

## **“HIV in My Day”**

**October 8, 2019**

**Participant:** Robert Birch (RB); **Interviewer:** Art Holbrook (AH), Charlene Anderson (CA)

**AH:** Okay we are rolling. So please identify yourself, or introduce yourself to us.

**RB:** Hi, my name is Robert Birch.

**AH:** Robert Birch. And how long have you lived here on Salt Spring?

**RB:** Been here for twenty-two—twenty-one years.

**AH:** Okay. Where were you before that, where'd you live before that?

**RB:** Vancouver and Victoria for a number of years. I came out in ninety-two from Peterborough to Toronto, Ontario.

**AH:** Right yes, eh most of us came from the east at some point or other. So what did this part of the world—whichever those you choose—look like before HIV/AIDS?

**RB:** Hmm, I'm thinking about Salt Spring and I'm also thinking about Toronto, so two different time periods. So I don't remember a time—just referring to Toronto in the eighties—I don't remember a pre-AIDS time, other than being a teenager while living in Peterborough, Ontario. So I moved to Toronto just as the epidemic was coming on. Whereas Salt Spring there was a very small group of some phenomenal people—[name], and [name], [name], and [name]—I think it's okay to say their names. Anyways so GIGI: Gulf Island Guerilla Immunologists was called. And then a bunch of us as gay men within I think about a year and a half, maybe two years, an influx of gay men came and joined the organization at that time. I always like to think of it as Canada's smallest AIDS service organization, which turned into the Gulf Islands—Southern Gulf Islands AIDS Society is what it's now registered as.

**AH:** So what was the response of the community? How did people respond to your being here?

**RB:** Yeah I mean the response of the community was in a small rural place was phenomenal. I remember Mark, we'd been here maybe three years and Mark—maybe four—and Mark had got sick. Yeah, with non-Hodgkin's lymphoma and the PCP a number of times. And he was very sick. And for some reason just 'cause I'm—like to be transparent. We took the risk of sharing his medical journey, with his full permission. And basically it was me writing to say one of the things I've learned from a lot of my mentors and just from a—I guess one could say spiritual experience is the value of learning to ask for help. So, and yeah comes through some of my associations with other twelve-step groups, all these kind of processes. And so I wrote, every two weeks I wrote about his medical—our medical process and what that means to be living in community. So we're very open about our HIV status. This was early about two-thousand-three, or four. And it was remarkable, the community support is—we've never had direct stigma, as a result because we were fully, we felt in our power. And we came through that part of the epidemic where we learned to try on and then discover what it means to be proud to be living with HIV. And then here in a small community we learned how to communicate that and recognize the tremendous benefit that is for others. So we would get responses—I mean gosh, up until even several even a few years back, we'd have community members on Salt Spring who would reference those articles ten years later and say thank you so much, my husband was going through this process, my wife

was going through this process, or they went through their own chronic illness of some kind, and they were bolstered by showing how people can heal within community settings.

**CA:** Where did you publish those?

**RB:** The Driftwood article—uh the Driftwood Newspaper.

**CA:** And that's a local?

**RB:** It's a local news, won a—award winning newspaper.

**AH:** That was my next question.

**RB:** Yeah. So yeah that's uh—and we also marched in every PRIDE parade with uhm, Southern Gulf Islands AIDS Society so we—

**AH:** Is there a PRIDE parade here on the island?

**RB:** It per capita it's the third largest—was the third largest in BC. So yeah we get anywhere thousand, two-thousand people out, on a small island of ten thousand people.

**CA:** Oh so much fun.

**RB:** No commercial entities, no vehicles, it's just pure community.

**AH:** That's lovely. So when did you first hear about AIDS/HIV?

**RB:** The memory as it's coming back to me at the moment is—two things are kind of overlapping at the moment so I think it was around eighty-three, eighty-four, and I was the sunshine boy in my grandmother's eye. And I remember being about eighteen at the time and she said two things—maybe two different moments and I'm overlapping. She said, 'if I ever found out you were gay I could never love you.' And somewhere within that time period it was the whole thing about the panic, and the socialized panic that was emerging. So uh, funny from today's perspective I wonder—because I know she loved me—so I wonder if her comment was some kind of attempt a detriment towards what she probably understood, intuitively knew I was gay otherwise she wouldn't have said it. But also wondering if in a backhanded loving kind of way was her way of trying to protect me.

**AH:** So how did she respond when she did find out?

**RB:** Oooh, wow. I'm just noticing a lot of emotion as I'm connecting to these things.

**AH:** You don't have to respond to any of these things.

**RB:** Oh thank you, I totally get it. It's a blessing to be asked, it really is. It really is. I'm imagining she was devastated, she was a profound worrier, like she had the art of worrying down to a science. But I can also re-feel the sensation of how I handled other people's reactions. I was transparent from the moment I was diagnosed. I was diagnosed in ninety-six. And we were doing a Canada Council project with my theatre company called Generation Studio in partnership with AIDS Vancouver Island. And we were doing a five week process called Latex Café, I don't know if you remember that? So it was a huge deal, uh, complicated rich. But really brought HIV in ninety-six—I mean it was at the same time—so we did this project and three months later was the Vancouver, uh the big breakthrough conference where the

