

Confronting HIV and AIDS: A Personal Account

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Background

Rene Boucher is a 33-year-old First Nations man from Sioux Lookout Ontario who is living with AIDS. Since 1995, he has been an advocate and a speaker for HIV and AIDS awareness and education. This is his story of confrontation with his illness and the spiritual growth that ensued.

Sioux Lookout is a town of 5,000 people, 400 kilometres Northwest of Thunder Bay in the midst of a vast hinterland of boreal forests. To the North, 15,000 Oji-Cree persons live in 30 scattered First Nations. The area is part of the broad political group called Nishnawbe-aski Nation (NAN) (see Map).

Traditionally, the Nishnawbe-aski people were hunters and trappers who had limited contact with mainstream Canadians until the 1970s. The first language of most of the people is Ojibway or Cree, and many of the traditional ways of the people still exist and are practised. The Oji-Cree, as they are called, endured in the early days of contact with European society the devastation of famine, and infectious diseases such as small pox, measles and tuberculosis. Now, they suffer from life style diseases associated with moving off the land to settlements and changing to a European diet. The prevalence of diabetes and cardiovascular diseases, depression and suicide are disproportionate.(Young 1988) Likewise, tragedy, death and epidemics are no strangers to the people.

Before HIV was identified in North America, contact with Euro-Canadians was limited to visitors to the communities, such as nurses, teachers, technicians or Hudson Bay store managers. The chance of exposure to HIV was remote. With recent political movements and growth in economic, educational and health programs, travel to cities has escalated the risk of exposure. The concern about the effect of this disease on the North has been only quietly expressed.

With increased movement and more disposable income, it is feared that HIV could pose a serious problem in the North. To date, there have been less than five cases of AIDS, two known deaths, but the number of HIV identifications in the Northern communities is yet unknown (Medical Services Branch Health Canada). Although the incidence is much below

that of Ontario¹, intravenous drug use is thought to be the most likely venue by which HIV will be spread among the Aboriginal population. (Canadian AIDS Society 1999)

Despite the creeping prevalence of the disease, much silence still shrouds this entirely preventable disease. Given the history of devastation by diseases in the past as well as new chronic illnesses and depression, the difficulty in facing another potential killer is understandable.

To prevent the needless spread of this devastating disease, the silence must be broken. As Rene's personal experience in contacting HIV illustrates, the lack of knowledge by not only the public but also by professionals is the greatest danger. Rene's passion to educate himself and others has transformed him from the status of victim to that of a survivor and spokesperson for hope.

Rene's story of confronting HIV and AIDS through knowledge and culture-specific survival skills is a story of promise and spiritual awakening. His illness opened spiritual paths about life's purpose that he never thought possible. His story not only brings awareness of the possibility of love and acceptance in a climate of fear and hostility, it breaks the silence. Silence and ignorance are the greatest danger. Openness and education are the greatest hope.

My Story

I come from a family of 15 children; 13 of us are still alive. I came into this world in October 1966, three days after my parents were in a car accident. I wasn't due until November, but after the accident, my Mom was rushed to the hospital. She told me I was a miracle baby because during her ordeal she prayed to God and asked Him to spare me. This fortune and grace have followed me through my battle with HIV and AIDS.

My Journey Begins

My mother was born in 1927 in Frenchman's Head of the Lac Seul First Nation near Sioux Lookout Ontario. Her parents were famous trappers, but they passed on before I was born. My father was also born in 1927 in Lac St. Jean, Quebec of French parents. In 1975, we returned to live in this area. I began to learn more about my native heritage and the many traditions

¹ Data on HIV in the area is difficult to ascertain and this is likely an underestimation. HIV is reportable only in the area the testing occurred and since most Aboriginal people at risk for AIDS are likely to be living and/or diagnosed in cities, the incidence of HIV specific to this area is not known.

still practised. My mom began to talk about how it was growing up on the reserve. These traditions would come to be strong forces in my life.

When I was 12 years old, my parents, who were full-fledged Christians, did a lot of travelling from town to town hearing speakers preaching about God and His plan. After a meeting at one particular revival, a young woman came up to my parents telling her that she had a vision about their son, who was me. She said that she saw me standing in front of a large group of people carrying a strong message. What the message was she did not know, but she knew it was an important message from God that people needed to hear. My parents talked to me about it and told me they believed I would be a preacher one day.

