

Hump away

PWA gets the provincial government to pay for his surgery

by Taz Fletcher

It's not easy being first. Just ask Sandy, a First Nations PWA who was the first person to get the BC government to pay for surgical removal of his "buffalo hump."

The term buffalo hump refers to a common side effect of anti-HIV medications: due to lipodystrophy, fat accumulates on the back of the lower head, the neck, and middle of the upper back, creating a hump many times larger than the average grapefruit. It causes such physical problems as loss of range of motion of the head and neck, inability to sleep without assistive devices, and problems with standing and balance. Even more disabling is the psychological and social impact of having a visible disfigurement.

"Being out in public was a living hell," says Sandy. "As the hump grew, I became more self conscious in social situations. Eventually, all anyone sees is the hump. It's like the person beneath it no longer exists." Like many people with buffalo humps, Sandy developed social anxiety, struggled with depression, and eventually confined himself to his home except when absolutely necessary.

In April 2002, Sandy's family doctor wrote a letter to BC Medical Services Plan (MSP) stating that the liposuction surgery for removal of Sandy's hump was a medical necessity.

MSP refused to cover the surgery.

Sandy went to see a specialist who put him on a drug regimen in an attempt to lessen the hump.

Drug treatment didn't help, so Sandy's specialist prescribed daily shots of a human growth hormone. MSP refused to

cover the prescription; fortunately, though, the federal First Nations and Inuit Health Program agreed to pay for it. The cost for a month's supply of human growth hormone was around \$6,900, meaning that the annual cost of Sandy's prescription would be approximately \$83,000. Sandy considered this outrageous.

"The liposuction surgery was around \$5,500, which meant at least twelve people could have had their humps removed for what it cost for me to be on hormones for one year," says Sandy. "I decided I needed to become an advocate, not just for myself but for others suffering with buffalo humps. Someone had to lead. I decided, right then and there, that someone would be me."

And lead he did. Countless doctors had told Sandy that he'd never get the government to cover his surgery. "Just you wait," was his reply.

He applied to MSP over and over again; finally, in December 2004, they agreed to cover the cost of his surgery. In April 2005, Sandy had his precedent-setting surgery, easing the way for another person's surgery the next year.

"I couldn't stand up straight," says the other person, Jeremy. "The growth hunched my back over, straddling my shoulders, upper neck, and into the middle of my back. I needed three pillows to support it just to sleep. I had a 15-inch neck that couldn't fit in 20-inch collars."

Luckily for Jeremy, he and Sandy shared the same family doctor, who told him how MSP had just agreed to cover Sandy's liposuction surgery. In October 2005, Jeremy's plastic surgeon wrote a letter to MSP requesting coverage for the surgery. He received approval in January 2006 and had his surgery the following month. (The surgery removed four litres of fat and fluid—equal to a gallon-sized jug of milk.)

"I'm sure the reason it happened so fast was because of the precedent Sandy had set," says a grateful Jeremy.

It took three lonely, frustrating years of doctors' letters, photos, measurements, applications, and denial of coverage for Sandy to set that precedent. It wasn't easy being first, he says, "but I'm First Nations, so I know what it means to be first." ⊕



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