# HONOURING OUR JOURNEY











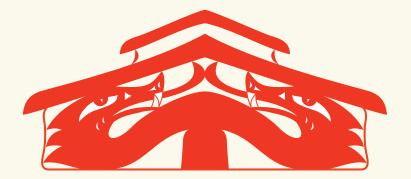


Personal stories about living with HIV

## **Dedications**

This book is warmly dedicated to the participants who graciously shared their time and their stories so that others living with HIV/AIDS, their families and their communities may draw from their strength.

We share these stories to support their journey.



### Introduction

Statistics are human beings with the tears wiped away. – Author unknown.

In BC, Aboriginal people are over-represented in HIV statistics. The reasons for this are complicated and rooted in the long-term effects of colonization which has resulted in the loss of culture and traditions. This loss has left Aboriginal people vulnerable to HIV infection. Connecting with culture and traditions is an important step to healing and improved health and wellness.

The impact of living with HIV has far-reaching and lasting effects, and people living with HIV need support from us all. It is important to remember that every statistic is a person living with HIV who is part of a family and a larger community.

In January of 2014, six Aboriginal people from across BC who are affected by HIV gathered for a day of sharing hosted by Chee Mamuk, Aboriginal Program, from the BC Centre of Disease Control. The participants shared their personal stories about their HIV journey. This booklet is a collection of those thoughts and ideas. Chee Mamuk praises the brave individuals who shared their stories so graciously and openly.

The purpose of *Honouring Our Journey* is to raise awareness of how HIV affects Aboriginal communities and to provide information about HIV through personal stories. Our hope is that through generating discussion about HIV we can reduce the stigma in our communities. We can all do our part in helping prevent the spread of HIV and creating more supportive communities for those living with HIV.

We invite you to read the words of these warriors and to share your thoughts with others – in your family and in your community.

> - Chee Mamuk, Aboriginal Program, BC Centre for Disease Control



## **Bernard Andreason**

Bernard Andreason is Inuit, born and raised in the small northern community of Tuktuyaaqtuuqt in the Northwest Territories. He was living in London, Ontario, when he was diagnosed with HIV, over 21 years ago. He moved to Vancouver when he heard about research being done in the lower mainland. Currently living in Prince George, Bernard is active with a community HIV group where he is able to offer support to those newly diagnosed with HIV.

RIGHT NOW WHAT GIVES ME HOPE is the medication, it's gotten so much better. People used to take 20 pills, but I only take one pill a day now so that's a big change, and I know it's going to get better.

*This hope he feels is quite different than what it was like for him in the early years.* 

I got really depressed after a few years of living with HIV, it was almost every day I was thinking about dying. And it wasn't just whether I was I going to die today. I would wonder if I got sick, what hospital would I end up in? What would my family do? I live so far away from them.

I woke up one morning and said enough of this dying, how can I get better? I'm going to start learning to live with HIV. I'm going to take better care of myself, get counseling, get help from my doctor and talk to people about my HIV.

It became easier to ask my doctor things like, "How long do I have to live?" She told me that with medication, I could live to be an old man. I felt very good after that, I was in my glory for at least a week! I've been living with HIV for 21 years this year.



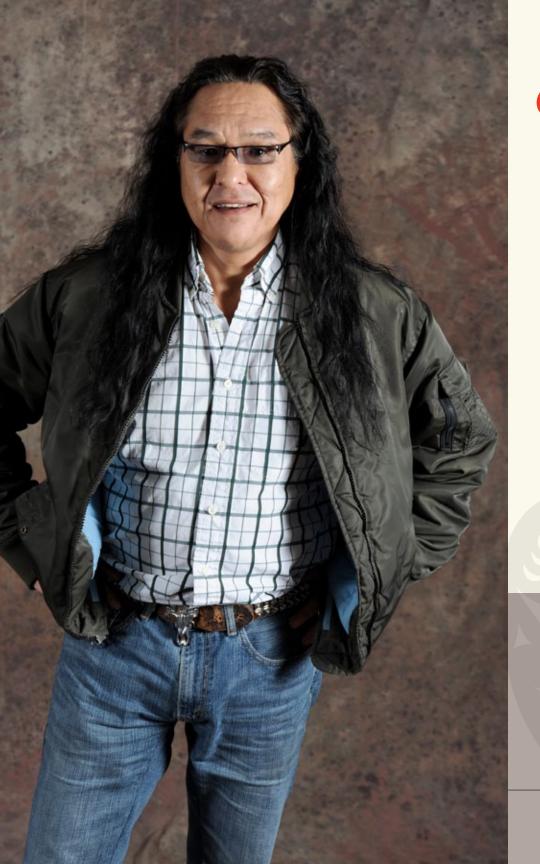
If you are curious and you want to see if you are HIV positive, go and get tested. There are AIDS organizations now that can support people living with AIDS and HIV. I think it's just better to know if you're HIV positive or not.

