HIV in My Day – Interview 19

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Interviewee: Rick Waines (RW); Interviewer: Ben Klassen (BK)

Ben Klassen: Just sitting down this afternoon with Rick. Thank you so much for agreeing to do this and share your experiences of the epidemic with us. We're looking forward to hearing your story. I guess maybe to set the stage a little bit, when were you first hearing about HIV and AIDS and what was that information looking like at the time?

Rick Waines: It was – it was probably between – the summer between grade ten or eleven, or eleven and twelve. I don't exactly remember. What I do remember is that the Canadian Hemophilia Society let me know that there – or probably my parents – that there was a bunch of hemophiliacs, a bunch of hemos, that were going to travel across Europe to the World Federation of Hemophilia meetings – I think it would have been '82 – in Stockholm. So, my parents sent me and I basically got on a train in London with – I don't know – fifteen or twenty other guys with hemophilia and a couple of chaperones. I was chaperoned by a fellow by the name of Scott who was a fraternity president from Baton Rouge, Louisiana, and I thought this was pretty cool. And he knew how to make gin and ton- - no, gin and sevens, and I had my first adult drinks in adult environments as we hurdled across Europe to this conference in Stockholm. I remember arriving in Stockholm, getting off the bus and walking across – I was really into photography, I had my camera. Walked into the park and as a post-pubescent but not quite sure about this whole sexuality thing kid, I walked across into the park whereupon I saw everyone on their lunch break, only all the women had their tops off, because I guess that's what you do on lunch break in Stockholm. And I was, you know, again as a fifteen- or sixteen-year-old kid away from his parents and away from North Delta for the first time, I was just like, "Oh my gosh, I'm not in Kansas anymore." So, it's that context…

The very next day we were at the opening plenary and a doctor by the name of Bruce Evatt, he gave the opening address and he said – and I actually was so curious, years later I got the trans- - I got a recording of the transcript. At this moment I forget exactly what he said but the gist of it was, "There's this new opportunistic infection. It's called GRID – gay-related immune deficiency. We've already seen it in a couple of hemophiliacs and we expect it to be a significant issue and mortality – and the mortality rates are very high." And I remember looking at Scott who was two seats over and looking at him and going, "I don't think that's very good news." And so, for me, just as someone who's done some writing, and thinking about those two realities, you know – looking back at myself at fifteen being sort of this sexual human and then the very next day, in essence, being told I was going to die was a very… very jangly, you know. Like, it was very – I knew it was a big moment and yeah… I guess that's the best answer that I have for that.

BK: That's a very early juncture at which to be learning about – and not just to be learning about it, but learning "this is going to impact me."

RW: Yeah, it seemed – it didn't seem that there was any room for avoiding this. Looking back and listening to the recording, the speech that he gave, it wasn't like he was – I mean he was giving a very measured, even, not hysterical talk on what was – what they were witnessing. But however he said it, it was very clear to me anyways that this was not, as the first of chapter in *Angels in America* – this was not good news. This was bad news. Yeah, so that was… that would have been it.

BK: Not fast-forwarding but moving on from that initial point, was that something that was… We hear a lot doing these interviews that gay men were immediately tied to HIV, GRID before it was even known what the cause was. Was there a lot of information that followed that initial news that continued to tie you to the idea of what HIV was?

RW: Yeah, I mean, so the hemophilia community was in complete shambles as a result. And I think that our doctors and nurses were doing the best they could [laughs], but it was a mess. There weren't… The only information I got about HIV and AIDS between that – between like '82 and '87, really, when I was diagnosed would be what I saw on television. Our doctors weren't really talking about it and in fact I wasn't tested until '87. Obviously, some people were having conversations about it because there was a decision made with my parents and my doctors, I guess, that I should be tested after I graduate from college so that I guess I would get through that without losing my mind or something. It seemed a bit of a risk. I wasn't having sex with anyone. I don't know whether they knew that – I don't know how they would have, but it seemed a bit – it seems a bit bold. But I think everyone – and I'll probably say this a hundred times – everyone was doing the best they could with what was, in both the gay community and the hemophilia community, a giant calamity, right? So, it was like this disaster that you can't always – I think you can't always expect – I don't think you can expect everything to run according to plan… Or, with hindsight I don't think we can expect that things are going to be handled the way they should be, because people are scrambling and it's not something that people are prepared… We weren't prepared for that – certainly in the hemophilia community we weren't prepared for this.

BK: What did that community look like? We've heard a lot of insight on what the gay community looked like, but I know a lot less about what the hemophilia community looked like.

RW: Yeah, the sketch would be a little bit like this. Until the late-'60s – well no, even further. Until the mid-'70s, the only – we had to go to the hospital every time we would get a bleed. And until – and to back up a little bit, until the late-'60s, that treatment wasn't particularly effective. So, there was a lot of bleeding, a lot of disfigurement, a lot of mobility issues, a lot of death. So, the hemophilia community until the mid-'70s was a very tight community where… I remember going to, like, pool parties where it was just everyone in the Lower Mainland who could manage to get there, all of the kids and all of the parents, and we'd all get together at the Dayton's house and have a pool party. And the parents would try and figure out what the fuck they were going to do with this really difficult disease. And then homecare came along where we were able to infuse at home. So, in the late-'60s they learned to fractionate blood so that meant that our product became a lot more – it worked a lot better. And then in the mid-'70s, we were allowed to take that product home so that we could do that at home, which was fantastic 'cause it didn't disrupt your life as much. You could infuse sooner, so that you wouldn't have as much bleeding into the joints, and less bleeding and less pain. But at that point, the community started to disperse a little bit because our – hemophilia wasn't really a culture, it was… Like, the gay community is a culture. The hemophilia community is a disease. If my life here with this disease has taught me anything, most folks, once they got their basic needs met, are going to be less likely to need to commune over that. And so, as our treatments got better and better, the community became a little bit – a little bit more fragmented. There's still – today, there's still lots for us to figure out, but it wasn't as tight as it was in the late-'60s and early-'70s. And then, of course, they learnt how to take that fractionated blood product and pull it apart even more and freeze dry it. So, then we had something we didn't have to keep in a freezer and we could travel. Before it was IV pulls and plasma and saline and, you know, an hour of hijinks. Now, it was these two little vials and it mixed in four minutes and you put it in your arm, and blammo.

The problem of course was that in order to make it – like, when I was getting plasma, I would get donated blood from one or two or three people at most. To make this fractionated freeze-dried product, they would take a thousand donors' blood, put it in a big vat, spin it around, freeze dry it, and then I would get my portion of it. So, what that meant, obviously, was that if one person in that collection had HIV, then everybody would get that product – everybody that got that product, which would be thousands of doses, would probably get HIV. And that happened. And so, what that resulted in is that ninety percent of us who were severe – had severe hemophilia – ninety percent of us became HIV positive, virtually everyone. In my group, I know one guy who managed to avoid it. So, at that point, the community went… You would think – you might hope for a re-coalescing of that support. Not so. People went further underground and I think probably the… Well, first of all, there's just the trauma – that, "I guess we're all dying." So, there's that and I don't think we can undersell that. But the hemophilia community was no more or less homophobic than the community at large, so I think – well, I know – that at the time none of the hemos I knew wanted to be associated with HIV because that meant you were associated with gay people. And so, that just drove everything further underground and created for me an untenable situation. It wasn't how I saw the world. I grew up in the same homophobic world as everybody else did and I can't proclaim that I was without all homophobia because I don't think it's possible to avoid it, regardless of your sexual orientation.

But I knew that in order to survive, I couldn't crawl under a rock and I didn't really see any good reason to not associate [laughs]. Probably the best way to put it was that my parents didn't reinforce our culture's homophobia. I don't think of my family as being super progressive or out front of any of these issues, but they certainly didn't reinforce any of those societal problems like homophobia. So, I think I just realized that in order for me to survive, whatever that meant, I needed to reach out to people who were being proactive. And it was very clear from watching the news between fifteen and twenty-one, it was very clear who that was [laughs]. That was gay men with HIV. And so, I first of all wanted to be open about being HIV positive, so I started talking about that within the hemophilia community, which I was discouraged from vociferously by pretty much everyone, except my parents – they were good. To stop short of going too far down the road, it's safe to say that the hemophilia community went – in general, went as far away from the issue as they could, to the point where it was clear to me… It was clear to our clinics who used to take care of all of our medical needs, not just the hemophilia stuff, because we were seeing them so regularly, you know, if you had something else going on, you'd just talk to your doctor about it. He was handy, he was right there. And they understood, I think, that they needed some help on this one – it was a little above and beyond. So, I was sent to a doctor to – you know, for him to handle my HIV care. I knew right away that – well, it took me a while to do anything about it, but I knew right away that this was a problem, that he was figuring this out on the fly like I was figuring this out on the fly. And I didn't want to be with a doctor that had like two patients with HIV – I didn't think that that was a good coping strategy. So, I found help within – again, within the sort of gay HIV doctor world. But to sort of just finish the thought on the hemophilia world is that they went one way and I went another.