My home in Sioux Lookout was where my son was born, but unfortunately, my relationship with his mother did not work out. In 1992, I moved to Vancouver to pursue a career in Accounting at a Native college. I was in my second year and doing well. During Christmas break, I went out partying with some of my peers. Sometime during that period, I became infected with HIV. At the time, I really never paid attention to the warnings because I felt HIV was not something I needed to worry about. All it took was one night of unprotected sex with a stranger to turn my life upside down. I remember waking up the next day and couldn't remember a name or anything.

In February of 1993, I came down with what I thought was the flu. I went to see my regular doctor to have a check up. While I was waiting, I picked up a pamphlet on the signs and symptoms of HIV. As I read it, I became concerned and asked for a test. I didn't think much about the test or what the results were going to be. Two days prior to getting my results, I began to worry. I questioned myself on how I would react if they came back positive but convinced myself I had nothing to worry about. My appointment finally came. When the doctor came into the room, he seemed nervous. He stumbled, dropping my medical file on the floor, and as he gathered it up, I noticed a coloured dot on my file that made me uncomfortable.

I remember it as if it was yesterday. *"I'm sorry Mr. Boucher but your test results came back positive for the AIDS virus."* I was shocked and stunned. I wanted to scream out *"No!"* but nothing came. I asked him what that meant. It was obvious that he had never told anyone they had HIV before. He seemed uncomfortable talking about it and said he would try and get information on HIV/AIDS. With that, he left the room, and the nurse returned. She took me to the waiting area and asked the receptionist for some forms. We went into another room, and she began to explain what the forms were for. I signed them, and she arranged for me to see an expert in infectious diseases at St. Paul's Hospital in Vancouver. I asked her what did this all mean. All I could think was, *"What is happening? What does this*

mean? How long do I have to live?" They were obviously not trained to handle an HIV patient. She just said, "*They'll answer any questions you have at the hospital*". They were not very knowledgeable about the illness, and with that, they sent me on my way.

I began to cry as I walked down the street. Reality began to set in, and I was overwhelmed. What do I do now? Who can I trust to tell? What does this all mean? I hopped on the sky train and headed for the bar. It seemed the only thing that made sense at the time. The emotional pain I felt was great, and alcohol seemed to numb it.

I continued to use alcohol and did not think much about my feelings or what had happened. I guess this was my denial period. I come from an alcoholic background, and I thought drinking was the only way to keep anyone from finding out. I kept my secret for three months. I finally shared it with a close friend. He was surprised and began to cry. He eventually convinced me to tell my brother. Together we called the rest of my family in Vancouver and told them too. We all cried and comforted each other. We decided to have a family meeting once a month. They wanted to help me come to terms with this as well as learn about it themselves.

I continued drinking, hoping this HIV was going to go away. I decided to find out more about the illness. I went to AIDS Vancouver and the Person's With Aids (PWA) Society. Before going there, I remember being paranoid about someone seeing me. After all, I was quite ashamed and afraid of HIV. I didn't tell any of my close friends. When I arrived there, I looked around and ducked into the building.

My life was spinning out of control. I was still drinking, feeling sorry for myself and hoping everyone else felt the same way. About six months later, I checked myself into a treatment centre. I was still afraid to tell anyone I had HIV. I eventually asked my counsellor if she could arrange an educational workshop on HIV/AIDS. Then, I would tell my peers. She agreed, and after the presentation, I stood and announced that I had HIV. I felt good to have it off my shoulders, and many came, shook my hand and hugged me. Another man stood up and told us he was HIV positive. It felt great to unload my burden. Eventually, I became strong after realizing I needed to accept that I was *living* with HIV and *not* dying from it. I left the treatment centre after two months. It wasn't the alcohol that was my problem but my diagnosis. I had already told my family, my Mom and Dad being the hardest people to tell. How do you tell a parent that there is a possibility that you might die before them? It was a very hard time for them, and at that time, I was very emotional. To this day, they are still trying to deal with it.

