“HIV in My Day” – Interview 82

April 23, 2019
Interviewee: Richard Macnab (RM); Interviewer: Ben Klassen (BK)

Ben Klassen: Just sitting down with Richard this afternoon. Thanks so much for being here and agreeing to share your story with me. I’m looking forward to hearing it. Just to get started, could you tell me a bit about how you first started connecting to the gay community or engaging in gay life?

Richard Macnab: I guess probably when I was about eighteen – or, yeah about eighteen years old in Calgary, when I was still living at home in Calgary. And I think like most young gay guys, started off in parks, meeting guys in parks and playing around, and then I met my first partner in – god, when would that be? I guess it would be ’85 – no, it was before that, because it was before I moved out here, so it would be about ’83 I guess, yeah, is when I met [name]. And he was my first love slash long-term partner, but he passed away from AIDS in ’93, as did most of my good friends – or they died between about ’88 and ’93, ’94, ’95, ’96 – up until the new meds came out in ’96. What’s the next question?

BK: I was going to poke a little more about what gay life was like in Calgary at the time. Was there a lot of formalized gay institutions, like bars and stuff, there?

RM: Yeah, there was lots of bars and lots of bathhouses, and lots of sex going on. It was just the way it was. It was a different world – it was a very different world back then prior to AIDS and HIV, and much freer. You know, all the bars had back rooms, and it was just the way it was – every bar had a back room. Yeah, it was just the way it was.

BK: And when did you move out to Vancouver?

RM: I moved here in ’94, because I was applying to UBC and UVIC, and I got accepted at both and basically had my choice of where I wanted to go to school, and I chose Vancouver. That’s what brought me out here and I came out here with my partner. Yeah, lived a pretty wonderful life for the first few years, and then I remember I guess about ’86, we started reading in the newspapers about the Kaposi’s Sarcoma and the rare gay cancer, but at that point, it was still pretty much localized to LA and San Francisco and New York, and hadn’t really been affected by it here in Vancouver at that point. I just remember it wasn’t very long before it started to, before Vancouver did start to be affected by it, and then we started seeing more and more signs of people getting sick and sort of seeing people on the streets here covered in Kaposi’s Sarcoma lesions, and just the wasting disease back then. It was starting to get scary – it was starting to get really scary about ’88, ’89. And then, like I said, the majority, I’d say eight of ten friends died before ’96 – everybody died. That’s what we used to joke about was it was the trendy thing to do was to die. I know, it sounds kind of morbid now to say it, but it was just if you didn’t laugh about it, you cried, because it was just so awful. I remember my first friend I lost, [name], I lost him in – I guess [name] was gone by about ’88, and then there was [name] and [name] and [name], and then my partner, [name] – it was just everybody, everybody I knew pretty much. And… I’m not sure what else to say.

BK: How was the community here in Vancouver responding at the time?

RM: Oh well, it was wonderful. That's the one time in my life – not the one time in my life, I shouldn't say that. But that's one of the times in my life that I was very proud of my community, because nobody else wanted to even touch us. Like, I remember paramedics refusing to even touch us if they found out we were HIV positive, and it was just dreadful. And that's when my community, including my gay sisters, really came together, and we built BCPWA and AIDS Vancouver, and went on to build the Dr. Peter Centre and Friends for Life, and we did that all on our own, because nobody else was helping us back then – in fact, nobody even wanted anything to do with us, let alone even acknowledge the fact that there was this disease that was just decimating our community. So, we rose to the occasion, you know? Yeah, it's one of the times in my life when I've been the most proud of my community was how we responded to that terrible, terrible time.

BK: Did you get involved with any of those organizations?

