"HIV in My Day"

October 8, 2019

Participant: Mark Stephens (MS); **Interviewers:** Art Holbrook (AH), Charlene Anderson (CA)

AH: Alright, okay.

MS: Where am I looking by the way?

AH: Talk to me, please. Unless she pipes up, and she does occasionally.

MS: Cool.

AH: So please introduce yourself. Who you are.

MS: Hi, I'm Mark Stephens. Living on Salt Spring Island on the West Coast of Canada. I've been alive for sixty-one-and-a-half years, and happily a Taurus, male-identified person.

AH: Okay. So what's your—how long have you lived here?

MS: This'll be our twentieth year as of May, so we're into our twenty-first year. And living in a relationship with Robert Birch for twenty-two, going on twenty-three years.

AH: Watch out for twenty-three, that's when my wife asked for a divorce.

MS: You're editing things are you—out of the interview?

AH: This is not part of the interview.

CA: Happy anniversary.

MS: And it's our thirteenth anniversary for wedding.

AH: So where did you come from before Salt Spring?

MS: My mother.

AH: Well yeah, okay. Okay smart ass. What community did you come from, what city, town?

MS: I was raised rurally, I was born in Burnaby and raised in Coquitlam when it was very rural, like I never saw someone when I took the dogs out for a hike for a whole day, in those days. Now you couldn't do that, so it was a very rural environment to grow up in.

AH: Did you enjoy that environment?

MS: It was my—yeah, it was the best, and I reflect on it very often when I walk here on Salt Spring with dogs, back to those days when it was just me and the animals. A very important part of my growing up.

AH: So uh, did you come from Coquitlam to here or?

MS: Uh no, that's a longer story. After graduating from high school, my high school was a very large senior high, but they had a huge art department so I was involved much with more with creative art expression in those days. And my instructor said, 'well have you though about post- high school?' And I was like uhh. And he's like, 'well what about applying for Vancouver School of Art.' And in those days it was all over Vancouver, they had a campus that was quite broken up. It was a four year program, and I was accepted right away. And I was one the of two youngest—I was eighteen years old when I went into Vancouver School of Art. They moved to Granville Island so my fifth year deferred grad was to Emily Carr. So I commuted back and forth and house sat. So I was doing kind of house-sits in Vancouver but living in Coquitlam most of the time. Commuting every day. And through one of the house-sits I ended up getting up getting a place, that they were moving out of and it was sweet. And I just been hired to work as the art installer—it's called a prepatore—at the Burnaby Art Gallery. So I was commuting the other way rush hour, but living in Kitsilano and going back and forth. And I did that for ten years. So still working on my own artwork, but living in Vancouver but working in the City of Burnaby, so Deer Lake Park. Yeah ideal for an artist to graduate, work on his own artwork and then get recognized and hired in a public gallery that had close to three thousand pieces of art on paper. So I was the prepatore and did installations of shows, and worked in the art world again for the rest of those days.

AH: Just as an aside here, did you know a fellow named Allan Todd, who was the—he was the person who hung the art in the national gallery? I know you he some work out here.

MS: Yeah they probably would cross over at different times.

AH: Anyway he was a good friend of mine, he died a year or two ago. Leukemia.

MS: Ouch. Yeah.

AH: So what did Kitsilano back and forth, what did that look like before HIV?

MS: Wow, I wasn't out as a MSM—a man sexually with men—until I was twenty-eight. So I was well into that career. Uhm, and went back and forth with men women for about a year and a bit, and then basically just flowed right into male relationships. And I was starting—my brother's queer identified and has been his whole life, so I've seen him with men and he was living in Toronto at that time. So I went back East to come out to him first before my parents. And I was negative at that point, as far as I knew. And had met somebody out clubbing one night with my cousin, a female, straight-identified woman and through probably having hemorrhoids, I wasn't penetrated but I was probably infected by pre-seminal fluid on my anus at that time. So none known, but a diagnosis between negative and positive was in that time period so—and I wasn't very promiscuous and I wasn't very—I wasn't an anal receiver at that time so, it was very likely through a hemorrhoid, a bleeding hemorrhoid an infection entered my bloodstream. So, it happened in that time frame and I don't know whether we're going with the doctor and the diagnosis day, are we going there with the interview?

AH: Yeah, sure.

MS: A family physician—it was the son took over the practice from the doctor that brought me into the world. So his son went doctor school—whatever it's called and uhm school for doctors—and uh became the family practitioner. So he had very little, very little. So this in—oh shit I just forgot the date—ninety-two, nineteen-ninety-two. June sixteenth. And very little practice at bedside, this is what's coming. And HIV was even further down that line, so cancers and all the possibilities of terminal disorders were not his forte. And HIV was completely un—so sits down, Mark I have to tell you positive. We're going to do another test in case it's a false positive. But I was working at the gallery and I basically went back to work and didn't tell a soul. Kind of sat with that moment, because I had started to see people in my community sick. And this is ninety-two, so definitely from larger, major cities had seen and heard about the conditions that people were dying from. Kaposi sarcoma was the kind of more physical one, wasting, physical visible deterioration of what I had remembered being people athletic, and very physically active and muscular. So I was aware that his conversation with me with you are positive from the bloodwork, we're gonna do another one. And I don't recall if they were the exact same words, but they were that kind of conversation of you have upwards of three years, that we know of to continue living in this form that you are in. I was an aerobics instructor and a swimmer so I was like, very similar structure to I am now, very lean and physically fit. So he said you don't have a lot of body mass that if you do get sick, your condition is that you're not going to do so well, is basically how he said it. Again so the little information that he had as a physician at that time to decipher out to a patient in a rural situation. It was out in Coquitlam so.