BK: And that was because there wasn't a sense of that community being able to provide support on that particular issue?

RW: Yeah, it seemed like if I wanted – it seemed like if I wanted to die alone, that that would be the thing to do. And I didn't. I wanted to die with people. [long pause] It wouldn't have been alone. I would have had my family, of course, and in some ways I would have had the guys. And I don't want to paint all of my brothers with hemophilia as a bunch of homophobes – they're not but our culture is. So, I would have had them as support but it didn't seem like a very… I just knew instinctively that that wasn't where I was gonna survive, and I don't mean live. I think I just mean, you know, be around people who were being courageous about it… And that doesn't sound right either, because a lot of hemos were battling. But I just wanted to be around people who were open about it and the hemophilia community in general wasn't – that much I can say.

BK: And by 1987, the gay community had been mobilizing around the issue for…

RW: Yeah, years.

BK: … you know, five years already, so of course that was where the support was.

RW: They were the people in the streets and I wanted to be – I wasn't sure where I wanted to be, but I didn't want to be in an HIV closet. [Laughs] I wanted to be out of the closet and they were out of the closet. My mom used to say – we'd be watching the news. I think the very first candlelit vigil in San Francisco we watched on the news because it was on every channel of course – all six of them – and she said, "I wonder if we'll be marching with them one day." And it was before I had been tested but we all knew what was coming. And it ended up being one of those moments, you know, that you don't forget.

BK: That's pretty amazing that your parents had that…

RW: Yeah, I'm sometimes a little hard on us. I sort of wonder whether the comment should have been, "We should get in the streets with those people… [laughs] regardless." But considering where we came from, yes, I will agree that it was amazing. And I don't ever want to be hard on my parents. They're fantastic.

BK: One obvious difference to me as you're telling this early part of your story is that for gay men very quickly there was this idea that we can do things to mediate the risk of getting HIV. We can – well, eventually it kind of coalesced around the idea of safer sex…

RW: We can not use poppers! [laughs]

BK: Initially, yes. [laughs] Then it slowly became, "Well, we can use condoms." There's not really an equivalent for…

RW: Yeah, that's one of the tricks for us for sure was that there wasn't a way out and you knew it was coming, and if you used the blood product with any regularity, you were going to get HIV – there wasn't – and Hepatitis C and Hepatitis A and B – well, not A but B. Everything. And there wasn't a way to get around that because the not taking it wasn't any solution either. That means you – at the very least crippling pain and long-term – you know, the kind of joint damage that would get you into wheelchair and get you dead. I mean, hemophiliacs before there was any treatment died very young, so there wasn't a way… there wasn't any way to mitigate those risks. That being said, I don't know whether it was Saskatchewan or Manitoba – one of the enlightened provinces – one of the hematologists in one of those provinces said, "I don't know about this fractionated baloney," and he kept a lot of guys on plasma which meant that the transmission rates in that clinic – and I don't know whether it was one clinic in the province or the whole province – doesn't really matter – that clinic had much lower rates of transmission.

BK: That's very interesting. Not something that a person in your shoes has any control over.

RW: No, and it wasn't – I remember once getting a phone call from the clinic saying that there was a recall on our product. I don't – only I'd already used it all. And I don't how all that – yeah, I don't know anything about that recall, but that sort of symbolized a little bit what it was like. We all knew that there was – on some level, we all knew what was happening, but there was nothing to be done so it wasn't… We didn't think there was anything to be done and so what do you do? You just – you just wait – you just wait to be told you have HIV, really.

BK: What was that like, that period of knowing but not knowing?

RW: I think I had fairly, relatively – so, I'm sixteen, seventeen, eighteen, nineteen. I'm – I think I have fairly strong coping slash delusion mechanisms at work. I don't remember those years as being… I remember it would – you know, the idea would rise up from time-to-time when we would see the marches in San Francisco. Or I remember, funnily enough, when the first shuttle crashed, I remember sitting on – next to the television watching that and on my way to school, college and thinking… Just that portent of disaster, I remember that, really. And that was probably just months before I found out. So, it would rise up from time-to-time and of course you would hear about other guys who were getting it. I don't know who had been told, but it was very – it was very… There wasn't a lot of communication about it and if you were going to learn something about it or if you were going to cope with it, it was going to be by your own effort. In those years, I think my efforts were directed toward just being a teenager and putting it somewhere else. Yeah, I think I put it somewhere else for a couple years.

BK: Were hemophiliacs talked a lot about in the news around HIV as a "risk group?"

RW: Yeah, Ryan White of course was a thing. And then the brothers – I just looked this up as well but there was another two brothers who were from Iowa, Idaho, who had their houses burned down.

BK: I remember that story.

RW: Yeah. So, that kind of thing. Again, I don't really remember – again, 'cause everyone went underground – we weren't going to the Daytons to hang out at the pool anymore, so any time I'd bump into guys would be at the clinic maybe and that would be kind of in passing. We would all have known about the kids having their house burned down. We all would have known that this was happening on some level, but I think that every family dealt with it kind of in their own way and there wasn't a lot of – yeah, there wasn't a lot of communal commiserating about it – not that I remember. And that was my problem was that I wanted to talk to people about it and I didn't have that opportunity.

BK: It's interesting to me to think that hemophiliacs were being identified consistently in media as being at-risk and yet so much of it ends up tied to gay men anyways. The stigma attached to gayness somehow seeps over to these other risk groups that aren't at all associated with…

RW: I know it was – yeah… Again, that was the problem that the hemophilia community was having was that they didn't want to be associated with the "gay plague." And that isn't how I saw it. But it is curious that – I guess that our society in general wasn't – first of all, I think that they were afraid because in the first decade, of course, it was terrifying. I think of it a little bit like – I'm not really a scholar but in the early-1900s, opium in the Downtown Eastside, you know, Chinatown – that was no problem until white women started getting hooked on it and then the shit hit the fan. So, I think of it a little bit like that in the sense that as long as that dirty plague stays with gay men, everything's groovy, but once it starts to leak out, then people get their knickers in a knot. And maybe hemophiliacs represented that in some way. I think people were just afraid – afraid. And people have always been afraid of gay men, so I think it was easy for our culture to just – anybody that had that "gay disease" was a threat.

BK: I think there might have been some degree of a difference in conception between "innocent victims," right, and gay men who are not innocent victims.

RW: Yeah. And I spent ten years touring with the BC theatre and my principal message to the kids I spoke with was dealing with that. How I – despite the fear. So, I mean, this is what I experienced was that everyone was telling me, "Don't tell anyone. You're gonna… It's going to be a problem." No one said, "Your house is going to get burnt down," but that was the underlying message, aside from the fact that you don't want to be associated with gay men – that classic, regular old homophobia stuff. But once I started talking about it and being open about it, I realized very quickly that I wasn't being treated like gay men who were exposed to HIV. I was the innocent victim and that made me – that, I knew, made me insane. What I mean is that made me crazy because it wasn't at all how I saw it. I didn't see – I very adamantly didn't see myself as innocent of anything. I was HIV positive like everybody else was. All of us were doing exactly what we need to do to be human. For me, it was, you know, infusing a blood product. For someone else, it would be infusing heroin. For someone else, it would be having sex. Myself personally couldn't rationalize any difference in those stories. I understand that there are some technical differences but I don't really see… I don't really see expressing your sexuality as being an option, so I never really saw it as, "Well, you can just not have sex, or you can just do this or do that." I didn't – I couldn't wrap my head around being an innocent victim. I wasn't. I certainly wasn't victim either. I was just a guy who got a bug, like everybody else. But yes, definitely the world around me saw me that way.

BK: Had you had any interaction with the gay community prior to HIV?