meds were announced, the ARVS. So this was March of ninety-six and that day we had a workshop with HIV positive people, only one person bizarrely showed up, everybody had to cancel last second, and we had a whole team of HIV positive people, other actors and friends who had brothers—we were just a constellation of a really rich group of folks that had direct relationships with HIV. My partner at the time was living with HIV. And this particular day which we'd scheduled months ago was called Happy Virus Day, and we were—we'd signed up to do this thing at four-o'clock in the afternoon to do some public art in the middle of the street, on Government Street. So at ten-o'clock in the morning my doctor, out of the blue, totally—it was bizarre that it would even happen this way—he actually phoned me that morning to tell me that my test had come positive. So there it is, Happy Virus Day and I'm getting my own diagnosis that same day. So again having that kind of spiritual understanding of the world kind of like okay, this is happening like here's the ride. Number of things I remember, I remember supporting, almost counselling him. He was devastated. And I was somehow—I mean it was just my nature I suppose as a young gay man who felt like there was something to contribute to the road. So six hours later we're out on the road, and the actors are doing this viral dance in the middle of—we'd stopped the traffic, we're doing this performance art piece. I have fishnet stocking over my face, a camera—somebody's holding the camera behind me—and I've got a mic, and I'm interviewing people on the street saying, do you have any sense of what's going on here? And they're like no. And I'd say, so we're raising awareness around HIV in Victoria, and have you ever met anybody living with HIV before? And invariably almost everybody said no. And I said, Hi, I'm Robert, you have now. So I was never in the closet around HIV. For better for worse. Because it was just—it was all happening, and in a way I just I knew I had a—I felt in that moment anyways there was some intrinsic role. About being a community member, about participating in something that was affecting so many of our lives.

**CA:** How did you become involved in that?

**RB:** We'd done—my theatre company had done another series the year before called *As Deep As Your Throat*, which was looking at how homophobia impacted the creative process for gay male artists in this case. And it was a huge festival. And based on the success of that we kind of rolled it in and asked to partner with AVI. And Ruth Ann Tucker was the head of AIDS Vancouver Island at the time.

**AH:** Right. So going back a little bit, when did you first hear about AIDS, or HIV?

**RB:** Yeah gosh. So that would be eighty-three, I would've been eighteen or nineteen, is that right?

**AH:** And what was your initial reaction when you heard about it?

**RB:** Huh... Multiple reactions and all a little fuzzy, I mean I was just coming out as a gay man so it was like—and nobody—I mean we were all making it up at the time. I mean that's probably true of everybody in life in general, to whatever degree we have our heads and hearts connected.

**CA:** What do you mean making it up? Making what up?

**RB:** Well nobody knew what being gay meant. Nobody knew what living with HIV meant. Like, nobody knew what services were needed at the beginning, so everybody was just being called into it, one way or another. And I think naturally, or instinctively, there was a sense of holding it at bay until it was your time to walk through the door. Or my time to walk through the door. So we knew it was in the community. I think a lot of us were in a frozen state. And again unless you were already slammed into the middle of some kind of service-based response. We were aware of it, everything was condoms,

about condoms. But I don't actually remember having any conversations with anybody about it. I was in theatre school at the time so my life was completely absorbed in being a young actor and getting my career on, and kind of anonymous sex I was having. Today, I understand that I and everybody else was in a highly traumatized state. Like profoundly traumatized state. And carrying on. Not unlike we could say climate crisis today. Or any genocidal-style process you just carry on. And kind of have this lurking when's it my turn, or who's going to impact who, you know—but denial's a wonderful thing until it's not.

**AH:** So did you have any sense of the severity of the disease when you first heard about it?

**RB:** Well you know, silence equals death so HIV equaled death. You know so it was—it was—it was a death sentence.

**AH:** So yes you did know. And how did you learn about the disease, how did you not—okay you've already said you learned about it—but how did you learn about how you deal with it, and what adequate information sources were there.

[15:20]

**RB:** So the first several years was advertisements on bus shelters about condom usage. And everybody else talking about it on mainstream news with all the shame and stigma and the violence—systemic violence associated to that. So it was again it was like a spliced off reality. You know there's the social panic that's being induced then there's lived experience of kind of like mmm, swimming in the middle of it like a fish not knowing it's in water. It wasn't until somewhat later probably the early nineties or till I started getting more involved that people were actually having conversations, more and more about it. So again here I'm in my early twenties, late teens early twenties, so it came through those early social, the AIDS service organizations. As well as for those of us who were geeky—and I wasn't at that time again I was so focused on my early career—but there was *The Body Politic* and they were coming out strong. And I now have a better sense of what they were doing as a local paper. Really breaking the news over and over again. So it was there, you know that paper to read was always there and some days was only capable of reading headlines.

**AH:** And where was that?

**RB:** This is in Toronto.

**AH:** This is in Toronto, yes, okay. Yeah. Uh, so how did you respond personally—did your sex life change, did practice safe sex, did you respond to the ads about the condoms in the bus shelters?

**RB:** Yeah, I went into what I would've at the time identified—I remember being nineteen, so this must've been significant because that would've been eighty-one, eighty-two so I'd maybe I'd kind of heard earlier inklings of it—but I remember turning nineteen, and I was a young kid had a lot of mojo. And had already had my own company going, was teaching at university like there was a lot, I was a real active young queer guy. But I do remember very distinctly at nineteen, when I was just about to leave all that I knew—family, home, city—there was some click that went on in me that went, I'm going to become an addict. Not even you know having had some early formative experiences with an addictive, alcoholic mother but it was really just that huh, I'm going to open that door and go there. So how that manifested was quite soon I became a sex addict in terms of having a lot of furtive sex. I would spend

hours hunting for sex in bathrooms, toilets, parks. Latrine queen. Yeah what did I used to call it—bushes, baths and bathrooms. Uh bathhouses. However—so I would spend sometimes seven hours a day drenched in those hormones. Like literally just soaked and sinking from just that kind of adrenalin rush. Again how I understand that today is that actually was my safer sex protection. Because it was all furtive sex, it was occasionally blowjobs and jerking off at urinals.