CA: Did you have more information than him?

MS: I hadn't really got the physical aspects of what HIV and how it progresses, but I had been in the community enough to see the deterioration and see people starting to step up, and didn't know anything out of sort of the lower mainland area, not even anybody in Toronto or San Francisco. So those communities weren't—I wasn't aware of those communities, but it was just from watching and seeing in the Vancouver community.

AH: Is that how you first heard about AIDS or did you previous to that?

MS: It was something that I was aware of, and public information had really started to do a campaign about condoms safe sex. And it was in the clubs in the washrooms and different things. So part of it was penetration phobia for me, so it was kind of at that stage of not knowing what to do in those situations. Uhm, my brother and I never talked about it, and still haven't really talked about it to this day. Uhm, from what I gather he's a top so he's been probably condomed and been kind of the navigator through a sexual situation. I was never really a top, so I would never be in the situation of navigating through condom use. I guess I would, now think that I was. But at the time it was kind of more unknown to me, so I just had no anal sex. No penetration sex.

AH: So what was your initial reaction to the disease when it—when you—

MS: It was—yeah 'cause I consider myself to be healthy, physically, uhh I think even then I was a vegetarian, so I'd made a conscious effort to consume and be in the food groups that I wanted to be eating. And part of that stemmed from being at the art college, so it was kind of a carrying through of that was a lifestyle that I chose. And so physical active, cycled a lot, swam. And then to not be sort of—I never went to the steam baths, never the parks, I wasn't participating in that queer gay men's, MSM lifestyle so to be out with my cousin dancing. I mean Elan was amazing, he was just a beautiful, amazing person, uh to be with and—so that sexual encounter that I expressed earlier was most likely my transmission route. So to get a diagnosis, diagnosis of negative, negative and then you go to the positive. My mind just went to who? Like looking back over the course of my sexual partners and just deciding that that was the only time I remember that there was a situation where I would say, yeah that was a transmission route for me. So, the shock of it, the way my physician presented it to me, my parents I was—I'm sure I was out to them by then, so my whole family: my brother, only one brother, and my parents. So those were my inner circle of family that I was out with.

CA: Out with as a—

MS: Gay male.

CA: Gay male and positive? Or just as a gay male.

MS: No, definitely just as a gay male.

AH: So how did you learn more about the disease?

MS: It was kind of like how—I was very young and very matured very early. So I was hanging out with older men, younger—boy, or older boy-men for my age. So I learned a lot about sexuality from them. There was no kind of real concise sex education in those days, it was the banana on the condom and the whole silly giggling boys and girls in class. So basically learned a lot more about being sexually active by this group of older—I'd just say they're in their twenties when I was in my sixteens. I had facial hair so I just went drinking with them and hung out with them. So I learned a lot by that, so I would say the same thing was applicable to HIV information, was it was on the street, it was the people I was hanging out with. Interestingly, the first male that I had conscious physical contact and sex with was a lawyer, so he—I consider them all the A-gays, there was a lawyer, there was architects, there was—they had the Porsches and the Mercedes and I was a artist, and I drove a pickup truck and worked in a gallery. And I was always confused why I was included in their—like I had to learn which fork to use proper—all the rules of etiquette of high fine living. So hearing from them, the plague and the this-and-that it was always going to be the others. The barflies, the tub people, the bush people, meanwhile they're probably all doing it. But they were condescending towards it, but they were talking about, that's what it is it's this other disease for them, at that point. So the white, cis, gay, A-gay, very wealthy men in Vancouver that had included me in their social circle were my education source at that point. I had even thought that there was a resource for going to BC PWA or any of those institutions. Never even crossed my mind that was there. And not being from that area I never knew that St. Paul's was an epicentre, still kind of went back to the rural area where I was. That was still my physician at the time. Yeah.

AH: So how did you respond when you learned you were positive?

MS: Uhm, I was like—the three year—in retrospect it was setting up for a determination to go through, I wouldn't say fighting it, but this wasn't going to be me. It wasn't going to be—an understanding that it had been kind of diagnosed long enough that they were—they, the physicians and scientists—were getting onto another pathway of looking at uhm, because my first medication was AZT. Which I found out was the cancer drug or something from Germany, they couldn't use it and it was too toxic to bury and so they started fooling around with it with positive patients. Even in those days the information was coming out like photo developing chemicals painted on your arm and absorbed into your skin and—and then I started doing much more research. So this is where the coming through with alternative healing was I used to buy bitter melon in Chinatown and puree it and take it rectally as a enema. And retention enema so the bitter melon was absorbed through your rectum, and they were proving that there was compounds in this bitter melon that was anti-retroviral. So there was kind of this hope with getting through with not doing the chemicals, of some kind. So that's where it started, it had started with—I relied on my immune system all the way through my growing up. Any time I got a cold or flu, I just closed the door turned out the light and slept in bed. And just sweat it out and curled up. And it's kind of like a dog would look after it's health until you were well again.

CA: So you educated yourself?

MS: Educated myself. It was way before the all the computer generation and all the information comes into your own home that way. So I was very proactive in what was going on in alternative healing, and was seeing a Chinese practitioner in Chinatown, doing the pulse taking the herbs and simmering them. Tastes like shit. And thinking well if it tastes this bad it's killing something. If it ain't gonna kill me it's killing something. It's like, it's bad. I never drank like elk penis or ground up seahorses but there were some nasty, really nasty. I laughed because he used to laugh when I left, I'd have all these paper packages with all these things all piled up. And he's like, 'see you Mister Stephens.' And I'm like why is he laughing? He's laughing because this white guy is going out with all this—this white guy's going out with another nasty.