I began to learn about HIV/AIDS in small little morsels. I met others from PWA; it felt good to know I wasn't the only person with this

disease. I wasn't aware how the disease was transmitted. My four-year-old son would greet me at the door with a big sloppy kiss. When I learned I had HIV, I began to turn him away and just pull him close and hug him. He and his mother were confused, and she questioned me. I realized I needed more education to relieve my extended family's confusion. I learned that it was okay for him to continue greeting me with a kiss. That part of my life returned to normal.

They sent me to a supposed AIDS specialist whom I refer to as "Doctor Death". He scared me into trying AZT (zidovudine which was the only licensed drug for HIV at that time in Canada). He had me sign forms for a clinical trial where basically you sign papers so the doctor is not responsible if something should happen. At that time, they prescribed me almost 2400 milligrams, and for the next 2-3 weeks, I took it. The AZT was making me very ill, and I would lash out at my family. I felt detached from myself. My family decided it was time they mentioned something because I was not acting like Rene.

I went to a support group where we talked about medications. I asked about changing doctors and if anyone knew of someone who was more compassionate and didn't push the drugs. So I left "Doctor Death" and began seeing another doctor. I later learned I was lucky I had quit the AZT because it became known that it was poisoning people, and the dose should have been half of what I was receiving. I attended many support groups, seminars, and an AIDS Mastery group. I became stronger and stronger the more I talked about it.

My spirituality began to kick in, and I thanked God for sparing me again during this difficult time. I yearned to be back in my home town where my parents and best friends lived. I had also heard that the Sioux Lookout AIDS Committee needed someone with HIV to speak out about prevention of the disease. The North's first person with AIDS, Norm, had been an avid spokesperson but had recently died. So, I moved back to Sioux Lookout in 1995. It was difficult because I was the first person with HIV actually living in the town. At this point, I had extensive knowledge of HIV and was very self confident. I decided not to hide my diagnosis because I accepted it. I moved home to my Mom's to be closer to my roots, family and friends. At the beginning, it was very difficult. Many of my friends turned their backs on me. Rejection is something an HIV positive person must go through. We must accept ourselves as we are. It hurt but I knew God would never give me more than I could handle. I was still asymptomatic and felt really good about myself.

Receiving Messages

After I moved back to Sioux Lookout, the Dryden High School asked me to speak to the students about HIV and AIDS. I asked my parents to come along. I was the last on a panel of three to speak. I told them about the vision of the woman at the church when I was 12 years old who told my parents that I would be delivering an important message from God to a large group of people. I introduced my parents, asked them to stand up, and told them that the vision had come true because here I was standing in front of a group of people telling them about HIV and AIDS and that I felt it was God's message. When we were driving back to Sioux Lookout, I asked my mother what she thought the vision meant, but Mom still wasn't sure.

Later, I was invited to a workshop in Thunder Bay called "Opening More Doors". There I met other PWA's and beautiful people who were the front line workers who were trying to learn more about this disease. I met an old acquaintance who asked if I would be willing to share my story with communities in Northwestern and Northeastern Ontario. Having some public speaking training, I decided to share a piece of myself to help others not only see the human face of HIV but accept it and prevent it. In 1995, at a workshop with Mary, the HIV educator for NAN, I had a dream but did not think anything of it. As we were driving back, Mary told me her story: One night five years earlier, Mary's partner woke her to tell a dream he had just experienced. In the dream, a dog-like creature was running around the reserve killing people, but nobody could see him. He kept trying to warn people about this dog, but no one was listening to him. Eventually the dog caught and killed him. He awoke and immediately wanted to tell Mary. He was talking as if something was going to happen to him. He said he needed to tell her this and that someday she would meet someone who she would know is the person she was to tell the dream to. A week later, he died in a house fire. She always remembered what he told her. Just the night before, I had an almost identical dream. I was being chased by a dog and was trying to warn people, but people were turning a blind eye. It was as if I was the only person who could see what was going on. I ran into a Church, found a basin of holy water, scooped it up, ran back outside and threw it on the dog. The dog vanished. After Mary told me her story, I knew what it meant, and that I was the one her boyfriend wanted her to tell. We were astounded as to what this dream was about. I now believe that the dog represented AIDS, and the people who were dying were not listening to the message about prevention, so they continued to get the disease. The experience was another spiritual awakening for me.

