

**“HIV in My Day” – Victoria Interview 14**

**March 4, 2019**

**Interviewee: Andrew Beckerman (AB); Interviewer: Art Holbrook (AH)**

**Andrew Beckerman:** - first uh 2005.

**Art Holbrook:** Okay yeah. So uh, how have you – what sort of changes have you observed in the city?

**AB:** What sort of changes have I observed in the city? Well, the skyline of the city has grown from a relatively low-rise city with one or two medium buildings, to a skyline of a lot of medium buildings and some buildings that are verging on high-rise. Um, I started volunteering at AIDS Vancouver Island, probably within months of my living, moving here, immigrating actually in that case. And at the time, the agency was an HIV service provider that ran a needle exchange later in the afternoon. The agency is now a harm reduction agency that minors in AIDS services work. The number of people living on the street I think is probably constant, and I think it's due to the mildness of our climate compared to other parts of the country. The number of people who are using drugs and overdosing on the streets has risen dramatically. And the tolerance for people living on the streets, I think unfortunately has dropped because of what the general public perceives as the overlaps of – overlapping, I mean of substance use and homelessness and considering that the bulk of the overdose deaths both here and throughout the province are people at home, on their own, the linking of the two—homelessness and drug use—is not exactly accurate. If one takes time to talk with people.

**AH:** Right. You say you immigrated. Where from?

**AB:** I immigrated from Santa Fe, New Mexico.

**AH:** Ah. I immigrated from Ohio.

**AB:** Okay.

**AH:** A long time ago.

**AB:** Okay.

**AH:** So, when did you first hear about HIV/AIDS?

**AB:** I think that it probably came on my radar in the early 1980s, because I was living in Berkeley, California, which is just across the bay from San Francisco. My first boyfriend, after I came out, who I knew in late seventy or eight-- 1978 or early '79 would've been when I met him, was active in the LGBT community from more from a professional point of view, but was in, sometime before 1985 where he became involved in HIV services. He was one of the founding members of the, I wanna call it the San Francisco AIDS Society but that might not have been the actual name of it, but it was the first service organization.

**AH:** Could you move the microphone up there? It's just a little bit buried under your shirt, just flip it around. No if you move it, just move it up to the other side of your shirt there, so where it's point up towards – yeah, I think that's the right, yeah, good. I don't know if it's a big difference, but it'll be some.

**AB:** Okay.

**AH:** Good, thank you. So, you heard about it through him?

**AB:** Uh, no, I think by that time it was a news story. It was in you know the period of gay related infectious disease, GRID. I'm struggling to think when the HIV ward would've opened at the San Francisco General Hospital, which was one of the first, if not the first in the country, it would be whatever dates the ward opened in St. Vincent's Hospital in New York, I think. And I was single between when I came out in 1977 dating, had a boyfriend, dated a number of people, and then I was also again single between January and August of 1980, and dated a lot of people, and by 1985 all of those people were dead except for me. And that boyfriend of me. And my doctor at the time I was diagnosed, which would've been in New Mexico, a decade or so later hypothesized that my period of infection was between my first HIV negative lover, and my second HIV negative lover, that eight months of 1980.

**AH:** But you weren't diagnosed until ten years later?

**AB:** Yeah, because I was beginning... May of 1979, I was in a monogamous relationship through the late eighties, and it was only because my ex-partner and I had good friends whose relationship was about as long as ours was, was monogamous. And [name] was a psychiatrist and he was being called to pay back the government loans by doing government service, and he was foolishly moved from a Chinese language clinic in Richmond, California, and he was Chinese-American, to the Navajo reservation, a hospital that was in Windsor, Arizona. And though he could visibly pass for Navajo, he didn't speak a word of Dene. And as a prospective government employee, he was tested, and lo and behold he was positive, and that caused our whole circle of friends, who assumed we had been fortunate, to test, and I tested positive.

**AH:** Right. Yeah. But you look pretty healthy today.

**AB:** Well, the healthy person you see today is dramatically different from the very unhealthy person you might have seen, oh, probably starting in June of 1995 when I was kind of in the middle of my long, slow, decline to no T-cells and a concomitant rise in my viral load. And I was a subscriber, as were, you know, many people in the community, to AIDS Treatment News, which I think was still actually in print form, coming out of San Francisco in the mail twice a month. And in August, when I was pretty ill, they announced the first Crixivan trial, which was a lottery, and there were fourteen hundred places, and as I recall forty-thousand people applied. And I got the only place in New Mexico. And at the time I got the place – let me backtrack a bit. My AIDS diagnosis came from the point when I tipped under two-hundred T-cells. I'd had pneumonia, but they could not isolate it as PCP versus another form of pneumonia, so the way to tell, my T-cells dropped. Towards the end of October, the drug was technically, was hopefully

going to be available, first in November, I was living with two or three T-cells and a viral load in excess of a million. I was probably just ten-pounds lighter than I am, because I seem to be going through a periodic weight-loss cycle, but you know, I had facial wasting, I looked, like, near death, because I was. I was literally within days of dying. And the medication – because I was being treated in a very small clinic, and I was the only person who got a number, the paperwork was done immediately, which meant that I got the medication, I believe it was the first of November, 1995. The friend of mine who tested positive and got the rest of us in our circle of friends to test had had a couple of opportunistic infections. He was being treated in the clinic that I would have been in, treated in if I had stayed in Berkeley – had a much larger client base, had a number of people who got places on the trial, and his paperwork was slower, and so he didn't get his medication until just after the New Year's holiday, January 4, 1996. Well, those two crucial months, I would've been dead, and I would've been dead if I hadn't gotten the medication on November 1, probably by November 8.

And I used to think that, well. I got the medication November 1 – by American Thanksgiving, I was on the road to recovery. And I was introducing Julio Montaner to some public event over here, a decade or so ago, and I was telling him my story, and I said that, with the link to US Thanksgiving, and he said, “Andrew, you were in recovery with the very first dose of that medicine you took, because it obviously was efficacious, and it only took a dose, to get you on that road.” And the drug as I recall in the US, didn't hit the general HIV population until around April first of '96, so I had a November, December, January, February – I had a five-month head start. And a lot of people died in that five-month window. And I was still relatively weak enough that I wasn't paying attention as to why that lag existed when they were already tracking people like me for whom the medicine worked. And at that point, five months in, I was just starting to show the side effects of the lipodystrophy, the redistribution of body fats, changes in my cholesterol level and blood sugar level, and I was susceptible to—you know I went from a size twenty-nine waist to a size thirty-six waist and I just basically had all the weight in my body...