AH: What about in your social life, how did things—how did you respond?

MS: Uhm it was a big secret. It was just the big secret. And uhm just through the course of dating others and starting to try to understand how do you have that conversation. Because I was becoming aware that there was a lot of people out there that weren't having the conversation even still in ninety-whatever, they were getting to ninety-fours. So there was still that undiagnosed, undisclosed statement coming through sexual encounters. So still not really promiscuous, and still not really wanting to have anonymous anal sex. It was still just not there for me, even though it was like if you're positive it's just an STI now that you're worried about, more than contracting HIV. So, yeah it was just starting to understand what life was going to be like if I was to survive. The partner that kind of set off all the butterflies and this might the be the person to live with, that conversation needed to be forefront before too much intimacy for me to be honest and carry on into that relationship. So it was the development of relationship skills as well as the diagnosis.

AH: So how did your identity shape your experience of the epidemic? Did any aspects of who you are shape your experience—other than being a gay man—you know, your race, your religion, your upbringing, any of those things, did those alter your identity, did they—

MS: We were never brought up religious, my mom tried when we were young to try to get us to go to Sunday school my brother bit the teacher's hand we were never allowed to go back. So we ever had a day in church. To this day I think I've counted on one hand how many times I've been in a church. Robert has made me go into some in Latin America, and when his father died I went into a church. So religion I never had to deal with am I condemned, am I damned, never had any of that bearing on my shoulders. Being a very small, nuclear family there was the development of how is this going to happen. How is this conversation. I remember going to my parent's place, they lived in Burnaby at the time. So I left work, Burnaby gallery was twenty minute drive away. Went to their home and they were kind of—they're definitely aware of their kids, their two boys—and they're like getting nervous and you know they're not, I'm not there to come for dinner or lunch, it was just kind of in the middle of the afternoon. So I can still see them sitting on the little loveseat and they're like—their hands are in their laps and they're kind of—they're definitely starting to ramp up. And I'm like, so there's something that I want to talk to you guys about. And they're listening and I said uh, I just need you to know that I have come out and that I'm sleeping with men. And they both just looked at each other, and they go oh, well we were kind of waiting for that, we knew you were queer—they didn't say queer they said gay—but we thought you might be positive and you were coming to tell us that you were sick. And I wasn't at the time, so I remember that conversation and thinking so are they ready for the diagnosis conversation? And I was like, you were waiting for me to come out, I was that obvious? And they're like, well you know you were with women and then all the sudden you weren't and you're telling us about Scott and you were going to Victoria with Ken and all these—so I was like, okay good, yeah you—okay great. And there was never a blip, there was never like oh you're not allowed in our life. There was nothing. My brother wasn't really out I don't think to them in that conversation way, they probably, maybe even have asked him. And the situation was that they had two queer, homosexual boys and there was no daughters there was no other boys there's just the two of us, and that's the way it is.

AH: They didn't have the where did we go wrong?

MS: No there was never any of that. They were very grandchild oriented because all of their friends have grandkids, and it was interesting because we had kind of had the conversation days or weeks later about them having to come out now. Because everybody would ask, well your kids are in their thirties and twenties and there's no grandkids and they're not partnered and they're not married, like when's that happening? Or what's going on with the boys? And they're like oh you know they're artists and they're free spirits. It's like they always had this conversation, and it's like how do you envision coming out to your friends and your community? Because you now have two homosexual boys and there will be no children. And they're like it's none of their business. And I was like, I see you react in different situations and I've been with you in this way, and I think it is. I think it is your business to come out. And they've come out to many people, but lots not. And they tended to move away, they moved away to Vancouver Island and never really developed that relationship within community. So it was preparing me for how—years later when I seroconverted—how do I bring that conversation ethically and supportively and everything? Because by this point I'd already figured out in my life like, I'm not an A-gay, I'm an in-between, I'm an interloper. As someone has known or unknown to them allowed the virus to enter my life, I'm now a host of the virus. Yeah, big parts of growing up.

AH: So what impact did having the virus have on you, the people you were around?

MS: It heightened, uhm, I mean I think I have a pretty good life and I think I have a pretty happy personality in this life that I love. And I think it just reinstated enjoying my life even more. So in those days there wasn't the hope of anything. There was no hope towards ninety-six, or ninety-seven whenever the first combinations of protease and anti-retrovirals came out, so there was no crystal ball forecasting—thank you Robert—that's what's gonna happen, so it was day to day, enjoy the life you have. Yeah. I never spent all my money and bought you know, crazy things that once you're dead—but I did start to see that happen. I saw a couple that, one maxed out their credit card and they knew they had very short period of time left, and through the insurance policy of it they knew it would be written off. And I was like wow, that's intense. That's so intense to know that you'd be driving along and a train's going to hit you or you know that you're going to fall off a cliff. Knowing that you are going to go through your body dying out and maxing out your credit card so your partner could have a new couch and a car. It's like wow that's intense, for me. So I was aware that I wasn't doing that, but I was increasing my life force. I literally was increasing my life force.

AH: Now there's a little jump in this sheet here. What did the—what was the governmental response?

MS: Hmm. In regards to?

AH: Well to the epidemic, what did it look like? I guess we're talking about the Vander Zalm days here.

