of sheer caring, and it was also – he lost his work and he had to go on disability because of the HIV thing, so I took his hand and took him to the welfare office to go through the humiliating procedure. Then I took him to AIDS Vancouver and showed him to the nice lesbian woman who processed me, and he gave her a key and told her his story, and we became… And then I got him – I was really concerned, he would try and impress me – oh, you have all this education. He would read all these books, and he would say, "Oh, these books give me a headache. And I said, "[Name], I don't care what you think, I just like being with you." So, we were kind of like puppies, playing in bed, and he volunteered at Friends for Life and got him doing that.

But gradually things began to fall apart because losing completely decentred him, and then again, I guess what the key issue was, the horrible relationship he had with his mother, and he didn't feel he was a person that was loveable. So, that led to a really dramatic spiral where he was admitted to St. Paul's, and from that point on he acquired a drug resistant infection which eventually killed him over a period of over a month and a half. I forgot to mention that I did actually fall in love with a gay guy and it was really remarkable, but it was also bittersweet because of the HIV thing. And he was a really sweet guy, and all of his girlfriends and his parents came down from [town], and his father and his twin sister, and the father was inconsolable, so he would go into a room and cry. These were people who were completely separate from his life, but they came here for his funeral. And if you remember the Rod Stewart song about the guy that comes on a bus and goes to New York City, it reminded me of my friend. And that was the other point and his – he had really good care here. The other thing, he had an empathetic doctor, and so I actually – interesting that I had forgot to mention that, it was a huge gap. I thought I am never going to fall in love with a guy – and sex was actually peripheral to it, it was just a remarkable sense of caring which will sustain me for as long as I live. If I never fall in love again, I have had that wonderful experience of falling in love but real love. A lot of gay guys, when they call it love, it is something else.

But that is something that happened to me because of being involved with the HIV community, because I wouldn't have met him, the circumstances, all of his past boyfriends were HIV positive, and I met all of them. So, it really introduced me to another world, and it also showed me – you mentioned the thing about being lonely, and about people being fearful and being lonely, and I thought about that, and it really is an inoculation. If you have actually loved someone, if you have actually had that authentic experience, I think it inoculates you from the dread of ever being alone. I don't know if that makes any sense for people who have fear of being alone. If you have had that wonderful remarkable experience, and it doesn't – it can be anyone actually. And I see it in my straight relatives, they wonder – they told me – my sister behaved poorly when I cared for my parents, so she doesn't know that I am gay or HIV and I reconnect with them, they always ask me, why don't you see her? I don't think I ethically have to talk to her anymore for these reasons, and it was really interesting, these were straight people – aren't you worried about being alone? And they were really earnest, and they really cared about me, and then they talked about their relationship with each other, brother and sister, and that is when the truth came out, the absolute fear of being alone, which was quite amazing, it flabbergasted me. Behind all of this, there is that fear of being alone, and I see it in my straight relatives, and it must be even more prevalent with gay guys. And I don't know what you think about that, but it is something that I think about.

And I don't know if having a caring, more caring community can do anything for that, because that depends on people, individuals relating to each other and their capacity to care for each other, and actually to – gay guys can be very narcissistic too, so dealing with those issues too. Because it is impossible to falling love with someone if you are very narcissistic, because if you really fall in love you actually have to think of that person – that person becomes part of you, and if you are a narcissist, you can't do that. That is sort of not a predominant stream in gay socializing that I see in my gay friends who are looking for boyfriends, HIV positive or not, and that might be one of the challenges in guys who like guys. And even if you have got HIV and that need for pair bonding, that powerful need, you know it is there, that could be an issue. And I remember going to a few support groups – PWA, the first year, they often talked about guys meeting up and connecting, that was an important issue. Would they ever be able to have partners? Sex is easy, but actually going beyond the sexual aspect to actually have the emotional maturity to actually have the capacity to care for someone, which is wonderful because it takes you out of yourself, that might be a challenge for gay guys and HIV guys. Who knows. Anything else? I am kind of babbling, going all over the place, just a stream of consciousness.

BK: You have covered most of our questions.

BR: Indirectly, I don't want to be too negative, I don't want to criticize people in any group, any HIV, gay or whatever. There are good and bad people, but if you are going to organize and do things, if you are going to help people, you really have to have a means to get rid of bad actors, to stand up to bad people who can break apart organizations and harm people, and that is what – that would be one thing. I never met so many – since I entered the HIV system, emotional people, since I became involved in the HIV organizations and disability organizations. I have my suspicions, but that is not the majority, but huge number of people who are really damaged, and that is unfortunate for them, but it is also unfortunate for the organizations that arise to care for people, because they can also disrupt the organizations. And I don't know how you organize protocols to limit the damage these people can cause. And finally, the issue of leadership, competent leadership, it is a problem in Toronto. The guy who was instrumental in establishing – he was a gay HIV guy who established the AIDS organization in Montreal, became chums with him, and again it was something that he brought up, corrupt people and people gaming the system. So, I don't know, it is a challenge, and to keep those things in balance, and you have to be careful because I know a lot of volunteers, HIV people who used to do a lot of volunteer work have become inactive because they have become put off by people's sense of entitlement. So, it has diminished people's ability to volunteer, and I see that in myself because I used to volunteer extensively at Friends for Life, but after talking with some people, I said, I am not going to do this anymore. These people have to behave properly, I am not their slave, and being sick does not mean you can act poorly or unethically. Weakness or even imminent death is not an excuse for bad manners so that is one thing I have also come to the conclusion of. Not only dealing with HIV guys but others who are dying as well.

BK: Unless you have anything you want to ask we can leave it there.

WF: Yeah, can't think of anything extra.

BR: Yeah, all right.

BK: Well, thank you so much.