**AH:** Yeah, the Crix's belly.

**AB:** Exactly. Exactly. And when would it have been....? Three, or four years later, I was transitioned on to Sustiva, also at a point where the side effects – some of them were known but not all of them. And not long after I lost my Crix belly, which it seemed to happen, you know, in the three weeks of a European vacation. I had these great pants, they were slightest weight wool I'd ever had, and they were so comfortable, but they were so big compared to what my body went back to in, in its normal weight once I got off of Crixivan that they were beyond tailoring and alteration. [Laughs] But I... At the time, it was unfortunate that I developed a black – a diagnosis of a black hole, suicidal depression, that came out of nowhere. And the linkage to Sustiva took almost nine months. And of course, putting me on.... and it started with broken sleep, trouble falling asleep, not sleeping at all, and then just crashing. And because that side effect hadn't been identified, I was sort of treated like, you know, a severely depressed person. You know, I had a therapist, I was started on anti-depressants. The only problem was every morning and every evening, I was re-infecting myself with depression, because it was part of my response to Sustiva. And fortunately, before I could kill myself, which I tried to do twice, I was picked up, and again I don't know why it took so long to make the link, but I was picked up and I was referred to a pharmacological psychiatrist, and she had my medication list and she said,

“You know, I’ve started to hear uncomfortable stories about the psychological effects of Sustiva. Let’s take you off of it and see if it helps.” And of course, since it was causing my uhm, depression, it eased my depression. But, I wasn’t very good at killing myself, obviously, ‘cause I’m here. But it was that black hole, where your life is a misery, and it seems to exist with blackness here and here.

And my ex – at this point we would’ve been together close to our twenty-year anniversary – who was able to deal with my decline and imminent near-death from HIV, had little or no patience for my malingering depression, which was ironic, because he himself was trained as a licensed clinical therapist. And he just, you know, his notion of me getting better was well if you get out you’ll feel better, if you go to the gym you’ll feel better, if you walk the dog you’ll feel better, with no real understanding, which may not have been available then, but certainly is now, of how overwhelming that black hole depression is. In retrospect, it’s given me such an incredible tool, because if I had had access to the drugs that obliterate your present misery, like crystal meth, like heroin, like crack cocaine, before, I definitely would’ve become an addict. Because the misery of my life was what I wanted to get away from. And I wasn’t able to do it by sticking a plastic bag over my head effectively. I mean, maybe the gauge wasn’t right on the bag. I don’t know.

But... So, when I started doing work up here – and aside from being the volunteer receptionist at my clinic there, ‘cause they had no money to pay anybody until I got sick – I hadn’t done much HIV-related work. And the clinic had morphed into a comprehensive medical psycho-social service, multi-purpose facility with just first-class care. And who I am and the work I’m able to do and the way I’m able to connect with people struggling here, is because I’ve been there. And I’ve come, I’ve been – I’m the rare exception, I mean whoever recovers from depression, you know people are depressed for decades, and the medication you know, weeks to get onto it and weeks to see if it’s working, and weeks to get off of it if it isn’t, trying that, trying that. And you know, I understand why people who were sexually abused as children just can’t “get over it” or people who are descendants of people who had the awful experience of the residential schools are still struggling, because you just don’t get over these things, even if you say “I want to.” Wanting to is not enough, it requires a lot of really good therapeutic support in terms of rehabilitation, and you know, quite honestly, if the provinces rehab programs in their entirety were ranked as major league baseball players’ batting average, they’re batting you know, around one-hundred. It’s shocking, how ineffective they are, and how repetitive they are. And I know people who’ve been to Burnaby three times, you know, which is one of the better rated, you know months at a time. Hasn’t changed a thing. But I understand it. Because I’ve been there.

**AH:** I have some understanding of that. My son was sexually abused. I had separated from his mother, and I wasn’t there, and he had, you know, bought a piece of candy, the guy that ran the corner store, kind of crap. And I’ve been dealing with that for, what, thirty or forty years now. Long time. Anyway, you’ve gotten well ahead of my list of questions here.

**AB:** Oh, sorry. Sorry.

**AH:** No, that’s okay. It was an interesting story. So, how did you first learn about HIV?

**AB:** [Sigh] Newspapers.

**AH:** Was that when you were in San Francisco?

**AB:** Well I was in Berkeley, but...

**AH:** Berkeley, yes.

**AB:** It would've been *The San Francisco Chronicle*. Yes.

**AH:** Well, they, San Francisco is one of the hubs for information, wasn't it?

**AB:** Mhmm.

**AH:** So, you were ahead of most people on that.

**AB:** Yes. Although, I was ahead but I was clueless that I was actually infected because, you know, the chronology of my life didn't seem to suggest that.

**AH:** Right, yeah. So, once you learned you were infected, how did your life change?

**AB:** Well, because when I tested positive, and back then you tested and two weeks later you went back and got your results in person, and were offered counselling support. I was perfectly healthy and had a hard time imagining my imminent death because I was healthy. I cried. I cried a lot. I probably cried for a couple weeks, and then just got on with life. Probably aided by the fact that somewhat out of the blue my ex and I left a relatively perfect life in Berkeley, California, spur of the moment, and immigrated—because it's enough of a foreign country within the United States—to New Mexico in 1991. So, had all of the change of environment, new location, we built a business. And it wasn't until two years later that I started this kind of long, slow loss of T-cells, and probably, closer to 1994, you know, loss of body weight and facial wasting, that kind of identified me.