From there, I travelled, met and shared with many people. I spoke at conferences and on panels with other people infected and affected by HIV/AIDS. My family actually told me they were jealous of my travel and

the recognition I had. They were receiving flack from other people who were ignorant about HIV. I helped them learn how to deal with this and realize these people were talking from ignorance.

I was not coping and felt isolated and alone. I found a counsellor who still remains my confidant today. To him I could talk about my isolation, my loneliness and my frustration.

Hope Emerges

In the spring of 1996, God would send me an angel because I still felt there was something missing in my life. I met someone, Joanie, who would later play a big role in my life. Unlike others, she would really listen. Although more than 20 years older than I, she became my best friend. She was going through her own difficulties. Six months earlier, my friend had lost her husband in a boating accident, and it took her a long time to accept this loss; to this day, she is still working on it. The way they parted was terrible. They had a misunderstanding and weren't talking the day he drowned. She lives every day with that fact, never seeing his body, never making amends. She knew someday God would send her someone. That someone was me.

Our friendship became a solid rock on which both of us could rely, a gift from God. We would talk into the wee hours of the morning about life and its many wonderful and sometimes difficult lessons. We would laugh and cry on each other's shoulders. Life didn't seem so precarious anymore. We didn't feel so alone. Joanie knows she will see her husband again and meet him back home. I may go home before Joanie, but we have learned valuable lessons, the two of us. We have learned that we can't take life for granted.

Townpeople began to talk about us, namely because of gender, age, race and my having HIV. Often people who knew Joanie would ask ignorant questions such as, "*Why do you wanna hang out with someone who has AIDS? If you're not careful, you're gonna get AIDS*", and "*Why do you want to get close with someone who's going to die? You will just be hurt all over again.*"

As I pursued my speaking, I became despondent and concerned that it was to no avail, and then an incident of hope occurred in an isolated community north of Sioux Lookout. An experience for me in Sandy Lake showed me just how people can change and was a remarkable awakening for me in my work. The Sioux Lookout area's first person with AIDS, Norman, was from Sandy Lake, and he had suffered immensely from violence and persecution in this community. He was unable to spend his last days at home because his safety and that of his family could not be guaranteed. Norman died in 1993, but his death resulted in a miraculous

transformation of his community to one of the most ardent advocates of prevention and awareness. After doing two workshops there, I was down and discouraged one evening. Why, I do not know. I prayed to God and I asked Him, *"God If I am doing what I am supposed to be doing would you please show me a sign of some sort. I feel so down, and I need you now more than ever; I do not know with the work I am doing, if I am getting anywhere, if anyone is listening."*

The next morning my workshop partner went to the airport without me because there was no room for me on the plane. At the last minute, a seat came up; I made a dash to the airport, grabbing my bags and running to the road where a driver picked me up. The driver turned to me and said, *"I have a message for you. I want to tell you that it is a wonderful thing you are doing. You know it is in God's plan for you to talk about HIV or AIDS to not just young people but to everyone whether in our First Nations communities or in towns. If ever you are feeling discouraged, remember what I have told you here."* I thanked him and told him about my prayer and my feeling the night before. He said: *"You are doing what you are supposed to be doing. It is wonderful and just continue doing it for as long as you can."*

I was ecstatic. That was my sign, my message from God! I only told my friend Joanie what the driver said to me because I thought people would think I was crazy. They already thought we were crazy because of our relationship.

Confronting AIDS and Mortality

As time progressed, I would soon face the loss of friends from AIDS, and I would confront my own mortality. I had developed a friendship with a young woman named Tammy. She visited me because she had heard that I had HIV and wanted information about HIV for a friend who was HIV positive. We met often and became very close. In February 1997, I received a call from the hospital that Tammy was ill and wanted to see me. At the hospital, a teary-eyed nurse took me aside and asked me not to talk to Tammy about death because she might not make it through the night and had not come to terms with her death. When I saw Tammy, she told me that she had been in a Winnipeg hospital for six months with what she told everyone was terminal cancer. In fact, it was AIDS, she said. Nothing further could be done, and she wanted me to help her to tell her family. I now knew that the "friend" she talked to me about was herself.