I know a couple of people that have been diagnosed maybe 6 months ago, and I could feel their frustration and anger. I talked to them and let them know it's going to be okay. There was one person who was recently diagnosed and was feeling depressed about it. And he said: "I have grandchildren, can I play with my grandchildren? Can I hug my grandchildren, can I kiss my grandchildren?" I said: "Yes, you can hug them you can kiss them you can play with them". He asked how long I had been living with HIV, and I told him: "21 years", and he was surprised. Now I've seen him a few times since and he seems a little happier, and he doesn't feel so down.

#### What is HIV? Human Immunodeficiency Virus

H	HUMAN	HIV can only live in humans
Ι	IMMUNO- DEFICIENCY	HIV breaks down the immune system, the body is unable to fight off diseases and infections
V	VIRUS	A tiny being that uses the cells of the human body to make more copies of tself , destroying healthy cells over time that would normally fight infections

Is HIV the same as AIDS? No!



I woke up one morning and said, enough of this dying, how can I get better? Start talking about HIV with chiefs and band councils and let them know that this is preventable.

I'm glad I'm helping somebody out, because at first I was scared to touch people. I would just give them a real quick hug, but never like a real hug. Now it's different – I'm learning different things about what it's like to live with HIV, and be on medications.

In Prince George, we have a group that goes out to any school, community or reserve that invites us, and we educate the community on HIV prevention. People share their personal stories.

We also do education work at a drop-in centre for people that are living on the street or in low-income housing, so they can come and have something to eat and get information. All of this is to try to prevent HIV from spreading in the northern communities.

We encourage people to start talking about HIV with chiefs and band councils, and let them know that this is preventable.

- Bernard Andreason

HONOURING OUR JOURNEY

## What is AIDS?

#### Acquired Immunodeficiency Syndrome

A	ACQUIRED	A person is exposed to HIV and becomes infected
1	IMMUNE	Refers to the immune system which fights off disease and infections
D	DEFICIENCY	Not working properly
5	SYNDROME	A group of signs and symptoms, having HIV plus one of a specific list of infections that only a doctor can diagnose



## **Charlotte Brooks**

Charlotte is a member of the Tsimshian First Nation near Prince Rupert BC. She is currently living in New Westminster BC.

HIV IS STILL HAPPENING. People are still not using the proper precautions.

I got HIV from my partner at the time – he knew he was HIV positive and didn't tell me. We had unprotected sex for three years, off-and-on dating.

One night my partner ended up hurting himself badly and we had to go to the hospital. My doctor found out he was HIV positive, and started asking me a lot of questions about whether or not we'd been taking precautions. When my doctor finally told me I needed to get tested for HIV, I was really scared. I was tested in Prince Rupert in November 1991. Waiting for the result was the longest three weeks of my life. It was an emotional roller coaster ride. And when my doctor told me it was positive, I just cried. My heart was broken. I was afraid because I didn't know who was going to accept me or push me away. I didn't know who to tell, or who to turn to. I was only twenty-nine. It's one of the toughest things you will ever hear.

I was a single mother of four sons and I thought I was going to die and not see my sons graduate and grow up to be men. I thought I wouldn't see my grandchildren. Now 20 years later I watched two sons graduate and now have grandchildren.



## What we're looking for is trust and a safe place.

People are still afraid to disclose their HIV status. They're too afraid because of discrimination and that nobody will hug or touch them. What we're looking for is trust and a safe place.

