<u>"HIV in My Day" – Interview 26</u>

February 20, 2018 Interviewee: George Astakeesic (GA); Interviewer: Sandy Lambert (SL); also present: Ben Klassen (BK)

Sandy Lambert: Would you like to tell us where you come from?

George Astakeesic: I'm from Manitoba. I moved here from Regina to here several years ago in 1987. I became involved in the drug scene not long after that, so I was using drugs quite heavily in those days.

SL: How did you get involved in the community. Did you get involved in the Two-Spirit community?

GA: Yup.

SL: Did you get involved in the gay community?

GA: Yes, I got involved in both. I would come in and party downtown quite often, met a lot of people. I wasn't yet positive when I was meeting all these people, I was just socializing a lot. With my diagnosis, it was either from working the street or from IV drug use at that time, so I wasn't really sure how I obtained my diagnosis.

SL: So, in what year did you get diagnosed?

GA: 1990.

SL: That was – you were around for the early years in '82, '83 when the AIDS epidemic or gay plague was evolving.

GA: It was starting then, yes, when I was here.

SL: How did you react and how did you find out about it?

GA: It was just through friends that I knew, initially, when I was first diagnosed. I started to become involved with [the Vancouver] PWA [Society], and Healing Our Spirit at that time was quite small. And then about a year after my diagnosis, I started volunteering at PWA for several years.

SL: When you were diagnosed, were you scared? What were your inner feelings?

GA: I was really quite shocked when I was diagnosed, even though I knew I had this really gut feeling that I was already positive before I went for my test 'cause I just felt differently. In those days, they didn't really have much support at the clinics for when they were diagnosing people. You were just told your diagnosis and you were on your way. Not much counselling at all.

SL: When you were diagnosed, did you connect with a doctor or a clinic?

GA: I found a doctor in Surrey that was willing to take on HIV patients, and I was one of her firsts, and she was a really great doctor – very understanding, very supportive.

SL: The support mechanisms – you had to learn about your disease.

GA: Yes.

SL: How did you do that? Was it through PWA or Healing Our Spirit?

GA: It was a little of both. The first year, I didn't bother with any of the AIDS organizations, I stayed in Surrey and lived out there for that first year without being connected to any of the organizations. I became a member of PWA and that was it. I decided not to come in and get any support from them.

SL: Did you have any family support or friend support?

GA: I had family that was living in Surrey at the time that I would go visit and hook up with. I met my partner later on in '93. We stayed out there for a number of years before coming into Vancouver.

SL: So, your community was in Surrey. So, you moved into the West End?

GA: We moved into the West End in 2000, when they first opened Wings Housing, the one that is on Comox St. We were one of the first tenants to move in.

SL: Just going back, in 1981, '82, '83 – those years, it was a different kind of community back then.

GA: Yes, it was.

SL: What really resonates with you from that time?

GA: I was really biased towards people that were positive. I didn't really associate with too many people then. I stayed with people, I would party a lot – that was the big thing, there was a lot of partying happening at that time for me.

SL: Was it mostly Indigenous people you were partying with?

GA: It was everyone. [Laughs]

SL: So, you did the bar scene?

GA: Did the after-hour scene, the baths.

SL: You have seen all the history. You probably remember – you said you were here in '82?

GA: '87.

SL: So, you remember when the boys used to work up here.

GA: *I* used to work up here.

SL: As time goes on, you start to learn about your disease.

GA: I became hooked into the community a little more and did my volunteer work which was very good. I was supported a lot by the other volunteers that were there as well and the staff. I got to know some of the people from Healing Our Spirit when I got involved too.

SL: Back then, there was a lot of organizations, a lot of activism, like ACT UP, and people would get body bags and they would draw outlines on the sidewalk for our government to provide meds. Were you ever part of that?

GA: I think I did a protest in front of an MLA's house in East Van. A whole bunch of us were taken up there in a big van and do our protest, and we walked in front of his office back and forth for a while, picketed in front of his office.

SL: And how did that feel?

GA: I thought we were doing something proactively, and I thought it was a good thing. There had to be something done. And I remember the only medication available was AZT and I didn't tolerate it very well and I stopped using it

SL: How long did you stop using AZT for?

GA: For several years.

SL: Your viral load must have...

GA: My viral load never got higher than 91,000 – I don't know why. I was very fortunate that way.

SL: What was the lowest your CD4 dropped?

GA: 280, maybe? 180? Yeah, not bad.

SL: So, after AZT, we started getting the cocktails.

GA: I tried several of those and I didn't tolerate them. I was taking drug holidays and not really adhering to the medications that well, being partying all the time or missing days and days of

medication so I just stopped taking them for a couple years. And then something new, the new ARVs came along, and I was able to tolerate those a lot better.