We set up a meeting with her family, and we told them. I gave them information on AIDS. When I returned to Tammy's room, she was getting weaker, and the family was arguing about whether the children

should see her because they were worried they might catch AIDS from her. I tried to tell them that this was not possible.

When I left that night, Tammy said that she was going home soon and would see me there. That was the last time I would see her conscious. She passed away three days later. I knew then what she meant about "going home." I was asked to do the eulogy for the funeral. I asked my counsellor to review it. He said it was good but that the Rene he knew spoke from the heart. When I delivered the eulogy, I talked about Tammy on a personal level but still had not grieved her death.

The next day, I was giving a workshop for 50 nurses. When I was telling my story, I began to cry, but I felt a warm feeling come over me. There were many teary eyes in the audience. Afterwards, a woman approached me and told me that she and five others had seen a woman standing behind me who placed her hand on my shoulder. I knew it was Tammy's spirit. The loss of persons close to me from AIDS, and the grief I feel for their loss now allows me to understand what my family is going through.

Next came my diagnosis of AIDS. The HIV/AIDS spectrum involves two different things. When I had HIV, I was very involved in education because I was strong physically with no symptoms. I saw the doctor only every six months. Now, with a diagnosis of AIDS, I see a doctor once, even twice, a month. I am in the hospital frequently.

My life with AIDS began in February 1997 when a bad case of shingles² took over my body. I thought I had chicken pox, but one morning, I awoke in pain and the sores had become blisters. Usually shingles is in the small of the back. I had it head to toe and checked into the hospital. Sure enough, that is what it was. The probable cause for the shingles was my high stress level. I was ignoring my personal problems. I remained in hospital for 20 days.

When almost ready for discharge, I developed a secondary illness because I had such a low T-cell count³. My doctor needed to talk about it, but instead of telling me himself, he insisted on calling my family into the hospital. We had the meeting, which included my family, a doctor, a pharmacist, the head nurse, my counsellor and my friend Joanie. He announced he would now have to give me a diagnosis of AIDS. This statement hit me like a ton of bricks. The same feeling when I first learned I had HIV crept back. This news devastated me. There was silence. Everyone had questions except for me; I was feeling lost and devastated.

² Shingles is a disease that is associated with weak immune system (Health Canada 1999).

³ T-cells are white blood cells (lymphocytes) of the immune system divided in to groups, T4, T8 etc. They are much lower in people with HIV (Health Canada 1999)

With time and the help of my counsellor, I came to accept it. "Mortality" crossed my mind frequently. With the help of my friend, Joanie, I learned to live in today and to worry about tomorrow when tomorrow comes. For six months, I was in and out of the hospital with different illnesses. I could not travel or do workshops. Counselling made me realize I needed to put my health first.

In the fall of 1997, I was again hospitalized while on vacation. I had a huge stomach. I had joked about being pregnant, how the baby was kicking and trying to get out. On my discharge, they still were not sure what was wrong. They told me that basically I was "*full of 'shit', no pun intended.*" I had developed Mycobacterium avium intracellulare (MAI), an AIDS related bacterial infection which can affect the digestive system. Later, I was having very bad abdominal pain, and that night I passed about a litre of blood. I was immediately hospitalized.

My doctor thought I might have lymphoma cancer and put me in a room with three much older terminally ill patients. One evening, another patient was in much pain and wanted to get out of his bed. Sometime during the night, he passed away. My fear of death was overwhelming. Earlier in the week, we had discussed exploratory surgery for which the chances of surviving were 50/50. I was in such extreme pain that even Demerol did not work so they switched me to a morphine pump. I began at 15 mg every 12 hours. Nevertheless, as the days went on, it was increased. The surgeon pressured me to have surgery for a biopsy, but this surgery would not take away the pain I was having; in fact, the pain would worsen if it were cancer.

It was the morning of Princess Diana's funeral. I awoke, turned on the T.V. and saw her coffin in the procession. I cried uncontrollably and was filled with the fear of my own death. I began bargaining with God, reading my Bible and asking God to please give me more time, more time please! My mother, sister and Joanie arrived and began crying with me. All I would say is, "*I don't want to die. I'm not ready yet.*" We talked about it and discussed the exploratory surgery. By this time, my morphine pump was at 400 mg every 24 hours. I decided not to have the surgery. If it were God's will, then so be it.