MS: Again, I wasn't really aware of any other sources of information other than through the community that I was hanging out with, and the odd times that I was out dancing at clubs and you'd be in the washroom and there would be posters on the wall up above the urinals. And there would be kind of directions towards a support system and leading up to I guess what became the underground of all the information that was coming together for people that were in death situations far worse than myself. Because that would've been ninety-two to two-thousand and—I'm trying to remember when I started on meds, uhm I can't remember myself. But through the experimental parts of it before the cocktails came out, so.

AH: How about the medical community's response at that point, were you involved with that in anyway?

MS: No, it was still my family physician out in Coquitlam. So it was through him that the AZT protocol came through, so he must've been in contact with St. Paul's, through some source. And that's probably when I started to—through him—become aware, that St. Paul's was the medical center for Vancouver, at the time. Yeah it was still—it was still the unknown and being kind of, for lack of a better word, kind of like a country hick. So going into a big city centre and going into St. Paul's Hospital seemed overwhelming to me, it just never really fit as a comfortable—I never found the physician that I was comfortable with, I never found the source of information giving it out as that comfortable. So it was always kind of like get in, get whatever I had to do and get out. It was never encouraged to go to PWA nothing like that. So it wasn't till years later that Friends for Life Society and the West End and then BC PWA and all the aspects of the support system started to come online for me.

AH: And what's your perception what the public reaction to the epidemic was?

MS: Those were the days when you were shunned for sitting on toilet seats, drinking glasses, definitely blood. Like wounds were like the plague was pouring out of you. Beyond sexual fluids. And uh, yeah it was even the kissing thing, still putting together all those horrific phobias. Until you know what the circumstances are, yeah, it's where prejudice really stems from. Fear of the unknown. To be Caucasian, cis, white, healthy looking uh—being able to go between all the communities I got to see the ks's and the wasting syndromes, and the retina failures. That was a big thing in those days was the blindness was coming. And so within that phobic—all the sudden, even within the gay male MSM community was the phobia of like, they're not invited to the dinner parties anymore, I just can't deal with their condition right now, I'm trying to be presenting straight at work and all these things. So there was quite a bit internalized and represented phobias within the community itself. So it was trying to be the go-between still, between my artistic community, my family, the A-gay community, and watching them become more and more phobic and paralyzed. So it was really interesting to live with the virus, present non-somatic, still not having a lot of anal sex and intercourse, and still having a pretty good outlook on life. So it was a really interesting combination of it all.

CA: I have a question. So was people being out with their status, or HIV more prevalent in the artistic community in Vancouver, than the A-gay or the club scene, like was there one of those communities that you travelled through that was over-represented, that you can think of?

MS: Interesting. Well it was really interesting because it was literally in the spring time of my twenty-eighth birthday, so how nothing had been sparking my interest in sleeping with men all through art school, as you can imagine I don't even know what the percentage must be, high. And then in the art world and working in art galleries and working on my own art career and going to galleries, and being involved quite heavily in the art world, so the percentage was a lot higher. That is a good question in that I don't see anybody that I know that seroconverted and succumbed really quickly to some of the external conditions that the body goes through, there might've been a lot more internal cancers and different things, but I wouldn't say that there was a higher percentage. And then in the A-gays as I mentioned they, if they did, and I do think of one person that got really sick, they just stopped going out. They stopped answering phone calls, they just didn't include themselves anymore in the dinners, the going to theatre, whatever it was. So it was really interesting they internalized their own phobia to going within for themselves. Because I did have questions at different times, like oh where's Johnny? Oh he's with his mother. Or he's out. And then never saw them, they never returned my phone calls. So it was really sad in that way, because I felt alone at the beginning, who am I going to turn to with my diagnosis. And then that whole thing that I expressed, it's like I will do my best to keep a positive—literally, it's so funny to say that—keep a positive attitude. And look at my alternatives, and had a very good supportive family. So yeah, it was interesting to watch those two communities, as you asked about the artistic and the other.

AH: Did you—I guess given you were sort of able to move between the communities—did you ever experience any of that stigma or homophobia? Or were you closeted enough that you were able to avoid it?

MS: Yeah I wasn't--yeah again I mean the goddess said well if you're going to be gay right now, we're not going to make you effeminate we're not going to make you unattractive, we're not going to do all of those things, you're just going to be the go-between. And it was very similar to my life in high school is that I wasn't a sports person but I knew enough about sports, I wasn't a geek but I knew that I had learning disabilities so I kind of like—it was in general math and flunking all these other courses, so I was with some of the geeks. And then there was like the gnarly kids that didn't fit in at all, so I literally floated amongst all of those people at school. So I kind of had training on how to be that as a young adult. So I would say that yeah, yeah it was definitely a float between all those realms of society. Growing up fast.

AH: So how did you see the community respond to the epidemic, the gay community?