**AH:** Hm. But you were together with your partner through this period.

**AB:** Yes.

**AH:** But did your social life change in any way?

**AB:** Nope. No, no.

**AH:** Okay.

**AB:** Although, when I moved to Victoria, and within a year I was volunteering at AVI, and when it became apparent that I was willing to talk in public, which ended up with me being the face of HIV positivity for AIDS Vancouver Island – radio, television, print media – that wasn't the person I was after my diagnosis. Nobody asked me, "Would you speak about it?" So, you know, I didn't give lengthy interviews to *The Chronicle* or *The Sante Fe New Mexican*. It wasn't that

people know I was positive, because my doctor who started the clinic was everybody's doctor that we asked for a recommendation. And out of the blue, he sold his practice and started the clinic. And I was one of his very first clients. So, the fact—even though Sante Fe was a city of about seventy-thousand people—the fact that Doctor Hawkins was your doctor was a dead giveaway.

**AH:** How big's Santa Fe now? It's a lot bigger than that, innit?

**AB:** Sante Fe itself is probably ten thousand people bigger, but the surrounding area, the county has been built up.

**AH:** So – this is one of the questions on the form that kind of throws me a little bit, but how did your identity shape your experience of the epidemic?

**AB:** Well, you know, at the time, well at the beginning of the epidemic, you know, the negative connotations were directed towards gay men and Haitians. And at that point I was a gay man, so HIV was linked with my sexual orientation and identity.

**AH:** Right, yes. So, were there any alteration in your identity at that time?

**AB:** No.

**AH:** If you can think of that.

**AB:** Nope, no. I was almost immediately comfortable after I came out, which was after the first thirty years of my life being exclusively interested in women, not looking at guys, not fooling around with guys. A chance encounter threw a switch I didn't know I had. You know, the only sticky wickets for me were going home that night to explain to my fiancée that I had cheated on her. And when she said who all I said was, "It was a guy you don't know." And then having a similar conversation around my coming out with my parents. But that was you know long before HIV was even around in North America in any form.

**AH:** Yeah.

**AB:** In any reporting, in any hypothetical patient number one.

**AH:** Yeah. How did things go with your fiancée when that came out?

**AB:** It was a proverbial, everything that I owned in our apartment got tossed out the window onto the street. Understandably.

**AH:** Yes.

**AB:** And it was more the cheating aspect, as she viewed it, I think, than – she didn't care who it was with. It was just that, you know, we were monogamous, and I had broken that. And that was a deal breaker, as it often is.

**AH:** My sister was married to a guy who discovered over time that he was gay. I mean they have three children. They lived together for, I don't know, fifteen, twenty years, and then, sort of gradually worked its way through him and uh, he's [inaudible – audio cuts out] good about it though, and he's very honorable about not risking anything with her.

**AB:** Yep.

**AH:** But uh... So, how did things go with your family when you told them?

**AB:** Well, I was just starting to be... noticeably sick, in terms of wasting, and my parents were heartbroken. They were supportive between their tears. And you know, throughout my adult life while my parents were alive, I spoke with them once a week on the phone. We had a Sunday morning phone call regardless of where I was in the world, and that was, you know, a nice part of our connection. My relationship with my parents was good. My parents were—were angry when I came out as a gay man, because they realized – I think ultimately they realized I wasn't going to be producing grandchildren for them, but they were terrified in ooohhhfff... '93 when I had to tell them about HIV, because all people were doing were dying. And I looked like I was starting on the path to death.

**AH:** But they didn't reject you for it?

**AB:** Oh, absolutely not.

**AH:** Either of these conditions.

**AB:** Absolutely not. I had very little rejection. And I had as much rejection, which again was relatively little considering where I was living – Berkeley, California, Santa Fe, New Mexico – around my sexual orientation, as I had around my HIV status.

**AH:** Right. Yeah. Huh. So, I'm not sure why these questions are in this order but what was the governmental response to HIV?

**AB:** Well in the—in the early days, coincidentally, I had gone to high school with a woman who ended up marrying a Hollywood, fairly well-known celebrity, who, through a blood transfusion, [name] contracted HIV. And it was not known until both of their children were born, and they subsequent—the kids were—everybody was HIV positive and everybody died. But because of her marriage to a TV star and his position in the Hollywood community, she met everybody, and started a number of mainly young people-related HIV service organizations. But you know, I would get invitations to big Los Angeles fundraisers, because I was the one of the people she knew in California. Although at the time I had no idea that I was actually positive as well, and it's thought that [name] was the person who finally got Ronald Reagan to say the word AIDS. So it was – the government response was, you know, complete avoidance, and it took, in what in hindsight, and this may not even be historically accurate, but it took, you know the diagnosis and subsequent death of one person, who although he wasn't known to everybody in positions of government and power, his lifetimes and ultimate death were so well chronicled in the US press,

and around the world as well I imagine, that... I'm going to say, I'm going to hazard a guess, not long after Ryan White died, the US congress passed the Ryan White Care Act.

**AH:** I'm sorry, I don't remember who Ryan White was?

**AB:** Ryan White was a... I can't remember if he would've been a pre-teen when he had a blood transfusion, and a teenager when he died. But he was out there, for I'm gonna guess five years, and his visibility, and his clear link to infection through a blood contamination, as opposed to gay male activity, or Haitian activity, was something that the government could embrace at the time. And the Ryan White Care Act is still in existence in the US.

**AH:** So, how did you perceive government response here? Were you here during the Vander Zalm years or...?

**AB:** Well I think, you know, and I only hear it anecdotally from friends who were here, that the response was sluggish, the insults were similar, although tempered by, you know, our innate, better manners, and you know, when people ask me, "Well, why did you emigrate?" my short answer is "Kinder, gentler Canada." And that tempered a lot. But I work with people who were you know, were diagnosed and watched lots of people die before Crixivan, which showed up here months after it was available in the US, and certainly the trial did not happen here, that saved my life. You know, people, I—I interact with a whole demographic that transcends the border of people who got the diagnosis, cashed in their life insurance if they had it, prepared to die, and didn't. And never went back to living. And many of the clients, many of my peers at AVI, are living those minimal lives.