RM: Oh yeah, I didn't take my long-term disability myself until '93, because I had just graduated from UBC in 1990 and so I had put off getting tested. My partner already knew he was positive and most of my friends were already positive and either getting sick or knew they were positive. So, I didn't need to find out because I just thought, you know, what is that going to do to my ambition if I find out that I've got a death sentence to look forward to. So, I put it off and I put it off, but then [partner's name] passed away, and I lost [name], my best friend, and my partner, [name], in '93 – they both died the same year, and after that, I had to know. So, I went and finally got tested, and sure enough, I was positive, which I pretty much already knew. And then I got quite involved once I took my long-term disability, because at that time, when you tested positive, your doctor just told you, "You have to take your disability because every day you continue to work will cause you stress which will kill you that much faster. So, you need to take your long-term disability and get your affairs in order. You have five years." I remember being told that point-blank by my doctor and just thinking – just leaving the doctor's office that day kind of feeling a bit numb, but that was just the way it was. And pretty much once I found out I was positive, for some reason I was able to maintain my health for longer than most of friends and my partner. I think it's because I was in school a lot of the time, so I wasn't out partying with everybody else, I was home studying.

So, I didn't get sick myself until – I started to get sick in the summer of '96, and then by Halloween, I was admitted to St. Paul's Halloween night with severe PCP pneumonia. I'd already been home with horrible night swears and nausea and fever for a few weeks at that point by the time I was admitted to St. Paul's. And I remember being admitted to St. Paul's and I remember quite clearly it was Halloween night 1996. And then saquinavir, the very first of the new protease inhibitors was being given on compassionate access, it was available at the very beginning of November and my doctor – I was one of the first patients that was granted access to saquinavir in 1996, and what can I say, it saved my life. It turned everything around, and who would have ever guessed it was going to turn things around as much as it did. Because here I am, what, twenty-three years later, and it's crazy, but I've never been as healthy as I am now. And I've gone on to beat colon cancer, which was again related to the HIV meds interacting with another virus that caused my colon cancer or my anal cancer, but I survived that too – I beat cancer, survived that. And then most recently, I've had a heart transplant in 2013. But in the big picture, now I run five days a week, I've got a dog, I work part-time – it's not so bad, you know? But who would have ever guessed?

BK: That's amazing.

RM: Yeah, it's pretty remarkable. I remember the heart surgeon talking to me about it and saying, "Well, you've got somebody up there looking over you. You must be here for some reason." And I said, "Well, I just wish I could figure out what that reason is," but maybe it's so I can tell this story – I don't know. Anyhow, here I am.

BK: Wow. With saquinavir, was it this really dramatic, instantaneous…?

RM: It was unbelievable actually. Like, I was so sick, and I remember when I was first admitted to St. Paul's, they were only giving me a 70-30 chance of dying – like I had a 30% chance of living. And then I started the saquinavir, and god, within about six weeks, it just turned everything around. I started gaining weight again – like, I was down to 101 pounds, I think – it was either 101 or 103. I'd lost a lot of weight, and it was definitely wasting disease, because that was one of the big killers back then, right up there with KS and PCP and thrush and cytomegalovirus, the one that caused you to go blind. God, it was a terrifying time, it really was a scary time back then. Yeah, but here I am – who would have ever guessed? I don't know what else to say.

BK: I can poke around a little more, but just let me know if I'm going anywhere you don't want to go.

RM: Sure.

BK: So, information back then, what was there out there, thinking back to the mid '80s when you were first hearing about HIV?

RM: Not a lot. That's back when they were calling it GRID, gay-related immune deficiency, and yeah, there wasn't a lot of information. They had no idea how – well, they suspected it was being sexually transmitted, but they had no real positive proof, at least not that I recall – possibly I'm wrong. But I think once they had actually isolated HIV, which I think was in '86, then they knew definitively that it was being sexually transmitted. And then the big push for the safe sex. But I remember at one point having this attitude that I was HIV positive and I was going to die with everybody else – what does it matter if I have safe sex? And I don't really remember being unsafe when I was out and about, but I wasn't out and about a whole lot. Again, I had a committed partner up until '93 at least, and after '93, between '93 and '96, I don't remember a whole lot of promiscuity, just because I was grieving so much and I was starting to get sick myself, which usually doesn't lend itself to having a really active libido. But there wasn't a lot of information out there. The only information I recall off-hand is to make sure you have safe sex, and that's about all I can recall right off-hand. Ask me some more questions.

BK: Sure. So, there was an emerging consensus around using condoms?

RM: Yeah. But everybody hated using them because they didn't promote an erection. Yeah, it was just – thirty years ago, the condoms thirty years ago were different from the condoms these days.