MS: Yeah, I mean I remember being in someone's vehicle, and this image is stuck in my mind and it loops every once in a while especially like today when we're talking, is somebody coming out the front entrance of St. Paul's they were covered in Kaposi sarcoma lesions. And it was somebody that I had known from the pool, so they were very physically fit and there was not much left of them at this point, and they were walking with two canes and getting in a car. And we made eye contact, I was in the passenger seat in the back and the car was stopped at Burrard and Davie, so there was enough time to sit there and actually make eye contact. And it was a very physical reaction of—of where did they go all that time. They probably were in hospital, maybe going home to die. So it was seeing as—and I didn't know that like there was like floors starting to be set up for palliative care at St. Paul's, so I had no recollection from Toronto and Montreal and San Francisco and New York where the real epicenters were in North America. Vancouver I guess was, but not as—in my mind not as much, it seemed like it wasn't as prevalent. But with setting up St. Paul's as the contact centre for all the information and dissemination and testing and experimentation, uh it was kind of starting to understand that it was underground, but it was starting to become much more. Like to have this person walking out onto the sidewalk and getting into a vehicle it started to become more exposed. It felt like it was hidden or subculture. As I mentioned earlier when people were kind of out of the loop within the circle of community that I had developed from that first contact with the lawyer, was all the sudden it was starting to become—couple people got sick in that community. And I think the most prevalent one was my brother's roommate and when I went to Toronto, [name] was a bartender and very flamboyant just from like, made a hundred dollars and would spend it on the night drinking with everybody and buying everybody drinks. We kind of fooled around in Toronto one night, and just through this wild—wild crazy night. And he came to Vancouver to die, and we went out for lunch and it just started to really come through. So I was starting to get now people that I knew come towards me and I still wasn't out to them. So it was starting to become evident that the veil was thinning. That there was going to have to be a divulging coming out soon for me. Just sort of gain more power for it. Because claiming as a host, as opposed to a victim of why me, seemed to be empowering me more and more. So the veil became thinner from people that I knew, and now it was my turn to show that there are other ways of living within this system.

AH: Did you or people you know become involved in the HIV communities, the PWA's and other kind of organizations?

MS: Uh it's interesting because the couple that I mentioned earlier where the one was on his way out and the other couple, they worked up the Mastercard, Visa bill whatever it was. They were involved with BC PWA, so they got me into the program where you could send in your vitamin receipts and there was, from the walk for AIDS they were doing the CHA's community health—

CA: CHF.

MS: CHF. Thank you. So all a sudden I became aware that there was a cause that was doing palliative support in the HIV community so uhm, I think through that time is when I got involved with Friends for Life, I started to cook for the Sunday dinners. Started to partake in some of the facility's offerings of massage or acupuncture, because it still fit in with my alternative health dynamic. PWA I went to a couple of the retreats and gave some nature talks, plant identification, herbal medicine from some wild plants that were beneficial for somatic symptoms like uhm, neuropathy, there was plants that were working on feet and hands for bringing relief from neuropathy, and liver and all these medications going through our bodies. There was herbs—so I started giving informative talks when we went to Loon Lake and some of the BC PWA retreats. So Jackie and all the different people that were front-line in those days, we started to develop a relationship. And I still wasn't really out, out, out so I was starting to become aware that there was less for me, less stigma if I wanted to own the power of this is what's going on and this is what you've already known living with me all these years. And we've been very careful and uhm, so it was a coming out, for sure there was no question.

AH: Were you involved in any of the activism, the ACT UP sort of stuff, protests.

MS: No, I became aware of what was going on in the US, I don't know if those were the Regan years that sparked off a lot of protests. Still through going to San Francisco quite a few times with art school, they did twice a year journeys – New York, San Francisco, New Mexico. So I was aware of San Francisco as a gay centre and aware of ACT UP and all the alternative groups looking for government funding and relief towards, in those days they were still talking about a cure, but they were not aware of managing it as a manageable condition. So no I never really got involved, no protests no—I'm the one in the kitchen cooking for the protesters.

AH: They also serve. So how did the community deal with the burden of care and support, the people dying all around you, must've been a very intense time.

MS: Yeah it was and I didn't really get involved, I mean going to BC PWA and seeing people that I thought were in so much worse physical shape than I was—walking with sticks. The inflammation, it was apparent that there was something really going on with the body and the reaction to it by—I mean as I was kind of described in the early days it was kind of like having a flu twenty-four-seven, three-sixty-five-days a year. So your body's constantly working to eliminate whatever this pathogen is, so some of those kind of images became my image of what not being healthy constitution was, was that they weren't eating properly or they weren't sleeping or they were drinking too much or they were smoking and it was all adding to this kind of physical deterioration as well as and I would just, was again I'm not super sure, I wish I had those figures. Between my diagnosis and my first kind of application through Julio, he was my contact at St. Paul's in those days. Sat down with me and blurbed away into his microphone the same way—anybody who's had an experience with Julio Montaner it's an incredible experience. I've never heard anybody speak so fast in my life. So he was my contact and uhm—

CA: How did that come about?

MS: That was through St. Paul's being the contact through PWA and this is going on and are you open to the experimentation of we've got something we think might work kind of conversation.

AH: So were you experiencing symptoms that you needed to go to him or was it just this—

