



HAPPY DAYS: Sandy Lambert
at his home in Vancouver



OVER THE HUMP

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Whether he's speaking out on foster care or fostering AIDS awareness and activism, **Sandy Lambert** doesn't take 'no' for an answer. Just ask B.C. Health.

For almost 20 years, Sandy Lambert's family doctor told him, "If you feel well, don't get an HIV test."

He doesn't have that doctor anymore.

It wasn't until 1996 when Lambert underwent surgery for an out-of-control staph infection in his thigh that he got tested for HIV. The circumference of his infected leg had shrunk to half the size of his other leg and he was in excruciating pain and couldn't walk. "My doctor told me that she thought my immune system was compromised," recalls Lambert, an Aboriginal man from the Tall Cree First Nations in Alberta.

Getting the results was an emotional rollercoaster ride: the first HIV test came back positive; the second came back negative; and the third came back positive. "The last time the doctor came in she said, 'You know why I am here.' I said, 'Yes, I know what you're going to tell me and I need my partner here.'"

Through the tears and the talk about the new antiretrovirals (ARVs), Lambert's partner reassured him that he would stand by his man. "He's still with me," says Lambert, proudly.

Within two weeks of starting his first regimen, Lambert became deathly ill once again. The vomiting and diarrhea were so severe that Lambert's weight plunged to 125 pounds. (He is 6 foot 1 inch tall.) His skin started peeling "like a snake" and he became dangerously dehydrated.

Back in hospital, Lambert was sure he was dying. "They started doing all these tests and I thought, 'I am leaving this earth. I need to get all my friends in. It's critical.'"

It turned out Lambert had Steven Johnson syndrome—a severe allergy caused by the drugs Dapsone and co-trimoxazole (Septra) that he was taking for PCP (pneumocystis pneumonia).

TOUGH TIMES

Lambert is no stranger to tough times. Born in Dawson Creek, B.C., he was taken from his family and placed in foster care when he was just one month old. He never saw his

mother or father again. Or five of his six siblings.

By the age of six, Lambert had been in and out of six foster homes. He knew he was different from the Caucasian families he was placed with but nobody would tell him why. It wasn't until he was 19 and down in Wyoming that a Native American asked him a question that changed the course of his life. "He asked me what tribe I was from and told me, 'You look like our people.'"

It turned out that Lambert's "people" came from Alberta but their territory extended down into the U.S. "What he said piqued my curiosity," says Lambert. Fuelled by the realization that he had to be Aboriginal, Lambert set out to find answers. All he could unearth was a government file that held an old school report card, a handful of photos and some meeting reports from social workers. Still, it was enough to set the wheels in motion to obtain a status card and find out more about his roots.

Lambert's need to know propelled him forward. He talked to local organizations in Vancouver where he was living. He went to the University of Alberta in Edmonton to look for any records that would help him put together a family tree. "I figured if anybody knew, they would, because that was where I came from," Lambert says.

In Dawson Creek, he got a copy of his birth certificate, went into a local hospital and "started asking a lot of questions." Eventually he was put in touch with a cousin who tried to reunite Lambert with his mother. But it proved too much for him. "I didn't want to go down that path," he says. Shortly after, he had a face-to-face meeting with his older sister. "It's weird to see your own blood," says Lambert, "same features, same bone structure."

That was 15 years ago and Lambert has long since moved on. These days, he says, his claim to fame is getting rid of his buffalo hump—or rather, humps—a side effect of anti-HIV therapy that resulted in fat gain in his neck. This side effect is known as lipodystrophy and it can also lead to fat wasting or atrophy in the face, arms and

legs. (For more on facial lipoatrophy, see page 23.)

The larger of the two unsightly fat deposits sat across the top of his shoulders; the smaller one protruded from the base of his skull. There was just enough room in between the two to insert an index finger. “I didn’t like it and knew that somehow, I had to make it go away,” says Lambert.

At first, his doctor prescribed the diabetes drug metformin, but Lambert couldn’t take the nightmares that were a side effect of drug therapy. Lambert was finally put on human growth hormone, a horrendously expensive drug. “It cost about \$6,000 a box for 12 vials; one vial a night,” notes Lambert, wryly. “You do the math.”

