

# International Women's Day

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March 8, 2004

Stories of Leadership  
in the AIDS Movement:  
A tribute to the women  
living for change



*Canadian AIDS  
Society*



*Société canadienne  
du sida*

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*Some of the most powerful moments that I have experienced at the Canadian AIDS Society have been through the interactions that I have with the strong and creative women living with and working in the field of HIV/AIDS. These Canadian women represent the optimism, hope, vision and creativity that ignite change. They demonstrate the dedication, patience, anger, persistence and courage that are needed to challenge the status quo. Despite the many barriers that stand in the way of women living with HIV and their advocates, these women refuse to stand on the sidelines at watch. These are the movers and shakers of the AIDS movement. Thank you for leading me.*

*-- Ainsley Chapman*

*When I first became involved with the International Women's Day Committee on this project, I didn't have a clear picture of the kinds of stories our questions might provoke. We hoped that women would find their own ways of responding, making connections between the issue of visibility and their own lives. We hoped for diversity; we hoped for women's truths. As the stories began to come in, I was alternately moved, inspired, angered and enlightened by what I read. Now the collection is finished, and the picture is clearer. There are many voices on these pages, each one strong and built from a different place. But there are also connections, places where those voices come together; there is community. And I realize now that this has been our purpose all along. What we have in these pages, as in our work, are voices united in their diversity – let's listen to their songs.*

*-- Caroline Dickie*

# Minneh's Story

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**I am a woman. I am living with AIDS. I am a leader in the HIV/AIDS movement. I am willing to share my experience and help make HIV/AIDS and women a visible part of this year's International Women's Day. What an interesting thing to ask women to write their stories. I am gratified that women from around the globe are celebrating International Women's Day in this way.**

*In general and because of perseverance, my experiences in leadership roles have proven rewarding and successful. The road there has not been easy but it is getting easier. I came to Canada in 1996 to the International Conference on AIDS as a presenter. From an ignorant young African woman, and living with AIDS for three years, I had done the circle and was addressing a world conference. I was confused and excited. I did not know if it was real or a long dream that carried with it the cry of my child as she saw me off at the airport in Nairobi! I was ill with pneumonia – second attack. It was the first time I had been so far away from Kenya. In fact, it was the only time I have been away from my country. This move and the agonizing decision to stay in Canada made a difference in my life. I was empowered; I could make decisions on my own that were huge. I chose to let go even of family in pursuit of*

*my health. I was taking care of Minneh – for the first time in my life. It was risky and scary. I had to choose between life and my friend that I was afraid of: Death. I chose Life. I have found it very difficult to do the work my heart wants to do because of issues of immigration in my head.*

*As I attempted to settle in Canada, the blow came that rendered me speechless. My daughter that I had left in Kenya at 5 years 10 months passed away at 6 years 10 months, a year exactly to the date after I left Kenya. Following this loss, I did not do anything with the AIDS organization. However after a year and police cell visits and detention by immigration Canada, and the salvation by my escort to Kenya to whom I told*

my story and stated I needed medication, I was back in the community, training as a Public Speaker and doing the actual public speaking. This was in 1998. I was thirty years old.

In 1999, I joined the local PWA Society as a Board member. I was asked to join; I did not bring myself in. I served for a while and then I suffered my first breakdown out of three in total. Because I could not attend meetings while I was hospitalized that first time, I was said to have missed three meetings and was therefore not a Board member anymore. Women must be given time to be ill and get better. After all, everyone on the Board, other than the ED has had to be away for one illness or another. I felt rejected. I was not as strong as I am today.

As long as I live, nobody will catch me doing Board work for this group. If I offer my help and I am not appreciated and not treated with respect, I know when to walk away. I felt personally that I was asking too many questions, but I needed to. This was the first Board I had ever worked with. I wanted to learn.

With the public speaking, I enjoyed getting out of bed to go do a presentation. I came back motivated by my own words. However, I found that no one fed me if a presentation was outside town. I mean, I could get fed; but it was not a guarantee. Presentations were not given to me on time. There were days I had to book my own cab and had a difficult time figuring out the time and would show up on a cold morning way too early for class. I seemed to have more enthusiasm than the group I was volunteering for. I have done over 600 hundred presentations for this ASO for a period of over five years. Through them, I have attended CAS meetings and Pacific AIDS Network meetings. I have presented at the first national women

HIV/AIDS conference in Toronto 2000. Through my work in the community, I have been given the award of Woman of Distinction by the YM/YWCA 2003 in the category of health and wellness. This recognition made me realize that my ability demands a wider scope than is possible in one community. I am spreading my wings and have come back to the beginning of the circle – a Global Speaker.

At the moment I have stopped volunteering and putting time into SAN-FAN Educational Group. My fiancé and I have founded this group. The wedding is on July 17, 2004: My 36<sup>th</sup> birthday. As well as educating others about my life with HIV/AIDS, I specialize in teaching about self worth. A lesson I learnt and still continue to learn from my young daughter as she broke the circle of abuse in the family by asking me quietly and gently, "Mum, why are you yelling at me?" I had to go through my whole life over and over and over again to be the Public Speaker that I am. I learnt that people die so that others may live. I also know I am living so that others may live. To me, it is all a matter of free will.

I have lately been asked to join an out-of-town women's group as a board member. They will cover transportation (not cab) and will not take care of a caregiver to accompany me as a board member. More sadly, accommodation is not covered. I continue to save and attend meetings because I want to and because I want to learn. I pay my own accommodation because I want to be safe and self sufficient. You would think they would think about that without being told. Remember, I came from Kenya only seven years ago and I only know how to live in the jungle. I will end my board membership at the end of one year. I cannot continue to work this way.

The issue of "visibility" means to make obvious. Make open instead of closed. Speak up as opposed to suffering in silence. Total exposure. Making known, making public, not hiding behind the scenes. Be seen and might I add, be heard.

**-- Minneh Kamau**

# Sue's Story

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Since 1996 Sue has worked in several visible capacities within the HIV/AIDS movement, serving on boards and working directly with the community as a peer mentor and educator. She explains that these are roles she finds empowering, that they give her a voice in the community and allow her to pass on her knowledge of HIV/AIDS issues as well as such practical skills as giving workshops and writing articles. She looks forward to the work she performs in these capacities and feels good about the interest others take in what she has to say.