By now, living alone had become impossible. I moved in with Joanie who agreed to be my caregiver. Mom and my sister Vera took care of me during the day when Joanie went to work and then she would take over when she returned. Every day they would warm up five or six hot water bottles and place them around my body because I was always very cold. They would keep me warm.

Not long afterwards, Vera and Joanie began to organize a surprise birthday party for me because they thought it would be my last. They called some of my family from Vancouver to come. I will always remember how emotional it was for everyone who thought it would be the last time they

would see me alive. The day they left, as we cried and hugged each other, I thought to myself that the next time they would come would be for my funeral.

Relieve and reclaiming spirituality

Around Christmas of 1997, I started a new combination of drugs that looked promising. I began to feel better. My bedroom was no longer a prison. I started to go out. This surprised many people in town because the rumour around town was that I was not going to live to see 1998. I was winning my battle to overcome the illnesses caused by HIV despite the side effects of taking 35 pills a day. I returned to doing workshops. We did a television workshop on the Sioux Lookout community channel. We had many people volunteering to help in producing it. We taped a T.V. talk show. There were two panels - AIDS educators, a drug and alcohol counsellor and a home care nurse; and myself, a woman also infected with HIV, my care giver and my sister. The show was a success; many people phoned in with questions and comments. The audience had 25 people or so, and there were many questions and comments. Sioux Lookout was not in a state of denial as I had thought.

In the spring of 1998, I become ill again with nausea and abdominal pain, and I lost much weight. They again changed my medications. By summer, I had gone through about six different HIV medications but was resistant to them all. I was hypersensitive to new ones. I began to question my life and wondered what was more important, quantity or quality of my life. I decided quantity of life was more important. I continued trying different combinations that caused me so much distress that I quit all drugs. My appetite improved. I gained my weight back. Still, the results of a battery of tests did not look very good. I would need to decide about taking medications again. I declined further tests for cancer. They increased my pain medication for MAI to 75 mg of Morphine, and I started another medication regime.

Later that spring, after this crisis, Ted, a fellow Lac Seul Band member, invited me to a sweat lodge. I was afraid, not just because of the unknown, but because my Mom was a strong Christian and does not believe in these things. I was torn. When I told her, she seemed against the idea of my going. I realized it was up to me to decide. I also had to bring a pouch of tobacco. I was quite nervous and still had ideas in the back of my mind of what my Mom told me. But, I was determined to get something out of it. Ted sat with me and explained the procedure. We decided that we would go four rounds taking five hours. When it was over, I felt wonderful. It was chilly outside, but I did not feel the cold. An elder who participated told Ted that a spirit spoke to her and told her my Indian name. She wanted me to

come to a naming ceremony the next day. When I entered the sweat lodge, I had a 50-mg morphine patch⁴ on my arm. I was also taking about 60 ml of Morphine in pill form. Later that night while telling Joanie about this wonderful experience, she noticed that my morphine patch had almost fallen off, and I had not noticed. She suggested I try to be without it for the night.

As the elder had requested, the next morning, Joanie, her grandson, my son and my sister went to the naming ceremony. Our group, Ted and the woman who had received my name, formed a circle with a blanket in the middle. During the ceremony, two eagles flew over. About half way through the ceremony, a butterfly landed in the middle for about 30 seconds. After the ceremony, Ted said that the butterfly carried a message to Joanie from her father. Just before her father had died, he saw a beautiful field of butterflies and said to her "Gee these drugs are making me hallucinate!" Since then, she has associated butterflies with him. Ted felt this was a message from him that he was OK and is still with her. At the end, I received my name, Geesh-sha-ba-Geeshik, which translates to "the whole sky horizon to horizon."