I connected with an AIDS organization in Prince Rupert, and ended up becoming life-long friends with someone from the organization. He's always been my backbone. He's the reason I went public.

We have our highs, we have our lows, but if you let us live a normal life then we'll live a normal life, and not be in fear of being discriminated against.



For over 20 years now, Charlotte has been sharing her story of living with HIV. But she had to get over the pain of how she was treated when she first told people about her HIV status, and the fear of being discriminated against.

The first time I gave a talk I felt so much shame. It was to a group of fifty or sixty Community Health Representatives (CHRs) at an AIDS conference in Prince Rupert. I was so scared because a lot of people knew my family. They knew me from when I was a little girl. And I didn't know what to expect.

So I was shocked when everyone stood up, full of compliments, saying how strong I was, how brave, and how much courage I had. I didn't expect that. One guy stood up, and he said: "Charlotte, I don't want to say anything but I do want to give you a hug". And I'm like, "Wow!" I stood up to go hug him in front of the table, and all the CHR's all stood in line to hug me.

That was really something, just for that man to say: "Can I hug you?" Because so many people are afraid that when you're near someone who has HIV that you can't touch them, you can't hug them. That you can't share the same toilet, the same plate, dishes. They think you can catch it all those ways and you can't. There's just no way you can.

In 2007 Chee Mamuk created Star in Your Own Stories, a youth video workshop series to educate about STIs and HIV. The first of the videos in the series, Stand True, was created by youth from the Haisla Nation. (All the videos can be seen at www.YouthHaveThePower.com) The film was launched at a community feast, and Charlotte was asked to share her story.

*Stand True* was amazing because it was about gossip, and about using precautions to prevent STIs. It's about the way gossip spreads fast in a small town, which I've experienced. When I watched the clip about the girl that others were gossiping about, and how the rumors got back to her, I remembered what happened to me in Prince Rupert. When I was diagnosed with HIV, I had told people that I thought I could trust, and people talked behind my back. Sure enough, it went around and it came right back to me. The look on that girl's face in the film was like what I felt.

I told those young filmmakers that they were doing something important. And it was very emotional, speaking about how the film reminded me of all the rough times, and how hard it was to go through. Then a friend who I'd known from when we were younger, who was at the screening, walked up to stand with me. I'd never had somebody from the audience come and stand by me. So that just blew me away, it was really something. – *Charlotte Brooks* 

We have our highs, we have our lows, but if you let us live a normal life then we'll live a normal life, and not be in fear of being discriminated against.

## **HIV Transmission**

#### How Does Someone Get HIV?

In order to get HIV, 3 things are needed. If 1 is missing, HIV cannot be passed.

#### 1. BODY FLUID

that can pass HIV: blood, semen/cum/pre-cum, vaginal fluid, breast milk

#### **2.** DIRECT OPENING INTO THE BODY

cervix in the vagina, urethra (pee hole on penis), anus, puncture hole

#### **3**. ACTIVITY

such as unprotected anal, vaginal or oral sex, blood to blood, a woman to her baby during pregnancy, childbirth or breast feeding

> **1+2+3**= POSSIBILITY OF HIV TRANSMISSION

Protect yourself, be aware of your rights. Your body is a temple.

## **Claudette Cardinal**

I'M CREE FROM ALBERTA, ORIGINALLY. I have four kids. I'm a grandmother of five.

Protect yourself, be aware of your rights. Your body is a temple. I know the peer pressures out there, I lived it as a teen and as an early mother – my first child was just three months old when I turned 16. So my advice to young women is to get your education, so you will be better able to support yourself and make it easier to maintain a healthy lifestyle.

December 18, 1995, I was 27 and was diagnosed with HIV and given two years to live. In the beginning it was dark because I didn't know anything about it. I was in Alberta then, and I just wanted to self-destruct, and the only way I knew how was through alcohol. The doctor said I had to take these pills in order to live, but I didn't take the medications as I was suppose to in the beginning.

When I came to BC, I had one of my tubes tied. I feel that I was coerced into it and that's the biggest regret for me because I didn't have the guts back then to stand up for myself and say no.