RW: Yeah, none – I don't think. I mean, there would have been the odd kid at school that, looking back, I knew – I now know, "Oh, right. Of course." But no, I don't think – no. There was one but I don't know if I met him before I found out. There was one hemo I knew – one hemophiliac who was gay but I don't know if I met him before I knew I was HIV positive. So, in short, no.

BK: Did that diagnosis change the way you felt about all of this or was it kind of like, "I knew that was coming?"

RW: It was a very… So, the diagnosis was… So, college was done and at the stroke of me getting me diploma, I became super sick with what was probably my seroconversion. And then right after that I was tested, and it was time to get my test results. We all knew what it was probably going to say, but my parents had said, well we'll go down next Wednesday or something. And I said, "No, I'd like to go on my own." So, I went in the morning and my parents went in the afternoon to get the news. And I remember the room like it was yesterday. I remember my hematologist sitting behind his desk. I remember the little weird paper note holder, woodpecker thing that I'd been playing with since, you know, I was four, on the desk. And he just said, "Well, let's get right to it. You're HIV positive and what that means is that you can't have sex… without a condom," I think he said. Yeah, he said, "You can't have sex without a condom." That was it. [Laughs] So, I remember at that moment it just felt like we all knew this was coming. Like, immediately there was this giant – well, I guess you could say an elephant in the room – but it was this giant stone that was immediately kind of over my head or in the room or above me. You know, there was immediately this presence that wasn't there before even though it was very clear – this was no surprise, but the fact that he sat there and told me brought HIV into the room and it became a physical presence in my life that… yeah. That I knew was going to – that I knew had the potential… And I don't mean just dying – I knew that it had the potential to kill my spirit, like to kill me before I died. I knew immediately that if I didn't address that giant thing in the room, I was going to die. And again, that didn't mean that I had any illusions that I would be fifty-one and sitting in this room, but that it would destroy me.

And I remember I had a little sports car at the time – a Scirocco – I remember driving home way too fast with the music turned way too loud and just kind of… With this… Another thing and a recurring theme, and I think it's kind of a classic – there was this white noise too that immediately became a part of my world in those kind of catastrophic moments, if you will. Sort of this really loud, silent thing. And maybe the music was trying to tune that out. So, I just drove around and met up with my folks for dinner at home. And my father looked up from the mashed potatoes and said, "We'll just get through this like we've gotten through everything else. We'll just get through it." And at the time I just thought, "What an idiot." You know, like, this isn't like fucking anything else. This is the end. But of course, years later, I realized it was… what else can you say? "We'll get through it." And somehow we did. I wish we could say it was because of anything we did – I don't think it is. I think we got through it because I got lucky. I mean if there's sixty-four reasons why I'm still alive, fifty-nine of them are about just luck. And yeah, that was the first day, if you will. Yeah, life was very different after that. It couldn't – yeah. Like, yeah… A whole different reality. And I knew immediately that I needed help of some form. And I knew where it was, but I didn't really know how to access it.

BK: So, how did you get connected to that support?

RW: Yeah. So, this super amazing executive director of the Canadian Hemophilia Society at the time – his name was Bob Scheer [sp?], Robert Scheer… still close – we're still close. He – I don't know why he picked me… maybe… Well, I guess I do know. I was the only hemo that I knew of that had spoken publicly about being HIV positive and I just did it at a local chapter in a little room, but I'm sure he was told about it. And so, he invited me to come to the Montreal Conference in '89. And there, because he knew Alex [Kowalski] and Don [deGagne] and Pei Lim and these guys, he introduced me to them at the conference and that was my introduction to PWA.

BK: That was a big conference. There were some interesting things that happened there. What was it like being there?

RW: It was amazing. I knew immediately – I mean none of these… It's not like I can look – well, maybe I could, but I don't really feel like I could open up a journal from 1989 and I don't think it would be filled with realizing the importance of 1989 in my life, but I knew immediately when I met Alex and Lim and Don, and a fellow from Brazil, Herbert Daniels, I knew that I was home in a way. You know, like these were men who were fighting… and I wanted to fight. So, I felt like I'd found my people. Even though they weren't my people, they were, clearly. And so, the conference is super exciting, right, because ACT UP is there…

BK: Yeah, and the Manifesto…

RW: Yeah, it was fucking awesome. I didn't have anything to do with it, but I did bring home a poster, the ACT UP poster that Keith Haring had built, and I met a couple of the guys from ACT UP. That, for whatever reason – I mean, because I got hooked up with the PWA guys, that ACT UP activism… I didn't fall into that crowd, for whatever reason, but I did fall into the PWA crowd which was doing their own kind of activism but just in a different way. And Alex and Don and Lim were so kind to me and so welcoming that I knew that was where I wanted to be. And so, virtually every day after that, that's where I was. I don't know if it was seven days a week – it felt like it. Starting out at the Bute location and then down to the Hornby location. I didn't really spend any time at the – was it the Richards location? Even though… Yeah, we'll get to there.

BK: Sure. What was it like for you walking into that space?

RW: Yeah, I was terrified a little bit because again I didn't really know anything about this world. I knew I had to be there, but I didn't really… So, there was also things bounced around my head. Like, the obvious one was, "Does this mean I'm gay?" [Laughs] Because none of my other friends, none of the other guys with hemophilia are here. What does this say about me and my sexuality? Is that why I'm here? I knew that I wanted to – I knew that I had to be there. It didn't matter whether I was or wasn't, I needed to be there. And I think… well, I know that the leadership of PWA at the time needed me to be there too, because they recognized very early on that the world of HIV was a lot – I don't know if a lot bigger is the right word to use, but was larger in some way than the gay man's world and that I represented someone else with HIV that seemed to be ready, willing, and able to join them in that struggle. And so, I was terrified but I was very well taken care of and soon learned that while I would – you know, being twenty-one and – that there would be a sexual energy around me, being moderately attractive and young and HIV positive and ready to go. But that everyone was, despite – not despite… I never found that attention a problem and it was always very fun. I never felt – I just felt at home, right? And people wanted to know for sure whether I was straight or not [laughs], it never felt uncomfortable, it only ever felt… Well, it was uncomfortable for me because I wanted to – needed to understand what this meant about my sexuality if anything, so sometimes I might have been uncomfortable, and I guess sometimes some of the other guys might have been uncomfortable, but it never felt uncomfortable. It was my home. I didn't want to be anywhere else. Wild horses couldn't drag me away from there.

BK: And you were the first hemo…

RW: First hemo, first straight kid that I know of in Canada that jumped in. Yeah.

BK: What did the support that they offered look like from your perspective? What would that community feel like or how did it look?

RW: I think probably the biggest thing for me was just – it may be a worn-out cliché, but just being in the trenches with people, like facing it together, dealing with the DMC – dead man's clothes would come in in garbage bags, it seemed like every day – being heartbreaking, but it also being fun. Like, "DMC. Here comes more DMC!" And there'd be some categories: DMB – dead man's boots; DMS – dead man's shirts. And we'd all go through them and, "Oh, this looks good on you." And, "Oh, this is fabulous. You should take that." And some people recognizing clothes. "That's John." So, super hard but super constructive as well. Like, how do we deal with this? Let's make it a game. [Laughs] Which is a bit dark but it was coping, and it felt – it didn't feel disrespectful. It would have felt disrespectful to just send those clothes out the door somehow. So, just – I mean, there was lots of practical things. For example, I started going to conferences, learning more about my disease. I met an amazing doctor who I called up one day and said, "I know we're just pals and we hangout occasionally at these conferences, but I need a proper HIV doctor." And he said, "It would be my honour." You know, so he was my doctor until just a couple years ago and he retired. So, things like that.

In fact, there was another doctor downtown, Dr. Mc-… he was a "skin guy," so he got involved early on because of all the KS and hairy leukoplakia – I'm forgetting his name right now, it doesn't matter. I saw him once right early on because I had hairy leukoplakia and he wanted – people wanted to determine whether that was what it was. So, he saw me and he said, "Yup, that's hairy leukoplakia." And then I saw him fifteen years later or something and he's kind of a gruff guy. I wish I could remember his name, he was fantastic – Alastair, I want to say Alastair McLeod – I don't know that that's right. Anyways, he's retired now too of course. I walked in and it was some wart stuff, and someone sent me to him, and he said, "You know why you're alive, right? Don't you?" I said, "No. I'd love for you to tell me." [Laughs] He said, "Phil Sestak," who was my doctor. He said, "You didn't handle it like any of those other hemos. You found a guy like Phil. That's why you're alive." [Laughs] And Phil is a big – if there were sixty-four reasons why I'm still alive, Phil is definitely one of them. I think it might be over-simplifying it a little to say that's the reason I lived. I still think fifty-nine of those reasons are just dumb, blind luck, but I wouldn't have had Phil if I hadn't gotten involved with PWA – I wouldn't have met Phil, he wouldn't have been my doctor, I wouldn't have known where to go.