When asked about the challenges facing women in leadership roles, Sue cites a lack of role models for women looking to serve the community in more visible ways. Many women don't know how to get involved or in what capacities. Others suffer from low self-esteem and feel unable to take on new responsibility. Women, she explains, often shy away from roles that require them to be assertive or to state their opinions for fear of

evoking negative stereotypes – that women who are assertive are also demanding, power-hungry or ultra-feminist. She also feels the general public carry more definite and punitive ideas about positive women than they do positive men. There is the idea, she says, that positive women are drug-addicts or prostitutes, and that their status is somehow punishment for their life choices. Some women simply do not want HIV/AIDS to take over or define their lives.

Sue also cites practical concerns such as spending money, travel arrangements, childcare and food as barriers to women's presence on

boards. Not all expenses are covered for those serving on some boards, making it difficult for some to participate in events and meetings which require travel, food, and lodging.

Though Sue admits leadership roles may not be right for all women, she claims her own experiences have been both rewarding and successful, despite their challenges. Sue does not see herself as an activist. Rather, she is someone who has valuable things to say about HIV / AIDS. She explains that her work in the community has given her the opportunity to meet other people who have the same visions as she does, and to acquire such practical skills as team-building and

forming a workshops. For Sue, "visibility" means knowing people can come to her with questions, and that she in turn can be there to provide the answers. If she doesn't know the answers, she will know where to get them. It means self-empowerment, leadership and self-knowledge. Visibility, she says, not only means having a voice, but being confident enough to use it.

-- Sue

# Shari's Story

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## FROM DIAPERS TO DISCLOSURE: EXCERPTS FROM THE LIFE OF AN HIV+ MOTHER

**Living with HIV is a challenge. Throw in motherhood and life becomes a roller coaster. I have experienced the ups and downs of positive motherhood from diapers to disclosure. Throughout the years, I have found support from many wonderful women, some of whom are no longer with us and others who continue to be my pillars of strength. All of these women have children and all of these women have stories. Mine is only one of them.**

### THE ROAD TO DIAGNOSIS

When I found out I was pregnant in 1992, the furthest thing from my mind was HIV. I had enough things to worry about. I was about to become a mom – in my particular case, a single suburban mom with a great career and a supportive family. What was on my mind was preparing for the baby – making sure that I had an appropriate place for us to live, stocking up on diapers and reading about “what to expect when you’re expecting.” At nine months, I even decided to upgrade my life insurance policy. The insurance company sent a nurse to my home to take blood and urine samples. When I asked her what they were

testing me for, she said, “I don’t know except that they test for AIDS.” She then slapped an AIDS brochure on the coffee table and asked me to sign a consent form.

Later that month my son was born. The test never crossed my mind again until February 1993 when my mom and I were watching an AIDS documentary on TV. I said to my mom, “I haven’t heard from the insurance company and they’ve cashed my deposit cheque, so I guess I don’t have AIDS.”

March 13<sup>th</sup> 1993, I picked up the mail and there was a letter from the insurance company. It explained that due to health reasons they could not accept my application for life insurance. I was directed to contact my doctor in 10 days to find out why. I knew it must



have been bad, but not knowing exactly what it was, I called the insurance company that day and asked for my test information. Of course, they would not give it to me. I asked them to fax it to my doctor's office and they finally agreed. When I spoke, by telephone, to the nurse at the doctor's office she told me she had received the fax and that I couldn't get insurance because I was HIV positive.

I had many emotions to deal with when I was diagnosed. I felt very guilty that my family would have to go through this. I felt confused and powerless. It was as though I had lost complete control of my life. I was afraid: Afraid of what would happen to us. Afraid of what people would think. Afraid of notifying my partners. I was curious about how I was infected. I wondered if I would die. And I was angry. Angry with the doctor who told me I wasn't in a high-risk group. And just plain angry.

These are many of the same emotions that many other women have when they are diagnosed. However, I really couldn't take the time to deal with these emotions.

I had to concentrate on the baby – who was now 3 1/2 months old – reduce his risk of transmission and get him diagnosed. First, there was the process of putting him on a bottle. I had been nursing him for three and a half months. On the day of my diagnosis, I

learned that HIV could be transmitted through breast milk, so I stopped nursing immediately.

The next step was to get him diagnosed. At the Hospital for Sick Children's HIV clinic, I met with a highly skilled staff of doctors and nurses, dentists, psychologists and social workers. It was heartbreaking for me to see my tiny baby being poked and prodded for blood. Two months later, my son was diagnosed with HIV. When the doctor came and told me the news I didn't ask too many questions. I didn't know what to ask and I think I was in shock.

## REACHING OUT

JOURNAL ENTRY, MAY 1993

**Today was the worst day of my life. Today I found out the baby has it too. I was so sure that he wouldn't. I was so sure that it couldn't get any worse. As soon as the doctor came in the room, I knew. He didn't even have to say a word. I couldn't help it and I started to cry. The baby laughed. It was almost as if he were saying, "Don't worry mom."**

In the first few months after our diagnosis the stress was overwhelming. I bordered on a nervous breakdown and left work on disability. I spent most of my time fussing over the baby and attending doctor's appointments

for one or the other of us. During this time, a concerned family member brought me some resources about HIV. I started to research the disease I was facing and realized that if we were going to survive I better pick myself up and find out as much about this virus as I possibly could. I started by contacting my local health department, which referred me to Toronto-based Voices of Positive Women (Voices). I attended my first support group about four months after my diagnosis. I could not believe the number of women there. Most of what they talked about went over my head and mostly I just sat there quietly and cried.

Later that summer, I attended the first camp for HIV positive moms and their kids sponsored by Toronto's Hospital for Sick Children. At camp, the moms met several times to discuss issues that we felt were important to us as parents. We all found the experience to be very rewarding and decided that we would try to continue our newly found support group in some form. In the fall of 1993, the first support group for moms met in my grandmother's living room! Some women traveled up to 100 km to attend. With the assistance of Ontario-based AIDS service organizations, Voices and the Teresa Group, our support group met once a month. We discussed issues specific to moms such as "Who will care for our children if we get sick or die" and how to talk to our kids about

HIV. Many of the women in our support group served as resources for various guides and booklets now available to help HIV positive moms make these choices.

Facilitating the moms' support group was very therapeutic for me. It allowed me to get support while volunteering my time and feeling like I was part of the solution. Today, many of the other group members also volunteer or work in the HIV/AIDS community. While I am no longer involved as an active member of the moms' support group, it continues to thrive as a vibrant part of Voices programming. In fact, similar programs are now available in other communities. Volunteerism and activism have become a very important part of my personal support and resource system.