BK: And gay men weren't used to using condoms.

RM: Not at all, no. No, not at all. In fact, I remember going to the bathhouses, and the bathhouses used to sell little Dixie cups full of Crisco for fifty cents a Dixie cup – everybody knows that Crisco and condoms don't go well together. But that was just the way it was. It was just a different time. People were trying to get their head around practicing safe sex, but it's like you said, prior to AIDS and HIV, gay men just weren't used to ever even thinking about condoms, but when we started seeing how sick people were starting to get, it gave more and more people incentives to be safe. And I remember friends of mine from San Francisco being so terrified of seroconverting that they would douse themselves in bleach after having sex with somebody – even though it was safe sex, they would still go into the bathroom and pour a bottle of bleach over themselves, because that's how scary it was – like, that's how scary it was. Young men in their prime dying, and not just dying but dying quickly, like from the time they first started feeling that first bit of sickness, like nausea, to the point where they were dead sometimes was a few weeks. Other times it dragged on for a few years, but it was – we called it the rollercoaster. It was just a series of ups and downs and then you would finally finish the ride.

BK: And really horrifying, graphic deaths.

RM: Yeah, it was awful. It was awful. I remember my good friend, [name], when he died, he was thirty-one and it looked like he was turning ninety-one. I remember going to see him in St. Paul's the last day he was alive and thinking, oh my god, he looks like he's ninety-one and he just turned thirty-one. Yeah, it was pretty gruesome. And here was a guy who had been 180 pounds with a solid build, and he was probably down to about 105 pounds, 110 pounds by the time he died. There was nothing left, he was just a skeleton. But I'm not kidding, he looked like a ninety-year-old, little old man lying in that hospital bed – I still remember that quite vividly. And [name] too, my partner, by the time he passed, again, he was about 180 pounds and solid, and I think he was about 110, 112 pounds when he passed away – he was just a skeleton again. But that was just – that was how everybody was dying. So, it would start with PCP usually – one or two bouts of PCP, and then the KS and thrush and the wasting, and it was usually just a matter of time. And I thought I was well on my way out as well, and then came saquinavir in the fall of '96, and here I am twenty-three years later. Yeah. I don't know what else to say.

BK: What did support look like back then for somebody who was HIV positive?

RM: Well, within my own community, within the gay community, we were great. It's like I said, we built BCPWA in no time – that organization was up and running. And we basically were looking after ourselves, because like I said, nobody else was looking after us and nobody else even for the most part wanted to touch us. It was awful – it was just awful for about ten years there, it was really nasty. I remember even my family, like I thought, oh my god, it was tough enough me being gay, but when I was diagnosed with AIDS… And how they found out was one of my good friends I'd gone to university with, when I was admitted to St. Paul's with the really bad pneumonia, the PCP in fall of '96, he actually thought he was doing me a favour by contacting my family. Like, most people would just think that's a no-brainer, you've got to call his family and let them know how sick he is, but they had no idea and that's how they found out. And all I remember is waking up in St. Paul's one morning, so sick, and there were my parents standing there. And I thought, what the fuck, what are you doing here? But least to say, that's how they found out, and they were pretty great actually, the way that they handled it.

And I actually ended up going back to Alberta after I'd been discharged from St. Paul's for about – I think I was home for about three months, and I just convalesced in my parents' home. That's where the weight started to come back, and I remember my parents even commenting on the remarkable – how well I was getting. Everybody was because nobody would have ever imagined that the triple combination therapy was going to be as effective as it was, but it was. And next thing we knew, all these people that were on their deathbeds, myself included, were suddenly rebounding. And here I am, twenty-three years later. But on the other hand, to have the drugs that saved my life interact with another completely unrelated virus and cause my anal cancer in 2001 – of all the health issues I've been through, that was probably by far the worst, was the cancer, because the radiation and the chemotherapy, and I spent two years at the cancer clinic. And the process basically neutered me, and I haven't had much of a sex life since then. But you know, life goes on – you find other things.

BK: Even those early effective drugs had some pretty nasty side effects, I know.