I also did a lot of, in those first couple years… well, that first year, I did a lot of art therapy at the Bute office and that taught me a lot. I think, you know, being around all of those guys while they were going through it – like, there were the dead, there were the dying, and there were the "next" – and you know very clearly where you were on that spectrum if you were involved at all, and there was no notion of being anything other… Like, the best-case scenario was being, "You're up next." There was never a "Gees, I wonder if…" So, to be able to look into your future, if you will, as terrible as it was, it was important to know what that was like. Yeah. So, I think those were some of the… And also to be – I mean, just to be actively involved in trying to make things better, like trying to get the drugs covered, to get somebody to pay for AZT – it wasn't… We would all walk home from the pharmacy at IDC with these big – well, we'd get them in the mail, nice big fat bills for the drugs we were taking. So, we were also rolling our sleeves up and doing things, and that always makes one feel better. Those were some of the things. And just also learning about… I think… So, I went from being a young, straight kid from North Delta who didn't know much about the world – was open to learning about the world, but I didn't know much about it. I learned about the world. I learned that gay men get beat up on the way home from bars. I learned about what happens to women. I learned about all these things. I learned about racism. I learned about sexism, homophobia. I learned about that stuff there because it was all part of the same problem. And so, I wasn't someone who was going to grow up to be a part of the alt-right, but I don't know if I would have ended up with the worldview that I do have, which I am very fond of, which is that we're all in this together, so let's row. PWA and those guys helped me with that.

BK: That sounds like a profound shift.

RW: Yep.

BK: And also…

RW: I don't know what you're talking about. This interview is super easy. [Laughs] A walk in the park.

BK: It's not something that people talk about in their day-to-day lives.

RW: Yeah… Writing about it has been good but it's different from talking about it.

BK: Absolutely… Part of becoming involved in that community was also, it sounds like, rejecting that notion of victimhood. You know, feeling like you're doing something to create change or…

RW: Yeah, this was going to get us, but we weren't going to – we weren't going to – it wasn't going to be a passive event. [Long pause] There were things we need to – I mean, I guess at the end of the day, we were all hoping to survive. We knew we weren't going to, but the human spirit is dedicated to survival, so I guess at the end of the day, while none of us expected to, we were all trying to. And in order to do that, you needed to – there was some shit that needed to change or we weren't going to… That's what PWA was about. So yeah.

BK: So, it was support but also this kind of activist-leaning…

RW: Yeah. Yeah, well PWA first and foremost was about that activism. I mean, an activism that for us meant working… Well, at first of course, it meant acting outside of the – without a seat at the table. But you know, after '89, there were seats at the table that began to open up for people that were directly affected, and we wanted to be at the table, so we were. And that was important to be there, to have that say, if you will, to try to make sure that we had a – that while there might not be a – so that there might one day be a chance for someone to get out alive. [Laughs] You know? I mean, I don't think we ever lost sight of the fact that you know it might be that things change one day and the only way they're going to is if we get some fundamentals sorted out. So, that's I think what we were all trying to do.

BK: And was there a lot of sharing of information around treatment?

RW: For sure. Yeah, lots of… And everybody was, yeah… Lots of newsletters about what was going on in the world of research and lots of talk about how people were coping with all the different infections – you know, like CMV or PCP or… And lots of debate about AZT and all the drugs that came afterwards. But at the end of the day, I think that for me, I guess… Well, here's the thing. I think that we all had different roles and different things that interested us. There were the guys who were just neck-deep in the research and the meds and supplements, and the latest treatment for this and the latest treatment for that. While I – what was important for me was to be elbow-to-elbow with people trying to take care of each other and be – support each other emotionally and do the work.

BK: How did your involvement there develop over time? Did it shift a lot?

RW: Yeah, I think that because I was personable and represented something specific that I was pretty quickly asked to be on the board. So, I became part of the board in – I was looking it up the other day – oh it's probably in my book… it doesn't really matter – '88, '89, something like that. Oh no, it would have been '89 because it would have been after Montreal. So, I would have been a part of all of those discussions that happened in the board and also involved with advocacy. And then the speaker's bureau became something that I was super excited about. I liked – I liked talking to people about it, I liked trying to tease apart the "innocent victim" thing for people, so I did some of that, and eventually was sort of the chair of the speaker's bureau and the chair of advocacy for a while.

BK: What was the speaker's bureau exactly?

RW: So, it was just a group of us with HIV who were part of PWA who would go out to mostly schools, I guess. A request would come in. Or sit on a panel at some event. And there was a training that we went through and we went through other people. It was largely – we were largely responsible for trying to communicate with people about just the nuts and bolts. No one knew – like, how do you get HIV? How do you not get HIV? What is it? AIDS 101 stuff, mostly. And then Alex [Kowalski] died – well, Alex was dying and he asked me over to his apartment, which was the first time I'd been there. It's interesting, in writing this memoir I've been doing a lot of thinking of the time I spent with these people who were super important to me, like Alex and Lim in particular. And first of all, the time that I actually knew them before they died was, you know, like twenty-four months or something, but if you had asked me how long was it, I mean, hpw it felt was forever. But our time was mostly spent at the office and at conferences so we were never – weren't often at each other's homes, although the whole office came out to my parents' place for my twenty-second or -third birthday I think. That was totally awesome – out to North Delta. I was still living at home, or I had moved out and had moved back. So, all the men from PWA met in my parents' living room. It was totally awesome.

But this day was the first time I'd been to Alex's apartment and it was barren. Like, I think he'd been getting – well, I knew because he'd given me some stuff, but getting rid of everything. He was dying, he was in a wheelchair at this point. I hadn't seen him for a few weeks because he was… And he told me that he had some kind of – I don't remember what it was now, but some kind of peripheral neuropathy thing going on, but it was out of control and he couldn't walk anymore and that every morning he would wake up and more and more of his – like, the deadness, if you will, the lack of feeling would go further and further up. And he told me that when it got into his chest cavity that his organs would start to cease to function and that's when he would die. And he said that he didn't anticipate that being too far down the road and that he wanted to know if I wanted to be chair of PWA, president of PWA. And of course, I said yes. I'm not sure that it was the right decision. [Laughs] But when someone who has meant as much to me as Alex did asks you to do something, then you just do it. I think I imagined that I could do the job. I don't know – I think I had a couple of moments where I did the job, [laughs] but I ended up being a bit of a disaster and I ended up leaving before my first term ended. It was a bit of a sour ending and heartbreaking and sad, and in a sense, I never went back. I mean, the guys that I was closest to died and that was kind of the end of my PWA life, which is to this day a little bit heartbreaking and I really miss that world. But I think that world is in many ways gone anyways, a little bit like the hemophilia world, right? Antiretrovirals and everything's fine. [Laughs] So, we're all back to our life. And I don't know what it's like at PWA anymore, or Positive Living, but I know I miss what I had there.

BK: So, altogether that was a three- or four-year window or something?

RW: Yeah, three-ish I think. Yeah, three, four, something like that.

BK: Very formative.

RW: Never be the same.

BK: It provided you with the support that you really needed at the time.

RW: Yeah. Yeah, and then I fell in with this theatre company and that provided a lot – a new chapter that helped me to, you know, get through the next ten years.

BK: Well, I definitely want to talk about that, but I'm just going to stop this for one second.

[End of video 1, 1:03:15]

BK: So, we were just talking about how you – after leaving the PWA Society, you started working with a theatre company. What did that look like?

RW: So, before I left PWA I think, we got a phone call from Green Thumb theatre – they're a theatre company in Vancouver. You're probably aware of them. They do theatre for young audiences and have done since 1970-something. When I was involved, they were interestingly enough the largest theatre company in Vancouver, in the Province, and that is just I think a function of having three or four shows on the road at one time. They were – they wanted to address AIDS in some way and this was '91 or [199]2 or [199]3 – somewhere in there. So, they commissioned Colin Thomas to write a play. It was called… I just had this because I was looking it up the other day. I forget it… anyways. So, that's kind of an interesting story. Colin wrote this really interesting play. It had two men kissing in it. Green Thumb was like, "It's all good, but we're not going to be able to get this into schools (in 1991). It's not going to happen. Like, we don't have a problem with it, but we have a problem with it. Can you rewrite that?" And Colin was like – at least in my memory of it – was like, "Nah, ain't going to happen. This is the play." And so, they paid him for the script and then hired Morris Panych to write another script. And Morris wrote – and I should be very clear, Colin's script was fantastic and Morris's was as well.