## **TO DISCLOSE OR NOT TO DISCLOSE...**

**JOURNAL ENTRY, NOVEMBER 1998**

**There are days, most days, when it's like he doesn't even have it. He gets on the bus in the morning with all the other children; he plays soccer before the bell and takes his seat with the rest of the class. At lunch he eats his sandwich and treat, but leaves the apple for later. He goes to gym class and computer club and baseball practice – all the things that "normal" kids**

**do. So, then, why isn't he treated normally? Why does he have to hide? Why do there have to be secrets? I never thought there really had to be. I thought it was OK to tell. I never thought people would still discriminate, especially not with a child. But I was wrong. I was so wrong. And, believe me, that's hard for me to admit.**

Disclosure is a very difficult and personal issue. I chose to disclose to my son naturally over time. As a positive child, he was used to taking medicine and seeing me take it. He was also used to going to the doctor's office. At about age 5, he began to ask questions like: "Why do I have to take medicine and my cousin doesn't?" and "Why do I have to get an IV and other kids do not?" I answered him in partial truths. At first, I told him he had special blood. Then, that he had a virus. He also asked how he got it. This is when I told him he got it from me. Eventually he wanted to know the name of his virus. He now takes an active part in his own health care by sorting his medications and discussing symptoms and test results with his doctors.

While disclosure to kids is tough, asking them to keep a secret is tougher and there are certainly times that I doubt my decision to tell him. It was heartbreaking to explain to my son that a lot of people don't know that you can't get HIV from being friends and they may be afraid to play with him.

Positive moms, whether or not their kids are positive, often face stigma and fear discrimination for themselves and for their children while participating in regular family activities. Most parents do not tell schools and recreational clubs that they are positive for fear of alienation. One school didn't want me to drive in a car pool because the principal was afraid that I would have an accident and bleed on the children. Another school decided that they would begin using latex gloves to serve pizza on the day I was scheduled to volunteer for that task.

Moms of positive kids have added decisions around disclosure. Should I tell the babysitter, school or boy scouts? What about sports coaches? How do you handle medications for a sleepover? At first, I was afraid to leave my son with anyone who didn't know he was positive.

## **HIV+ MOMS AS CAREGIVERS**

**JOURNAL ENTRY, JUNE 2000**

**I really didn't feel like walking him to school today. Not that I didn't want to, I just didn't feel like it.**

Like most women, women who are HIV positive tend to put their own needs second to the needs of their children. The kids need to be fed, the kids don't have any clean clothes,

the kids have swimming lessons, and so on. In addition, for some, meetings with doctors at hospitals, in doctors' offices and medical clinics about the health of their HIV positive child leaves little time and energy for positive moms to do the same for themselves.

Sometimes I just don't feel well. I think one of the hardest things about being an HIV positive mom is going on with your day and trying to act like everything is OK when you really feel like you've been run over by a truck. There are days I don't want to make breakfast or lunch and walk to school. Although my son knows I'm HIV positive, I don't want him seeing me sick. I don't always hide how I feel, just enough so that he doesn't worry too much.

When I decided to start HAART in the fall of 1996, I was not prepared for potential side effects to the medication. I experienced nausea and vomiting for several months, followed by kidney complications. With a 4-year-old son at home, I was run ragged. I seriously considered stopping the meds for a while so I could cook, clean and

care for my son. Eventually I was able to get some help at home to get me through the roughest times.

Like all HIV positive women, I wrestle with treatment decisions for myself. In addition, I must consider choices for my son. One of the most difficult decisions I ever made was to give my child a medication that had previously sent me to the hospital with an adverse reaction. Such choices are further complicated by the small amount of research data available on which to base informed treatment decisions for women and children.

I have only begun to touch on the issues that face positive moms and their families. While we have many issues in common, family life with HIV is a different experience for everyone. Many different factors, including culture, relationships, geography and finances compound our problems and affect our choices about disclosure, support, treatment and the future – choices not only for ourselves but also for our children.

**-- Shari Margolese**

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This information was provided by the Canadian AIDS Treatment Information Exchange (CATIE). For more information, contact CATIE at 1-800-263-1638.

# Nicole's Story

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EDUCATION OUTREACH WORKER  
ACCESS AIDS NETWORK  
TAKING AN ACTIVE ROLE

**My name is Nicole Hicks, I am a 35 year old mother of four and I live in Sault Ste Marie, Ontario. I moved to the Sault in 1998 to be closer to my husband's family as his health began to deteriorate. We needed support, not only for me, but also for our four children. Our family has been living with HIV for 12 years. I was diagnosed during pregnancy in April of 1992 and later that year, it was confirmed that my husband was also infected. Following our diagnosis, we moved from Ottawa to Saskatchewan. In 1993, I began volunteering in local AIDS Service Organizations and that's where I found my strength.**

*At the time, I was living in a small town with a population of 100 people. I felt isolated and always worried about my daughter being stigmatized at school for having two HIV+ parents. I had had enough! Staying silent was emotionally draining my energy and my daughter was tired of living with a secret and we needed support. I decided that we needed to become vocal in our small community so I phoned the Rural*

*Outreach Worker at AIDS Saskatoon to find out how to organize a presentation to the residents of Waldheim. Later that day, I called our pastor at the local church and asked if I could speak to the congregation the following Sunday. The Rural Outreach Worker met with me and our pastor and family to organize our presentation. I remember sitting in the church an hour before our speak thinking "I can't believe I'm doing this," feelings of fear, rejection slowly dissipating as I listened to the Outreach*

*Worker's words of reassurance. I shared my experiences, good and bad. I spoke of isolation, loneliness, silence and what women go through being diagnosed with HIV during pregnancy and the devastation. What it's like being a caregiver at the same time and the struggles that come with it.*

*The outcome was overwhelming! Neighbors left baskets of baked goodies, and groceries to make sure we had a great Christmas, coming for coffee and visits when we were ill; we even had someone plow our driveway in the winter. These are just a few examples of how our small community pulled together and lent a hand. Sure, there were drawbacks like the guy who owned the grocery store who refused to let us shop there for fear of catching AIDS. But I felt good about coming out. That first presentation sparked my interest and I wanted to participate so I traveled to Saskatoon for volunteer and speaker's training at AIDS Saskatoon and presented in small communities throughout Saskatchewan. In 1994, I was elected to the Board of Directors of the PLWA Network of Saskatchewan and remained on the board*

*until returning to Ontario in 1998. During those four years, I traveled to Native communities and treatment facilities throughout Saskatchewan and when I wasn't on the road, I was busy with the National Women & HIV project – a project of the Canadian AIDS Society I loved being connected to other HIV+ women and learning from their experiences. Our stories as women are similar but unique to each. I met so many talented women whose backgrounds varied.*

*It was nice to be able to vent your frustrations with someone who could relate. I was sad to see the project come to an end but I was grateful to have had the opportunity to work with my peers.*

*In 1995, I organized a meeting with AIDS Saskatoon to negotiate a project of my own called Canadian Children with Positive Parents. The needs of children and parents living with HIV/AIDS were not being addressed at that time and we wanted to see that change. My family experienced first hand what was lacking in areas of service delivery and support, so we negotiated an agreement with AIDS Saskatoon to be our sponsoring agency and approached Brighter Futures to fund this pilot project. We created programs for families and set up office during the first*

year. HIV+ parents decided that after the first year, we needed to incorporate as our own agency so it was incorporated in 1996. Our family became the poster family so to speak because the media loved us. CBC

Saskatchewan wanted to do a story about our experiences and at the time I was pregnant with my third child. "Waiting for Robert" was broadcast across Canada. "Waiting for Robert" was a documentary about HIV and pregnancy and was filmed in our home and at our office.