RM: Yeah, very nasty. Neuropathy and – and also, who would have ever guessed that there was going to be an interaction between the AIDS drugs and HPV that would go on to cause cancer? Yeah, that kind of sucked. But on the other hand, I've beat cancer now too. So, I'm a survivor, that's for sure.

BK: No kidding.

RM: Yeah. Sometimes I don't really quite understand why, but I'm a survivor. And I'm, you know, very grateful to still be here to tell this story.

BK: Where does that resilience come from?

RM: I really don't know. I really don't know to be quite honest, because I often wonder that myself, because it's – I don't get it from my parents, because my father is still an alcoholic, my mother died of alcoholism when I was fourteen, my step-mother is still an acholic. And I've never been an alcoholic. I think that's just because – I don't know. I don't know where it comes from. I really don't know. I just know I'm a survivor. Maybe it's because I feel as though there's social functions that there's no damn way I'm going to miss out on, [laughs] and so I'm sticking it out just so that I don't miss those parties. [Laughs] And there's a lot of wonderful stuff in life too, you know, like my dogs and my friends. And it can be very frustrating at times too – like, it kind of sucked being told to take my disability in '93, because at that time, I had quite a career looking ahead of me. I had just finished doing an honours degree in molecular biology at UBC in

1990 and then to be told in ’93 that you have to stop working and take your long-term disability, and I never have been able to have any kind of career since then. I’ve gone back to work part-time in the last four years since the heart surgery, but it’s been pretty simple jobs, like working at the grocery store, and I worked at the art gallery for a little while until I found out that standing on concrete for hours on end was not good for my body. You know, just the fact that I’m here being able to go back to work part-time is pretty remarkable.

But I think I still grieve my career, you know, because at one time I thought I was going to have quite the career ahead of me, and it’s turned out that I’ve lived quite a meagre – at least financially, I’m a poor person. I think that’s probably the one – one of the toughest parts, I still find. I still find that at times I think I wonder if I really made the right decision taking my long-term disability back in ’93, but at that time, it was just a different time. And if your doctor told you that you needed to do this, because basically that’s the way it worked was that if you kept working, you’d die even faster. And so, we were all taking our long-term disability and then I think a lot of us were doing our best to basically party ourselves into the grave, because we were just going to die anyhow. Yeah, it was a different time.

BK: Part of what we’re hoping to do with this project as well is to look at what the needs of long-term survivors are in the present. A lot of folks are still on long-term disability from this time, and that can be a tough existence.

RM: Yeah, who would have…? And then, what was it? Three years ago, Canada Pension Plan long-term disability, they actually cut me off, because they said if you can work part-time, you can go back to work full-time. I said, “I’ve been on long-term disability for twenty-three years and you’re telling me that – you’re the one that encouraged me to go back to work part-time, and now that I have, you’re telling me that you’re cutting me off and I have to go back to work full-time?” Well, thank god for provincial policies, because all that happened is that I had to go to the province, but thank god that they said, “No, we’re not expecting somebody who’s been on long-term disability for twenty-three years to go back to work full-time. We’ll just top you up by the same amount that CPP has cut you off.” But I couldn’t believe that they actually cut me off after twenty-three years, you know? But that’s how much HIV has changed these days, you know? So, in some ways, it’s wonderful, but when it comes to a long-term survivor’s sense, it’s frustrating, yeah. To have my income taken away because they’re saying, “Okay, well you can go back to work full-time now.” Well, no I can’t. [Laughs] Yeah. Part-time, I can – I’ll agree, part-time, I’m capable of that, but I find that part-time even is taxing enough, and so I can’t imagine going back full-time.

BK: The meds around today, do you have side effects with those at all?

RM: Well again, I’m one of the very, very, very fortunate few in that I’m on the same combination, triple combination regimen, that I’ve been on I think for about twelve years now, and my doctor’s attitude is that as long you’re not experiencing any side effects and as long as you haven’t developed any resistance, that if it ain’t broke you don’t fix it. Because I was talking to her at one point about trying out one of these one pill a day regimens, but as she made me realize, it’s just three pills that have been combined into one, and her attitude was, again, don’t play around with something that’s not broke, because this way we have all sorts of options down the pipeline if we should ever need them. Carol Murphy – maybe I shouldn't have used the full name, but my doctor at the time, she said, "You account for about two percent of my HIV patients in the fact that you're just doing phenomenal on the regimen you're on, so in other words, let's just stay the course, as long as you don't mind." I said, "No, I don't really" – I just thought it might be more convenient to only have one pill a day, but I guess three pills a day is not a big deal. I find that being compliant, and I miss very few doses, because it's just morning pills – I've gotten used to it. I don't know what else to say.