**CA:** What's furtive?

**RB:** Furtive. Just like you know, checking out who's coming—you know, secretive. So I wasn't having penetrative sex at all, was terrified of it. Uhm, and had some slightly older men—maybe ten years older than me—kind of slowly mentor me into it but, eh. I think there was just too much sex panic. So I was in the panic, energetically, and my life force was—if you will—was being used up to somehow connect. And that's what I understand that addictive uhm—I don't even want to use behaviour—but that addictive process was really a profound desire to connect. Because everybody, and I mean everybody, was disconnected.

**AH:** Right. What you've—this is part of your life at the time, was there another social aspect that was what can I say, more conventional than that? Were there other things happening in your life besides, or was that your whole day?

**RB:** Oh yeah no I mean—I mean I was part of the—what I lovingly term are the gay mafia. And as a young, bright, good-looking kid like there was a lot of people in different positions of influence and power from the artistic director of the Shakespeare Festival—Stratford Festival to the—like this just incredible network of gay men who had a lot of influence on social and cultural evolution if you will. So that was also going on at the same time. So there was a lot of conversations, political, artistic—yeah it was a profound period, it was like one of the best and worst of times. Because again, we were all discovering and creating what it meant to be one of the very first generations of openly gay men. And HIV remarkably pushed a lot of people out of the closet into the scene. And for those of us who were into the scene and weren't—again we were looking at shame and doing something about it.

**AH:** So uh, this question's almost tautological here, uh how did your identity shape your experience of the epidemic?

**RB:** Yeah I don't there's really—how did my identity shape my experience of the epidemic—I don't think it's possible to even separate them. And again like I said, there is no gay without HIV. Whether these generations remember that or not is—and again projects like this may support people to understand that there was really no gay without HIV. And that's not to say there wasn't remarkable things happening, and as I've got, as I settle into my middle age part of that—the benefit of that has been to rediscover my culture pre-AIDS. And meeting the surviv—several surviving mentors who had realities of what it meant to be gay, or whatever they called themselves back then. So I'm learning history in a new way that has some breathing room from the epidemic, but being I think I'm known as the AIDS-two generation, I wasn't in the first wave I was in the second wave in terms of diagnosis. So for me there is zero separation in terms of an identity. I wouldn't have said that then, because everything was about pushing away the HIV identity, that's why we had the schism of positive and negative. That identity was I think one of the most—I mean it's understandable bio-medically—but it's cultural impact was ferocious. And we still haven't healed from that. And part of that understanding is that so many HIV negative gay

men—and I'm not only talking about gay culture, I'm not talking about a wider intersection process—but so many HIV positive negative men never got the supports they needed. Twenty-twenty hindsight.

**CA:** That is—that is such a good point actually. And no one even thinks about that—the people that were terrified, and negative. You know, there is no support for them—because what do you need support for, you're fine?

**RB:** Yeah totally and then yeah I want to be conscious of my language there but I mean again, the resources that were needed were so much greater, and the violence—the political violence, the people in power, by not giving earlier resources for all the related stigmas. It was the negatives guys—the so-called negative guys—who were driving the epidemic, to a certain degree. Because I think it's fair to say in some of the research that I've read, you know if you were diagnosed there was a different panic, and there was a different responsibility. Whether that's around getting to your doctor, whether it was out of self interest or a communal interest, community based interest. But it was the panic and the hiding and the shames, and all those other social psychological processes that were really the driver of the epidemic. So we failed, from that perspective. In the face of the impossible.

**CA:** Do you think that's still an issue today?

**RB:** Oh yeah.

**CA:** How so?

**RB:** Well one, we're just not having the conversations anymore. So I don't know how people are locating, I mean when we think about identity politics and the history of identity politics and how HIV negative are part of that from the viral perspective, uhm, yeah wherever any population isn't getting the level of support they need, there's a greater level of susceptibility. Whether it's to an addictive pattern, to a virus, or any kind of condition—poverty. Whatever. The social determinants of health process. So when people aren't able to actually openly talk about their needs and wants and desires, there's going to be a backlash of some kind, there's going to be a deficit of response.

**AH:** So in those early days, did you have personal relationships with people with HIV? Did you—before you came out—you said if not before you came out but before you realized you had the disease?

**RB:** Yeah of course. Again, I'm loving doing this interview right now, I'm not sure if I was prepared for it as much as—and that's okay. I mean what I now know in hindsight is I had relationship with hundreds of people living with the virus, and didn't know it. Ultimately that meant everybody. Whether we had the virus or not it was in our culture. So that from a pan perspective—and yet I'm thinking on a more intimate level I my first—one of my first roommates around my own age, I was nineteen. And I remember opening up the medicine cabinet and just seeing pills—like holy fuck—beautiful dignified Jamaican Canadian. Classy guy. And yet, he referenced his medical condition to the specific symptoms and in my naiveté never put together that he was actually living with AIDS. So it was right in the apartment that I was living—the virus was right there in his body and yet it was never discussed. And I didn't have the skills or capacity or even the imagination at the moment to ask. But I do remember him being very uh, yeah I want to say motherly about it all. I'm recalling him reminding me about condoms, and warning me against scenes or situations. I'm just thinking about that now. That was the most direct experience. That was about nineteen-eighty I think eighty-eight, eighty-nine.

**AH:** Well that's interesting. On our little outline of questions here, there's a little leap here—what did the government or the medical community respond, what was their response, what did that look like in those days?