It was called *The Cost of Living* and it was a sort of coming-of-age story, a little bit of *Brighton Beach Memoirs* meets *Ferris Bueller's Day Off*. This young kid in high school gets asked by social studies teachers to write a report on the cost of living. He figures two things: one is a picture is worth a thousand words, so he's going to make a video presentation, so he gets himself a camera; and that the cost of living is like about what it costs for clothes and food and that kind of thing. So, he goes out in the world and the first interview he does – well, he interviews his mom and his dad, and then he meets a woman at the library, an older woman – well, two years older, and he falls in love. And just a lot of slapstick hilarity ensues, but also this – he's going – he figures he's going out on a date with this woman and he's going to lose his virginity, that's what he thinks is going to happen. And of course, that brings up all sorts of things about condoms and his mom, and again more hilarity, but she – so instead of… So, he picks her up for their "big date" and he thinks they're going to go somewhere and have sex, but what she does is she takes him to the hospital and introduces him to a really close friend of hers who's dying of AIDS in the hospital, and he's left alone with him in this room and just has a melt-down. And then has a melt-down with her and she tells him to take a fucking leap 'cause you're being a real moron. So, he has this, you know, coming of age moment where he sees that the cost of living isn't about these things, it's about living and dying and fucking things up. You know, a nice story. So, he's giving this video presentation to the class, which is the audience, the school audience that we would go to. And there was a big rack of television screens behind him and he's working VCRs and tape cassettes and filming Barbie dolls, and there's also two big mannequins – it's amazing.

So, they had this script and this show and they were about to do a little mini Lower Mainland tour just to test drive it if you will, and so they wanted… And Green Thumb almost always has the actors come out after the show to take questions from the kids. They felt like this one was a little over their head, you know, given the time and the place, and so they wanted – they weren't quite sure how they were going to handle it, so they wanted to have someone from our speaker's bureau come out and watch the show and see if we had any thoughts. I've always loved the theatre and so I was like [raises hand], "Sign me up. I'm coming." And so, I went and saw the show and just fell deeply in love with the script and the message and the fact that it wasn't about AIDS really, it was just about being human. So, that meant something to me. They didn't know quite what they were going – how they were – they thought maybe the best thing to do would be just to have the play do its thing and then a week later have somebody following and doing follow-up with the classes. And I was like, "No. I'm going with this. [Laughs] I need to go with this." And I think everyone was a little nervous, myself included, because the play is amazing and it wouldn't take much for some idiot to get up there an wreck it, right? But they were game to try it out. So, I went and it was very different than being asked to come to a school to do an AIDS 101 thing. This was – a lot of little doorways got opened up in these kids from the play itself, so it was a much more open, spirited space, if you will. So, I felt like the AIDS 101 thing wasn't what I wanted to do. What I wanted to talk about was the way we treated each other.

And what I also realized pretty quickly is that the very first question I was always going to get asked was, "How did you get it?" And what I realized that question was, was first of all, A) are you gay? – and therefore this is how we'll know how to treat you. I don't mean to suggest that all high school students are little hate mongers, but our culture was set up at the time with that innocent victim, not innocent victim – guilty party scene. And so, like clockwork, every time, first question. I spent a good long time setting up the space before – like, so the play would end, I would come right out and say, "Hi, my name is Rick. I'm HIV positive, and here's what I need you to know." You know, the Cole's Notes version is: "It's really important to be open and honest and I'm never going to lie to you about anything, and no one is going to get a hard time about their question." So, I think – but I took five minutes or so to set that up. And so, I think – well, I know that by the end of that, people were feeling ready to go, you know, because the play had done its work and I had done my work, and so I think they were feeling safe enough to ask what they really wanted to know. What they really wanted to know was, "How'd you get it?"

And so, I would – and that was my – one of my favourite things in the world because it gave me the opportunity to talk about those things and how we treat each other different based on how we got the virus. And I would spend probably another seven minutes answering the question, never once telling them how I did get HIV. So, sometimes kids would just stop me in the middle – "Would you just tell us how the fuck you got it?" And I used to wear this funny vest that was a bit clown-like with different colours swirling around, and one kid one day said that, when someone said, "Will you just tell us?" another kid said, "He's gay! Look at his vest." So, I took them on a bit of a trip, you know. Like, look, if you're gay, you did it to yourself, you asked for it. If you – this is how our world looks at you. If you use needles, better off dead, you know. And then if you get HIV through a blood product, you're an innocent victim, everything's fine and you didn't do it to yourself, and "What can we do? How can we help you?" And after all that I'd say, "I got it through the blood system," which they weren't expecting because of the way I set it up. I think it just allowed me to address that thing that was so important at the time, which was that we need to treat each other better than we are, and I'm not an innocent victim. And then of course questions would go on from there.

So, we did that first tour where I kind of had to negotiate with schools everyday how much time I would have, because they weren't planning to send it out with a "me," but after that first tour went so well, I was part of every other tour after that. And we toured across Canada three or four times, across the States once, and across Scotland once too. And it was like seven tours over ten years, although six of those tours were probably over five [years] and then there was a bit of a break, and then one last tour. And it was – yeah, a great experience. I got to do the work with, you know, thousands and tens of thousands of kids, and talk about that thing that meant so much to me, which was that you needed to treat each other better. And I got to talk about guys like [name] who I used to go to art therapy with who didn't show up one day, and I thought maybe he'd died, but he then showed up a few weeks later and looked like he'd been hit by a truck. [Name] didn't die, [name] was beat up on the way home from the bar. So, I got to tell the kids those stories that were from my experience as a straight kid from North Delta like ninety percent of them were. So, I'm one of them, except for the three kids in the class who were gay and they loved it because I was on their side and that was empowering them. So, as someone who was just this straight white kid from North Delta, I was able to say, "You know what, this is fucked. We have to change that." So, that made me feel really – like I was giving something back to the men who had given me so much, and had a great time doing that.

BK: Yeah, that's a very unique but very powerful advocacy role to be in.

RW: Yeah. I feel like it was probably some of my – well, probably my best work. [Laughs] Some of the stuff I'm most proud of anyways, that I didn't get stuck in the AIDS 101 thing, because that wasn't really – I didn't see that as being much of an answer to what we were going through. And obviously still feel that learning how to – like I said earlier, learning how to row together is probably more important than learning about how the virus is transmitted. That doesn't hurt either.

BK: They're both useful.

RW: Yeah, they're both useful. [Laughs]

BK: Yeah. And such a powerful way of challenging stigma around the epidemic.

RW: Yeah. It just felt like the only thing that I could – at that point, the only thing that interested me at all was trying to get in these young kids' head… You know, because one of them is going to be the guy that ends up in the West End on a Friday night drunk with his buddies and things get out of hand, and they beat somebody up, not because they're terrible humans, but because things got off track. And maybe some of them are terrible humans [laughs], but one or two of them were going to be able to be – maybe see it – understand the "other" as human, so that's where the stories… Every question would trigger a very specific story from me, so it wasn't exactly a question and answer, it was question and story that I'd sort of build to try to get at those things.

BK: How old were the students that were seeing the play?

RW: Yeah, between grades eight and twelve, although we did do a few runs in theatres where it was open to the general public, so sometimes older audiences, but it worked best with grades ten, eleven, and twelve, because the themes are more in line with what they're actually going through. But it worked fine with everyone, it just seemed to hit the right note with a little bit older kids.

BK: Well, it is interesting that talking about using condoms and talking about sex, in vague terms probably, that's okay. But two guys kissing – no way!

RW: Yeah. Fascinating. Both Green Thumb and Colin were dead right. There was no way Colin should have rewritten that script and what Green Thumb needed to do was to get in there and do the work. Both of them were kind of stuck. But yeah, it is super interesting. Although, it should be said that in Arkansas, it was not okay what we were up to under any terms. [Laughs]

BK: And you went there?

