



Leading the Way

**First Nations Leaders of BC's Northern Interior
and Northeast Speak About HIV/AIDS**



Dedications

To Aboriginal people living with HIV/AIDS
and to those who have passed on.

To the individuals, families and communities leading the way in raising
awareness of HIV/AIDS, and who are supporting people living with HIV
in their communities.

Melanie Rivers

Chee Mamuk, Aboriginal Program
BC Centre for Disease Control



Emma Palmantier

Northern BC First Nations
HIV/AIDS Coalition

Introduction

Every week, approximately one Aboriginal person in British Columbia (BC) is diagnosed with HIV. Behind this statistic is a person, his or her family and community.

This reality affects us all.

Leadership in First Nations communities can play a critical role in HIV awareness by not being afraid to speak about HIV in their own communities, lobbying for adequate funding, supporting HIV programming, and establishing policies that ensure people living with HIV are not discriminated against.

In October 2011, Chief and Council members from First Nations communities in the Northern Interior and northeast BC came together for a two-day HIV/AIDS forum. This forum was hosted by the Northern BC First Nations HIV/AIDS Coalition and facilitated by Chee Mamuk, Aboriginal Program, from the BC Centre for Disease Control. Leaders shared their thoughts about the HIV epidemic in their communities while making recommendations for action. This book is a collection of those thoughts and ideas.

The forum hosts praise these brave leaders for taking this important step.

The purpose of *Leading the Way* is to raise awareness about HIV/AIDS and to inspire others to step forward and speak about HIV. By generating discussion 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 leaders and share your thoughts with others — in your family and your community.

– Chee Mamuk, Aboriginal Program, BC Centre for Disease Control

– Northern BC First Nations HIV/AIDS Coalition

A SPECIAL THANK YOU to the Aboriginal People living with HIV/AIDS who have

Charlotte Brooks



IT'S NOT SCARY to be around a person who is living with HIV or AIDS. It's just better for the community to get all of the knowledge and awareness, and to learn how to support a person with HIV. If it wasn't for support, I don't know if I'd be here 20 years later. Because I am approaching my 20-year anniversary of being HIV-positive.

I'm here to tell people that it isn't easy living with HIV when people don't make it easy for me. But it can be easy if you just let me live my life to enjoy my life, and help me move forward — to embrace me, to empower me, to encourage me, and also to do that for my HIV-positive brothers and sisters.

openly shared their stories of living with HIV. Your strength is truly inspiring.

Bernard Andreason

HIV IS NOT THE END OF THE WORLD. Be careful. When you get into a high-risk situation, maybe you can try to find a way to get out of it.

I think they have to get more involved with the health department in their communities and see how they can get more harm-reduction supplies. You know, condoms, needles. Where they can get that stuff for smaller communities and always learn ways to find out how they can always have access to them.



I HOPE TO GET THE LEADERS of our people to understand that HIV is here, it's coming, and if they're not prepared, it can hurt them badly, and the sooner we stop it the better we are.



Keith Prince (Blondie)

I think the best hope that they can have is to learn all they can about HIV and hepatitis and understand that they are 100 per cent preventable and they don't have to catch it. There's just so much that they can do to support those living with HIV, but just open your arms and welcome them home. I think is the biggest. I was at St. Paul's Hospital one time, I was walking by the 10th floor (which is the AIDS ward up there) and there was a person, an Aboriginal fellow. He was lying on a bed, and he was by himself. There was a nurse and a doctor standing beside him and I asked, "What's wrong with this guy? And they said, 'Oh, he's dying. He only has a couple minutes or a couple of hours left. But he's dying.'" And he was by himself.

Aboriginal people don't die like that. They die with their family, surrounded by family and people who love them. And it just, you know, it really made me think long and hard. That's why I went home... If I'm going to die from AIDS, I'm going to die at home. And I think everybody should have that chance.

William Christiansen

AS A PERSON LIVING WITH HIV, I'd like to do whatever I could to help people recognize their strength and their ability to deal with HIV and AIDS within our community. It's all about taking care of ourselves at that family level. I think it's important because my grandmother — having lived to age 105 — has helped her family, through a number of years, get through issues like alcohol, drugs and the impacts of residential schools. Because HIV has such a focused area in my life, I'd like to be able to get into the role as an individual who can help my family, or my community, get through this HIV or AIDS epidemic.



First Nations leaders of BC's Northern Interior



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“ *Get empowered by knowledge.* ”

I would say we want all of our community members to be healthy and happy and lead productive lives. If you believe in the future of your community, get involved, from the teenagers to the elders.

There are a lot of misconceptions about HIV and AIDS. My message would be that a person with HIV and AIDS can live a healthy, productive and happy life. We need to make everybody aware of how we can involve that person and keep them in the community, because it's the community where the support is, from their families, from their band, from their friends.



Brenda Gardiner Nazko

“*Love yourself,
stop taking chances.*”

Education is key, increased efforts to promote youth involvement and commitment, more parental involvement participation.

Be the voice that can help change their world

Everyone should be getting tested, for prevention. Let's be the cure by minimizing the chances until it's gone forever.