MS: No I was still asomatic. Nothing. Nothing was happening for me. Probably the most pronounced one was the fat pads on my feet started to deteriorate so it wasn't really true neuropathy at the time, but it was stuff that development the starting of neuropathy. So that was probably my most notable symptom to begin with. And I don't know how far I can go forward right now, but I was on whatever my first protocols were DDI and 3TC and some of the early guns that they had. And lots of side effects. Lots of side effects. You had to be near a toilet for three hours after taking them because you had explosive diarrhea. Lots of things, they had to be in a fridge whenever you travelled. There was so many new dynamics to being alive, once you'd accepted going into the basically trial of what the medications were, testing every two to three months with bloodwork and it went on and on. So I started to understand that I was now in the loop. I was in the loop. And uhm, I was with Robert at this point we had met up in Vancouver, and we had travelled Canada we had first date divulged our status, and that was fine both positive. Probably were in the same kind of era and basically, it was taking a drug holiday. I had kind of got to the point of understanding how toxic going through the liver and kidneys these medications were. So I had taken myself off medications, and fine, fine, fine and then all of a sudden I was having incredible stomach discomfort. And it grew and grew and grew to the point where I wasn't sleeping. I was sleeping in front of a fire place for maybe an hour a day, it was excruciating. And a nurse that does outreach came visiting and said, 'he has appendicitis. He's going to go, it's going to burst.' And I'd already been to Thailand with this whole thing for a month of everyday, holding my guts. Diagnosed there, nope nothing can't see anything. And she said, 'no, it's an ascending appendix instead of a descending.' So went to our hospital, sure enough appendicitis. Operation. Still everyday back pain, back pain, back pain. And worse and worse. Went back over to St. Paul's immediately and was diagnosed with non-Hodgkin's lymphoma and it was seen as having been on drug holiday, and the meds at that point weren't as powerful as they are now in the combinations. So taking yourself off the virus just replicated very quickly. I don't even recall what my CD4 count was at that time, but it was full-blown lymphoma, and didn't even leave the hospital went straight up to the tenth floor and started IV chemo. And that was another experience of seeing the community that was supported and not supported in those days. People from up country, up in the interior of the province up in the north, mostly Indigenous coming down, no family support in these hospital wards by themselves. My family came over they were living in Vancouver Island at that point. It was very similar to my going to my physician and saying you have three years. This was a diagnosis that Mark's in trouble. You need to get to see him right now. So my brother and my mom and dad came. And we were taking down the hall into the room where's the your family member's dying. This is the room where there's the Jesus on the wall, and there's flowers and soft music and a little fountain. And you're talking to people and it's like, bye. And I just basically said, okay when we're through this we're going to start talking about how much we love each other, we're going to express our love much more than we just know we have each other's love. We're going to say I love each other a lot more, and they're just like, you're dying. What are you talking about? And they didn't have any other information than what the physician had probably at some point pulled them aside, or they'd done their research. And I said no, it's not terminal for me, it's not. I'm already onto my alternatives, I'm already onto a healing dynamic and I really was. It was quite—for me one of my, I don't know what other word—it was just kind of like a stellar moment to pull in all of my healing. All of my animus animals, all my deepest darkest healing dynamics like going back to when I was a kid and having a cold and just closing the door and turning out the lights and healing. So I was back into this healing dynamic at forty—can't even remember forty-one or forty-two years of age. Went through the chemo, came back here did all the alternatives, acupuncture, craniosacral, back to chemo and did the ten rounds. Because the lymphoma tumours of my lymph glands on my spine had swollen so much with cancer, I was having to do spinal injections of chemo. So briefly Robert came with me to all appointments in Vancouver and I just dropped into basically a coma, and he had to hold my hand and squeeze it to communicate. So the physicians were trying to get a communication from me, is this painful, is he feeling anything. So he would squeeze, I would squeeze back for yes or no. And that's all we did. They were mesmerized by the whole process of who is this and what's going on. And one of the key ingredients to even Julio trying to say you're going to have to fatten him up, he's losing weight. I was two-hundred-pounds when I started and I was a hundred-and-thirty at the lowest when I started trying to look at a rebound. Okay I'm healing, but my body is having a struggle physically to keep itself going. Like my mind I'm healing but it's not working. So uhm basically going onto baby food, I pureed everything. It was rice and lentils and no meat, no grease, no nothing. And basically that it was it, it started turning the weight gain started and the energy came and the life force came back. Whew. Sure it happens. And Julio even couldn't believe it, nobody in St. Paul's could be believe it. Because it was the Walking Dead. You're just basically—from the eighties—you're the corpse on legs. And seeing a couple of photos that we have, there wasn't much. Yeah. But again it goes back to that life force for me, there was so much uhm, community support here, there was incredible—like people paid for airline tickets to fly over to Vancouver on the seaplane. There was three coolers at the end of the driveway filled with food everyday. There was thousands and thousands of dollars donated for health and healing, and I knew that I had the core here, I knew I had my relationship with Robert, my family. And it was up to me, it was just pulling out everything that was left as a maturing male that had been kicked around pretty good with this one, this was a big one. And a shocker, because going over to St. Paul's with no expectation of a diagnosis of cancer was, it was fast. I had to work as fast and as big a project of healing as I've ever done in my life. And I'm back up to two-hundred-and-something pounds, and I dance three days a week and I have many lovers. We have an open relationship, and I consider myself a pretty vital life force at sixty-one now. So yeah.

AH: When you were speaking about the community and food at the end of the driveway and so on, are you talking about Salt Spring?

MS: Yeah here on Salt Spring, because this was all going on here. We had chickens and we had a dog and cats so Robert had photographed them and they were all around the room. And when the nurses came with their hazmat suits on and a plastic shield over their face and the plastic bags with the yellow with the red symbols of hazardous material. We said, well we have to have them left alone for awhile so that we can do our energy work with them, and they're all freaking out and one witch of a nurse said, 'fine, you have ten minutes. Do your work, we'll be back.' And so they all left, she ordered all the nurses to leave, we had ten minutes to work our energy work with these medications of chemo drugs, all the pictures of the dog and the cat and the chickens are around the curtains. There was a bowl of salt water under the bed, which was clear when we started and it was black when we finished. And I had a complete vertebrae of a deer strung up on cord so when I went in for my spinal taps I wore this spine of a deer around my neck. And so the physicians are freaking out, but I walk in and I said, this is the only way we're doing this. And they're like okay we'll leave you, what's going on. So they had no idea that as they're injecting their chemo into the spine of my body it's going into this vertebrae so when I get home I'm smudging it and letting it disseminate the chemicals and the conditions that go along with the medications. So it was basically a community effort living here on Salt Spring and people started to see that there was a way of dealing with illnesses, other than just totally surrendering to allopathic. Which I wouldn't be alive without it, I have no doubt that chemo and the medications that they perfected with lymphoma saved my life along with—I would never say it was, it was along with all my alternative healing methods for sure. It was a fantastic journey. It was epic.