**RB:** Oh my heart remembers the testing clinic the first. God my names won't come to me, but the gay male nurses who were so front and centre, and so loving, many of them I think probably had the virus themselves at the time. Uh, yeah that was the Church Street clinic, Hassle-Free Clinic it was called. Yeah, amazing just—I mean—so that kind of first responder in the trenches approach was extraordinary. So however the funding got through for that, and whoever the gay men and those allies who got that up and running I just thank you, thank you, thank you. So that kind of street-level community-based responses on a street level make a world of difference. Because of course they're all relationship based. And that was one of the great aspects over those first fifteen years, is we had relationships with the secretaries, the pharmacy people, the doctors. And I can't say that for the earliest years because I wasn't there, but from the time I was diagnosed in ninety-six it was—I mean those relationships saved Mark's life. I mean I remember going to St. Paul's Hospital in ninety-whatever it was—this I'm jumping ahead—two thousand. But it was because we had a relationship with Julio Montaner's secretary, and she said 'oh you know' in her Irish—Scottish brogue I think it was. Amazing person. I just said, oh you know he's having real back pains uhh he had this weird appendix thing. And she goes, 'tell me more about this.' So she wasn't medically trained, but intuitively aware because she'd been on the beat and known so many of our stories. So she instantly picked up the phone to say, 'Julio, Mark's got some strange back pains.' Julio had him fly over from Salt Spring to Vancouver within two hours and had—Julio said had that not happened he would've been dead. And it was because—my point being it was because of the relationship, the community feel to it all that saved his life. So that—that—what I would love history, or the future to understand if there is to be a future, to understand what so many of us have lived through is it took a community—the immune function of these communities, our intersecting communities, and the people who were living and surviving through this process that made the difference. It was extraordinary. All under the state of national threat. Whether it was in the States and or here, just not getting the resources that were needed. So it was people helping people. What we now call peer navigation was happening on the streets in the coffee shops. Pillow talk. Like I learned more with my sexual partners sometimes than I did from any other public messaging. Yeah.

**AH:** So government you've—I think you've just touched on that. But the government response, how did you perceive that?

**RB:** Oh god, it's so loaded. Yeah. My mind just—I just think of the horror of what indigenous communities have lived through over generations, right? Still not having water. So we can touch on this fifteen-year period, twenty-year period, well longer, of that equal dismissal, you know second-class citizens, divide and conquer, having to convince conservative, right-wing people of the basic dignities of equitable rights. I'm thinking of people not being allowed into hospitals to see their lovers dying. There's just so many stories that would just break our hearts open again and again. And the community fighting each and every step of the way at the same time hosting this virus. Again I'm a little caught up in the gay man's HIV epidemic and I just at the same—of course history revealed to us how of course the women's community, and the Haitian community, and again a different cultural access—that's not really the right word—but just another route into people having to fight to get their needs met.

**AH:** So what was your perception of how the public reacted to the epidemic?

**RB:** God my mind's racing to what were people really thinking about those years. Because they sure weren't thinking about HIV and AIDS in a let's get down to this, let's solve this we can do this. It wasn't that.

**AH:** Well did you see an intensification of discrimination and stigma or homophobia or—

**RB:** Mmhmm, oh yea. I think if I recall correctly there's this sense of everything coming to the surface. As somebody who is a wide-systems thinker, there was a sense of things starting to break down in the eighties. Like let me go wide for a second but we had the ozone, so the kind of world's immune system kind of getting holes in it. We had the internet breaking things down. So it was kind of the age of HIV and AIDS was the beginning of systems breakdown. That is radically changed the world to where we're at. And had we responded earlier to that, similar to how we've repaired the ozone or that's gotten better, the epidemic would've been contained a lot more. So we—whoever was driving the boat at that time failed miserably from that perspective. They could not see the science and have an imagination of where that could lead us. So how the public perceived that? I don't blame the public because other people were diverting our attention in other directions. And so it was easier to stigmatize this and you know—and again, whether you were a person of colour or a woman with HIV, it was still associated as a gay disease. And still to this day, it is a form of a pandemic of sexism. When we think of homophobia as another version of sexism, meaning uhm, that kind of intimacy between men is related to hatred towards women. I mean if you link up all oppressions, which each the whole HIV movement as the first world's intersecting health movement, where it brought everybody to the same page. To then look back from that and kind of go wow, all these oppressions that drive stigma are interconnected. All the supremacies—white supremacy, hatred towards women, hatred towards queer people, poverty, like we now understand that all of those oppressions. So to look at the public to fully understand that, we're not even quite there yet. But we're actually having the conversation a bit more. And I have to say the HIV movement as a whole, this is one of the many things we can be proud of. Is been some part playing our part in that recognition.

**AH:** So do you think that the uh, gay people have they—the response is, that the community is stronger or weaker for all the losses and the responses?

**RB:** Hmmm that's a loaded question, it's a little too simplistic of a question. Uhm the gay community will never recover from the losses that happened. And the generational reactions to it and the assimilation patterns that came as a result. Including marriage. Like it's great to have our rights, but we only have our rights if we're assimilating into the existing social patterns. Whereas you think about pre-epidemic the queer community, which at that—my understanding, the research and the people that I've talked to who were there—like there was a lot going on around challenging economic systems, challenging church and state, women's rights like this burgeoning movements were all coming to this frothy exciting edge and then boom—HIV and AIDS comes along and the women's movement has to splice off to support their gay brothers, leave behind their own agenda. So like a lot went on. So I'd say—if the world was in a better place today, some of this profound sacrifice might have been worth it.