RW: Yeah, we were in Arkansas. We got ready, we rolled in for the first show. On those bigger tours, we would set up in a theatre and schools would come to us, and we said as we rolled in for – I think that day, we were going to do a public performance that night and then schools would be coming the next few days. But we realized when we got there that things weren't going to be going as planned, because there were like four people at the show. Three of them were the staff from the theatre – like, all of the people from the theatre – maybe there was five, I don't know. And one guy who was the youth pastor from the church in town and they had put the kibosh on anyone coming to the show, so no one was going to come. And he came just to sort of have his suspicions confirmed, because he'd heard all sorts of funny things about the play, none of which would have – he wouldn't have had any of those suspicions confirmed, but he saw enough to know that it wasn't for his community. So, we didn't do many – we might have done one show during that four- or five-day stretch there and then moved on. It wasn't always like that. Mostly, it was pretty good. Yeah… Arkansas.

BK: That kind of work, was that something that really felt like it was sustaining you? Is that one of your sixty-four reasons, too?

RW: Oh yeah, probably. Again, the things that were within my control, that contributed to my survival, take up, you know, four percent of the pie chart. I don't really believe in – I mean, people always used to say, "Positive attitude has really helped you, and Dr. Sestak and the fact that you didn't hide." And I knew lots of really brilliant, positive, fantastic, strong men who didn't make it. So, it's not me. I got lucky. I had some random DNA luck. That's the only reason I can imagine… Those other things didn't hurt, but those alone didn't mean anything I don't think, at least in my experience they don't.

BK: But it certainly would have helped to sustain – you talked about your spirit. It would have helped to sustain that.

RW: Yeah, and I think that's part of the trick in the post-dying guy years – part of the trick is finding out how to feel like a contributing human, you know. Like, those years, from '88 to '98 – yeah… I felt – first of all, I knew I was dying and I knew I was involved with an important thing. And then after that, when it started to dawn on me very, very slowly – well, first of all that HIV started to lose its… grip on society, which is probably a good thing, but it also meant that a lot of us – and you'll hear this time and again, you probably already have dozens of times already… those of who lived inside of that for all those years were all of sudden now kind of – at least how I felt – a little bit without a purpose. Because I graduated from photography school and was told I was HIV positive and a career meant nothing, because I was going to be dead. What meant something to me was, you know, PWA and doing school touring. So, when that was all over, I didn't really have a career, I didn't really have anything. And… Learning how to live became – like, dying – being the dying guy, while terrible, was also technicolour and beautiful and vibrant, and any day that you woke up was – without some terrible thing happening in your body was a victory. When all that started to wane in the late-'90s, I started to have a hard time understanding where I fit. I probably still do, I guess because, A) nothing's going to sort of match that in intensity, and I wasn't – I mean, I didn't prepare myself in any way, shape, or form for surviving. So, that's been – I think it probably gets easier with time, but it hasn't been easy.

BK: Does survivor's guilt factor into that at all or is that just a different thing?

RW: Yeah, I don't know. I've heard of this thing called survivor's guilt. I don't know. I don't feel guilty. I feel lucky, but I have felt lost. And I'm not… [long pause]. Yeah, I'm not sure if I understand that – I mean I think there are – and it could be quite possible that I don't understand what survivor's guilt actually means. What I think of it meaning is feeling guilty that you made it while others didn't. I don't really – and what does that imply? It implies you did something wrong, which implies you might have done something right somehow, like, to make it that you didn't share with others. And I don't believe in any of that garbage. I just think that I fucking got lucky. And so, I don't really feel guilty about it. I miss people terribly. I wish they had gotten lucky, but they didn't. So, I think just having that – an incredible world wrapped around you for as long as it was and being so very clear about what my role was on the planet, and then that kind of evaporating was a challenge.

BK: Because as horrible, awful as the epidemic was, it did give you this sense of purpose or meaning.

RW: It sure did for me. There was no question about who I was and what I was doing. Yeah.

BK: So, the theatre…

RW: And I was young enough when it happened that I hadn't established myself as an anything. I was a straight kid with HIV who was working in the world of AIDS but had nothing – I wasn't formally anything. I was just someone rowing the boat.

BK: Whereas, if you'd been at a more established point in your life, you might have had something else to go back to.

RW: Might have gone back to that if I felt like it or maybe if I had… It's all silly, but yeah. I mean, I don't think it's uncommon for any of us who went through it to feel a little lost regardless of what you had going on before HIV came along, so I don't know that that's a particularly good crutch for me to lean on that because I was as young as I was… But I think in my story, it did have an impact on – it did have an impact on my life as someone who… I felt really good about myself when I was doing that work and then that work went away, so your identity kind of goes with it in some ways. And I didn't – I mean, I have found ways to feel like I'm a part of this world and not lost, but I've never found anything that has replaced that. And that's perhaps a – it's not probably really realistic to have those kinds of expectations, but I'm… yeah. It's a little – it took a long time to figure out I wasn't going to die and by then you're like thirty-five and even then you're not quite sure. And then you're forty-five and you're like, "Huh, I guess HIV isn't what's going to get me." And I'm forty-five and something is going to get me that has nothing to do with HIV. I thought I was prepared for this and I'm not. [Laughs] I was more prepared then when I was going to die as a twenty-four-year-old, because there was nothing to be done about it. And now I'm here and there's nothing to be done about it again, but it's all just so mundane and just getting old. And that's really boring. [Laughs] Not nearly as exciting as dying at twenty-five from the great pandemic.

BK: Yeah, if you were living with the expectation for ten years that death was an inevitability, that's not something that just goes away.

RW: No, it took a long, long time for me to wrap my head around that… And I guess I have wrapped my head around it. I mean, for whatever it's worth, I am going to die and HIV might play a role in it, you never know. But it doesn't seem that I'm about to expire anytime soon, so I can presume that I may well live reasonably close to a normal life-span. And yeah. I guess in some ways, and it may sound a little melodramatic, if nothing else, I'm pretty glad that… You know, that old chestnut, a man dies three times: one, when his heart stops beating; two, when he's put in the ground; and three, when his name is spoken for the last time. I'm super stoked that I get to, you know, say Alex's name once in a while and Lim's name once in a while – that's more or less enough.

BK: That's very powerful.

RW: And this project will help with that. Like, I think that stuff like this, for people like me will likely – I hadn't really thought about this but will help create some closure around that as well, that if there's a record that there's some way that you can contribute to that story that isn't going to be lost, that's meaningful. It means something.

BK: The speaking of names is such a – and it was part of the vigils, it was part of the memorial we have at Sunset Beach – it is so powerful.

RW: Yeah, it's nice to go down there and see the names of the guys you remember and remember people that you had forgotten. Yeah, that's really good. And I guess at the end of the day, there's always going to be a lot of people who are just forgotten. Did you know that Gaetan Dugas has a cherry tree planted for him down by the Bayshore? "Patient Zero." He lived in Vancouver – you know that probably…

BK: I did know that, yeah.

RW: … And – I don't know whether it was the incarnation of – an early incarnation of PWA or AIDS Vancouver maybe… It might have been AIDS Vancouver. They wanted to memorialize – this was before Gaetan was "Patient Zero" and he was just a guy who lived in Vancouver for a while and died, and he was one of the first men in Canada to die of AIDS, and so they wanted to plant – it was three or four trees in the names of those first three, four, five – I forget. Yeah, so there's a bunch of cherry trees down there. I took a picture once and I probably have it somewhere, but I think I found it through the city archives, so it is possible to track them down at some point. Yeah, things like that are important. I always thought – I really should do this one day, but there's this hilarious, amazing of Gaetan on a swing set. You've maybe seen it. He's in fantastic tighty-whitey shorts and his flowing hair and his moustache, and he's on this swing. And I had it in my mind, and I've never done it, but I thought it would be beautiful to make sort of a poster on cardboard of him on the swing and hang it in one of those trees. [Laughs] I never did it, but… anyways.

BK: After you left PWA, where were you finding support, because you were involved in this theatre project, but that wasn't support so much.