BK: I might have a couple other quick questions. Do you remember anything about how the government was responding back in the '80s and '90s?

RM: They were awful. They didn't – they weren't even acknowledging the fact that – I remember in the States, Reagan wouldn't even acknowledge the fact that we were dying in droves, you know? And I don't really recall off-hand whether it was just as bad here, but I don't remember it being all that much better. I just remember that in the '80s, there was just so much stigma attached – like, once they had identified HIV and they could actually diagnosis you as being HIV positive, there was just so much fear. And I remember people being afraid to drink out of glass that we had drank out of, even though it had been through a dishwasher, but that's how much stigma there was revolving around HIV. And I guess rightfully so, because if you saw the way people were dying back then, it was terrifying – yeah, it was terrifying.

BK: But I imagine a lot of those fears and the stigma stuck around for a lot longer even after there was more information out to the contrary.

RM: Yeah, we're still dealing with a lot of stigma surrounding HIV, but these days, the stigma has almost evolved somewhat. Like, these days, if you go into a community health clinic, or just a walk-in clinic, and you identify yourself as being HIV positive, they just jump to the conclusion that at one point you've used IV drugs. And it's like, you know, there's still some of us around that got it the old-fashioned way [laughs], from having unprotected sex back when we didn't know any better. And that's the way that stigma has evolved. Like, it's gone from everybody just basically knowing that the way it was transmitted was you were having unprotected anal sex, whereas it's true, these days, I've had to correct medical professionals and just say, "Look, no, I've never been an IV drug user. I got it back in the old days." [Laughs] It's interesting how – but there's still a lot of stigma revolving around HIV even these days, it's just it's evolved just like the treatment has.

BK: It's interesting because obviously initially it was the "gay disease."

RM: Oh yeah, it was the "gay plague."

BK: And now it's not.

RM: No, not by any means. It's evolved. In fact, [name] – I shouldn't use full names. A friend of mine who's chairman at BCP- or Positive Living these days, he was trying to convince me to come back down and do some more volunteer work at Positive Living about six months ago. And he was saying that – he goes, "You are right in the assumption that 90% of people accessing services down at Positive Living these days are IV drug users. It's just the gay guys, we just run the place." So, it's evolved in that sense. And it's true, I don't have much to do with those organizations anymore, just because the crowd that for the most part is in there, it's quite a rough crowd, and it's not who I am – it's not who I've ever been. And I find that they can be a lot of work to have to deal with – a lot of angry people, a lot of… And I can understand somewhat where it's coming from, but on the other hand, I don't necessarily want to have to deal with it myself. It's not who I am or ever have been, you know? It's evolved.

BK: What did your involvement look like at those organizations when you were involved?

RM: Oh, I volunteered with Treatment Information with Positive Living from – god, from the time I took my long-term disability, which was '93, right up until I think pretty much 2001, 2002. I volunteered with Treatment Information and I was very involved with them, but then I kind of got burned out on HIV and took a break. Well, 2001 – that's right, that's when I left Positive, or BCPWA, because 2001 was when I was diagnosed with cancer and I had to just remove myself, because I was dealing with cancer. Since I've beat cancer, I've just kind of concentrated on my health and my dogs, and now the heart surgery. But the heart surgery is what really changed things dramatically, and now I've gone back to work part-time, and I run five days a week, and it's pretty cool.

BK: It sounds like you're in a good place now in a lot of ways.

RM: Getting into a better place. Still working on it. Yeah, still working on it. I think at times, being on long-term disability can be – it's frustrating because it's just – at times, it's not really living, it's just existing. The working part-time is what's allowed me to live a little bit again as opposed to just existing, and I think that's the problem with long-term disability is it can be a bit of a trap. But who'd have ever guessed that we were going to be on long-term disability for as long as we have been? You know, I was originally told five years – get your affairs in order. And that's what I did, I got my affairs in order. And it was just about right on schedule, but then came saquinavir and changed everything. Yeah.