Once I gave up drinking it was a different path, it was more of a sacred path.



We all need the basic things like food, shelter, love. Love is the big thing. Start by loving yourself.



HIV is not passed through:

- Waste fluids sweat, tears, urine (pee), feces (poo), saliva
  - Sharing cutlery, drinks, clothes, make-up, bathroom
    - Hugging, kissing, shaking hands
      - Sweats, smudging, dancing, or singing
        - Smoking, coughing
          - Mosquito bites

• Swimming or other sports

I've been involved in speaking, travelling and telling my story and it's the path that has led me to where I am today. For me it's important to get the message out to the younger ones, because many of the people with HIV/AIDS are in the age bracket of my daughters and they are having kids. I don't want my little grandsons to have to live with what I live with. So prevention, education and awareness are all the things that still need to be heard, especially through sharing stories of people living with HIV/AIDS.

You cannot contract HIV/AIDS by just shaking my hand, or sitting next to me. Myths like those are all out the window, they are ancient! If we are not sharing any bodily fluids, you can't contract it. You can hug and kiss people.

Hope is in my bloodline. I don't have to be alone.

#### You know, we're just like

everybody else. We all need the basic things, like food shelter, love. Love is the big thing. Start by loving yourself. I've actually lived this long, to see my kids have kids. I take my HIV meds and I smoke my herb, which I'm licensed to, from Health Canada.

Doctors said I shouldn't have made it to 30 and here I am, almost 50, and my kids have grown up, and I have grandchildren.

– Claudette Cardinal

# **Claudette and Allan**

Claudette and her partner Allan have been together since before she was diagnosed with HIV. It has been 19 years, and Allan is still HIV negative.

ALLAN: When I met Claudette, it was like we just wanted to drink and party all the time. I didn't know that she was sick at the time, until she went into the doctor and they told her. We gave each other the choice of what to do, either to stay with each other or to leave, so we stuck it out and I'm glad I did. There's no empty spot in our life really, I'm grounded to her.

#### Signs and Symptoms

- When a person first gets HIV they may feel as if they have the flu
- Sometimes there are no symptoms
- There may be no other signs for many years

CLAUDETTE: Allan is my soul mate. He's gone through a lot, and I've put him through a lot. We've been open and honest about things. We could have left each other, but we've stayed together.

Claudette and Allan are a 'sero-discordant' couple, meaning that one has HIV and the other doesn't. When they first came to BC they lived on Vancouver Island where they attended a support group together.

What was nice about the group on the island, was that they welcomed Allan too. Al's been negative as long as I've been positive, and it's often difficult for him to access support services because he isn't positive. That's the biggest kicker for us because we'd like to find support together and also meet other couples like us and give them support. It doesn't matter if they're male or female partners, but HIV negative partners.

It's important for couples to come together to meet and discuss issues like getting an appointment with a doctor or psychiatrist or any kind of therapy. Before we left the island I was going to the support group every



second Friday of the month in Duncan and Al could come as well.

Getting over all the hurdles and obstacles with a HIVnegative partner has its challenges. We just have that openness. He has his issues, I have mine, and we just work through it. Laughter and being in nature grounds us. I think that's what kept us together this long.

The most comforting thing is that he's taught me so much about myself, about giving up the alcohol and being in nature, because he's more the country boy and I'm more the city girl. I teach him a lot of stuff too, you know. I opened his eyes to the two-spirited people and how they are.

ALLAN: I wish there were more groups for people like us, where one person is HIV positive and the other is HIV negative. It would really be a pleasure meeting other people like us. I only know a few, but I know there's couples out there.

There's not a lot of places I can go for help really, just Claudette, just talking to her and to other people. I go to the forest when I can, by the water. I smudge, I'll pray a little bit, not lots but enough.



We've been together since 1995, and I'm still HIV negative. We practice safe sex.

**66** The biggest thing I have is the support of a partner, my soul mate and he's the one that helped me with giving up alcohol, got me hooked on fishing. ~ Claudette

### Testing

THE ONLY WAY someone can know if they have HIV is to get a blood test. In British Columbia all HIV testing is confidential.