FROM HUMP TO HIP

After much campaigning on his own behalf, Lambert got the provincial Ministry of Health to cover the drug under the provincial health insurance plan—the B.C. Health Plan, First Nations Inuit Branch. Unfortunately, after all that effort, the drug didn’t make much of an impact on the size of Lambert’s humps. “Not enough for me to feel comfortable,” he says.

Then, before anything more could be done about his hump, Lambert’s hip blew. The staph infection had gobbled up 75 percent of the cartilage in his leg, leaving nothing left to support his weight. Lambert was using a wheelchair, unable to walk. To make matters worse, the hospital refused to fast-track him for total hip replacement, calling his situation a “non-emergency.”

In all, Lambert waited about a year for surgery, during which time he was forced to make a lot of changes. One of them was selling his beloved Jaguar XJS. He could no longer get in or out of it, and besides, there was no room to stow the wheelchair.

The struggle to get hip surgery turned out to be just a warm-up for another round in the ongoing battle with B.C. Health. Lambert learned from his doctor that surgery for removal of his buffalo hump wasn’t covered under the provincial health insurance plan—and never would be. Knowing he’d have to step up to the challenge again, Lambert told his doctor, “You just wait.”

Lambert started a letter campaign and involved everyone in HIV treatment he could think of: his chiropractor, his dermatologist, the pharmacist who filled his prescriptions, even a supporter from the B.C. Aboriginal Health Coalition. In all, he gathered eight letters.

He was rejected twice. Finally, B.C. Health requested X-rays to see how much the humps were affecting Lambert’s cervical and upper-thoracic spine. Then, just before Christmas, his surgeon called and gave Lambert the good news: B.C. Health was going to cover the cost of removing the humps. It had been three long years. “I started crying and told him, ‘This is the best Christmas present I’ve ever had.’”

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Lambert’s case set a precedent on a provincial level, paving the way for other HIV-positive people to undergo the same kind of surgery at no cost. With the date for his hip surgery approaching, Lambert told his surgeon: “First the hip, then the hump.”

Now back on his feet and standing tall, Lambert misses no opportunity to spread the news about provincial health insurance

coverage for hump removal. “I’ve always been an activist,” says Lambert matter-of-factly. “Anything I wanted or thought other people needed, I always went for it.”

Lambert speaks with great passion about everyone’s duty to speak out, whatever their heritage. “Ask questions and if you get ‘no’ the first time, go back. It’s like sales and marketing: For every 10 calls you will get one back. I don’t sit in the back of the class and expect somebody else to ask the question or wait until later. I want to know now.”

People with HIV are all on a learning curve, he points out. And more people need to step up instead of relying on others. “The same handful of people can’t keep doing it over and over. Everybody needs to get involved.”

Now Lambert is working to bring better access to HIV/AIDS information and treatment to Aboriginal people living on reserves and in rural areas. He’s also outspoken about the need to support Aboriginal people who, like himself, have been raised in foster care.

As well, Lambert is helping those who are struggling with treatment and side effects of medication. “Some people think, ‘Oh well, I’ll just take a pill and everything will be fine.’ They don’t understand the side effects.” Lambert knows about side effects firsthand: “I have gout, which I take a pill for; I have high blood pressure, which I take a pill for; and I get rashes maybe once or twice a year. Your skin becomes much more sensitive once you start taking anti-retroviral drugs.”

Lambert also got involved in other ways, and now sits on the boards of many organizations devoted to HIV/AIDS. He’s a director at the British Columbia Persons with AIDS Society (BCPWA), where he also does treatment information peer counselling. He’s the Aboriginal representative for the Canadian Treatment Action Council (CTAC) and is Aboriginal-at-Large on the board of directors for CATIE. He’s also director and co-chair of the Red Road HIV Society Network.

Lambert is grateful to his “real” family—his partner and his friends. “They’ve been there from bad to good,” he says. In the end, Lambert remains an optimist, counting his lucky stars.

“I have both worlds—the white world and the Aboriginal world,” says Lambert. “We all need to help each other and learn from each other. And that’s one thing I believe the Creator has left me on this planet to do.

“There were two times for me to go—when I had the staph infection and then the allergic reaction to the meds. But it turned out that it wasn’t time for me to go after all. It turned out I have work to do.” +