BK: I know the Treatment Information component of PWA was innovative at the time and doing a lot of their own research. What was it like to be involved in that?

RM: Oh, it was really interesting actually. In fact, I used to be involved with what was called the Treatment Information Project, the "ABCs on the Road" show, and we would travel all over the province, and we would talk to doctors and nurses and all these small-town clinics and hospitals, and we'd talk on all the recent treatment updates. And it was actually very interesting and very rewarding, and I miss it sometimes. But again, by the time I was dealing with cancer, I just thought, okay, I need to take a break from HIV. I'd been living HIV for twenty years at that point and I had to deal with my cancer, so I let all of that kind of go, and I'm just starting to – just this last year I've done to PLDI [Positive Leadership Development Institute] training through Pacific AIDS Network – I've done the core training and the communications training, and I've been thinking about going back to work in my community. But I'm not sure – I'm not sure whether it's necessarily what I want to do anymore, just because HIV has evolved – it's a lot of drug addiction now these days in HIV, and I think it takes a special person to work with that community, and I don’t think that I’m one of those people. I don’t think I have the patience, to be quite honest.

BK: So much of that work is peer-oriented, and you’re not a peer in that part.

RM: No, I’m not. Exactly. Because it’s never been who I was or who I am. Yeah, I find that that community can be very trying at times, you know? I try to be compassionate, but at times, it’s trying.

BK: There are still a lot of young gay men getting HIV, so I don’t know where they are in terms of organizationally…

RM: Yeah, well that’s – I think they’re all going to Health Initiative for (gay) Men these days, because Positive Living and the Dr. Peter Centre is – until they started up this recent Wednesday night men’s group at the Dr. Peter Centre, the drugs have just – it’s just, there’s a lot of drug usage going on. Again, it’s not who I am, and because of it, I’ve stopped going to a lot of these organizations over the last few years, just because it’s not who I am. I don’t know how else to put it.

BK: That Wednesday night group though sounds like it’s…

RM: Oh, it’s fantastic.

BK: … Long overdue.

RM: It’s fantastic. It is. It’s been so long overdue, and it’s wonderful. It’s a small group still – there’s not that many guys, but it’s growing continuously, because there’s still a lot of us out there that have been living with this now for twenty-some years, you know? And we still have needs too – we still like to have our little social groups, and social groups where we’re not having to deal with people who are high on drugs, because at times it can be a bit trying. Anyhow, I think I’ve developed almost a bit of a prejudice towards drug addicts and IV drug users, just because – I don’t know, I just find them very high maintenance. And because of that, I’ve stopped going to these organizations that my community built, you know? But the Wednesday night men’s group, all of us there agree that that’s what we love about this new Wednesday night men’s group because all of us felt almost pushed out of these organizations that we built. But it’s just the evolution of HIV. You can’t say, you know, “You can’t access services here because you have an IV drug habit.” You can’t do that – it’s HIV these days.

The Wednesday night men’s group, the way that they’ve kind of gotten around that is by stipulating fifty or older – you have to be over fifty just to go to that group. And by doing that, right away you eliminate the drug addict portion for the most part – it’s guys like myself that have been living with this virus for thirty years now. And it’s kind of nice to have a group of guys that we meet once a week, just as a support group and social type thing. And in fact, I’ve recently met the first guy that I’ve dated in eighteen years, I’ve just met him at that. Six months ago, we’ve been seeing each other now. It’s been really nice actually. Who would’ve ever guessed that I was going to be falling in love again? And he’s a wonderful man, he’s a retired school teacher, and he's got a lovely condo right on the park. Yeah, it's really nice. And I'm falling so in love. It's really nice. [Laughs] I almost feel like crying.

BK: It's a wonderful feeling.

RM: It is a wonderful feeling. Who would have ever guessed that I was going to be falling in love at this point in my life, you know? I'd gotten so used to being single since the cancer, because it just changed things so dramatically, but you know, this guy, he's not expecting miracles, and he's patient and he's kind and he's sweet, he loves my dog. Yeah, it's kind of cool.