#### 2 TYPES OF HIV TESTING: Point of Care (POC), and Standard

*If the test is negative, and the person has not had a possible exposure to HIV in the 3 months before the test, the person does not have HIV.* 

POC TESTING: a quick, finger-prick test that gives immediate results

If the test is positive for HIV then a standard blood test is done to confirm the positive result.

STANDARD TESTING: blood is taken and sent to a lab for screening

If the test is positive, a follow up test is usually done. It usually takes one to two weeks to get the results of a standard test.

If a person tests positive for HIV, a public health nurse is available to help support them. The nurse can also work with them to contact any partners who would benefit from getting tested.

#### WINDOW PERIOD: 3 weeks to 3 months

The window period is the period of time between when a person is initially infected with HIV and the time it takes for antibodies to be detected in the body. Once infected, it can take 3 weeks to 3 months for HIV to show up through a blood test.

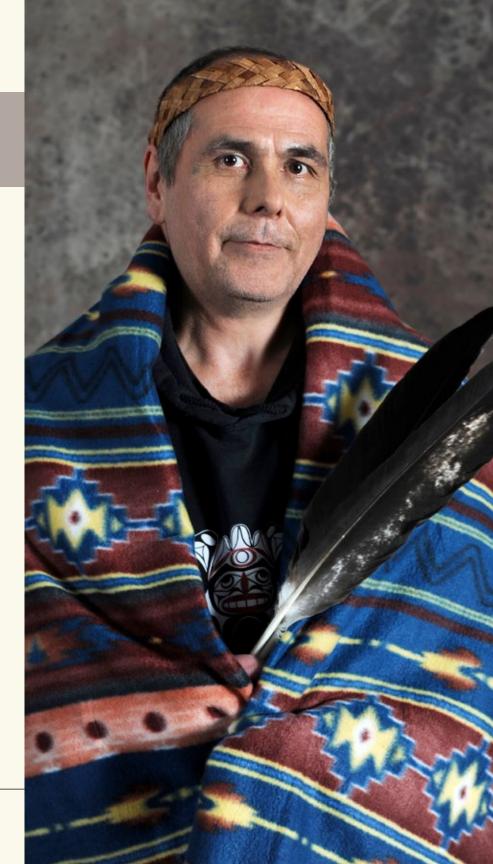
## Allan

HIV IS A LIFE-CHANGING SCENARIO. There's lots of discrimination towards people with HIV and I'm just trying to do my part, help out in whatever way I can, be part of it.

I'm Cree Métis originally, from Alberta and I moved out here with Claudette. Probably about two years after we moved here, that's when I realized she knew how to deal with her situation. At the beginning we didn't think she was going to live that long, because the doctors only gave her a couple of years. But when that didn't happen, we realized that she could live a long time.

We've been together since 1995, and I'm still HIV negative. We practice safe sex. I still go get tested every year. I do the needle testing, and now the rapid testing.

When you do your rapid testing, I believe there should be someone there with you because it's pretty quick. Within three minutes you'll know if you're positive or negative. Once they get the news, whether it's good or bad, they're out the door. I feel that there should be someone there with you when you get tested, so they can direct you where to go for support.



To give support to someone with HIV, you have to understand the person that you're talking to, their life story, and find out what they like to do that will benefit their life. Whether it's art, recording videos, fishing, walking, or biking.

Just be healthy, find something that you want to do. Instead of drinking and partying, go for a walk, go to the river. Just be yourself. You don't have to act like how everyone else is acting. Get used to life.

There's fear, right – but take precautions, keep safe, use condoms, make sure your partner is doing all right with their meds, their health. You have to find out what you're about, find something to do, and that's how to have a happy, healthy life.

– Allan

Just be healthy, find something that you want to do. Go for a walk, go to the river. Just be yourself. Get used to life.