SL: So, really it didn't change the way you sort of handled life. You were partying and you were still taking these HIV – the ARVs – and so you are doing both.

GA: Yes.

SL: So, it didn't change your lifestyle at all.

GA: Not really, no. That happened later.

Ben Klassen: What was the catalyst for that change eventually?

GA: My partner really objected to my drug use - just hated it, hated it. And I would leave for days at a time and then go home afterwards, and it was just so hard on the relationship, was really what it was. It just wasn't going to work out really well if I continued to do what I was doing.

SL: 'Cause he would worry about you, right?

GA: Yes.

SL: "Are you alive," or whatever, or in the hospital?

GA: There was no contact for days. It was very inconsiderate on my part. I was just not really caring at the time about some of the things I did

SL: So, you kind of changed your lifestyle and cleaned up.

GA: Cleaned up and got more involved in volunteer work – did a little work at a Bingo Hall out there where I was being paid and became a little more settled.

SL: How do you think from back in those days to today that things have changed, or do you think they have?

GA: In many ways there is a lot more information now and a lot more support being given by the various organizations that are still around. More education is important.

BK: You mentioned a couple AIDS organizations that you were either involved with or volunteering with. What sort of work was Positive Living doing at the time?

GA: They did quite a bit. There was different workshops being offered, like peer counselling. There was – they would do the AIDS Walk, of course, and that sort of thing. I did volunteer work in the lounge, I did counselling and some of that stuff. They also had retreats for people to go on. Very helpful, very nice to go on. SL: Do you think some of that volunteer work...?

GA: I'm sure they did more administration work and governmental stuff that I wasn't too interested in.

SL: You were more front-line stuff. Do you think that helped you with coping with HIV, that you were surrounded by community?

GA: Yes, it makes a huge difference. I got involved with Friends for Life as well. They were quite supportive too.

SL: Just thinking on the Indigenous part, where you very involved with the Indigenous organizations?

GA: I did do as much as I could, whatever programs were available. And of course, that lessened over the years – yeah, funding cutbacks were always an issue it seemed.

SL: Still are.

GA: Still are.

SL: You are connected with organizations down here right now.

GA: Yeah, I am connected with organizations here in Vancouver. I am also connected to an organization out in Richmond as well, the Richmond AIDS organization.

SL: Did the PWA society – when you got involved with them, were there a lot of Indigenous people there at the time?

GA: There were quite a few at the time doing volunteer work as I was, and some are still there.

SL: Yeah. I guess it is an organization that started as a gay white male organization.

GA: It was changed. It wasn't where it is now, it was down by the beach. It was a on top of a roof, the rooftop. I don't know if you remember that - it was a while back.

SL: That was before I was involved.

GA: It was a rooftop building.

SL: Thinking about our Indigeneity, do you think that PWA doesn't have a lot of culturally relevant programs? Are you missing that from Healing Our Spirit? Did you get involved in the cultural aspect?

GA: Yes, some of it.

SL: Did you grow up with culture?

GA: I grew up in foster care, so I didn't really have it.

SL: You were part of the Sixties Scoop.

GA: Yes. Yes, I also put my name into the lawsuit.

SL: Like most of us.

GA: I didn't have that around. There was a lot of discrimination where I was growing up even in the foster home I was growing up in. The just had this prejudice to Natives and the only reason they had us is for the money.

SL: When you got back involved... how did you find the doctors and the medical care system? Was it good? Did you find discrimination there?

GA: I didn't really find any there, whenever I had any interactions with people in the health care system. I thought they were very good, they gradually got more knowledge, more experience and got better.

SL: There is a new generation coming up that is HIV positive.

GA: I have been hearing that about isolated communities and they are not getting support from the government or from other agencies, just not getting the support they need.

SL: What do you think needs to be done? What can we do as peers to change that?

GA: There used to be speakers that used to go around to different communities. I remember that Healing Our Spirit used to have a speaker's bureau that there were people that were peers that would go out and do some workshops and educate people and prevention is important and all that sort of stuff.

SL: We are missing that component, where people, long-term survivors go out into community. We need to hear our voices.

GA: We need to do more of that whether it is at high schools or community centres, wherever it may be.

SL: You mentioned that when you moved to Vancouver and got involved with the gay community that you didn't associate with HIV positive folks.

GA: Not really, no. I am a little bit ashamed about that because I was kind of prejudiced toward people that were positive at the time. I just thought no way am I going to become... and you

know, later on became positive myself. But initially, I was – I guess maybe I was angry a bit, maybe.

SL: Scared?

GA: Maybe scared. I think that might have had something to do with it.

SL: Would it also be the fear – we used to go to the bars and that, we would look at people and we would say, "Oh, that old queen," and we would...

GA: Distance ourselves.