Jenine Solonas McLeod Lake





“ *Love and respect –
that’s a strong message.* ”

I think that we really need to start taking care of ourselves holistically, which is our mind, spirit, body and emotions. It’s really important to be aware of the risks of unprotected sex. And with drugs, to be really safe with what they do and just be responsible.

In smaller communities, there’s more stigma attached. With more information, there will be more understanding. And when you have more understanding, you create more compassion and care because they are still our community members whether they have HIV or not. One person can make a difference in our community, and I think it will spread throughout the community if we can all promote health and wellness.

Karen Ogen *Wet’suwet’en*

“ *AIDS is no longer a death sentence as it used to be.* ”

Kathi Dickie Fort Nelson

So we have to have hope, and we have to include all those within our communities, because they are going through so many personal struggles of their own. We need to pull together, and tackle it together, to work on it together.

It would just save so much heartache and so much pain and so much sadness, just taking those few couple of minutes or seconds to do those prevention activities, just to keep yourself safe, and your partner safe, and others safe as well.

How do we reduce the stigma? Probably just by education. It's just to realize that it's not confined to someone who might be living a high-risk lifestyle. It could be anyone, and it could be any one of us. Again, it's not a bad person's disease. It could be any one of us.

We just need to recognize that they're dealing with an illness. We need to support, we need to love, we need to pull together to help each other. ”





“ ***Be safe, be healthy.***

Don't take a risk, get tested.

For the youth: have a safe, healthy lifestyle,
get informed about AIDS and the risks involved. ”

Margo Sagalon Nak'azdli

“***Be protected, be safe.***”

Educate our community as a whole. The elders and the youth need to be educated properly on it. A lot of people are really scared to even come into contact with a person who has the virus, not knowing they can't get it. They need to know how they can get it, and how you can't. Like, you can't get it by shaking hands, or toilet seats, that sort of thing.

Ramona Austin Skin Tyee





**“ We’re family and we are First Nations and
we stand strong together,
as a community.**

To our older town band members, I’d like to say, they are welcome home no matter what kind of addictions or any kind of illnesses they have. They’re always welcome home, and they are always loved.

Theresa Poole Tsay Keh Dene



“ *I don't want to isolate
the people who have AIDS.* ”

Wilfred Adam Lake Babine

I think it's important that we have prevention programs up and running, and also support for the people who have AIDS. It's not a disease where when you touch a person with AIDS you become infected. That seems to be the issue around the community... once somebody has AIDS, the community just shuns them. And I don't think that's the proper way.

It should be known, within the community, how we can help the people who are infected by this disease, so that we can get proper medication for that person, or a living condition that's suitable, and be helpful to the people who are affect by AIDS, and their families.

My message to the youth: stay clean, and have a good life. And you can do it without drugs or alcohol. ”

“ ***As leaders we have an important role and responsibility*** *to enable discussion about HIV/AIDS in our First Nation communities.*

Peter Stone Daylu Dena

In order for our members to understand and have knowledgeable conversation on this health matter, we need to provide current information. Through this open education, we can all build a comfort level and respect towards helping those who live with HIV/AIDS at home or elsewhere. Community health workshops will help serve this purpose and assist us in creating a local action plan.

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“ *At one time I served on
the HIV/AIDS task force*

as it was identified as an epidemic in Northern BC. Seeing how health is a huge file in itself, I figured this would be a good venue for working from the outside to make a difference for my First Nation as well as all First Nations in the North. The task force has made impacts across the board, however a lack of funding has impeded this good work going forward. ”

Ray Morris Nee Tahí Buhn

Sherry Dominic Blue River

**“ We, as leaders, need to have
a better understanding.**

We have a small community, and I remember HIV/AIDS was first mentioned in the '80s, but there was not enough information about awareness and prevention. We need to educate our youth and members about prevention.

To our youth: respect, honour and value yourselves, as you are the future generation.”





“*I really want to learn more about HIV and bring it back to the people.*”

Wayne David Saik’uz

One of my friends passed away of AIDS, so now I really want to learn more about it and say, ‘This is what we have to do for our people that are unfortunate.’

It’s a really hard subject, and you can’t put a label on it. You don’t need to discriminate. Your family member, your brother, your mother, your sister, your brother, your cousins, it might be one of them. And you’re going to say, ‘I don’t want nothing to do with you?’ That is no way to live.

To the youth: stay in school, make sure you have protected sex, and always listen to your parents — ‘cause your parents are always going to be behind you. Right until the end.

”



“*There’s a need, in all communities,
to slow this disease down.*”

It’s a disease that’s been forgotten, almost put aside in BC and Canada. I think the concerns are not just with First Nations, but with everybody out there. Other diseases out there, that are really high, like cancer, heart disease, they’re getting all the attention and focus right now. And we just can’t forget that there’s still this problem in Canada. Educate yourself, or learn from people who have HIV. I know there have been a lot of new treatments.

For prevention, use common sense, use your judgment, be safe. ”

Wesley Sam Burns Lake

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