**CA:** It's a big question.

**RB:** it's a big question. Are we smarter for it? Are we more loving because of it? Can we resist? Well I mean let's face it, we get the meds—so I mean trauma after, just profound cultural personal biological trauma—and then we get the meds, and then oh my god, some of us might actually survive. Some of us



survive. And then comes two-thousand-five and there's an epidemic of meth usage that doesn't even discussed for ten friggen years. We've got thousands of gay men dying, and not even the AIDS service organizations at that time were really—because we're still scrambling on one end of the project. Right? And then so only now, god I mean I participate in a lot of communities, around the world but up and down the west coast, and it wasn't until two-thousand-fifteen in some of the heart-savvy, politically-charged, social change agents, it was until two-thousand-fifteen somebody actually stood up and said, I'm a meth addict. And that's after two decades of people being able to say, I live with HIV. Like, what the fuck happened? So we are better? No, we're highly traumatized. And, do we still have good mojo going on, well yeah. People are contributing a lot. Are they connected? Sure they are. That's not for me to figure out, or us or maybe not even this project, but to not put all into some kind of relationship to each other is a huge mistake. That our gifts, our wounds are connected to our blessings. So I'm a little angry at that question. And it's a totally valid and necessary question. I think that it could be a little smarter.

**AH:** Fair enough. So turning to the community, what actions did you see happening in the community in the early days?

**RB:** Yeah, I've named some of those.

**AH:** Yes you have.

**RB:** Uh, it has been a profound joy and a healing for me, again as a middle-aged person and somebody who's also worked within the HIV and AIDS community and gay men's health, and many other related processes. But to re-learn the history of what—again what the women's community have done, the people of colour's community, again just to look at the extraordinary hard work of how people responded. So the movies coming out, *We Were Here*, you know all the about four years ago there's this—*FiveB* just came out in the last two years, you haven't seen that yet? It's an incredible film, I got to meet last year—no this year, god, a few months ago—what was she called, she was Nurse Jane Doe. And we went to a viewing down San Francisco, was just a review theatre and there's my mentor Ed, who was in the film *We Were Here*, big tall guy. And he turned over to me, he says 'there's somebody from this film in this audience, we'll see if they want to talk to us later.' In fact it was the very nurse that was the first nurse to contract HIV by pricking her finger. So here's just one small but profound—well it wasn't small—this profound experience. She was one of the only straight-identified nurses in the first AIDS ward down in San Francisco. And these nursing lobbies were about to—in their understandable terror and the fear of the risk to their own family—they were lobbying the government to have a no-touch, hazmat-suit style approach to HIV care. And here's this one woman, who's got the whole of the case on her shoulders, right? And because of all the lobbying and the smart loving—I mean the loving people that fought at that time they were able to push off that court case. That allowed a heart-centred, patient-driven healthcare that's impacted everybody's healthcare in Western society. And that all came on the dime—literally and metaphorically—of HIV and the people that were the early responders in it. So we have everybody who and again there's so many things in the world that people have done we'll never know that we need to be grateful for, but I do know, based on my lived experience and my research, there's been so much that's happened in the HIV community that has benefited the world as a whole, in terms of the ability for a community to rise up, and resist and respond. And that's only one case, out of thousands. Is that answering the question, or did I go off on a tangent?

**AH:** I think so.

**CA:** That just gave me goosebumps.

**RB:** I know right? And she was amazing. Got to meet her, just to finish the story. So she pauses, there's a bunch of five gay me—one-two-three-four-five gave men, one of whom's been on the beat since eighty-three—Ed was the first, one of the first volunteers with Shanti project in San Francisco. Anyway. So she was feeling ashamed, because it was all about her and her story. And I was able just to say, you know on behalf of so many of us living with this virus, and so many of us who have been around for a couple of decades the survivors, I just want to say thank you. Thank you for stepping up, and one telling your story, but two for going through the madness and showing up with such dignity. She fell into my arms weeping. Right? I mean what a blessing to me! What a healing for me. But just to be able to hold this woman that god how many years ago was that? Twenty-five, thirty years ago—more. She was carrying—and there's she's seeing herself up on the screen, knowing she was her—her story was at Cannes two months earlier. And she couldn't go to any of the openings, because it was too fucking hard. And there she was alone, by herself in a revue theatre, watching her life story for the first time up on the big screen. Well I mean there's so many people that I know—some people I don't know you well enough, but I know other people's story in this room listening to this who could also go through a very similar experience of seeing their life story up on the big screen and the rest of us going you lived through that? Woah. Ow-wow.

**CA:** Some remarkable people.

**RB:** Remarkable people. That never—here's my little edge—that never got thanked, not just for surviving. But surviving and serving. Like so if I get a moment here, if this was my moment this would be my moment to say thank you, like thank you. And hopefully this project, one of the best gifts that come out of it is all of us in our own way having survived, and still be so damaged, and still be able to say thank you. Like woah the capacity in a person's life to go through that and still show up with love and care. That's the people I know in the HIV community. And the supporting allies.

**AH:** So uh, hate to take it down a notch here—

**RB:** Please. Probably good, what goes up comes down.

**AH:** Did you or the people you know become involved in the HIV community and the responses, organizations?

**RB:** I resisted for as long as I could, just until I could find my way in. My way in was as an artist, as a artistic director as an actor and director. So I brought what I had to the game board, and my approach was not just a biomedical or social service approach, it was understanding the aesthetics of how to live in a time of a virus. So we got people safely—I mean some people might challenge the ethics of how we did it—but everybody was wanting and willing to show up. And desperate to tell their story. Because there was no place to tell your story. No place. You know maybe amongst friends, but even they were traumatized. So you kind of just want to get your party on and get away from the horror. But here we created really strong, safe, community-based, cultural processes where people would get up there and tell their stories. We had people performing their stories. I remember one fella, beautiful man in Victoria named Norm. And it was called Playback Theatre during this Latex Café. So that was my entrance point. And his—we did this process where kind of like, had like an oracle version where the actors would spontaneously perform something back to your question. So Norm gets up on stage—and this is in a