**AH:** So, what do you mean by "never went back to living" – what do you, how do you perceive it?

**AB:** Well you know, when I recovered my health I went back to work. My ex and I had a business and you know, I got pulled back into business. And kind of create, re-entered, with a gap of two or three years, the life I had formerly been living. I have friends in Vancouver who, although they may not have gone back to the lives they were living, became major forces in the volunteering side of HIV advocacy and support. I mean, I have a friend who was the Chair of the Board of virtually every AIDS service organization in Vancouver and the Lower Mainland, all of it voluntarily, and is a spokesperson, you know, who is a board member at CATIE, and he's not leaving there any time soon, talks at the medical program at UBC to give the HIV 101 from a real person's perspective, may or may not be dealing with a heart issue that's been accelerated because of his HIV positivity and the medication he's been on. But there's a whole group of people who never went back to active living, sadly.

**AH:** So, they live on welfare or just sort of quit?

**AB:** Yep, and that's a marked difference, because I was well known, you know if I moved here in November of 1995, by Spring of that year, people knew Andrew Beckerman was HIV positive because they had seen my picture in the paper, or heard me speak on the CBC, or wherever. And so, since then if friends, or acquaintances have friends who are newly diagnosed and they



themselves are not positive, I'm the person that these people come to. And of course, these new diagnoses are decades younger than me, but after they get over their six months of I'm going to die my life is over, and realize well they're on medication and you know, you are still in fact alive, they seem to have a tendency more to go back and pick up their lives, the way I did. At the time I was diagnosed and near death, my liquid assets were about a hundred thousand dollars. And probably around October first of the November first drug trial I gave that money to the Santa Fe Community Foundation. And five weeks later I wasn't dying! And I said, "Can I have my money back?" and they said, "No, you can't." And within a year I was given a prize that I probably didn't deserve due to my position in the community, but because I had given them all my life savings, and I was the co-chair of the kick off lesbian and gay funding partnership, which was a fundraising endeavour of Tides foundation, that asked community foundations to raise fifty thousand dollars a year for sexual minority services and they would match it with fifty thousand. So, we did it. You know, we raised that money. And some of those services because of the coincidence with gay men and HIV, had some HIV-ness attracted.

**AH:** What about the response of the medical community, as opposed to the governmental community?

**AB:** Well, again, I'm extremely fortunate because I personally have only experienced one real bad stigmatizing situation. My doctor, who left a very lucrative private practice to open up what was about to become a publicly funded in a very minimal way, in the beginning, was interested in infectious diseases and this one in particular. And I was an early, you know, I was probably within the first ten patients who enrolled. And I was the first person he "saved," because people died around me. And so, I was treated like a little prince. And Sante Fe had a very charitable community, and I would say not long after the clinic opened, the annual benefit, which is called AID In Comfort was struck, and it's still going, and it still produces a hundred and fifty thousand dollars or so, US, year in and year out, net, to support the clinic and other HIV-related organizations.

**AH:** You mentioned one instance of stigmatization. What was that?

**AB:** Well, you know, once I became eligible for health care here, when I became a permanent resident, you know my doctor is Chris Fraser at the Cool-Aid Clinic, you know, the barriers don't get any lower. And I'm also adherent, and my story is very compelling, so I get treated very well. But, I was recruited for a program at the nursing school at UVic, that for some reason—I'm a little bit fuzzy—but involved training their coterie of the med school class, you know the joint program with UBC, in doing digital prostate exams. And you know, I interviewed and it was fine, and I filled out the paperwork, and then it wasn't so fine, because I was HIV positive. And there was a lot of, foolishness around denying me a place in that program because I was HIV positive. And it took me, you know, submitting a formal complaint to the nursing school to get them to change that, and offer me a position, which I gracefully declined at that point. I wanted nothing of it. But because I've been a board member and a public spokesperson for AVI, because I was a board member and outspoken around the Pacific AIDS Network, and met people through my work at Pacific AIDS Network, I met lots of people who were dissed, because of their HIV status, and for a variety of reasons were not in a position to stand up like I was, and call people on it. And until everybody is secure enough with their identity and willing

to call everybody in the community, we're going to continue to have stigmatization coming from the medical profession in its widest sense.

In the same way, we still see on the most sexually oriented of gay meetups, "I'm HIV negative, you be too." The reality is I have not actually been able to infect anybody for twenty-three years, so why do I be too? But the fact that the Attorney General of British Columbia promised, at a public meeting, in response to a question I posed, in April, "When are you going revise the prosecution guidelines to reflect current science?" Which is you know, abbreviated-ly described as "U=U," which isn't of course the whole thing. And he said, "Well, you know, as the Attorney General, you know I defer to my prosecution services and I would wait for them to make that change." I said, "Well if they don't, when are you going to act?" and I asked the question four times. It was a reception at the CAHR Conference in Vancouver last spring, and he said, in the end he said, "As soon as possible." Well, as soon as possible is coming up on a one-year anniversary, and when I speak with his colleagues, whether they're in the legislature, or people like Murray Rankin, I refer to "Have you spoken with that liar, David Eby, the Attorney General of British Columbia?"

**AH:** Yeah.

**AB:** So, and I believe, that his intransience, gives HIV-phobes license to disseminate nasty words around HIV. Well if the Attorney General doesn't think it's worth – UHHN.

**AH:** Yeah. Going back to earlier days, how did your community respond to the epidemic? I mean, you were in Berkeley, it must've had quite a community there?

**AB:** Uh, yes, I mean it was, it was two things, it was people trying to offer services and trying to offer help in a situation where everybody was on a wait-list for death. You know, there were rare exceptions of people who were HIV positive who never progressed. But that percentage is minimal. There are people like me who were infected in 1980 and didn't bother testing until 1989 and didn't get sick until 1992 or early '93, who were slow progressors, but everybody else was just dying. And there was little or nothing to do except, you know some form of palliative care. But the stigma that existed in other parts of the country, other parts of the state, even other parts of the Bay Area, which are you know, sort of the counties that surround the Bay and have rural hinterlands, you know, in the inner Bay Area, you know every body was horrified and heartsick. There was very little push back in the effort to help and support. But the newspapers, the gay and lesbian oriented press, *Bay Area Reporter* for example, you know, where obituaries you know were one an issue – issues became obituaries with one or two news stories.