That year I kept busy with interviews and articles in local newspapers. I sat on various committees and successfully lobbied through the Saskatchewan AIDS Network to have social workers trained. To see how I could make a difference in my community increased my self-esteem and made me a better person. Setting an example for my children to follow was important to me. I have been working as the Education Outreach Worker for almost two years now. I know the importance of AIDS education especially in rural communities. Changing perceptions of risk is not always easy.

Discrimination still exists today and myths still need to be dispelled. HIV+ Women need support in order to participate in conferences and attend workshops. Building skills is beneficial not only to the woman who receives training but to the agency she volunteers or works for. One way of ensuring women are included is to address issues like childcare considering the cost and availability of childcare providers. It is my hope to see more women involved in AIDS service organizations not only as volunteers but as front line workers.

**-- Nicole Hicks**

# Tracey's Story

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Looking back I find it hard to believe that this month marks the sixth anniversary of my HIV diagnosis. I was so scared and frightened back then, sure that I would not survive more than a year or two. Things certainly have changed since then. I have been fortunate enough to meet some very wonderful women who have helped me come to grips with being HIV positive and helped me to realize all the things I have to contribute. A few of these HIV positive ladies, whom I consider friends, have helped me to accept and be proud of the person I am and encourage me in my endeavors.

*I faced many challenges on my journey. Initially I attempted work at a local level. At that time there were no PHAs on the Board so I decided that would be a good place to start. I faced much resistance as the PHA seats tended to be token seats. Being a very outspoken individual I continually brought up issues of concern that faced the HIV positive population in a northern rural community, which in fact differ quite greatly from the traditional HIV population. This ended up causing much stress and tension in my life, as I did not feel that I was being respected and honestly believed that my voice was not being heard. After much thought and heartache I decided to step away from the*

*local AIDS Service Organization and put my efforts into projects that I believed I could play an active role in.*

*I became a Board member at Voices of Positive Women for four terms serving one term as Vice Chair and the remainder of my time as Board Secretary. I have also been involved in the Peer Network since the Advisory Committee was struck in 1999 as well as many other areas within the Organization. It was here that I felt my opinions and ideas were respected and could actually see some type of change being effected.*



*I have been a part of the Canadian HIV Trials Network for four years. This National organization has provided me with wonderful mentors, educational experiences and opportunities to hone my leadership skills. I cannot thank them enough.*

*I have also participated on a number of committees with the Canadian AIDS Society and Canadian Treatment Action Council as well as a number of other organizations. It is here that I have always felt respected and that my input is valued. Last January I was honoured with a Queen's Golden Jubilee Medallion for my voluntary efforts.*

*I sometimes feel bad that I have not contributed more to where I live but it was a choice I had to make. I now choose projects that interest me and that I am*

*knowledgeable about. I feel good at the end of meetings knowing that I have been a part of something. I no longer come home in tears questioning my abilities and whether or not I am a good person. I know I am. It was hard for me to step back but I am now glad that I did and am very proud of my accomplishments.*

**-- Tracey Conway**

# Donna's Story

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**I am a woman living with AIDS for 11 years now. Was diagnosed in '92 with full blown AIDS. I was amazed how there was such little information back then for women and I found that there wasn't really anything directed towards women's health issues. I finally got in touch with other women through the Positive Women's Project, led by Jane Allen. It was there that I found the support and courage that I needed to continue to live, with dignity, with this disease.**

*By holding these positions and having a say, I found it empowered myself and other women to learn to speak our minds when it came to "our" disease and to make sure "our" voices were heard and understood. It took a lot of tears, frustrating moments, but the end results were worth it in my case.*

*I found that most of the positive women that I knew, plus myself, seemed to complain a lot about how there was nothing available to us as a minority group within the AIDS movement so I decided, health permitting, to do something about it. I joined our Board of Directors at the Aids Coalition of Nova Scotia. From there, I had joined smaller committees that had a say on women's policies, funding, and women's issues. I found that this was a great outlet for myself.*

*The challenges I have right now, being a positive woman and being chair of the board of directors of the AIDS Coalition of Nova Scotia, is finding the time and energy to do the work that needs to be done in a fashion that I would expect from others that have held this position. I would like to add also being the first female to hold this position with this organization in itself is enough to make me push myself to achieve excellence in my work.*

When taking on these roles as Chair, and sitting on a couple of committees, I made it quiet clear in the beginning that my son comes first. And, this, as many women can relate to, is a BIG challenge in itself. Juggling his schedule, my own personal schedule with doctors appointments and other commitments it can be very overwhelming. Being involved in this work with HIV / AIDS and being on both sides of the fence, living with AIDS and having the best interest of the organization can be a juggling act in itself. I find just stepping away for a moment, taking a look at the larger picture helps me and having someone close to me that I can bounce my feelings off of helps very much.

The issue of "visibility" means to me that I am taking a chance every time I take part in anything that relates to HIV / AIDS. I have had some very bad experiences in the past with disclosing to the wrong people, so I am quite limited to who, how and when I do it.

Basically, in a nutshell, the only way to describe why I do the work that I do is that when I was newly diagnosed there was someone there for me, and I took and took until I was strong enough to give back. It is now the time to do just that, give back to a group of people that have been there for me all these years. I stay focused on my health, son and try very hard NOT to burn myself out, as many have done before me. I do what I can, what I can't I will be the first person to say it. My "perfectionist" days are over now. I am human like everyone else, and can laugh at honest mistakes that I have been known to make. I don't beat myself up anymore and have learned to love what I am doing.