small theatre in Victoria—and says, ‘hey I got a question. I got a question, why did HIV hit these particular communities first?’ And I’m like oh shit, so turned to the actors said let’s watch. And the actors do this kind of amorphous process, and we turn back—I turned back to Norm and I said, so did you get an answer? The audience is like, baited breath. And he says, ‘yeah. The reason it happened to all of us was because we were the ones who could handle it.’ So that was my intersection point, and then I got a Master’s Degree, I went around health and healing efficacy of using art-based response, mostly theatre and ritual—container making. And then I kind of got head-hunted into working for AVI again, and VPWAS—Vancouver Island Persons Living with HIV/AIDS Society, and then I got head-hunted into doing a PhD for five years. And escaped, barely. After working with extraordinary people. I say escaped only for my own sanity. Uh, so again amazing loving people who I know are going to be watching this maybe but, I love you and appreciate you. And I’m glad to be out of the stress of it being—that was it—we moved to Salt Spring—so this kind of this is interest—I’m kind of just realizing this for myself, it’s not a huge a-ha but it’s similar to the patterns one can live in their life. So my pattern was we’d left Vancouver just after ninety-six, ninety-seven, I’d been diagnosed—everything was about HIV and AIDS. The whole day—it was a full time friggen job to live with HIV—you had at least one doctor’s appointment every two or three days, it seemed. Uhm, whether you were able to access mental health processes, or volunteering. It was AIDS-saturation. So Mark and I we were caught in the middle—we were just getting our groceries out of—my husband Mark—getting groceries out of the back of his truck and we got caught in the middle of a drug bust. You know—get the fuck out of the way—and the perpetrator’s like—and the poor guy and I was—I just slowly picked up the grocery bag and I said to Mark, we’re leaving. We’re done with the city. So that’s when we came to Salt Spring Island. So similarly having gone through this last decade, everything became HIV/AIDS saturated. And you know what, like everybody we got a shelf life. So I think partly—I had to get out of the—I mean I was asked to leave the—I mean my life just kept turning over and changing but you know I had to get out of HIV/AIDS mark for awhile. So it’s nice having this conversation so I could dip back in, because it is a huge part of my life.

**AH:** Were you—what was your role at AVI?

**RB:** I was the Gay Men’s Health Coordinator for two years.

**AH:** Right.

**CA:** And what did that entail, just out of curiosity?

**RB:** Well I think the reason they hired me wasn’t because I had a—although I’ve done a lot of counselling and facilitation, like decades of facilitation work—I think I came on board because I said I’m willing to use my skills to bring community back on board. And I think at the particular time I was there out of just sheer numbers and need for resources the whole culture of HIV and AIDS and its response had naturally shifted to people who were using substance, as a coping tool or mechanism. And a lot of gay men who were survivors were trying to normalize their lives and kind of pulled—radically pulled away from the ASO model. And I knew intuitively that we need a cultural-based response. So we brought dozens and dozens and dozens of gay men back on board. Many of them started volunteering again. So it was about information sharing, it was also about doing community-based research style response. But also just getting people to have conversations together. And we’d host these—we’d host adjunct parties, or one of the volunteers would host a party and we get eighty gay men back, back to just getting to know each other. Without making it just about HIV. We made it more about how do we take care—how do we support each other? You’re a young kid, you need a job you need to go talk to him. You need some

housing? Oh well he run's—he's got some extra room you might want to go talk to him. It was that kind of gay mafia style with just people supporting each other.

**CA:** Getting community going.

**RB:** Totally. Which was needed right? And still is.

**AH:** So, were you ever involved in activism of any kind?

**RB:** Yes, since eighty-three. Yeah in my heart, there's no separation between my identity as a person, my work as an artist, as a social educator, teacher. It's all—I mean the first thing we did in nineteen-eighty-three, I had my—I was fourteen, thirteen, fourteen years old—I had my first big fifteen-thousand-dollar grant from the government, and we were teaching kids theatre. And we'd have these six-hour performance art pieces with fifty kids all looking at the environment. That was in eighty-three. Yeah, eighty-three eighty-four. So yeah it was from the beginning, it's just—yeah, the personal's political so why not have it in the same table.

**AH:** Were you involved with any other organizations besides AVI?

**RB:** I've already named a couple. In Vancouver, Friends for Life was a big one, volunteering participating there. Great programs they had in those early years, I think they're still going. God, I'm trying to think—it's kind of jammed up there was just—cause everything was kind of tangential to each other somehow.

**AH:** You mentioned VPWAS there?

**RB:** Yeah VPWAS was on the board for a couple of years there. Uhm, certainly the local one here Southern Gulf Islands AIDS Society. Uh, did national CATIE gigs as rapporteurs, again as a writer I was doing a lot of writing around living with HIV and community-based responses.

**AH:** So, how did the community deal with the burden of care and support as people all around you were dying? It must've been a very stressful time to—did you experience fatigue, burnout, or any of those things?

**RB:** Mmhmm, I think I've referenced some of that or implied some—again my mind skips between the different places I've lived. And again it always had to do with—it was always related to involvement. So most of us don't grow—many of us didn't grow up with any sense of community—maybe church, certainly I don't think school, maybe if you were into a particular sport or something. But getting involved in HIV created a sense of meaning, belonging, and purpose, for many of us. Which is profound. And many people don't ever get that, especially if they've got a lot of privilege, they don't actually get to know what it means to belong. Or if they're so wounded, in so much pain that they can't get to the table they fall through the cracks. So all I can say is there were—there's again we were just saying there's incredible people doing incredible things, and sometimes it just felt like the luck of meeting the right person at the right time.

