

# Original ABORIGINAL

**From Alert Bay to being a PHA, Kecia Larkin has come a long way. This First Nations mom speaks her mind.**

*by Marie Belmont*

**"I DON'T WANT TO BE A ROLE MODEL,"** Kecia Larkin tells me in her cozy apartment on the west edge of downtown Edmonton. "It's a very loaded term. Besides, I'm not perfect. I've made many mistakes in my life, and I have so many demons it's not even funny. But I'm tired of hiding them."

On this hot summer day, with her 8-year-old daughter, Rakiya, away at Camp Moomba — a summer program for kids living with or affected by HIV — the very pregnant Larkin, 30, speaks without haste, weighing each word. Six days after our meeting, she would welcome her son, Owen Gabriel, into the world. But today she's reflecting on the past.

Several years ago, Larkin posed for photographs that appeared in the 1996 book *Look Beyond: The Faces and Stories of People With HIV/AIDS* (Snowy Owl AIDS Foundation). They show a smiling, dimpled young woman in jeans, her shiny chin-length hair swinging as she clowns around in a Vancouver fountain. Below her name is one word: *Fearless*. Long before those photos of a seemingly carefree young woman were taken, Larkin had been confronting such difficult issues as substance abuse and depression. And, in addition to the mixed reactions to her decisions to avoid HIV treatment and to have children, she had to face the prospect of moving on.

"I don't try to create this idea that people with HIV are invincible," Larkin says. "But I also don't say that once you're infected your life is over."

## *Memories of days gone by*

Larkin's adult life was just beginning when she left her hometown of Alert Bay, on the north tip of Vancouver

Island, at age 15. (Her family is descended from two First Nations: the Kwa,kwa,wakw coastal tribe and the Peigan Nation.) She fled to Vancouver after a sexual abuse scandal rocked the community of 1,200, leading to an increase in drug and alcohol abuse and a wave of suicides. There she lived on the streets, experimenting with injection drugs and the sex trade. It was the late 1980s, and Larkin ruefully admits she knew nothing about protecting herself from HIV. After her diagnosis in 1989 — she was infected by a partner who had concealed his HIV status (she found out accidentally) — Larkin went on a six-month drug binge. "I couldn't cope with it," she recalls. "I didn't want to cope with it." When reality set in, Larkin got clean in detox, disclosed to her family — "my mom and siblings are very much a part of our lives" — and began to live with HIV. (In 1990, she starred in the documentary *Kecia: Words to Live By*, about her life and the events that led to her testing positive. To order the video, call Gryphon Productions at 604.921.7627.)

## *Treating herself right*

Larkin's viral load is undetectable and her CD4 count has hovered around 200 for about four years. For more than a decade, she avoided anti-HIV drugs. "Medications are like trump cards," Larkin says. "You play them when you need to. They're a way to buy you time."

Still, she began taking anti-HIV meds this year, just for the duration of her second pregnancy. Soon after starting on Combivir (AZT and 3TC), Larkin says, "I went through hell on AZT. I got bone marrow anemia and my hemoglobin [red blood cell count] was bottoming out. So after one month I switched to d4T [along with the 3TC]." Though she stopped taking them after she gave birth, Larkin says, "Being on meds changed my mind about a lot of things, like accepting that



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there may come a time when I need treatments. Hopefully by then they’ll have gotten better. It’s a very difficult process physically, mentally and emotionally. I was tired and depressed. You don’t feel like you have any control. Your life revolves around taking these pills and there’s resentment, grief and pain. It allowed me to appreciate the fact that I’ve been so well for so long, and to feel truly blessed by that and learn to enjoy that more.”

Besides the ongoing support that she receives from her partner of several years — “Ernie is awesome” — Larkin credits the doctors and social workers at the HIV outpatient program at the University of Alberta Hospital and the Royal Alex Hospital with providing her with information and support. “All the people involved in my care have been there 100 percent,” she says. “I think a lot of that has to do with my willingness to accept that. You get what you give. I’ve been more involved in my health and my HIV infection and really keeping on top of it and being aware, keeping up with the things I need to do.”

### *Sweet child of mine*

Pictures of Larkin’s bright-eyed little girl decorate the apartment, along with one of her paintings — a splash of squiggly lines with the words *You Go Mom!* Larkin refers to her first child as her “miracle baby,” because although Rakiya was born before treatments to prevent mother-to-child transmission were commonly used, she is HIV negative. Ernie has tested negative for HIV as well. (Owen Gabriel was born by Caesarean section. Doctors gave him AZT right >

away. At press time, he'd had two PCR tests that both came back negative.)