RW: I guess it was. I mean, I think that was the only place I was getting it, and I think where I was getting it from was the people I was working with on that show and the students who would – were more or less unanimous in their affection and thanks. And I would get – I've got, you know, piles of letters that I would receive that they would send to Green Thumb theatre after the fact. That kind of stuff just meant a lot to me. And occasionally, like, I remember being on a beach on Hornby and this woman walking up to me and we got introduced and she went, "Wait a minute, you were at my high school and I was gay – well, I am. I just wanted you to know that that meant a lot to me." So, those sorts of things were important and helped. But it's true that I didn't have those men in my life anymore – largely men. Of course, there were… I didn't have those people in my life anymore, so that was missing and is missing to this day. I don't know why I haven't found that – I don't know why I haven't found that world again. I don't know what that is exactly about. I guess at the end of the day, it just kind of feels like it's all over, and I don't know. I do think about trying to find some – like, I've – on social media and joined the HIV long-term survivors group. And it's not the same, and it probably never will be the same, you know. And I remember leaving and coming to Victoria – I just moved here a couple years ago. And I think there was such sort of… I also moved away to a small little island for ten years and just – yeah, there wasn't anybody there, but it was a good kind of – its own kind of a medicine. I guess maybe trying to learn how to not be dying guy anymore and live a life. Yeah.

BK: I also don't know if there is programming or groups that are focused on just long-term survivors.

RW: In the States, there’s a few. I don’t think there’s any up here yet. And it seems like the peer support world has become bifurcated in a way – that’s not the right word, but that the groups I’ve read about are explicitly for gay men with HIV. While there may be other groups – it’s funny, I identify more as a gay man with HIV than I do as a hemophiliac or an IDU, and so I haven’t – I feel a little like I’m back on the outside and there isn’t really an easy way back in it seems like. I’m not sure that that – I want to leave room for my own sort of pathologies to have affected that. I don’t want this to all be about me being left out, but I think part of the story is that the world with HIV became so much more than – so much bigger than gay men in the West End that those folks needed a place that they could call their own again. And so, I get that, but it was also the only place that I ever really felt at home in a sense, as well.

BK: I have a hard time imagining that you wouldn’t be welcome back into that.

RW: I know but I’ve always just felt a little funny about saying, “I’m not gay but can I please be a part of your support group?” And maybe it would work fine. I imagine if I met someone who was part of one of those groups and there was some kind of a way in that… But I’m also the kind of guy that when I read “for gay men with HIV,” I don’t want to be the guy that’s crashing the party or being – I’m not really pushy in that way, probably to a detriment. They’ve put that in their description for a reason, so I’ll leave it at that.

BK: When you were at PWA, did you see that shift in who was getting HIV? Was that something that you were seeing?

RW: And we’re back to my indecorous exit.

BK: You don’t have to talk about that if you don’t want to.

RW: No, I’m okay with it. I’m coming more to terms with it. But what happened – so, we knew that there was – we all knew, we’d known for years really that there was a great many people, especially in the Downtown Eastside that were sharing needles and getting HIV, and they weren’t getting the services they needed because they had their own challenges getting into doctors, their own challenges getting treatment, and their own challenges… Like the hemophiliacs, no more or less homophobic than anyone else. Also, PWA, aside from me, was populated almost exclusively by gay white men from the West End and as an organization we were trying to come to grips with that. And it was very complicated because, as you can imagine, a group of people who have been dehumanized and ostracized and oppressed have finally found these places to call home – like, the village and the West End and the Castro. And then through that empowerment came HIV, so they closed ranks again and lifted all of us up. But the culture of that is very different than the culture of an IDU from – someone who’s using needles from the Downtown Eastside. Very different culture and not necessarily a culture where people are going to feel comfortable. And also, that’s not the people at PWA’s problem to make other people feel comfortable. On the other hand, if we’re – if we were the Vancouver Persons With AIDS Society, it was also our job to try to move towards somehow welcoming – anybody who’d walk through that door would have been welcome. I was. But there wasn’t something quite lining up.

So, when I first became president, I did this interview for *Xtra!*, which is based out of Toronto, and they said, “What are your goals for PWA?” And I said, “Well, one of my goals is to make sure that Alex’s dream of the one-stop shopping, which was the Pacific AIDS Resource Centre, came to fruition.” And my other goal was to make sure that PWA becomes that – the Persons With AIDS Society and not just the gay white man from the West End of Vancouver Persons With AIDS Society. And that – let’s just say that didn’t go over super well, and I totally get why and I wish I had found a different way of communicating that. It was the truth but there would have been sixty-four other ways to say that that wouldn’t have come across as, to some, homophobic. I – if I know anything about myself, I knew that I grew up in a homophobic culture and there’s always going to be stuff to rinse away. I also know that the same thing can be said about – a lot of the gay men I knew came to love – we all have to work that out. And that was a poor choice of words but it didn’t mean I was a homophobe, but it did to some. And so, there was a group within the organization that decided I was a homophobe and I was in control of their organization and that they needed to do something about that.

So, we had this [laughs] – so, we decided as an organization to undertake a review of how we operated. And at the time we operated that the chair, the president – the buck stopped there. So, we went through the process of deciding that each chair of each department should have decision-making powers. I thought that was a fucking great idea. But halfway through this process, somebody came up to me and said, “You know why we’re doing this, right?” “No, we’re doing this because we want to have a more accountable, a more productive, you know, organization.” He said, “No, they want to get all of the power out of your hands right away, because they think you’re a homophobe.” So, I was super sad. I don’t know if super – I don’t know… It was heartbreaking. And so, I sought the council of dear friend. I said, “I don’t know what to do.” No one had ever – no one talked to me – well, Don deGagne, bless his heart, came up to me after the paper came out one day and said, “You know, you’ve got to think sometimes about how these things are going to be heard.” I said, “You’re absolutely right.” But that was really the end of it. I didn’t hear another thing. So, I really didn’t know what to do and I felt – Alex was dead, so he wasn’t there to have my back and I didn’t feel like anybody did because no one was saying anything. Lim, my closest other friend was on the board at the time. Now, he wasn’t part of the gaggle that was trying to excommunicate me, but he didn’t say anything about, you know, how I could of – I just felt shut out all of a sudden.

So, a friend of mine said, “I don’t think you can just turn the other cheek on this one. I think you need to, you know, tell them how angry you are.” I don’t do that super well. Anyways, I went into the board room and I did my best impersonation of a very angry man for a while. Nobody said anything. And I said, “And I resign!” And I half expected the people on the board that I knew loved me and cared for me – I half expected them to stand up and say, “Look Rick, this has been a bit of a gong show, but please don’t go.” But no one said anything. And I walked out and I never went back… PWA did, in the end, become something different and that was inevitable. I think things were lost and things were gained in that story. Mostly, I’m just a little bit heartbroken about – and remain that way – about how that ended and how that… Like, to leave there with anyone thinking that that was who I was – the fact that anyone could have thought I was a homophobe after all of that time together was just a – just, again, heartbreaking. But what wasn’t heartbreaking was being able to go out and do that work for ten years in schools and to, you know, prove to myself every day with my heart filled with the spirit of trying to help people understand that we need to be better to each other. That helped me to understand and remember who I actually was regardless of whatever mistakes I may have made in that interview. [Laughs] I recently sent the interview to a friend of mine who is deeply political and queer and was involved back in the day, and he read it and he said, "I don't really see what the big deal is, Rick." So, that – while I was glad to hear that from him, it didn't change how that all felt at the time and how that… Yeah, it is what it is – I hate that expression. It happened, I left… I wish it hadn't. I wish it had been different – no way around that. But it doesn't take away from those years that I had there and my love for those men, and I know who I am.

BK: At least from what you say, what you said in the interview sounds like something that needed to be said.

RW: Yeah, I think it did. I think that I needed to have thought about a different way of saying it that meant the same thing but had a little less of an "us and them" feel to it. It wasn't what I meant. I mean, I didn't mean to – I didn't mean for it to read the way it read and I think that's probably fairly common for people who talk to the media about things. You go, "Hm, that didn't come off like I sort of had anticipated it would." And I was kid and I wasn't ready to run PWA – I really wasn't. I mean, I had a couple of good moments – chasing Peter Dueck out into the lobby after he announced his fabulous new AIDS program that was good but still didn't… The bastard came to this meeting and said that – he announced this new program which was an improvement over what they had been doing in the past, but he talked about fucking Alex and how if Alex were here today, you know, he'd be so happy that – blah, blah, blah. But nowhere in this fucking AIDS program did PWAs have a seat at the table. Like, it was "Here's all these wonderful things we're going to do for you," and some of them were very welcome and important, but nowhere was it, "We're going to include you in the decision-making." So, I chased him out into the lobby and I said, "How dare you use Alex's name when he died not having a seat at the table and nothing has changed." That was a good a moment. I like that moment. There might have been a couple others. But I wasn't ready to handle – I was a child amongst a bunch of very strong men. And if you get – and I wasn't prepared, I wasn't ready and willing… Well, I was willing but I wasn't ready to have that as a responsibility. I don't think I was – I wasn't doing the work that I needed to do to make that happen. I wasn't the right choice. I think it would have been better for me to have learned a bit more before taking that on, but it's okay.