**AH:** Okay. So how has the community changed because of the epidemic?

**RB:** Yeah so many different waves of it. So you're not asking how it changed, but how has it changed, is that correct?

**AH:** Yeah, how has. The question that they've given us: how has the epidemic changed your community or communities?

**RB:** Mmhmm. Yeah, I mean as the world's moved on to digital reality, or actually questioning what the nature of reality is, I think when you talk about fake news or anything—so I think it's not just us. And I would say, people's relationship to connecting has become more tenuous. That's not necessarily true for everybody, but I follow this and watch this and have the privilege of time and space and resources to watch cultural trends. And I have noticed in my own lived experience and in some of the research I'm doing, people are having a harder time connecting. And the level of—somebody described the internet as a mile-wide but a paradoxically a centimetre deep. And there's some truth to how it's all impacted our ability to have intimate connections. And crises often provides a level of intimacy. So maybe we're just—with this climate extinction process we may be—my hope is that part of our contribution, those of us in part of the HIV community, I've been talking for fifteen years about this with my mentor, many people around the world when I travel to facilitate is like how do we—we're not looking at replicating the skills and strategies but we wanna—as we're now moving into the elder stage of what it means to be somebody living and surviving as somebody with HIV and AIDS, and the elder stage in this case as a gay white cis man. Is looking at, so how do people resist? How do people fight back? How do people create sanctuary? How do people navigate profound crisis? Because now everybody's in the boat. This is a really horrific thing to say, and although it may come across as a bit of a chip on the shoulder, there's a deep dignity to it. My mentor said, 'so we all had to go through it in the eighties and nineties, now we're going to watch everybody else go through it.' So how then do you connect the dots over any population that's gone through genocidal processes? Indigenous people—like we're all looking to these communities if you have a half a—if your heart is anywhere near open, if your mind is connected to social processes, we're all kind of going oh right, how did they survive? And look, there the only one's resisting some of the profound court challenge—and winning these court challenges. If we're all to survive it's because of people that know how to survive. So I think part of the—that's why I love projects like this is for us to—for me and all of us to find our dignity of surviving. And claim that survivorship with a dignity and pride that says, we're needed. Maybe we've had a break. We've had the privilege to have some kind of normalcy, but frankly, we're all needed. And we've got some profound skills. The ability to face these horrors and still show up loving and smart. We know how to connect. The key is sometimes we need each other to remind each other of what we've gone through. We've never identified the skills and strategies of what survival means. And it's one of the most important uhm, assessment processes that we've never done. So I would hope that the researchers on this project really look at what are the hard core skills and survival strategies. What did we do to survive. And what resources did we co-create, and receive and all these things are important concepts and practical agendas needed for today. And so let's be done with the stigma, let's look at stamina. Let's look at we're actually needed. And the system in it's slowness and you know, because we do have smart loving people who are access to research dollars, you know they're bringing us on in the last fifteen years as peer-researchers and peer-processes, it's like yeah I should hope so. I guess so.

**CA:** Use those lived experiences.

**RB:** And again so much of that has come through the HIV community. And I think we're still coming into a state of primacy. Of deep value. Intrinsic value to what it means to survive. So I think we still have a—you know again this project should help us all kind of go, oh right, wake up. We're actually leaders. A different kind of leader. And we're not the only ones, but this is our version of it.

**AH:** Yeah, well that's good. Uhm, how should we remember the epidemic within the community?

**RB:** Well I think I've just spoken to that. And again Martin Prechtel's—amazing thinker, writer, philosopher, practitioner—talks about the need for grief and praise. So again the capacity to go to the depths of our grief so we can rise up in our joy. And there's no separation between the two. So this epidemic is you know as I said the best and worst of times, so we haven't healed from the grief of what happened. And because we haven't healed from it, we haven't been able to claim that praise, the dignity of surviving. Not saying that's true of everybody, but for many of us as a culture, we haven't gotten to the praise—we haven't given ourselves the dignity of the praise of deserving—that we deserve, and I'm not talking individually deserving, but as a culture we deserve to acknowledge and validate what survivorship means. And the only way we're going to do that is if we have more grief rituals. I think that's one of the reasons there's so much despair in the gay community, and probably so much connection to substance abuse is because we're still riddled with despair. And the STI's. And in my heart I know this to be true, that the despair that we will never have the intimacy, the connections. I don't believe that's true, I just know there's not enough social processes and cultural processes that can hold the depth of our experience, and help us be with the depth of it. And to do that would mean we'd mobilize again.