Rakiya has known about her mom's disease since she was 4 years old. She understands why her mom took pills to protect her new little brother from getting HIV. But even though AIDS looms large in her life, because of the stigma still associated with the disease, Rakiya can't talk about it in everyday places like school. "If I had breast cancer, it would be OK for her to talk about it," Larkin says. "But with HIV, it's still not OK. There's a lot of work to do out there."

### CANADIAN ABORIGINAL HIV/AIDS STATISTICS

The proportion of Aboriginal AIDS cases, after adjusting for reporting delay, increased from **1%** before 1990 to **8.5%** in 2000.

Although Aboriginal people (First Nations, Inuit and Metis) comprise only **2.8%** of the Canadian population, they accounted for **5.5%** of all prevalent HIV infections and **8.8%** of all new infections in Canada in 1999.

The proportions of Aboriginal HIV and AIDS cases that are under 30 years old, female or attributed to injecting drug use are **greater** than the corresponding proportions among non-Aboriginal cases.

From 1996 to 1999, there was an estimated **91%** increase in the number of Aboriginal people living with HIV in Canada, from 1,430 infections to 2,740 infections.

(Source: Bureau of HIV/AIDS, STD and TB Update Series, May 2001)

National Aboriginal HIV/AIDS groups such as CAAN and CIHAN are working to help their communities interpret and take action on these statistics.

### *Speaking her mind*

In 1990, when Larkin first began to speak publicly about her HIV, she was a novelty: a young First Nations woman confronting such a strong taboo as AIDSphobia. Because she was willing to speak out to educate others who might unwittingly follow her path, she became a kind of "poster girl" for the havoc HIV could wreak in small, tightly knit Native communities. "The events in my life that led me [to become infected] freaked me out because there was potential for so many more youth to end up in the same boat," Larkin says. "On the Coast, a lot of people would go down to Vancouver and party for a few days. It was just too easy to pick something

up and bring it home to a closed community that was a real breeding ground."

In speaking publicly about living with HIV for the past 12 years, Larkin refuses to apologize for her past or explain her personal choices. "When I talk to groups, I refuse to use scare tactics. I didn't practice safe sex when I was a teenager, even to this day — obviously, I got pregnant, I don't use condoms all the time — so how can I sit there and tell someone else that they have to?"

"Lots of people want me to talk about how horrible it is to live with this virus and to play up the whole victim role to scare people," she continues. "It's not true. I know

many people with HIV who live wonderful lives. It's very uncertain and fearful sometimes, but there's also an appreciation and a richness and a joy."

After her first pregnancy, Larkin pulled back from public speaking because audiences somehow felt entitled to criticize or judge her decision to have a child. "I encourage people to ask questions, because that's how you learn," she says, "but there was a lack of respect for me and what's important to me, as a person and as a woman."

Larkin scoffs at the notions that people with HIV don't have sex, relationships or babies, and that they always use condoms and are always honest with their partners: "For me, it's very important to be able to say that's a myth. Once we get past that, then maybe we can get to a place where we can actually provide some assistance for people dealing with these issues, as opposed to pretending we live in an ideal world."

While she strongly supports educating young people about protecting themselves, Larkin defends the right of two informed adults in a monogamous relationship to weigh the risks when considering how to negotiate a healthy sex life with HIV. "That's a personal choice," she says. "It's nobody's business what you do in your bedroom. It's important to teach people the rainbow of options they have, but ultimately it's up to the individual."

### *Lady sings the blues*

At the same time that Larkin has been coming to terms with HIV, she's been battling another disease: depression. Until recently, she didn't realize that her panic attacks and anxiety were anything unusual. "When I think back, for at least half my life I've had [depression], and I'm so grateful to have the freedom and ability to accept it now," she says. Besides treating her depression with Paxil, "I see a psychologist a couple times a month, where I can talk and not be edited. That's important for me, it's like a tonic for my emotions. If I can get a grasp on this, there are going to be longer moments of peace and joy and being centered, feeling in control."

Larkin says that in her community of Alert Bay "mental illness is not something you talk about — it's taboo, there's stigma. The way I used to cope with it was to go out and get high. I couldn't be alone. Suicide is not normal, but we've accepted it there as the norm. I'm hoping that if we educate people about mental illness it will decrease the incidence of suicide."



## *Spiritual healing*

Larkin's First Nations heritage is apparent in signs both small and large. In her home, you might catch a whiff of sage or sweetgrass burning. While her right forearm is boldly emblazoned with a red ribbon tattoo, Larkin's right calf is tattooed with a large Native "contrary," or sacred clown.

"His healing is through humour. *Heyokas* view the world from a different perspective," says Larkin, clearly relishing the symbol.