AH: How has your perspective about the disease and about prevention changed over time?

MS: It's so fascinating because you used to hear the days after being positive of bug-chasers, or people that just wanted to be infected so that they didn't have to worry about it anymore. It just did not make sense, and yet it did. It was this moment of wow, here I am knowing the way that I'm going to be living as a host and living in this life force and enhancing my life force, looking after myself even better. And checking in with people that your STI, your STD could take my life. You think you just take penicillin and you're fine after a while, but because I'm living with a compromised system that's always dealing with the edge of life, your non-disclosure of your gonorrhea, syphilis, whatever it was could take me out. So for me it was all of a sudden seeing the—the acceptance but there was still this kind of mystique that, I always said you know if you turned purple it sometimes might be easier because then you could hang out with purple people and you wouldn't have to do this whole disclosure. There wouldn't be my having to wonder because a lot of STI's don't manifest right away so am I playing roulette with someone that I have engaged with. So it was a whole new dynamic to watching what was going on when the meds came along, and then the cocktails really perfected themselves through St. Paul's and other institutes. It seemed to lessen the fear, but it also made me more aware that just through the community that was positive that I knew it was like, so how do you deal with a new hookup? And it was that whole conversation same thing is like, yeah it is just an STI STD for you, but for me it's a life-threatening key that could turn the door to death. So it was a whole new way of walking in that community for sure, out or in.

CA: What do you think of PrEP?

MS: I—yeah—wow. Uhm, I know people on it, I see they're relaxed feelings. It's interesting because I've always considered it natural—they just say wear a condom or don't wear a condom—it's to me it's just like natural sex is skin on skin. When someone's expressing that they're seeing someone or they may know that they're positive so they're taking the extra precaution, that works for me. But the whole—it's I guess just the years and years of the un-disclosure, the constant when not so much if, but if you engage with a community that's a higher prevalence of uhm HIV so there's all those years of living in that community and then all of sudden there's this incredible floodgate of freedom. It's an interesting dynamic because I've talked to older fellas, mostly fellas in my world, that now have survivor guilt. So they were the ones that lived the longest. They either—whatever their history is—I've heard a lot of Europeans that lived through plagues and their family histories allowed them to live longer without meds and different situations, whatever it was. But there are still a lot of people that have long-term survivor guilt and so they're living in these communities now where they're seeing older people even that maybe have come out later or very much younger that are open and allowed to kind of pick and choose, when and what kind of sexual activity they're going to have. Uhm, the toxicity of taking medications is a confusing part for me, but I guess one compared to having to take many for your life force uhm, it's an interesting scale of dynamics. Because I see the benefits but I also see the detriment. So it's an interesting question.

CA: The only reason—well not the only reason, I'm also curious—but I was just reading that syphilis has gone up thirty percent in the gay community, or the MSM community, over the last year.

MS: Absolutely. That's one of the biggest waves that came in after the PrEP came up on the beach, and it goes back down and then another wave come in and it's like the prevalence of STI's and STD's. Which adds to the dynamic of yeah, divulging and disclosing and constant testing. Like this phobia of not having portable STI clinics on the streets, and seen it in Portland, seen it in San Francisco travelling around, seen it outside the clubs. And it's just like let's get our community over these stigmas of going in and getting tested for something that could become resistant to modern medications. Which it's started to show in certain cities and certain conditions are becoming resistant to penicillin's and it's yeah, it adds to the complications of the freedoms. And big pharm's making big cash off this. Making cash, cash, cash off this one.

CA: Off of all of us.

MS: No they are. You can edit that out it you want.

CA: Never, nothing is edited out.

AH: Well it goes to the initial transcript, it may not make into some other things. Do you have any advice for health professionals, specifically in regards to how current prevention and support efforts can be improved?

MS: Wow, these are holes I never thought we'd go down. Yeah I mean time machine, I want to go back to my physician Dr. Shaw and I just want to send him some love and I want to send him just so many different ways of handling that situation of giving someone a diagnosis. But yeah today, wow, I mean the information that a lot of people that I've had relationships with as I mentioned Robert and I have an open relationship so the men or people that I've had relationships with, the disclosure conversation it's like oh yeah that's fine, you're undetectable right. And I'm like yeah and I have been for many, many, many years. Constantly testing, constantly remembering to take my meds. So that whole conversation with sexual partners is almost non-existent as a big event anymore. So the conversation that physician has possibly with giving a diagnosis to a new seroconverting person has to—I would see have the added benefit of having a positive long-term person in the room with them. If there was a clinic where someone could volunteer and say, we have two new blood tests seroconverted people coming in today, would you be willing to come in and sit in that room. Male or female, trans, whatever the conditions of the sexual orientation of the person was, I would love to see there be a bonding between the positive community and physicians in the allopathic system. Because for me it always was the alien system, it just—you don't know how my body works, you do physically know some of the comings and goings, whole nervous system blood system. But you don't know what makes me a more powerful shaman healer within my own self, you just don't know that. So if I can come in and express some of the things that make me tic, and make me a little bit more powerful to be a host for this virus, I could see that being a real asset to a healing community of physicians and nurses. I got more compassion and more understanding from nurses than I have in physicians and doctors throughout the system. They definitely are the—Patricia, I don't know what her last name is right now, who was Julio's assistant at St. Paul's—she's the one that came roaring down to the emergency room when I arrived, she's the one that got me back upstairs, and she's the one that got the test and she's the one. So Julio was there to like, well this is what it is and started administering the paperwork, but Patricia as a nurse practitioner second-hand person was it. She was it. She's retired and I think she's on Pender Island now.