**-- Donna**

# Heather's Story

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Heather is typical of so many women in Canada who suffer from HIV. She is a woman who constantly struggles with addictions and self esteem issues. She represents a minority group of HIV positive, Aboriginal, addicted women who face the daily struggles that the above barriers present every day. Diagnosed with HIV in 1994, she was unable to deal with the reality of a terminal illness and like many street involved people, the choice of drug and alcohol use in the downtown Vancouver East side was Heather's coping mechanism. It allowed her to temporarily be free of the harsh reality of living with HIV/AIDS. Over the years she has relapsed several times, but is currently fighting her addiction with ten weeks of sobriety. Heather's limitations on becoming more involved with the HIV/AIDS movement are a combination of addiction, low self esteem and the side effects of HIV/AIDS. However, when Heather is sober and doing well, she makes an effort to do what she can around the AIDS Society office to help with education and awareness.

Heather explains that her experiences in leadership roles, although few, have proven to be rewarding experiences for her. She feels good when she can speak with women at risk about her own life story of challenges and obstacles. She feels that sharing her story will help educate women on prevention as well as help them understand

the disease. Heather feels that her approach is very effective with women as she is living with the disease, and she takes a clear and concise approach to her presentations. Heather's motivation to be involved with an educational role is to give women inspiration, hope, and to become more self aware. Heather feels that by giving the support of a listening ear and being open to telling her story that women can learn from her story and take control over their lives and their bodies.

Heather explains that the barriers and challenges that she faces every day allowed her to become more active in the HIV / AIDS movement. Her low self esteem has been a recurring barrier. Heather feels that many women who have led a similar life to her own suffer from low self esteem, for many of these women have been told most of their lives that they are worthless. This has been a struggle for her to overcome and, because of this, Heather finds it extremely difficult to trust in herself. She wants to take on a leadership role, but at this point in her life she is content with taking small steps toward this goal. Working as an active volunteer with the AIDS Society gives Heather the gratification of helping make a difference in people's lives, one small step at a time.

The direct barriers that keep Heather out of leadership roles are those of challenges in meeting her basic needs. There are issues of relative homelessness, addiction, low self esteem, and mental and emotional health issues related to HIV / AIDS. Heather feels that the responsibility of being in a leadership role would only work when she has fulfilled her own needs first. Being in a stable and positive living environment free of addiction and in good health is what Heather identified as what she needs to accomplish before putting herself in a leadership role. In order for these conditions to change, Heather

feels that more support is needed for women with regard to asset building and self esteem building. She feels that if programs were directly designed for women with HIV / AIDS to help them with the above problems and if she had ongoing support with her self esteem issues she would be able to offer more of herself to the AIDS movement and become more involved in a leadership role. Until that day comes she will move forward in achieving these goals in the time and manner that is realistic for her with the support she currently has in her life now.

Visibility to Heather is a term that she feels she has offered since the day she came to terms with her HIV / AIDS diagnosis. She will tell anyone anything they want to know about her illness and all the challenges she faces due to living with HIV / AIDS. Heather's approach to life is a take it or leave it approach. "If they don't like what I am and what they see, then I have no time for them," Heather explained to me. She feels that being open about her life and educating people on HIV / AIDS is her calling, and that using her life to help other women is what she feels she is here to do. "I need to use my life to help and educate others."

**-- Heather**

# CeeCee's Story

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**Tansi/Hello:**

**My name is CeeCee. I am the current National Representative for Aboriginal Person Living with HIV/AIDS (APHA) for the Canadian Aboriginal AIDS Network (CAAN). I currently sit on Red-Road HIV/AIDS Network Council, Victoria Persons with AIDS Society board, and the Client Advisory Committee at AIDS Vancouver Island (AVI).**

*I am from the Kehewin Cree Nation located in Alberta but have resided in Victoria, BC since 1996. I was diagnosed HIV+ in 1995.*

*It took me two years before I would become a member of AVI and British Columbia Persons with AIDS Society (BCPWAS) in Vancouver, Positive Women's Network (PWN) also in Vancouver.*

*I found the courage to deal with this "new life sentence" through the services offered by AVI and various agencies. Through my worst and best times, I found the agency very welcoming and compassionate. I was overwhelmed that there were still people caring and patient enough to deal with this illness.*

*I am a distant parent of four beautiful children ages 12-20. I keep in touch with them all. Three of them live in Alberta and one here in Victoria. I truly miss each and every one of them daily.*

*When I think back, the conscious decision to get more involved happened at The BC Gathering 2002 in Vancouver. I joined the Speaker's Bureau at AVI to start telling women, youth, men about how it is living with HIV.*

My Specialist told me November 14, 2002 to take a drug holiday. After seven years of medication, it took some time adjusting from taking it everyday to not having to watch the clock anymore. Just to make sure I was having blood work every month. My CD4 is 390 and viral load is 4400. I have seen a Plastic Surgeon for Lipodystrophy (The Buffalo Hump) to be removed. I also saw a Specialist, Dr. Bondy in Vancouver. He suggested a hormone treatment for 6 months. It is very painful, a lot of tension from back of the head to the middle of the shoulder blades. I try not to focus too much on the pain.....

Some of the lessons I've learnt since 1995. One that I deal with on a daily basis is Disclosure. I learnt that one before I even knew the name of what I was doing. I told significant men in my life of being sick (long-time friends).

The meaning of Friends, ones that are there for you when you need a shoulder to cry on or to talk and share mutual interests.

"To embrace being positive", being okay with the status. To get rid of the negative in your life and focus on the positive.

And the most important is taking care of yourself mentally, physically and spiritually.

Yours Truly,

CeeCee

-- CeeCee

# Stories from the Positive Women's Network

**How have your experiences in leadership roles proven rewarding or successful? What have you learned from them and what difference have they made to you or to other women?**

❖ The members voted me off the floor and onto the Board; that meant a lot to me because it meant I had their trust. I am a middle person who connects the Board to the members. It is important for me to be here at the drop-in and be a woman living with HIV to our members. I like to talk to other members; I get a lot out of it. We just hangout and talk about the regular, everyday things you deal with. It's cool to get new info as well as sharing any info I may have. I think that is for me rewarding. I feel useful, helpful and a part of something. I don't feel alone.

❖ I am the one that members see first when they enter the building; they have to show me their membership card. Being in that position helps me by allowing me to get out of my own headspace. It helps me to help other people by sharing information.

❖ It is empowering to be able to help someone when at one time I was unable to get the help I myself needed. Now I

can say, "yeah that is over there, or you can talk to this person." It's cool.

❖ Whenever I share my story, I feel stronger.

❖ I talk to first-year medical students in their classrooms; I've been doing this for two years. I feel good when I talk to people about this. It's better they hear it if from me than a textbook and they really appreciate it also.