**AH:** How has your perspective on HIV and prevention changed over time?

**RB:** Talking about this, it's helpful to go back through the history. So this conversation, this interview, again has it's own healing function. Partly because—and I was talking to some dear friends, TJ and Craig about it—and for the first time—that sounds a little. Let me try this on. For the first time, three weeks ago when I was talking with TJ and Craig, got a little stoned, do our thing, talk about our histories. And I just went, wow, I'm survivor. And I was able to say it without—I was able to say it in a way that brought some wonder to it. So I feel like I've passed through a threshold of just carrying the burden of it—and I'm not, because I'm not just talking about me, there isn't just no me here anymore—that's the gift about being queer that's the gift about living with HIV is this constant coming out. Part of the challenge of is like you know going through those stages of coming out, why is this happening to me-me-me-me-me to like all the sudden when we're part of something, this we takes over this limited sense myself. So claiming that survivorship has just recently—it's not a new concept obviously—but there's a new growing of vitality to it. Again bringing new perspectives, new energy. I don't know where this is going. A few ideas. So that's—that's evolving and this feels pretty recent because the other side of is, somebody said to me who I deeply trust, who has been deeply, intimately woven into the HIV community down in San Francisco when asked a similar question as you asked, said 'HIV's just not interesting anymore. Just not. AIDS isn't interesting anymore.' And that was a shock to hear. It was also—this was about five, six years ago—it provide some relief. It was dissociative a bit. And there was a truth to it. So now five years later, reclaiming this survivorship, that's what's interesting to me in terms of the epidemic. Is not the epidemic itself, but again this notion of skills and strategies and how did we do it and how is this of value today. Again it's not so much looking at me as an individual, it's like huh, how are the survivors doing. And I know that's different because everybody's entering into the story at so many different points, and that's what's different too. There was no one movement. And there never was. But it did feel like a period there that—there was a growing swell in the early nineties, in the madness of all of that, there was a movement. So HIV and AIDS may only be interesting for it's historical value—and this is coming from a really privileged perspective so say this—unless you are somebody who's in abject oppression. Who is still struggling to survive, who doesn't have the support system. And we know the Southern

States and other indigenous communities where HIV and there's just not the same level of support, even though they think the drugs are gonna save somebody, HIV's now only one of—we understand HIV now to be one of many complex oppressive issues. So that's what's different. It's kind of blended into the horrors of social oppressions. A lot of it rooted in economic violence. Though HIV and AIDS has become a symptom of larger world issue—as it always was—but the reason we understand that now is because, in many respect, the formative work that this community participated in.

**AH:** Another little leap here—do you have any advice for health professionals and or politicians, legislators?

**RB:** Oh right.

**CA:** Another loaded questions.

**RB:** Another. Yeah it'd be like if I could wave my faggot magician's wand in your direction, and I have a good wand, it would be please go on your own healing journey. That's the whole thing about nothing for us without us, and that's across all forms of oppression we're finally getting there you cannot—and the only way people can truly understand that is to respect that people who have lived experience have gone through some kind of healing dynamic. We lost the conversation of healing when the meds came out. Out of sheer need and relief. And I'm talking particularly the gay men's community, I know in fact that's not true in the women's community, and I know that's not true in indigenous community, I know that's not true in people who are in twelve-step and recovery processes. But as a culture we were doing a lot of formative work on what is healing, how to heal, and trying whatever it took to heal. So that's my message to other people, you won't get it until you go on your own personal healing journey, whatever that is. And that means you have to look at your own places where you feel stigma, where you feel shame, where you feel dislocation and dissociative. So if you're intending to anything that's of benefit to others rather than just try to help—and thank you for trying to help or do something for the social good. I know, that it was only until I learned how to ask for help, to connect and have the humility to be susceptible to growth and transformation. And that's been one of the great gifts of living with HIV within a community and cultural construct setting. So there's a lot of other things I'm going to leave it other people to give their good advice. To them I would say thank you for doing your best, and good luck.

**AH:** And uh—last question here—do you have any advice for future generations? There's gonna be another epidemic of some kind somewhere, another evolution of some virus.

**RB:** Yeah I think maybe there's just, coming out of this process of looking at the wounded healer. Right? And my fascination has been cultural mythology. So I look like Chiron which is the half-man half-horse figure, not to go into the whole story, but he was the teacher of one of history's great faggot couples which was—oh my god I'm losing it, his lover—who was the great warrior, Trojan warrior? Achilles and his lover Atroculus, so here's the warrior and the healer. So they got trained in the twin arts of fighting and healing. And they were lovers. And that's a key piece. So it's bringing the heart to the war, and the heart needed for the healing. And none of those work, like being a warrior fighting the good fight, doesn't work if there's no heart to it. And we've seen that in the spade of we're maybe just coming out of call-out culture, maybe not, just constant blame-game. And we know that unless people are calling each other in, so you can fight that good fight and it needs to come from a place of us as fighters taking care of our hearts and each other's hearts. And so to if you're going to be in the helping and healing profession, you've gotta have heart. It's like the secretary story, it was only because she—if she was just

there doing her job getting paid it wouldn't have saved my husband's life. She had a huge heart. So that's my message if there's to be any message. It is not a Pollyanna idea. The whole Western, the San Francisco model of healthcare—and forgive me I'm just so attuned to San Francisco so I'm kind of this West Coast, Cascadia culture right? Culture of care. That whole process. So we had the East Coast ACT UP—although ACT UP was everywhere—but there version was fighting and performance art and get it out there and throw your dead lover's ashes on the Whitehouse lawn. Woah. Right? And the West Coast was like support systems, the first AIDS ward, taking care of people's pets, food. All of those initiatives started on the West Coast, so my point being is both of those had profound levels of heart, rooted in profound levels of grief, and you cannot separate those two. So any clinical approach, although it has it's place, it needs to stay in it's place. And never—that's what I love about so many of the researchers who found their life's purpose in working within our communities, and being welcomed into our communities. And then recognizing that we're the ones welcoming them into our communities, what's left of us. And we're attracting profoundly gifted talented people with heart. So it's no small thing. It's everything.

**AH:** Is there anything else that you would like to say to anybody, of anything? You've said a lot.

**RB:** Mhmm I've said a lot. I just want to say thank you to both of you.

**AH:** Well thank you, it's been a very profound interview, thank you.

**RB:** My honour and joy. And again it's because of these relationships and the people that have supported me, allow some of whatever I got to offer to come forward. It's because of who we are.

**AH:** Well it's been a privilege to meet you, I really enjoyed this. I should say that I'm a straight, uninfected guy, do you remember VARCS?

**RB:** Yes I do.

**AH:** I became involved—