CA: They're generally the ones that know you, not just know you.

MS: They know your family, they know your pets name. And Julio was fantastic, there was no question as a physician and he has had—because he's a training hospital—he's had many physicians in his office when I've been there for diagnosis. And Sylvia Giami was a miracle worker, she really took on another female, motherly, nurturing aspect to HIV and the clinical aspect of going in for the bloodwork and for some of the protocols and changing meds. And you've been a naughty boy taking a drug holiday without telling us. And yeah, it was an incredible experience working with Sylvia. And she's on Pender now so she's retired. Island women.

AH: Do you have any advice, thoughts, for future generations? Who have not experienced the epidemic, people are casual about it now, they don't see what happened in the past.

MS: Mmm I was lost in a thought there, can you repeat that question for me? Or that comment.

AH: Do you have any advice for future generations who have not experienced the epidemic.

MS: Because there's so many more dynamics coming that I've never had to think of and face when I was growing up, environmental comes to mind as the number one for a lot of younger people. The climate strikes that are going on right now, and bringing a family into that world. To know that it's a manageable condition right now, we don't know the long-term. Ninety-five, ninety-six is kind of when the meds really were concrete and this is what we're going towards never finding a cure yet, but finding a way to supress it till the body can live with the virus, host the virus. Yeah it is complicated because the planet kind of has a virus on it right now, and it's an immune compromised planet in it's own situations of over-population and toxicity, so we're kind of living in the same condition that was what was going on within the bodies of seroconverted individuals. So it's a difficult expression of we are living kind of in a viral oriented society right now, in North America. Other parts of the world are just basically surviving, trying to find the next meal, or house. For someone coming up it would be—and I'm really surprise and very grateful to be in this community of non-binary, asomatic, asexual individuals that don't really have issues around their orientation. I've been so surprised so many times by someone who would identify as male not having an issue with being touched, I wouldn't know how far into romance they would go but definitely not, there's no stigma associated with so much—it's still here there's a large enough population on Salt Spring that there's definitely going to be phobic, homosexual phobic or bi-phobic reactions, but that generation that's coming along has so little labelling for their orientation that to understand HIV and I don't imagine many of them don't have a lot of information, either through their school or the internet on what HIV is now, but to actually try and express some of the anxiety that went on to be sexually active. Eighties, nineties. Because the seventies and the sixties were the flush of sexual revolution and all of that era of exploring and sexuality, so to have it come crashing down with something that was unseen and unknown, that you can't express that. I could express some of my stories that I've told you, seeing people and understanding some people were disappearing out of our communities, but I never was involved in queer, gay male MSM community where thousands of your friends died, like hundreds. And you went to funerals four times a week and you care gave friends because their families would reject them and they got kicked out of their apartments and their houses for being positive. Those moments never happened to me, I wasn't involved in the HIV community then. So I wouldn't be able to express some of that sorrow, but I could express the anxiety that came from still unknowns, they knew what was going on by ninety-two for sure, but they didn't have a direction of where they were going to go with it. So there was still anxiety about having sex and.

AH: Is there anything else that you wanted to say that we haven't covered?

MS: Uhm, yeah, I'm kind of pleased with being out, positive in that it's never once that I can think of been a stigmatized issue. Like I've never been ridiculed, or asked to leave or ostracized. And quite often questions come, but a lot of times it's not because they can see—and I can feel they can see—the confidence of not being ashamed to be positive. And not being uhm, seen as other than a vital part of community. And being able to love and give love and open this home where we live and live in a supportive community. Yeah I remember distinctly the day I came out positive to my—she's more my friend—but she's the one that owns the bakery where I work in the summer. And I just wanted to make sure that she knew that if there was blood at any time, that we had to be careful, right away. It wasn't to be fooled around with whatsoever. And they really appreciated it, both her and her husband I came out to them. And it was kind of the first public outing that I did for myself and in that situation where it was a work, and friend, I mean there had been sexual partners for sure, and my family. But it was the first kind of public, and I now see that as a reflection of that was the seed to coming out in a lot of different situations. For years at our pride parade here on Salt Spring it was the GIGI, which was an original group of support, Gulf Island Guerrilla Immunologists was what they used as an acronym. And it was two cis het women, both their partners I'm not sure—anyways, and a queer identified male who lived on the island, so it was the three of them doing their research, doing their alternative practices, whatever they could find in the early days. So we had a banner always in the pride parade, and it was Southern Gulf Islands AIDS Society, we developed that GIGI into a support network. So quite often, if I wasn't holding it

I was with that group and then floating—in drag—throughout the parade. It's actually an annual event, it's like what you are wearing this year? The top of the top was a red sequin dress, each sequin was hand done, shoulder to floor red sequins. Looked like a giant fish. It was one of the top dresses, but it showed the junk so it was kind of like an exposed. So yeah it's been that joy of feeling really supported in a community, that could turn definitely, you know in the olden days of early AIDS diagnoses the community could've turned. It could've been a time when—but I feel really fulfilled by being an out, positive human in this community, supporting this community, contributing greatly to this community. I volunteer quite a bit of time and energy and can't imagine right now being anywhere else on the planet. I feel like one of the most royal, privileged person right now on the planet. I do.

AH: That's a very nice place to end. That's nice.

MS: Thank you.

CA: Thank you so much Mark.

MS: Thank you both.