BK: You were also probably the first president or chair who wasn't a gay man.

RW: Oh yeah, and that alone was going to be a problem for some people. But – and maybe that's what started it. I don't know. It felt like it all started to pick up steam after that article. I'll never know, because…

BK: But if a gay man said that, it couldn't have been viewed in the same way.

RW: No, exactly.

BK: Which is the irony.

RW: Yeah. Yeah… And I just felt… [long pause] Like, it wasn't – the problem wasn't that I wasn't doing a good job or that I wasn't – it was that no one was… No one was talking to me about it and then – and there wasn't any open dialogue. Mostly, I just miss – I miss the people that I loved there and that will never change. They changed me forever and that's enough. Yeah. I had the opportunity with – I tried to continue to do the work in small ways. You know, I'm writing this memoir and I wrote a play that has to do with the criminalization of HIV, and I hope it will get produced. I wrote another play kind of about my life with HIV that was produced. So, I'll continue to do the work and I'll continue to be trying to be someone who's an ally.

BK: I guess in general, how did the HIV community get through this – like, the epidemic as a whole. Thinking large-scale, how did they collectively deal with the epidemic and navigate that?

RW: I think… I think that… Gay men had such a – had been learning how to organize and take care of each other and fight back in a sense for decades. And then AIDS came along and, in a sense, a lot of those – all of those skills were very transferrable, so they moved on to dealing with that, along with also the other things that they continued to need to deal with. So, I think it was a community of any community that was pretty well prepared to handle it. And I think that probably if it hadn't happened – if it hadn't sort of struck in the way that it did in cities like New York, San Francisco, Vancouver, or Toronto, that probably a lot more people would have died. I think that that community was so well-organized and so ready to go that they got through it because they were… Well, however – got through it because they were organized and then the community – whoever was on that boat – demanded that we'd be heard. And that they didn't take no for an answer and that they were organized enough to make enough of a rational nuisance of themselves. Like, you can't just crash the Montreal Conference and demand shit without knowing your shit – you can, but you're not going to get anywhere with that. The people that crashed that party knew as much or more than the people who were at the party. So, very bright, motivated people that were also ready to fight. And I think if I learned some things about that activism is that it doesn't work unless you have people who are willing to put in the work to actually understand what the issues are and how – and also to find answers on their own. Like, here's how you run a clinical trial. You don't run it like this. You run it like this. And if you're smart, it doesn't matter how many PhDs you do or don't have, if you find yourself with a willing listener – and I think that there were some willing listeners – you know, smart people listen. And so, I think that there were enough smart people on either side and enough rabble rousing to accompany it that the progress that was made was – I mean, the movement has changed the way we run clinical trials for all sorts of people. So, that's incredible.

BK: Even things like drug approval and expedited drug approval for potentially life-saving drugs. Some amazing legacies of AIDS activists.

RW: Yeah. So, I think we got through it because they were prepared and prepared to do the work, and were empowered enough, through their own stories – having lived through the oppression that they had to live through – that they were like, "This isn't going to happen. We're not going to take this shit anymore." Yeah. And they had the resources. You know, one of the things that kids used to ask me is, "How have you survived?" And I said, "Well, there's a bunch of reasons. I have a roof over my head. I have clothes. I don't have to worry about food. I don't have to worry about money. I have a family that loves me. I am a white male. I have everything I need to succeed." And while gay men would have had a lot more on their plate to overcome, there was a very empowered, "I'm not going to take this because I don't have to" group of men who just demanded things be done different, and had to be heard because they were bright, because they were angry and strong, and weren't – maybe in some ways weren't – I'm kind of extemporizing here now [laughs] – maybe weren't as beholden… or not beholden, but as reliant… In some ways freedom in some manner had been achieved and there were these little bastions of – these little strongholds in New York and San Francisco and all over the place, where they could fight from. I don't know. Strong – very strong – very strong men and women. Unfortunately, mostly who I met were the men because, again, PWA wasn't necessarily a place that women felt at home either, which is why other organizations sprung up to meet those needs. But the people that I was alongside for the most part were gay white men from the West End and they saved my life.

BK: It's such a unique story. There are aspects of it that are very sad, but so much wonderful…

RW: It was terrible, but it was the best thing that ever happened to me – and I wouldn't wish it on anyone. [Laughs]

BK: Quite the paradox.

RW: Yeah, totally.

BK: How has your perspective on HIV in general shifted over time? We kind of talked about that a little bit.

RW: Yeah… [Long pause] I always used to get bad news when I went to the doctor. I was never close to death but I – well, I was as close as you'd want to be without being close to death. [Laughs] Very low T-cells and different opportunistic infections, nothing life threatening. But regardless, you'd go to the doctor. I was resistant to… two of the three classes or three of the four classes – I forget which. It seemed like every time I went to the doctor, he'd say, "Well, these ones aren't working. You know, your viral load is still here and your T-cells are still there, and you've got this infection." And I'd go to my favourite little Japanese restaurant and cry into my miso soup, and go home and weep at a Sears commercial. I cried all the time – all the time, every fucking day. And now, I don't get bad news at the doctor anymore. When I go to the Japanese restaurant – well, my favourite Japanese restaurant is now gone, but I went to a Japanese restaurant before I came here and thought about all those other trips when I'd be alone at the Japanese restaurant. So, isn't that great? [Laughs] And I wouldn't have it any other way. I have a beautiful little puppy dog and a lovely wife and a boat, and I go free diving. And my parents are still alive and I've become friends with them. Life's good. I'm very thankful for all of that. And I sure miss that dying guy… because it was a lot easier sometimes in a way. That's not right – I'm not sure it was easier, but it was… yeah. I've said it all… [Long pause] It's a bit melodramatic. I don't want to be the dying guy, but you know, it's…

BK: I can totally understand. I mean, I can't *totally* understand obviously, but I can wrap my ahead around what you're saying, absolutely. I'm just about out of my questions per se, but the last formal question we like to ask is if you have any advice for younger folks that might be newly diagnosed or people that are becoming positive today.

RW: Find your people to go through it with. I think I don't… Yeah, you know, peer support is – was super critical for me to… And again, I don't know how many pieces of that pie having that peer support provided for my survival, but it certainly had a couple of them. And again, without – wow… It doesn't matter if you survive. You're likely to, given the drugs that we have access to and the fact that you probably won't be resistant to any of the classes of drugs right away, and you'll probably live until you're probably seventy-two and fall and break your hip. But it wasn't really the point. Getting involved with something like PWA, the point wasn't that we were going to survive till we were seventy-two. The fact was that we were going to take care of each other until we died. So, I think having people around you who understand what you're going through and understand because they're going through it, I can't imagine doing this – I can't imagine – I couldn't… The moment I sat down in that office and the doctor told me I had HIV, I knew that I couldn't do it alone and that I couldn't do it with parents, I couldn't do it with my sister. I had to do it with people who were living and dying with it. And I imagine that a great amount of what being HIV positive today is different, but it doesn't matter. You'll have all these other things that are in common. Despite the fact that some of the world is understanding that undetectable means untransmissible, there's still going to be anxiety about sex, there's going to be anxiety about transmissions, there's going to be anxiety about not being loved, there's going to be… you know.

BK: Criminalization.

RW: Criminalization, yeah. There's going to be – that's still a thing. And I guess there's been a little bit of progress as of late, but still a thing. And so, if you have people around you who aren't at the same threat you are, like, it's good. I don't think you want to be in the trench alone. You want to be there with your people.

BK: Well, I think that's a good note to end on from my perspective, but is there anything that you wanted to mention that I haven't had a chance to ask about or anything that you haven't had a chance to speak to?

RW: I don't think so. I think… that's it.

BK: It's a very rich story and I'm just really thankful that you shared it with us.

RW: I'm super thankful I had the opportunity to, so thank-you for having me along. It's good to feel like this is what it felt like, right? So, if I miss that, I had the opportunity to do it again. Phewf! [Laughs] Thank god I'm not doing it every day anymore. It's exhausting! Really easy to fall asleep at the end of the day.