## **Blondie Prince**

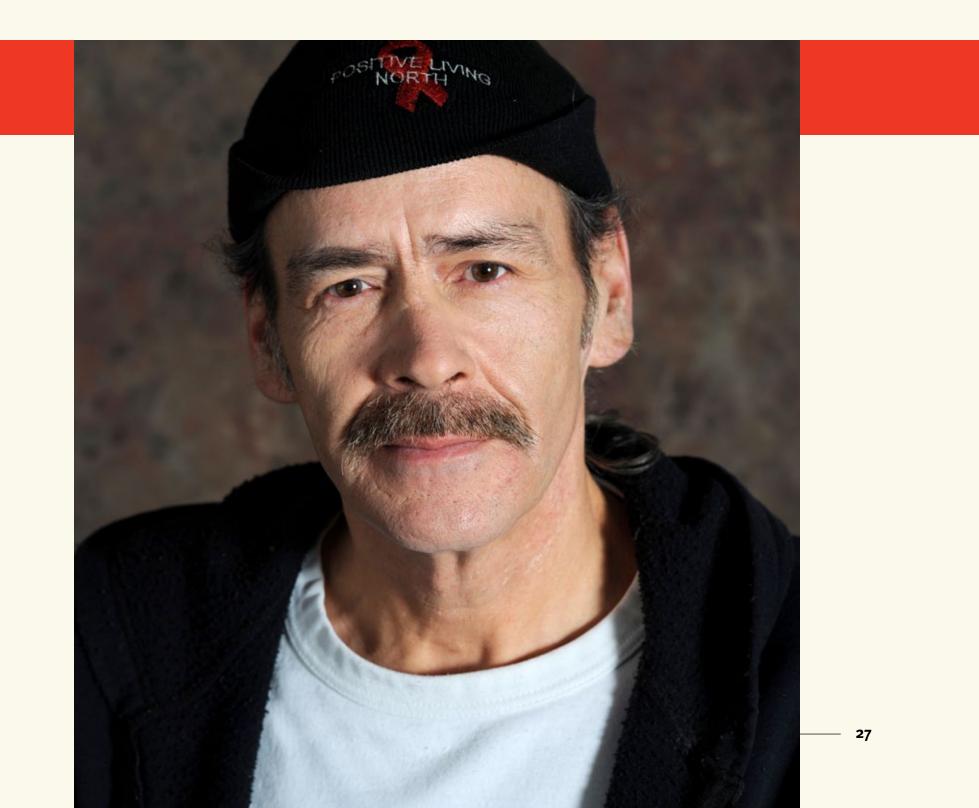
MY NAME IS BLONDIE KEITH PRINCE from Nak'azdli reserve, up near the Fort St. James area. I'm in the Beaver Clan, *Lhts' umusyoo*. I'm the son of Nick and Irene Prince, who are both passed away, and I love my life.

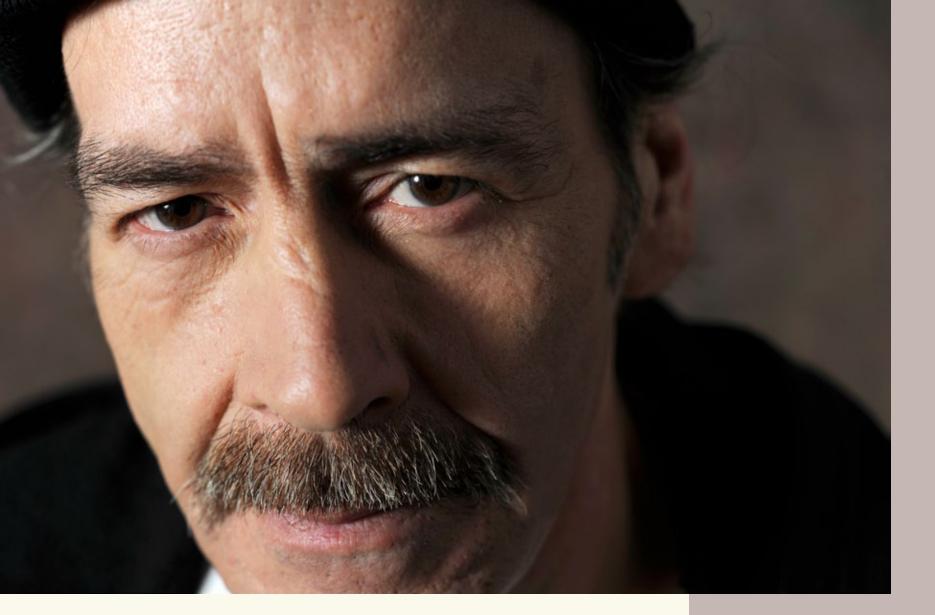
In 1997 I was in jail and I got a special visit. When you get a special visit in jail, it's usually the cops with new charges or something bad happening to somebody in your family, so I went there with a little fear. I was in the visiting room and a nurse, a friend of ours from Prince George, came around the corner. She had this look on her face that's really hard to describe, a really sorry kind of look. And she said: "I'm really sorry, Blondie."