❖ I have learned to take one day at a time, one experience at a time. And if I learn something I do, if I don't then I don't. I am not hard on myself.

❖ Doing good for someone else allows me to feel too good about myself, although sometimes it is hard to allow myself to feel good.

❖ I have always felt that I would live my life significantly. For me that means living a public life. A transparent, open, vocal life. Thankfully, I'm not concerned with any repercussions. I'm not concerned because I don't have any barriers: my landlords know



*my status and they love me as one of their family. I have a secure job – they too know my status. I have safety all around me and that allows me to be as vocal as I am. And in being in a leadership role, I have learned I have to live this way – publicly, visibly, significantly to be true to myself.*

- ❖ *I have learned the importance of honesty. I cannot hide this from anyone. I cannot hide away in a shell. As my self-esteem grows, so does my voice.*
- ❖ *It is okay to be a vocal woman and it is okay to live with it.*
- ❖ *I've learned not to compromise; skills I've learned in leadership roles have trickled over into my personal relationship. Leadership skills have fortified my sense of self-worth.*
- ❖ *I've learned that if someone doesn't like what I am saying there is nothing I can do about it. I have to be true to myself. Sometimes people don't like it because of what I got.*
- ❖ *I get very excited when I learn something new. And I can't wait to share the information.*
- ❖ *I feel more balanced when I'm in a leadership role.*

**Drawing from your own experiences, what are the specific challenges facing women in these roles?**

- ❖ *I feel judged because I am not educated. I am just a single mother raising my kids; but I live with this disease.*

- ❖ *Just being a woman is a barrier.*
- ❖ *Being gay.*
- ❖ *Finances are a big one. This is not gender specific, but for me it is a challenge.*
- ❖ *Woman will tend not to climb to the top of the heap. We would rather stand side-by-side, leading by consensus. Traditionally, most ASOs are set up with a top and a bottom. Hierarchy.*
- ❖ *Being HIV positive and losing my health. I would feel more confident if I had a higher level of health. My energy is sometimes low.*
- ❖ *Having balls on my chest instead of between my legs.*
- ❖ *Sometimes I don't know what I am doing; I don't know what my role is.*
- ❖ *My family responsibilities – children, partner, parents.*
- ❖ *Yeah I agree. Other people judge me and are discriminating against me.*
- ❖ *But you have the ultimate education, you have life skills, no one can take that away from you. You have lived through experiences.*
- ❖ *Ignorance is rampant, it is everywhere. Myths are still being perpetuated. The basic facts surrounding HIV are just not known! People just won't see the reality of it.*

- ❖ *Feelings around disclosure – fear, anxiety, insecurity.*
- ❖ *Being aboriginal and being positive just compounds the stigma and I'm a single mother.*
- ❖ *It's difficult telling my children; how much do I tell them?*
- ❖ *I'm scared to be open in all my communities. Some of my people know my status and other people don't.*
- ❖ *There's no support on the Reserves, and the misinformation is huge. There is huge discrimination.*
- ❖ *I fear for my own safety.*
- ❖ *I make too many commitments, and I put myself at the bottom of the list.*
- ❖ *I have to realize that I have to also take care of myself.*
- ❖ *I just recently lost weight and in our society with the preoccupation with thinness people have been saying how great I look and asking how I lost weight. Well, I got this life-threatening illness; do you want in on it? It really pisses me off because I'm sick, and people are telling me how great I look. It's stupid.*
- ❖ *Sometimes I give so much there is nothing left for me and then I begin to become resentful of those around me who are doing well.*
- ❖ *I got to know what my stuff is and what is someone else's.*

**If you are not currently in a leadership role, what kinds of things have kept you from taking one on? What conditions would be necessary for you to move into a leadership role?**

- ❖ *I don't feel smart enough.*
- ❖ *My Reserve would judge me harshly.*
- ❖ *I am afraid to take on responsibilities because of past failures and because I have addictions.*
- ❖ *I'm not sure if I'm physically able to keep up, so I tend to pull back and not commit, but at the same time I want to be involved.*
- ❖ *My health is not very good; I have been so tired and drained.*
- ❖ *Just getting caught up in the day-to-day stuff takes up most of my attention there is nothing left over for another role.*
- ❖ *I am just trying to keep my feet on the ground, I can't think about being a leader.*
- ❖ *Most ASOs are mostly men, I don't feel welcome.*
- ❖ *Having a group like this really brings up my energy, being able to talk about it with other women helps.*
- ❖ *ASOs need to be flexible to different leadership/involvement styles.*

- ❖ *Women lead differently than men, and further to that aboriginal women lead differently. We have different styles and that needs to be explored and honoured.*
- ❖ *We need to be able to debrief and have a way of learning new skills, mentorship programs. There needs to be a real person to go to answer my questions and listen to me.*
- ❖ *They need to let me know what is available to me for me to take care of myself.*

**What does the issue of “visibility” mean to you? What kinds of experiences does it imply?**

- ❖ *People have a misconception of what AIDS looks like. When I was going on Disability Assistance, the worker said to me “well you look like an able body to me” and I said “well can you tell me what AIDS is supposed to look like?” It went to tribunal, but the only way I won was by them coming to get me out of my hospital bed and taking me before the tribunal in a wheel chair. They had to actually see me and when I left they were crying. Is this what it takes? For you to see me dying in front of you to get help? Visibility.*
- ❖ *People want to see the stereotypical media image of AIDS – emaciated.*
- ❖ *Because I’m pink and plump I can’t possibly be sick.*

- ❖ *I began to ask myself, “well does AIDS really look like something?”*
- ❖ *AIDS medically looks different in a woman.*
- ❖ *In leadership roles being HIV positive has a good shock value. When I go talk to kids and share my story, when I tell them I’m positive their whole mentality shifts and when I get the evaluations they realize normal people get HIV too.*
- ❖ *If I look sick it would still be powerful, but only because that is what people expect. But there is also power in looking as healthy as I do. There are many perspectives.*
- ❖ *Being visible has saved my life; it has taken me out of my addiction.*

**How does Positive Women’s Network differ from other ASOs?**

- ❖ *This other agency wants me on the board really bad, but I just feel like a token. I don’t want the responsibility and the chaos. I don’t want to be the one woman speaking for all women. I don’t want that responsibility.*
- ❖ *But I go to other agencies because they need to see a woman’s face.*

# Are you a leader in the HIV/AIDS movement?

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On February 25, 2004, the staff of PWN gathered as a group to reflect on our roles individually and collectively as leaders in the HIV/AIDS movement. Here are some of our reflections and stories:

## HOW IS POSITIVE WOMEN'S NETWORK A LEADER?

- PWN is one of the few women's HIV/AIDS organizations in Canada and we have survived for more than ten years.
- We now have a voice in the HIV/AIDS movement
- We now have a position in the HIV/AIDS movement
- We're progressive in transgender issues
- We have strength as a staff team as evidenced by our commitment to dealing with difficult issues as a staff group. In this way we confront divisiveness. In this way, our diversity as individuals is valued.
- We care about each other: our relationships with each other are valued as part of us working effectively as an organization. We build the nurturing of our relationships into our organizational structure. To this end we have experienced low staff turnover over the years.
- We are a leader in creating and insisting on maintaining women-only space for our members despite the jeering we received repeatedly when we were located in a male dominated ASO building. We know women appreciate this space because they tell us so. Sometimes a woman's few minutes in our women-only space is their only sanctuary from their abusive partner who is standing outside the door.
- We have insisted on gender equity on the CAS board. We had much fall-out after we supported a woman over a man for the board. We have built allies on this issue though it has been unsuccessful thus far.

- As leaders we know the importance of taking our lead from the membership. One staff member started a support group despite being told that this was tried unsuccessfully in the past. Now this is a very popular program where women come early, where women who usually can't sit still come to talk, where women from different backgrounds find common ground, where women listen to one another tell their stories and where they say they can talk about anything.
- It's easy to lose the vision when you are under siege, but we have held fast on many issues.
- We have been developing our own model of operation that is different from the male model of ASOs. In this model, we have established respectful systems to protect the confidentiality of the status of our members and our staff. To use voting at our annual general meetings as one example, we ensure confidentiality despite the cumbersome process this requires. We have negative & positive HIV status women working hand in hand in our organization. We see leaders as nurturers, and leaders as models – of respect, of honest communication. We have institutionalized self care as an integral part of our work life because we see promotion of staff self care as imperative to the health

of our work. We think that leadership means drawing out the strengths of those around us; of our co-workers, of our members. We run our AGMs differently – we put a chair out for our members who are no longer with us, we light a candle.

## **“CHALLENGES”:**

**To your question about “challenges” we face as leaders, we added the words “threats and risks” we face and reflected on these:**

- *Misogyny:* We experience persistent patronization and fight against patriarchy on many levels to create our own space. We take a risk by putting voice to what a lot of people are thinking – sometimes we are told we come on too strong, but we speak up anyway.
- *Our very existence:* We have had to justify and protect our existence continually.
- *We have experienced resentment from other community organizations:* “Why do the women get that money?”
- *It is assumed that we will take the lead on issues that affect women:* ie: research on effects of therapies. Our allies will only go so far – When they don't take these issues on, it undermines the work we do.

- *No institutional process among the larger HIV/AIDS community to support and mentor women so as to retain women.*
- *Persistent threat of violence: The issue of staff safety in the building was not taken seriously by male staff in the other ASO – we were considered hysterical and over reacting when outlining our fears. Violence against women was dismissed repeatedly and our credibility questioned. We were finally taken seriously when one male recipient of their services banged on our windows and threatened one staff member's life.*
- *We have been accused of being “anti-gay-male-culture” when we demanded a lock on the women's bathroom because men were going to women's washroom to have sex; or when we demanded that posters of men having sex be removed from spaces shared with women and children. Now we don't think we would be censored as we were in those years. Even if we bring up an issue that is touchy – we have a voice that we didn't before. Our credibility has grown.*

## **WHAT DOES THE ISSUE OF “VISIBILITY” MEAN TO US?**

- *Our invisibility in the male AIDS world was repeatedly brought to our attention when different male AIDS workers would prepare their talk for an upcoming conference. Their recurrent soliloquy was, “Now, tell me again, what are the women's HIV/AIDS issues? Oh yes, ‘poverty, childcare, violence’ right.”*
- *Invisibility of women, especially Aboriginal women was a common theme. We remembered working alongside male ASO workers for years, and the men not knowing our names.*

# Linda's Story

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I was watching a popular talk show the other day, and the subject was, young girls from homes where they didn't feel loved by the father figure. The result was they were hungry for male attention. That was me. I was over developed at a young age as well, so I may as well have been walking around with a target on my back. I was so desperate for love. Not that I blame my parents...anymore. Twelve years of therapy has taught me they did the best they knew how. I left home at the age of 16, moving in with my boyfriend. I then went from boyfriend to boyfriend, never having a relationship that lasted longer than six months. To this day I've never had a relationship longer than six months. I needed to hear "I love you" from someone, because I definitely didn't feel it inside. I thought if I had sex with you, you would love me. In retrospect it's no surprise I ended up HIV +. I remember going for my results, this was in 1991 and it took two weeks for your results to come back. I was living in San Francisco, working as a bartender at the time, and had received a call from an old boyfriend that prompted me to go for a test. I was so sure that I would be negative, that I was joking around with my regulars at the bar saying, "If I'm not here tomorrow...you know what happened..HA HA". I was so arrogant! I had practiced safe sex with one, of my many partners!

When the woman at Planned Parenthood told me my test came back positive, I remember thinking, "oh, my God, I'm going to die!" Then another thought, "Good, it's all going to be over soon." I had never realized just how unhappy I had been until that moment!

I was thirty years old. I had never thought about my future. I had been bartending since the age of seventeen. If there was anyone who should have crawled into a bottle of vodka and waited to die...it was me. For the next year, that's almost what happened. I was positive, this was my punishment for being a bad person! I didn't follow up with medical care. I didn't want to know what my

T-cells were. In the U.S. they give you an AIDS diagnosis if, and when, your T-cells drop below 200. I told myself I had thousands. Then I proceeded to feel very sorry for myself. There were more than a few nights spent alone in my apartment, drinking, and snorting coke, so I wouldn't have to feel how scared I was. I was sure no one would ever love me! Plus, I couldn't have children, (or so I thought, at the time). Then along came Brian. We were at my apartment snorting coke and drinking and I thought, I better tell him I'm HIV+ so he can run screaming out the door. But he didn't run, he stayed...for six months. In those six months I started going to Alcoholics Anonymous meetings, because Brian wanted us to get clean and sober. So I did it for him, at the beginning, but I stayed after he left. That's the important thing. I now have ten years sober! I know that never would have happened if I had not found out my status. It's ironic, I spent my life trying to kill myself, ungrateful, and hating myself, and then I get HIV which could kill me, and I start to fight for my life!! After getting sober, I went for my first T-cell count. I didn't have thousands. I had three hundred and some. That was another scare. The doctors wanted me to start AZT right away. The problem was, that I was not sure that having AIDS killed you, OR, all the drugs that they give you when you have AIDS, kills you. I felt fine! So I didn't take the AZT.