A few months later, in the fall of 1998, my health deteriorated more. They increased my morphine because my pain became unbearable; eventually, I returned to the dose I had been taking before participating in the sweat lodge. I became less able to do workshops as often as I had before. When I did, I was repeatedly confronted with the realities of death from this disease. At a workshop in Thunder Bay for on-reserve front line health workers, I sat on a panel with other people infected or affected by HIV/AIDS. An elderly gentleman first spoke and talked about living with AIDS and the number of pills he was taking. I had met him previously when he was well. He had lost a lot of weight. At another retreat a year later, I learned that this good person had died a month after the workshop and that they had diagnosed two friends who had also died. I was very upset and sad. Joanie and I sat up all-night and talked about it and other things. I felt better the next day and was able to lead a workshop for people infected with HIV/AIDS. I talked about losing a friend to this disease. It happened often that I would attend a workshop, meet others and at later workshops learn that they had died.

In March of 1999, I spoke at a workshop called 'Walking My Red Path'. Feeling over whelmed, I decided then to write my story. My memory was not as sharp as it had been, and often I would forget what I was talking about. When it was my turn to speak, I asked my son and Joanie to sit with

⁴The "Fentanyl patch" allows for the gradual injection of morphine into the system over a 72 hour period.

me. It was a powerful and very emotional talk. Many people were choked up. It was then that I realized how important the support of caregivers is. People asked questions about care givers of someone with AIDS and who takes care of them? Joanie replied, her family, friends and a counsellor were her support.

During the spring and summer of 1999, I was very ill. My viral load⁵ was almost half a million, which meant I must have been fighting off some other major illness. My T-cell count was at 19 while in a healthy person it is 500-1,200 (Health Canada, page 27). I was indoors most of the summer and continued monthly medical appointment in Winnipeg. As the millennium approaches, my health seems to be improving. My viral load has come down to 10,000 and my T cell count has increased to 99, a miracle in itself.

I am still not sure if my mother has accepted my diagnosis. Just recently we were talking, and she suddenly blurted out that not only children but parents have to hear about HIV and AIDS. She feels there is a missing link when we focus on the young people only.

I was spared when she carried me, and I have been spared many times in the eight years since my diagnosis when others were not. I will continue to spread the message of AIDS prevention as long as the Creator has it in His plan.

Summing up

I am reminded of a story that would probably encompass my life, and the many lessons it has taught me. Even when we are born, our journey through life is just the beginning. We are all facing death, but if we have faith and hope, the transition from life as we know it to death is only a small fragment in the eyes of our Creator. The cycle of life is never ending, and if we learn to accept death as a part of the cycle of life, crossing over to the other side can be a wonderful experience. Death only means that the shell we are given at birth is on loan. Once we die, we leave the shell behind and go on to better things. The butterfly while in its cocoon needs to struggle to survive. I, like the butterfly, continue to struggle to survive in order to move forward.

I still have unfinished business with people, places and things. Life has sent me a wake-up call that I sometimes wish could be different, but God works in mysterious ways and has been an ongoing force throughout my life. I know the road ahead may look bleak, but no one knows what

⁵ This test determines how much HIV is in the bloodstream.

tomorrow may bring. The only guarantee is that making the most of each moment is where the question and answer to life as we know it lies.

My illness has been a difficult challenge but I have been able to turn living with AIDS into a positive experience. Now, my faith in God has come full circle. God's presence in our lives is like the wind - you feel it, you sometimes hear it, but you cannot see it, but you know it is there. I know not what the next moment holds for me, but I know He will be by my side.

My life with HIV and AIDS has many milestones and lessons. Friends, family and support groups lightened my burden. I hope that my story provides inspiration and hope for those with HIV/AIDS. Life does not end because one has HIV. We are all given a gift. It is searching for and finding out what that gift is that makes us unique. Learning to love and accept ourselves for who we are is just the beginning of a long and exciting journey.

Afterward

Rene's story is a story of hope and transformation. Through the telling of this story, Rene has been a major force in breaking the silence surrounding HIV/AIDS in the Sioux Lookout area. His story has brought a human face to this illness and offers hope that life does not end with the diagnosis of HIV. In many ways, Rene's life only began in 1992 with his visit that day to the doctor's office where he learned he had HIV. HIV and AIDS forced Rene to confront his mortality, his family, himself and his Creator. It brought out his gifts as a communicator and an activist but most of all his gift of passion. With tireless energy, Rene has worked to bring the message of AIDS prevention to the people of the North. His passion to educate others about AIDS prevention, his love for family, friends and fellow human beings, however, are his greatest gifts.

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