**AH:** Yeah. But what kind of actions did the community take?

**AB:** Well, I saw a film at the Vancouver International Film Festival the year before last called *BPM, Beats Per Minute*, French Film, without a date, but circumstantially appeared to be, well it was in Paris, and time-wise it seemed to be late 1994, early '95. There was a sense, and the arrival of Crixivan the drug trial came somewhat out of the blue, you know everybody had heard oh try this try that, none of it worked, and I think everybody had kind of gotten fatigue about, oh, there's something coming. And so, it was quite a shock. But there was a sense there was

something there. And of course, it was happening in the US before it was happening in France, and there was a scene that brought me right back to my last years in the Bay Area. And they were mixing fake blood to take to a demonstration that ACT UP Paris was organizing. And I remember being in somebody's apartment in the Castro, 1988, '89, '87, '90, '91, before we left for New Mexico, mixing fake blood to throw at a Federal and State Office building of the Civic Centre in San Francisco, because the government was not doing anything. Or if they were doing anything it wasn't doing enough.

**AH:** Right. So, what – so, that's certainly the, sort of the negative side of what was going on, but what about mobilization in the community or...?

**AB:** Well, the mobilization to take political action, you know, was one of the first in the US, since you know, the peace demonstrations and the demonstrations against the bombing in Cambodia. I mean it was, it was you know, the next big thing. And an unintended although wonderful side effect of the whole effort to get the drugs out before the drug companies or the CBC in the US thought—the CDC I mean—thought it was appropriate as salvage therapy has revolutionized how drugs are introduced. And not long after the reflective release of Crixivan, the government did an early release on a blood pressure—a breast cancer medication that again was awaiting you know--

**AH:** The appropriate trials.

**AB:** Trials. I always want to call it Temazepam which is not its name, but it has something to do with an evergreen tree, and it was very effective, and it came out before it went through the normal drug trial protocols, and that was able to happen because of the Crixivan trial. You know, so the mobilization that got the Crixivan trial, you know, which was the prize, we won medication, because we could take care of people, we just couldn't prevent them from dying, and only medicine could. The movement got the medicine. And that medicine has brought medicine out for other illness out long before it would've two decades ago.

**AH:** So, you mentioned you were mixing fake blood for demonstrations. What – any other kinds of activism you were involved in?

**AB:** ACT UP was more than enough, but I would say probably overlapping my work around HIV, I was a United Way trustee, and I was one of the two people who petitioned our Board of Directors to enforce our non-discrimination clause against... we had... United Way, the Bay Area is where all United Way ideas start in North America. Stuff that happens in San Francisco eventually comes to Canada, after it's swept across the US. And we had a non-discrimination clause and sexual orientation was one of the protected categories. And we funded the Boy Scouts of America, and they discriminated, so I would say at the same time I was mixing fake blood, I was arguing with my Board of Directors to kick the Boy Scouts out. And through showing that other youth helping agencies—Boys and Girls Club, Big Brothers Big Sisters, Girl Scouts—didn't discriminate, we convinced million-dollar donors not to abandon United Way because we were defunding the Boy Scouts. Which eventually defunded the Boy Scouts from every United Way in the United States and kicked them out a lot of public meeting spaces, because they were

discriminatory. Wasn't an issue for the Boy Scouts of Canada, 'cause they never discriminated, it's Canada.

**AH:** Well, we get some good reviews here. You've covered the next question here. Were you involved in any AIDS activism here in Canada? Or were you settled in at AVI? Well, you were a public spokesperson, that's activism of a kind.

**AB:** Well, when I started going to Pacific AIDS Network meetings, and I suspect I probably went to two AGMs, was when I was meeting people from other parts of the province, and you know as a new Canadian I'm learning about my country now, as opposed to learning about my country as a high school student. So, in some ways I have a better command of both the politics and the geography of our country than my fellow you know, native-born Canadians because it's been too long.

**AH:** I feel the same way.

**AB:** Yeah. And you know, I started hearing that services in the north are really marginal. Really. And where's the north? Prince George. Well, I took out a map and Prince George, it's about the geographical centre of our province. The north starts at Prince George and goes north to the territories. And I just started hearing about lack of services, and it got me thinking, as a former American, you know, big states have, and small states, have varying sizes of representative in the house of representatives based on population. But every state has two senators. And that's kind of a nice balancing, because nothing happens without both houses of government agreeing. It gives the little, the lower populated states an advantage. And I started positing, you know, a basic equity that everyone in this province should have access to a minimum level of HIV services, regardless of where they live. And that add-ons happen on a per capita basis. And, I of course, I'm trained as an architect, I'm not a social scientist, struggled for awhile to kind of get my mind around the social determinants of health. And when I finally managed to figure out what the fuck people were talking about, I started asking, "Well, why don't we have a geographic determinant of health?" Where people live really affects their health. I was at a Gay Men's Health Summit quite a while ago in Vancouver, and there was a representative, a medial representative from Northern Health, and I posed that question to her, and she said, "You're right, and good luck with that." And it's become somewhat of a cause for me to speak out about that.

I get the best care. I get better care I think than one of my friends who has Julio Montaner as his pet personal physician because of my friend has done so much in the community, I think I get better care here at the Access Health Centre. But that's not true for people up north. And we're both residents of British Columbia. You know, of course, once I realized that as Canadians we have a right to healthcare, it doesn't mean we have Canadian healthcare. And you know it varies you know from province to province. But why it varies so much within the province, I find disturbing. And why when I finally left the board of AVI, which I accomplished by bringing in term limits to get myself off of it, I was invited to join the Island Health STOP HIV/AIDS Advisory Steering Committee, and the committee basically takes recommendations from bureaucrats and sends them up the next level, and they'd been going a couple of years. I was the first HIV positive person on the committee for a program that dealt with the health needs, supposedly. Well, it's still mainly around STOP – seek, treat, and test and follow—and you

know the agenda, we had a meeting last Friday, if it's this long, this much of its stats around how well we're testing, treating, retaining, the cascade of care. And I'm always the person who says, you know, we've got a number of unmet needs here, on this side. We could use a branch office of Health Initiative for Men here, we could use... When Positive Women was still open, we could use a little chapter of that here. And we could really use Island Health, some programs related to the health needs of people who have been living a long time with HIV and are aging like me, because there is a lot of evidence showing we have health challenges beyond our chronological ages.