SL: So, maybe you wouldn't understand that. [to Ben]

GA: That whole atmosphere was part of it.

SL: So, you remember the days when there were lots of bars.

GA: Yes, I do,

SL: Not like...

GA: Not like it is now. So different now.

SL: It is. Everything's... do you think the computer age has helped or has it set us back a bit?

GA: I think a little of both, I think – that is my opinion. It is so instant, the media now, and at the same time there is some separation from the human part of it, the human equation 'cause everything is done, as you said, on phones.

BK: You talked about the prejudice toward positive people. Is that something you yourself encountered a lot when you tested positive?

GA: Well, uh... a little bit, not much. I didn't associate with too many people that were – we really stuck to ourselves mostly, me and my partner did. Kind of just – he was one of those people that didn't want to become involved with other people that much, he wanted to be at home all the time and wanted me to be at home. Yeah, he disliked my friends, he didn't like the friends I had that would come over and visit occasionally. He just didn't like it.

SL: Was there fear – I know we had all these drugs – fear of facing body changes and all that?

GA: Yeah, one of the key issues for me was a lot of medication was starting – lipodystrophy and the hump and all that stuff and crix belly. And when I was on crixovan, if I noticed anything – I am pretty skinny – I would stop taking the medication. I did that with three or four different medications where I just stopped taking them because of all the physical changes that would

happen, and I guess I had a lot of fear about that, and maybe was egotistical as well – not wanting to go through those changes.

SL: And if you would go through those changes, would you find as a human being that you would need to advocate for change within the medical system? Is that the sort of person you are?

GA: Something, yeah – to a degree, yeah. I would talk to the doctor's about it and how these medications were affecting me and how they were not going to work for me and how I was just not taking them.

SL: Are youth today – because we have organizations with youth and people are positive, how do you...? And then you have our age, our generation, how do... is there a way that we can connect that gap? Build that bridge so we can all start working together...?

GA: Maybe some sort of like a Big Brother's society of some sort where we become a little more involved with the younger people, the younger generation. Mentoring would be a good thing.

SL: We want to leave a lot of space for you to tell your story. Are there things we haven't asked you about? We have been firing lots of questions at you. One other question I want to ask: during your time of being HIV positive, did you ever end up in the hospital?

GA: I had one surgery to remove a lymph node up here [touches neck] and I was only in the hospital for three days and that was the only time I have been hospitalized in the last twenty-eight years. I have been really fortunate. What I learned early on was stress – handling stress, we all have stress, but it is how we handle it that is important. I learned to alleviate a lot of my stress by not becoming overly anxious about things I had no control over and by recognizing the things that I do have control of. The big thing for me was when my partner got sick. The last few years were difficult 'cause I was always present there and I was doing my work at the volunteering and I would come home and I would have to do all the shopping and go and make the meals 'cause he was just not doing it anymore. It was really difficult watching somebody deteriorate and them not being able to eat some days, that part was stressful.

SL: Did you find – because I lost my partner to cancer six years ago, did you find it – was it a way out of not having to deal with ever day of him, seeing him suffer, so you went to volunteer?

GA: Yes, it was a way for me to have some time away and being able to do something I was interested in doing and I was happy to do it. I enjoyed volunteering.

SL: Did you have friends come in during those hours you were away?

GA: No, he didn't really want anybody to come in. He didn't want hospital care, he didn't want to pass away in a hospital. He passed away at home – that was difficult too. You know that.

SL: Yes, I do.

BK: Was there support available to you as a caregiver?

GA: I had a friend that would come by that would encourage me to go out with him for coffee just to get away for an hour or two or go for a walk along the seawall just to get away for a while. He would come up, so he was very supportive that way and that helped.

SL: You must have had friends years ago that had passed. Did you ever go visit them in the old part where they had the HIV ward in St. Paul's?

GA: No, I didn't. I avoided the hospital.

SL: You avoided the hospital, so you never went up to 10-C either.

GA: I went up there once and I don't even remember – it was a long time ago, when they first built it. And there were so many people when I was volunteering, there used to be a bulletin board up at PWA where the names of the people who had passed away, and almost weekly there were four or five names. It was very bad in those days for loss. A lot of people that I used to socialize with are no longer here. The just didn't make it. There is a huge population of First Nations that didn't make it.

SL: Did you see – speaking of Indigenous, back in '83, '84, did you see an increase of Indigenous people coming to the city?

GA: Somewhat, yeah. When I was here -I was here in the later-'80s -I saw that happening. There were quite a few people I would meet that were new that would come in, and we would all kind of sit together at the pub to check in with each other.

SL: Did it ever strike you why that population was growing?

GA: I didn't – it never occurred to me at the time. I just thought, oh, people are doing what I'm doing, getting away from the rednecks. [Laughs] More acceptance was here, the gay areas, the Two-Spirited areas, more acceptance.