"To keep my spirit clean, I use ceremonies and rituals," she says. "I'm more likely to use First Nations things, but I draw from other traditions as well. When somebody dies, I burn a candle to honour them. I like to burn incense because it purifies the energy. We smudge and use eagle feathers for healing. The windchimes above my door help balance the *chi* [energy]. We try to use things that are available to us to heal and balance."

"Like with this virus, in my life I've had to take things that have been negative and create positive things out of them," Larkin says. "Being First Nations is certainly one of those issues. Now I have a lot of pride in having Native blood — and it's something I try to instill in my kids. They'll have stronger roots than I did while growing up, which will hopefully allow them to strive and achieve more."

While Kecia Larkin doesn't pretend to be the fearless young woman in those old photos, she says, "I'm very much a fighter, a survivor. Many times I could have easily given up, but I've always tried to keep going." Since moving to Alberta two years ago, she's remained involved in AIDS awareness: writing and researching for the Kimamow Atoskanow Foundation's newsletter, helping coordinate the second annual Alberta HIV/AIDS conference Matters of the Heart in February 2002, and conducting occasional workshops and speaking engagements.

"The resources are there, the people are there," Larkin says, "it just seems to be falling into place." Though she is referring to the work she does, with that air of contentment in her voice, Larkin could easily be talking about her own life. 

## ABORIGINAL HIV/AIDS RESOURCES

### Canadian Aboriginal AIDS Network (CAAN)

#### Réseau Indigène Canadien du SIDA

602 - 251 Bank St.  
Ottawa, ON K2P 1X3  
phone: 613.567.1817  
toll-free: 1.888.285.2226  
www.caan.ca

Provides leadership, support and advocacy for Aboriginal people living with and affected by HIV/AIDS, regardless of where they live.

### Canadian Inuit HIV/AIDS Network Pauktuutit Inuit Women's Association

131 Bank St., 3rd floor  
Ottawa, ON K1P 5N7  
phone: 613.238.3977  
e-mail: cihan@pauktuutit.on.ca

The national voice of Inuit on issues related to HIV/AIDS.

### YUKON

#### Blood Ties Four Directions Centre

7221-7th Ave.  
Whitehorse, Yukon Y1A 1R8  
phone: 867.633.2437  
e-mail: Linda Collins at lcollins@yknet.ca

### BRITISH COLUMBIA

#### BC Aboriginal AIDS Awareness Program

BC Centre for Disease Control  
Division of STD Control  
655 W. 12th Ave.  
Vancouver, BC V5Z 4R4  
phone: 604.660.2088  
e-mail: Lucy Barney at  
lucy.barney@bccdc.hnet.bc.ca

#### Healing Our Spirit

#### BC Aboriginal HIV/AIDS Society

Suite 100-2425 Quebec St.  
Vancouver, BC V5T 4L6  
phone: 604.879.8884  
toll-free: 1.800.336.9726  
www.healingourspirit.org  
e-mail: Ken Clement at  
kenclement@healingourspirit.org

### ALBERTA

#### Kimamow Atoskanow Foundation

R. R. #1, Site 1, Box 133  
Onoway, AB T0E 1V0  
phone: 780.423.3138  
e-mail: general@nativecentres.org

### SASKATCHEWAN

#### All Nations Hope AIDS Network

Scotia Bank Building  
1504 B Albert St.  
Regina, SK S4P 2S4  
phone: 306-924-8424  
e-mail: Margaret Akan at  
makan@sk.sympatico.ca

### MANITOBA

#### Manitoba Aboriginal AIDS Task Force Inc.

705 Broadway Ave.  
Winnipeg, MB R3G 0X2  
phone: 204.940.6000  
e-mail: maatf@escape.ca

### ONTARIO

#### Ontario Aboriginal HIV/AIDS Strategy

43 Elm St., 2nd floor  
Toronto, ON M5G 1H1  
phone: 416.944.9481  
toll-free: 1.888.743.8851  
e-mail: strategy@2spirits.com

#### 2-Spirited People of the 1st Nations

43 Elm St., 2nd floor  
Toronto, ON M5G 1H1  
phone: 416.944.9300  
e-mail: Arlene Bush at  
arlene@2spirits.com

### QUEBEC

#### Quebec First Nations and Inuit HIV/AIDS Permanent Committee First Nations of Quebec & Labrador Health & Social Services Commission

250, Place Chef Michel-Laveau  
Wendake, Qc G0A 4V0  
phone: 418.842.1540  
www.cssspnql.com  
e-mail: Guylaine Chastroux at  
gchastroux@cssspnql.com

### ATLANTIC

#### Healing Our Nations

#### Atlantic First Nations AIDS Network

45 Alderney Dr., Suite 607  
Dartmouth, NS B2Y 2N6  
phone: 902.492.4255  
toll-free: 1.800.565.4255  
e-mail: afnatf@unsi.ns.ca