And I'm not making a lot of progress, but Island Health is the most backward of the regional health authorities in the province, at least related to HIV. But I was very surprised on Friday when the medical doctor who's the head of the committee, [name], who's always been very pleasant to me, I was speaking about the anal dysplasia clinic in Vancouver, and how I have to go over every nine months to get treated, and how you know, the HP virus is linked to anal and oral cancers. And first it was around getting the vaccine out to older people who were HIV positive, as opposed to men and boys to age twenty-six, and now it's getting that kind of screening, which has a two year wait-list, and the only way anybody's getting onto that program is if I die, because they're at capacity. And that's not fair to everybody here. I just happened to be at an early Gay Men's Health Summit, and I heard a presentation about it, and I put my name on the list. And I'm followed. And that's important. And most of the people here are not on that list, and they're not being followed. And she says, "You know, we're starting to talk about perhaps having an anal dysplasia clinic over here." Well, I've been talking about it for three years I've been on your stupid committee.

**AH:** Yeah. I remember going to those meetings. I was the Chair of VARCS for quite awhile and I would go to those meetings with Michael, and so on. Yeah, kind of head scratchers, what's going on there?

**AB:** And it's in the same way, you know my time at PAN, was at the point where HIV positive people would show up for the AGM and forum, and if it was apparent there were drug users, which was fairly easy to discern from their behaviour, they were not exactly made to feel welcome. And of course, since I was a little bit ahead of the curve on that because of my work here through AVI, I said, "You know, you can't shun anyone who's HIV positive, regardless of their other behaviours." But it took a lot of work to get the Pacific AIDS Network to welcome HIV positive people who have substance use issues. And the linkage between why they have substance use issue and under what foggy cloud, on a torrid Saturday night they forgot about safe sex, you know is very well established. And we're gonna shun these people?

**AH:** Yeah.

**AB:** Shameful. Shameful.

**AH:** So again, going back over the years, how did the community, the gay community I guess in this case, although you can define it as you please, deal with the burden of care and support, in the bad ol' days, when people were dying left and right?

**AB:** Well, I think that it would surprise me if the situation here weren't similar to what happened in the US, which was a collaboration between gay men who weren't dying and women. And many of those women happened to be lesbians, and doing the heavy lifting. I mean it was a lot of what you see in the film who's title I always manage to gobble the wrong way but I'm going to say the film, *We Were There* [*We Were Here*]?

**AH:** I know what you mean, I don't have the title in my head either.

**AB:** And when the film played here, it was brought up via a then health, men's wellness employee at AVI, Robert Birch, and he had become friends with Paul – I can't remember Paul's name – who was one of those people interviewed who had lost his partner, had lost subsequent partners, and there was a lot of work. And I remember because I was going to be introducing the film here and then introducing Paul. I knew when I was watching a film about HIV it was going to be hard not to see a picture of my first boyfriend, Lynn Cotton, because he was such a mover and shaker. And of course, in the opening, establishing scenes there he was, and clearly identifiable. But it was, I think it became apparent very quickly that you did not catch HIV from touching. You didn't even catch HIV from kissing people unless you both had, you know, really bleeding gums and open sores. And I think, you know, the gay community and certainly the lesbian part of the women's community, although at that point, you know, the explosion into the heterosexual community had not quite occurred yet, were people who, you know, were theoretically not at risk, but felt the need to help because nobody else was. Nobody else was.

**AH:** Yeah, yeah.

**AB:** And the stories my friends tell me about what was going on in Toronto, in parallel years, sounds like similar stories.

**AH:** Yeah. Well, that's how VARCS started, you know, was the respite care society that changed its name as that side of things became more difficult to deal with.

**AB:** You know, and interestingly, not only for people with HIV, but we are undoubtedly part of the population, there was a story last year, and there were some questions as to whether the stories of the facts were straight, but it was somebody who needed cancer treatment and who wasn't getting it because of who he was. And that's kind of congealed and moved forward more quickly a palliative care hospice program for people who aren't little old retired military men and little old ladies, because some of us are not welcome in those settings. And on our last days, do we need to be dissed? I don't think so. You know, Cool-Aid is the medical part of that community-based effort.

**AH:** Yeah. So how has the epidemic changed the community or communities, however you define that?

**AB:** Well, from my perspective, being an HIV positive person who helped bring wider acceptance to HIV in my community here on Vancouver Island, brought me to the attention of larger organizations doing broader work. First PAN, then the Canadian HIV/AIDS Legal Network on whose board I serve, and Rainbow Railroad. Do you know about Rainbow Railroad?

**AH:** No, I don't.

**AB:** Rainbow Railroad is a sort of riff on the underground railroad in the US Civil War, and they bring sexual minority people from around the world to safety, where they're living in communities where their lives are threatened. And they used to be brought to safety in the US, Canada, the EU, and Australia, but given the conversation around immigration to a great extent in the US and to a slightly lesser extent in Australia, they're mostly coming to Canada and the EU, right now. And I fell into contact with them through a [inaudible] shift through the legal network.

**AH:** I'd like to learn more about that. I'm just finishing a book – the underground railroad in the States figures largely in it, a non-fiction history book, and might be someplace else I need to go after finishing that. But what other kind of changes? Did it damage the community or make it stronger?

**AB:** I think it damaged the community, at least in terms of what I see, without any scientific, is this twenty-five percent of the population that never went back – is it thirty-five? I think it's closer to twenty-five than it is to ten, but a whole bunch of people who might have been leaders, who might have done great things for our communities, basically withdrew, because they were so shattered by coming so close to death. I don't – I find it hard, you know, knowing people living on benefit what a struggle it is, it's kind of like, you know, nobody wakes up in the morning and says, "Oh, I've heard good things about crystal meth, I'm going to become a meth head." Nobody does that. And I don't think anybody chooses to go on benefit. But I think circumstances get people there, and sometimes those circumstances keep people there. And that's a whole group of people, that you know, they don't turn out for Pride parades, unless they're sitting a few rows back from the audience. And the parade is really about the marchers, and people being proud to be out there. So, I think we lost people who were just damaged by their imminent relationship with a death that, in the end never happened. So, I think we're diminished. And you know, the whole disproportionate number of you know, artistic types, but there were just an awful lot of them, and they're dead, and they're not producing work, not across any range of artistic endeavors, and that's unfortunate. And you know, just got a great look at that – would you rather have this Adam whatever he is, fronting Queen, or would you rather have Freddie Mercury if he was still alive? I'd rather have Freddie.