I thought something had happened to my wife, but then my wife came around the corner and she looked like death warmed over, like she had just gotten out of a concentration camp. She looked like she was the walking dead, and she told me: "Blondie you gotta go get tested for AIDS, you gotta take an AIDS test because I have AIDS." And I only had a little bit of time left in jail, so I said: "I'll wait till I get out," which is what I did.

In 2004 I lost my wife to AIDS and in 2006 I lost my nephew to AIDS. I've lost a couple of other family cousins and a lot of friends. Each day I wake up and I gotta take pills and I'm reminded that I have HIV.

I do a lot of work in my community to educate Aboriginal people about HIV and AIDS.





# **Having a big family** – their support really paved the way for me to come home.

I don't know how to give you a proper understanding of how HIV affects me, I really don't know how to put it in words. To a certain extent it's been good, in that it's refocused my life on being able to live as opposed to just surviving. But the bad part of it outweighs the good part, you know, by leaps and bounds.

I do a lot of work in my community to try to educate Aboriginal people about HIV and AIDS.

All my friends that I grew up with and all the people that watched me grow up – they still understand that even though I have a virus in me, I'm still Blondie. They used to call me "Keithy". You can tell somebody's age when they call me Keithy.

I think having the courage to go home and not be afraid of what people say or think of me has a lot to do with it.

Having a big family and their support really paved the way for me to come home.

When I first decided to come home, I talked it over with a couple of my brothers, and I let a couple of my sisters know I had to go home after my wife died, that I wasn't in a safe place in the city. And I would certainly be dead if I hadn't gone home. I know I would have gone back into the street life and continued my career as a heroin addict. There are about 130 of us in my family, with all my brothers and sisters, and their kids, and their kids' kids. I love all my brothers and sisters, they're there, they will support me and give me a hand. And it works both ways. I do as much as I can, you know – they need help building or moving something, or if they need meat or fish I'll be more than happy to go and help them get it. My family is great, you have to know them to really appreciate all the stuff that they do.

I'm here, I'm home, and I have HIV so you know, that's the way it is.

- Blondie Prince





# **Blondie and Frieda**

HIV has also had a huge impact on Blondie's sister Frieda, who lost her son to HIV. She credits the work Blondie did in the community with helping her find support when she brought her son Jason home.

FRIEDA: My younger brother Blondie has been pretty much a free spirit all his life. He and his older brother were in cahoots for a long time. Blondie started getting involved in drugs when he was quite young, probably at 11 or 12, so I only saw him off and on all these years. His lifestyle was so different from mine.

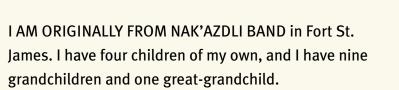
Blondie moved back to Fort St. James after his wife Brenda passed away, and became a very strong advocate for making sure people were informed around HIV and making good choices for themselves. I was really happy to have him in the community because HIV is quite an isolating virus. There's so much stigma involved. People don't feel free to go home or be with their family or disclose to their families. He's quite a voice for our community and across Canada – he talks about it everywhere. He wants people to keep themselves safe and reduce any risk.

BLONDIE: I lived across the street from Frieda when Jason, her son, came home to die. I'd be sitting there in the morning having a coffee and a cigarette, and I'd see her come out and stand on her low ramp, having a cigarette, looking up. I don't know how she went through all that and stayed so strong, was still able to laugh.

HIV is quite an isolating virus. There's so much stigma involved.



# Frieda Prince



My first encounter with HIV was in 1996 when my son Jason, who was living in Vancouver, called me and told me that he had HIV. He was in jail at the time, and he was just going to be released.