SL: Was moving to Vancouver the first time you connected to that community?

GA: Yes, it was actually. I grew up in a farming community in Manitoba. I worked in the hotel industry back then and I didn't know anybody that was gay, and I just didn't admit for a long time what was going on with me. I didn't tell people, I wasn't open about it until I moved here, 'cause there was just so much discrimination back on the prairies.

SL: It was here, too. There are so many different layers that it is hard for a lot of people to understand those layers.

GA: Yeah, it happens in the suburbs here.

BK: When you got to Vancouver, was HIV already pretty prevalent here?

GA: I think it was? I seen people with Kaposi, and that scared the hell out of me, really scared me. I think that is why I didn't want to associate with people that were HIV positive were things like that. Not knowing, I had very little information to go on, I guess – I wasn't very well informed.

BK: Was the information not out there?

GA: It probably was out there, I just didn't ask. I wasn't looking for it. I imagine if I did, I would have been informed and got a little more education happening with what was going on. I just didn't ask.

SL: What do you have to add? Do you have any thoughts or...?

GA: I think it has changed. I went back to work in the last couple years, I have been working. I have just taken time off now. I think employment is good for people because when you are able to do it, it's quite good for the ego. That is the thing that has changed for me. I had Hepatitis C for the longest time and I had no idea until about ten years ago. I was diagnosed, then I went on the Harvoni treatment and that cleared it up immediately, and I started feeling good, went back to work.

BK: Where did you find the resilience to continue on as you dealt with this – dealing with your illness and your partner's illness?

GA: I don't know. I get a lot of strength from prayer, I guess, and faith - I am pretty obstinate. Try not to let stress get you down. I also live with manic depression and I am treated for that, so it is kind of balancing all of the different things that happened.

BK: It sounds like you really got involved and stayed involved and that helped a lot.

GA: Yeah, it made a huge difference. Once I started becoming more hooked in and doing some of the workshops that were being offered, educating myself more, it made a huge difference to how I perceive things and how I dealt with things.

BK: How many years were you involved with PWA for?

GA: About ten years.

BK: Did you see the organization change at all over that period or any observations about that time there?

GA: I thought it was okay. There was some funding cutbacks that effected some of the programs, like the CHF [community health fund] program was reduced – it evolved into what it is now. I don't really go there that often anymore. I also volunteered at Friends for Life for a few years after PWA and they are quite supportive as well.

SL: Are you connected to the Dr. Peter Foundation?

GA: Yes.

SL: What kind of programs do they have available?

GA: They have art therapy, music therapy, counselling available, out trips available that people can take – that sort of thing. And they have a meal program during the day. And then there is the community there. I have a few people that I sit around with and play cards with and play dominos with, that sort of thing. We get together regularly every morning to do that.

SL: So, you could spend the whole day there.

GA: I usually do. I find the days, the evenings long. I am still having a hard time coping with that part of it, I guess. I still miss my partner even though it has been fifteen years, it still seems like yesterday. As you know, that feeling just comes over me once and a while – not all the time though.

BK: Having that community is so essential.

GA: It is. No man can be an island unto himself. It is good to have the community, you know, for fun, recreation, and sometimes talking more seriously. It helps, it all helps.

SL: Just a thought: do you think we need another Indigenous community, another front-line organization?

GA: I think that is one of the things that CAAN [Canadian Aboriginal AIDS Network] could get involved with, providing something like that. It would be important. I think it is essential, actually.

BK: On that note, what kind of work was Healing Our Spirit doing when you were involved?

GA: They had their functions that I could go to. There was Christmas time, they had retreats that I would attend, they had workshops going as well, they had a lunch program as well – stuff like that. Counselling too, of course.

SL: Did you ever go to conferences?

GA: Oh, conferences – I did one. I am not a conference type person. [Laughs] I did a couple at PWA too. I did some public speaking with the heart of Richmond AIDS Society with their fundraiser.

BK: With PWA and Healing Our Spirit, were they doing similar work?

GA: With Healing Our Spirit, there was more cultural work, where the medicine wheel was being introduced and used in health care around that, and I guess they were doing outreach work

as well – I am not too sure. I know I attended some of their functions and some of their workshops.

- **BK**: Do you remember when you got involved with them?
- GA: I think it was early. Leonard and Frederic were there.
- SL: Oh, my goodness.
- GA: They were people I met when I started going there. They were on Broadway then.
- **SL**: That's oh god, that's early days.
- **GA**: That's a while back.
- SL: Is there anything else that you would like to add that we haven't had a chance to ask?
- GA: You have covered most everything.
- SL: Thank you so much for taking the time.
- GA: I enjoyed doing it. It is always helpful to talk about it.