**AH:** Yeah, thank you, yes.

**AB:** And he's dead. Because face—and then there's this funny thing, that the film got panned by two groups of critics and people: people who are HIV positive and critics from that community, and gay people. And I'm thinking, after I saw the film twice, did you miss the fact that in that incredibly telling scene, where he walks out of some building towards a cabin or cottage that has the washroom, and the guy who looks like he's just gotten off of a big rig, and I'm worried that Freddie Mercury's gonna get the shit beaten out of him, and all it is, it's these looks back and forth, and then the camera leaves that scene, and you know that that was sheer, physical attraction. That said it all that I needed to hear. There was a side of Freddie Mercury that was gay. And in the end, you know, she was gone with her new boyfriend, and he was still having

sex, but it was with guys at that point. And then the scene in the film where they're gonna come back together for Live AID, they're all pissed at him, 'cause he walked away, but they do it. And he's struggling, because of health-related issues, and at the end of the first rehearsal he says "Guys, I have something to tell you. You can't tell anybody. Can't tell anybody."

**AH:** Yeah, I've got—

**AB:** "I have AIDS." Now, did they need to do anything else! But that scene with the two guys, and that scene with him and the band, that's all it is. I know. If you didn't know that Freddie Mercury had a side of him that slept with men, and you didn't know that he had AIDS and given when he died, he died of complications, you did now. So, what do you need? It wasn't a film about AIDS, it wasn't a film about gay, it was a film about a band called Queen, for fucking sake. But that's how, you know, nitpicking and divisive our own communities can be. You know, to me, the fact that a gazillion people are seeing that scene where Freddie Mercury tells his bandmates he has AIDS, Jesus, nobody's shouting with a bigger mega-megaphone than that. You know. What's to complain about here? But we'll complain. How 'bout you go bring somebody a hot meal rather than fucking complaining.

**AH:** It's the same thing with Greenbook, where there was the one scene where the one guy had been caught by the cops in a gay situation. I thought it was handled gracefully, and people complained about it.

**AB:** It's never graceful enough, it's never graceful enough.

**AH:** Yeah, you know just, okay, we dealt with it, let's move on. Yeah. How's your perspective on HIV and prevention changed over time?

**AB:** Well, I struggle in how our AIDS Services Organizations operate, which for the main part is basically the government dole. And so, we are not in a position because we have not actively embraced fundraising to provide the programs that we want and that we feel our community needs. And we have been unable to convince the health authority, at any level of government, to agree with us. And we have only ourselves to blame. And I'm going to an AVI Board Meeting at the end of this month to basically beat on their non-fundraising board members, because you want the services, you can't depend on fucking Island Health. And that's a lesson that I think every community service organization can take to heart. Yes, we're funded to the dirty work that the government feels should be done, but they're not going to do it, they're the bureaucrats. But they're going to decide what that dirty work is, and it may not be what we want to be doing.

**AH:** I hear that one.

**AB:** And we struggle, because in many cases, there was an underground overlap between HIV and drug use, and now there are just more people dying of drug overdoses than there are of HIV, and it's hard to keep people focused, and it's a battle I fight every Tuesday afternoon when I sit at the front reception desk at AVI. And I mainly sit at that desk so I can fight that battle, between staff members who refuse to move lingering clients who come up at one o'clock for a drop-in centre that opens at three. And because they're active drug users, if an HIV positive person who



may have drug use in his or her past, doesn't want to come in any longer because it's a trigger. It's the same reason why [name] and somebody else and [name] when he was still alive, used to come over to AVI and bring lunches here. Because there were people here who are HIV positive and had history with substance use and didn't want to be exposed to the population at AVI.

**AH:** Right... So...

**AB:** But this was the first year that there were workshops at the Gay Men's Health Summit, which is really what it is, it has a sort of more research-y based name now, but it really is the Gay Men's Health Summit. It's the first time there were sessions about crystal meth and chem sex. That was big. And HIM has this nice column carton that dispenses nicely boxed condoms and lube out the bottom, on the table, and next to it was, this very nice, nice blue, about the colour of this chair, plastic wrapped meth pipes. Because there were meth users there. Even though they were gay men.

**AH:** How do you feel about the biomedical interventions that are available today?

**AB:** Just got in an argument with a friend of mine around a totally unrelated medical condition he has, where he wanted me to take his position against our mutual doctor. You know, I'm only here because of biomedical intervention. Somebody developed Crixivan and it saved my life. And I went from Crixivan to Sustiva, and they still saved my life, although Sustiva almost killed me. And now I'm on Abacavir and Viramir, and they are saving my life. So, I am gung-ho on biomedical interventions. It's not to say that a good massage doesn't make me feel good, and I go to the West Coast College of Massage Therapy once a week to the student clinic, because I'm old and it's cheap. But, you know, it's the medication is keeping us alive, and keeping us here for, I'm not sure that we're gonna see a cure in my lifetime, but I think we'll eventually get there. Alive for the cure. And when I was dying, you know, a heathen, well not even a heathen, somebody who had no spiritual component to his life but had a long term relationship to someone who was very spiritual, my ex said to me, "You need to do a visualization." And my visualization was around staying alive for treatment. And I had been a high-school surfer on the East Coast of the United States, and it was always, you were staying alive for the wave. You wanted to be there for the wave. When you got the wave, you wanted to ride the wave as long as you could. And so, I got on a wave and just kept riding it riding it, I rode that fucking wave for about eighteen months, until the drug trial started. And it saved my life, and you know, I didn't believe in the power of positive thinking before, but I sure do now.