So I told him to come home and he met with his two sisters and his brother. We sat down and he explained to us what he knew about HIV and what was happening to his body, and what things he may encounter down the road. So it was pretty devastating for us all, because I didn't have a whole lot of knowledge about HIV.

Of course, I'm thinking that Jason's going to die right away, and I started to bug him — "You've got to look after yourself, get on medication you've got to do this and you've got to do that!" The more I pressured him to be healthy, the more he moved away from me.

There's so much misinformation out there that it's really hard to wade through all the information and find out what's real what's not real. You hear every second day that there's a new vaccine for HIV, and there's a new cure for HIV, but there is not.

Talk to the young people, talk to the kids, and actually talk to people my age who are also at pretty big risk.

I went to the AIDS organization in Prince George, and I got as much information as I could. I was astounded as to how many people are actually living with HIV. I thought "Oh my God, how did this ever happen?" You hear about it on the news, but it's always somewhere else.

#### Treatment

While there is no cure for HIV, there are medications which, when taken as prescribed, will help people live longer. These are called anti-retroviral drugs and in BC they are free.

Early treatment improves people's health

With treatment, HIV positive women can have healthy babies

Treatment can prevent the transmission of HIV to another person

Deciding when to start treatment is a decision the person makes with their doctor

Good nutrition, rest, exercise and other stress relievers help build a healthy immune system



I told a woman that was working there that "My son won't do this and he won't listen and he won't get on his meds", and she said, "Frieda, you have to allow him the dignity to live his life as he chooses." And I just had to give him over to God, so I phoned Jason and told him, "When you need me, I'll be here."

In January of 2005 I got a call that Jason had a stroke and was in the hospital in Victoria. I spent almost seven weeks with him there, waiting for him to get released. He had lost his speech, he could walk a little bit, and I thought, "They can't put him back in jail like this!" It took a long time to get enough people on our side to get him released.

## The more people that I can reach, even in a day-to-day conversation, as a community member, the better.

After he was released from hospital, he stayed in PrinceAfter his strokGeorge with his brother Clayton for about ten months.going, and heWhen Jason needed full-time care, which Clayton couldn'tAugust 2006.provide, I asked Jason if he wanted to come home, andI can't speakhe said yes. So I left my job, brought him back to Fort St.I can't speakJames, and took care of him.I

It was hard to bring him back to the community because I knew that a lot of people were scared of him, and scared of HIV. So I think that with Blondie living through it firsthand, and me living it through it second-hand through Jason — we really let people know that HIV is a reality and that it affects communities. After his stroke, Jason didn't have enough in him to keep going, and he just got weaker and weaker. He died in August 2006.

I can't speak for people who live with HIV. I don't know what it's like to have something in me that is going to impact me every day, with my body getting weaker. I can't speak on behalf of them. But I can speak on behalf of myself and my other kids, who watched someone they love die needlessly. Because it didn't have to happen. It doesn't have to happen, and it's preventable.

#### Prevention

#### HIV IS PREVENTABLE.

Know your HIV status Use condoms when having sex Use new drug injecting equipment every time (new needles and syringes)

Get tested during pregnancy

*Plan ways to talk to new partners about HIV prevention* 

Taking antiretroviral medications reduces the amount of HIV virus in a person's body so they can stay healthy longer. As well, the medication helps prevent the transmission of HIV The more we educate, the more people know about it. To have that in the back of their minds in any situation where they should take precautions, to take that extra second, pause and say, "Okay, what am I actually going to do"?

That's my role – to always talk about it. The more people that I can reach, even in a day-today conversation, as a community member, the better. Right now I work for the Lower Similkameen Indian Band. I have a lot of friends and colleagues in the Keremeos area, and the more I can talk about it, the more I can help people.



## **C** That's my role, to always talk about it. HIV doesn't have to happen, **it's preventable.**

Sharing this information is important because mothers shouldn't have to bury their children, fathers shouldn't have to bury their children, and we shouldn't have to bury our brothers and sisters, and our cousins, and our nephews. So that's the reason that I talk about HIV as much as I do.

– Frieda Prince



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