BK: Very cool.

RM: It's very cool, yeah. In fact, I'm going over there for dinner after I finish here.

BK: That's a good thing to do after a conversation like this, for sure.

RM: Yeah. I knew this was probably going to be a bit heavy, but I've felt as though, come on, Richard, you lived through this horrible time, and I think I've got something to share here.

BK: Well, thank you for sharing it with me.

RM: Yeah, sure.

BK: I only have a few questions left. Just some broader questions around, for example, how has your perspective on HIV changed looking toward the present?

RM: Oh god, HIV is the least of my concerns – it really is. Like, at one point, it was the most terrifying thing in the world and now it's just the least of my concerns. I know that HIV is not going to be what gets me, it's going to be just one of the diseases of aging. Like my heart issue that again was congenital – I'd known about it since I was four, that one day, I was going to have to have serious heart surgery, but nobody ever thought I was going to live that long to begin with, but here I have. And this is how much HIV has changed, because fifteen years ago, they would have never given me the organ, because they would have said there is no way we are giving a perfectly good, healthy organ to an AIDS patient, whereas these days, at least since 2013, I'm not kidding, I got all human parts, and it's because when it came to my other cardiac risk factors, I remember the surgeon telling me, "You couldn't present a better profile. You don't smoke, you don't drink, your cholesterol is perfect, your blood pressure is perfect, your weight is perfect, you don't live a sedentary life, you're active, you exercise. Consequently, that's why this is all happening so fast, and consequently, you're getting all human parts." So, there you go. That's how much HIV has evolved in the last fifteen years in particular, because I'm not kidding, fifteen years ago, there's no way I would have ever gotten the heart – they would have said, "No way, we're not giving a perfectly good heart to an AIDS patient." Whereas today, it's changed that much. Yeah.

BK: Wow.

RM: Yeah, wow. It's pretty remarkable actually when you think about it. And here I am, you know? Now I've got a new heart and a life to enjoy it with, you know? And now I've met a new guy – it's pretty cool.

BK: Again, thinking on a larger scale, how do you think HIV changed the gay community here in Vancouver?

RM: It brought us together as a community. In fact, I haven't seen our community come together that well or in that – it was just amazing, because it's true, nobody else even wanted to touch us. And that's when, I'm not kidding, all my gay sisters even, that's when the lesbian community – like, oh my god, they were amazing – they were just amazing. How we all came together and built these organizations and helped each other out and started the buddy program, yeah, we did it ourselves. It's one of the things that makes me very proud to be a gay man is how we handled the beginnings of that epidemic, because it's true, *we* did it, because nobody else even wanted anything to do with us. They were also terrified of us, and I guess rightfully so – it was really terrifying, it really was. Like, to see somebody in the prime of their life, to be whittled away to a skeleton within weeks or months, or at most a couple years – these are guys in the prime of their lives, you know? It's like, [name], my partner, he was thirty-six. Yeah, [friend's name] was thirty-one. Yeah, it was a different time back then. But…

BK: And that's what always stands out to me too from hearing so many of these stories is the immense loss on the community level but also the immense strengthening of the community that happened simultaneously.

RM: It did, it did. Like, we were dying in droves, but we really came together as a community. Yeah, it's like that AIDS memorial down at the beach, I still find it hard to go by there, because I just know so many names on that memorial – I know too many names on that memorial. But I still – every year I try to go by and put a flower in [partner's name]'s name and [friend's name]'s name – I still try to do that every year, but I still find it difficult. I still find it difficult to have to scan all those names to find where [partner's name] is again and [friend's name] is. I know basically the panel to look on now, but it's still tough to go down and see all those names on the memorial, because wow, do I ever know a lot of names on that memorial. And they've been gone for so many years now, you know? And time heals – it's true, that old adage – it gets easier, and then you start to remember just the good times as opposed to the awful times, but there was a lot of awful times back then. It was nightmarish, it really was. I remember that that was my biggest fear, I remember that when I first realized that my family knew, is being totally shunned by my family, and except for my older brother, but he's always been a bit of tight ass anyhow, but the rest of my family has been just amazingly supportive and continues to be to this day. Yeah, so I'm lucky in that sense, because I know a lot of guys back then, their families did just shun them. And I remember partners of – guys who had lost their partner, and then the family showed up and told them to get out of the apartment and that they were taking everything that belonged to him, because it was theirs. Oh, it was awful – it was an awful time. It was an awful time. And back then, we had no legal recourse, because our relationships weren't even acknowledged – like, we were homos living in sin, you know? Yeah, it was just – yeah, it was a tough time.