**AH:** Ah, good for you. Any advice you'd give to health professionals about where things are?

**AB:** Well.... If you feel that you as a health professional are in a position to look down on anyone who comes to you for care, you probably need to re-think what you're doing in the health profession.

**AH:** Mmhmm. What about in regards to prevention and support programs, anything there? I mean you make a solid point there about the attitude.

**AB:** Well, one of the things I like about the Health Initiatives for Men model is that it—and I’m so envious, it’s the only reason I want to live in Vancouver, because you know they have Front Runners – I was a runner, you know Front Runners was a big deal in my life. And I tease Rob Reed, I happen to know the owner of Front Runners, and I tease him all the about the confusion between the gay running movement, and his running store—but, you know, prevention, I look beyond you know, condoms, safe sex, trying to keep your head on your shoulders when you’re under the influence of drugs you want to take your head somewhere else, I want people to be living lives that they never go there. So, it’s a combination of getting money in rehab services that actually get people beyond the awfulness of what happened to them when they were children, or what happened to their grandparents, when their grandparents were children, but also providing healthy activities. You know, speaking as a gay man, where gay men can meet where sex is not immediately on the table, because it’s hard to do in a yoga class, or in a running group or going to a museum or any of the other things that I read that, you know sometimes I don’t, I just delete the HIM newsletter because it annoys me so much. They’re doing so much fucking stuff, and I don’t get to have, you know, a whole lot of access to that here. And I feel that the health authority could save money if they put some of their STOP money into HIM, because then they wouldn’t be testing because people would be living different and healthier lives.

**AH:** Yeah. That makes sense. Do you have any advice for future generations who have not experienced the epidemic?

**AB:** Well, you know, my life has certainly been affected by the fact that I’m HIV positive. I’m very lucky that I survived given when I was infected. I didn’t do a lot of HIV related work until I moved to Canada, and I’ve kind of done a very quick passage through it, and then now moving on to broader societal issues. I’m an architect by training, the fact that our fucking city government does not manage to pass inclusionary zoning, you know, I want to take Ben and Jeremy and bang their heads together. I don’t care what your excuses are and I don’t really care what developers think. They need to be providing percentages of housing for people—

**AH:** Sorry, what was that word?

**AB:** Inclusionary zoning. It means that in the last ten years, if we had inclusionary zoning like many Canadian cities have, anywhere between five to twenty percent of the apartments and condominiums built in any of these buildings, whether it’s the fancy Bayview one where I live, you know, or more down market buildings, a certain number of those units would be reserved for people. And every building that has been built in the last ten years is not going away for at least fifty, and those are missed parcels of land. And you know, there’s a real clear linkage between health and housing, and why the province is so late in the game. You know, our healthcare costs are what drive the budget. You want to get a handle on it, you give people like me free HIV meds and you lower the provincial viral load, so you keep me out of the ER. The same thing with housing. The people living on or very near the street are just in that very expensive ER a lot more than I am. So, put ‘em in a fucking house. And then if you don’t like looking at homeless people, you won’t have to look at them, ‘cause they’ll be housed and they won’t be in the ER. And when you break your leg in a car accident, you’ll be seen more quickly. But you know, my path to podium here came through my engagement and public work around HIV and my HIV positive peers. I may be doing less and less of that, in the same way that the Canadian HIV/AIDS Legal

Network you know, intervenes in every charter challenge that has to do with protection of person, and could probably make a case that your tripod needs its rights protected, vis-à-vis HIV. It's a really long thin thread, and it doesn't really operate in Canada, you know. My boss is probably somewhere meeting with some UN Committee that we support. But you know, HIV brought me to the microphone here. It's really shaped my life. And I feel that everybody's voice is important, and everybody's story is worth telling and worth hearing.

**AH:** I've certainly found that true. I've done a number of these interviews now, and everybody's different. And I'm guilty of sort of rearing back a little bit from a couple of the people that have come in. And then I just had to sort of, okay, there's a real story here and I'm being educated.

**AB:** See, and it's interesting because, you know, I don't know how long you've been involved with PWA here, but you know there was this historic battle between Vancouver Island PWA and AVI, around money.

**AH:** Well, VARCS was—

**AB:** Part of that as well, I keep forgetting that.

**AH:** PWA, back when. Yeah.

**AB:** And you know, I got sent to a regional PAN meeting where I didn't know that the main topic of discussion was to beat up on AIDS Vancouver Island. And people were saying, well this-this agency that gets all the money, this agency does this, this agency doesn't listen to us – and I had to raise my hand after a half hour and I said, “What's this agency you're talking about?” And they looked at me and they said, “Well, AIDS Vancouver Island.” And of course it was at a time when the board, and I don't know the history of the board at VARCS, but the board at PWA, you know, was like being in high school, and you know the board kind of went like this and people dated and then they fought and then they left, and then they dated and then fought and they left. You know it wasn't until Craig arrived here that there was some level of stability introduced. Craig and TJ blindsided me at a party, and they said, “You should write us a cheque for fifty-thousand dollars.” And I said, “Why?” They said, “Well, AVI gets all the money.” I said, “I don't write the cheques, I just counter-sign them,” and I said... Well, it was at a time when the board was... And I said, “You need to show that you're an agency that the money's going to be spent where it's supposed to be spent. And you need to recognize that AVI is not the AVI that you know here alone, it's AVI in Nanaimo, it's AVI with its tribal outreach in Duncan, informally, and its AVI in Courtenay, Comox, Campbell River and then Port Hardy. That's why we get most of the money. We're not just one organization.” And there hadn't been any effort to understand that. And I don't know why is everyone fighting? You know, for my mind, we're a region of under four hundred thousand people, why don't we have one agency, with you know, a bunch of free-roaming programs under it? Why do we need you know, multiple executive directors? We're all working in the same area, you know each one should have a mission statement and get rid of those high-end salaries and have more money for services. Doesn't make sense to me. I don't see it happening in my life time.

**AH:** Not likely.

**AB:** It's like the amalgamation between the police forces of Victoria and Esquimalt.

**AH:** Well, I think that's about it. Thank you very much.

**AB:** Well I tha-

[tape cuts out]