BK: All the more reason to remember it, in a lot of ways.

RM: I think so. I think that's why I thought this was important to do, because it was – it was a dreadful time. But here we are.

BK: What advice do you have for younger folks out there in the community as a long-term survivor who's lived through this and seen HIV for what it was? Do you have any advice for younger folks who didn't live through this?

RM: Um… Yeah, to not take it lightly. That even with the PrEP and the PEP that's out there these days, that you do not want this virus, because it's not a cakewalk, you know? Like, there's a lot of side effects and there are long-term consequences. And I look at what's going on right now with myself, like I've just had this heart surgery and about six months ago, I had a diagnosis of atrial fibrillation, and so the doctors wanted to put me on warfarin, which is a blood thinner, but because my bowel was so irradiated to beat cancer, which was caused by the HIV meds interacting with another virus, but I was bleeding so badly from my rectum that they had stop the blood thinners to stop me from having a stroke. So, there are complications further down the road that sometimes you could never see coming. And that's what's happening – like, right now, my new doctor, that's how he put it, he said, "Well, we're going to have to do a very careful dance around this, because you are dealing with such a badly irradiated bowel, and in order to get you on the blood thinners to get your INR up to a level that we know that there's no risk of stroke, but unfortunately in order to get there, you're bleeding so bad out of your rectum that we're risking you becoming anemic, so we have to stop the blood thinners so that you don't bleed so badly." And it all adds up, and it started with HIV, you know? It's just, don't take it lightly – it's not worth taking those kind of risks. If there's one message I could possibly try to pass onto the young gay guys these days it's don't take it lightly, to practice safe sex. It's not worth the risk.

BK: What about for folks who might be newly diagnosed?

RM: Gees. To make sure you're compliant on your meds and keep that viral load undetectable, and as long as you do, and as long as you're willing to do your own part when it comes to your health – in other words, stay away from drugs and actually work at your health – then HIV these days is not that big a deal. Like, as long as you're willing to do your own part when it comes to your health and you're compliant with your medications, for the most part, you're fine. Like, I've been undetectable now for almost twenty years.

BK: That's amazing.

RM: Yeah, it is amazing when you think about it. Yeah, because I remember when I was first – the first viral load I ever had done, it was shortly after I'd been diagnosed with PCP pneumonia, and I think it was well over 300,000 – like 300,000 or 400,000, which was scary, but that was when I wasn't on any kind of medication. That was when there was no medication. That was when the only medication available was AZT as a monotherapy, which was a total failure. Yeah, you've got to be willing to do your part when it comes to your health too. In other words, you've got to eat properly, sleep properly, and look after yourself – you know, love yourself. I think sometimes young gay guys have a tough time doing that as I did when I was younger, you know?

Again, there's still a lot of stigma. I think the whole just being gay issue is a lot easier these days than it was back in the '60s and '70s when I was a little gay kid. But when it comes to dealing with HIV, you need to do your own part when it comes to your health, because that's what I've noticed is the people these days that are still getting sick from HIV, for the most part, it's people who are using IV drugs and out partying way too much and not looking after themselves well enough, but that's not terribly surprising. You know, if that's the kind of stuff you're doing, it's not terribly surprising that there's going to be complications arise out of the fact that you're HIV positive. I don't know what else to say.

BK: That's kind of it for my formal questions. We do always like to leave some space at the end to let you add anything we either haven't touched on or that you wanted to expand upon before we turn off the recorder.

RM: No, not really. No, I think I'm good.

BK: Great. Then I'll just thank you again for sharing your story with me.

RM: My pleasure.

BK: And we'll stop this.

RM: I hope it's something you find helpful.