Then in late '94 my T-cells were at 3. Not 300. THREE. I named them, Curly, Larry, and Moe. The docs really started putting the pressure on me to start the meds. The fact that I was not an American Citizen, did not make things easy when it came to my health care. I had lived in California since '84, and believed that one day I would marry and then I would be a citizen...that didn't happen. So when I had a chance to get into a study, in May of '96, I decided, after much deliberation to do it. That way my drugs were free, along with my blood work. I had also read that people in studies do better than people who do not. I think that was the hardest decision I've ever had to make. I didn't want to take drugs that may cause side effects that would lead to taking more drugs to fight the side effects, and so on and so on...but you don't want to not take something that may save your life! And do you start them when you're still feeling fine, and wait for the nausea, vomiting diarrhea, and possibly a rash? Or do you wait until you start getting ill, but then you may not be able to handle the drugs?! I also didn't want to make a decision based on fear. But I started the meds anyway. I trusted my doctors.

So in May of '96, I started the meds. Two weeks later, I had an allergic reaction. I woke up one morning, to find I had turned a bright red from head to toe! I was so happy! I thought this proved I couldn't handle the drugs, and I would have to stop. But no...!



called my doctor and told him what happened. She asked me to please come into the circle because they were pretty sure they could get me through the rash, so I could stay on the meds. Well they got rid of the rash. But what they neglected to tell me was that the prescription they gave me, was a steroid! I must admit, I should've asked what it was! But this was back when I was naïve, and trusting. I was on the steroids for ten days, and gained ten pounds! I was up at five in the morning making apple crisp! It was awful I was so bloated but couldn't feel full! So I was able to stay on the meds.

Then a wonderful thing happened. My T-cells went up! From three to twelve! Doesn't sound like much but it was a 400% jump! Plus I never experienced the other awful side effects. I was handling the drugs fine. I had also gone through training to go into the schools to tell my story, and I absolutely loved doing it! Jump ahead to June '97. I had still been working as a bartender, but I had moved from the city, across the Golden Gate to Marin County. I had quit my job in the city at a nightclub, and found a much less stressful position at an Italian restaurant. My sister lived in Sausalito, (she was the reason I was in California but she was married, and legal), with her husband and brand new baby boy, Ryan. I was so happy when he was born. I always wanted to have babies. And now I was going to be an aunt!

Then the problems started. When I was twenty years old, my left ankle swelled up and I went

to the ER to find out what the problem was. Turned out to be arthritis, which I had apparently inherited from my father. It would swell up maybe once a year and then go away. But in June of '97 it returned, and never went away. In fact it started traveling to other joints.

Meanwhile, I had booked a breast reduction operation back in March, when I was still healthy. I believed it was a very life-affirming thing to do. It was scheduled for August 15<sup>th</sup>. By then the arthritis had spread from my ankle, to my wrist, and was just starting in my knee. I kept thinking it would go away. In fact, for the first year I thought it would go away. I had my surgery and it went fine. I healed quickly with no infections. I was so happy!

But the arthritis kept spreading. I never returned to work. And because both my knees and feet were affected, I was spending my time in bed, or on the couch. I was put on large doses of prednisone to deal with the pain but it didn't help much. It did cause me to gain 40 pounds in two months, and I had what they refer to as a "moon face". I had to face the fact that I could no longer support myself in San Francisco, where I had come to think of as home. I had lived there for 14 years when I had to leave. I was very lucky to have a best friend that lived in Windsor, ON, that wanted me to come live with her, and her family. No one in my family had the means or the space to take me in. I was feeling so un-loved. It was the saddest period of my life.

*I left the day after Ryan turned one.*

*I have been living back in Ontario for six years now. I stayed with my friend for a year and then I tried to live on my own. The doctors were still trying to find the magic combination of drugs to get the arthritis under control. In 2000 I moved into a supportive housing situation for people living with HIV, because I could no longer take care of myself, I was living on bananas and cereal bars. Then one day, one of my neighbours asked me if I would like to try what he was taking. When you are in as much pain as I was, you'll try anything. Twenty-four hours later the change was amazing! The drug was Celebrex. I let my rheumatologist know and she prescribed it for me.*

*I now live on my own again. I moved out of the supportive housing in January of 2003. But while I was there, a huge orange cat, with no tail, and a crooked little ear decided to make me his owner. We weren't allowed pets but I would let him in the window, and eventually he started spending the night. I found out who his owner was and learned that his name was Bobby and he was eleven years old. Then I had to ask the hard question. If I could take Bobby with me. They had another cat, and said they couldn't stand in the way of true love! Before I had Bobby my T-cells were around 230, a year later they were at 850! I can't imagine being without him. He's going to have to live to be 30! I now take 13 different prescriptions a day.*

*The last one was just added because I have the sugar count of a diabetic. Which could be caused by long term steroid use, (prednisone) which I started in '97. Or long term anti-depressant use, which I started in '95. Or it could be just because I am depressed and eat ice cream every night! I mean... would-n't you if you were me? I don't drink, I don't smoke, I haven't been intimate with a man since before my breast reduction, which by the way went horribly wrong trying to find the right drugs to control the arthritis! I also have lipodystrophy, which could've added to the problem. So now I'm seeing another plastic surgeon to see if he can help figure out where they went!*

*I often wonder, if I never started the "cocktail"... would I be taking drugs to control my diabetes... that may have been brought on by my arthritis drugs and my anti-depression drugs... for the depression that was brought on by my arthritis?*

*I'll never know, but I would like to know, how long someone can live, taking thirteen different kinds of drugs everyday.*

*I just hope it's long enough to have a relationship with a man, that last longer than six months?*

*Here's to Hope,  
Linda Peach  
March 4, 2004*

## I HAVE AIDS

*I have AIDS  
And I'm pissed  
I have AIDS  
And I'm healthy  
In fact I've never felt better  
Thank you.*

*I have AIDS  
And I want to know  
Why everyone who's had  
Unprotected sex, doesn't  
I have AIDS  
And I'm grateful  
The most mundane occurrences  
Thrill me, lucky me  
I have AIDS  
And I'm scared  
Scared that you won't  
Talk to me  
Scared that you won't  
Touch me  
Scared that you won't  
Love me.*

*I have AIDS  
And I'm tired of your theories  
And I want your opinions  
I have AIDS  
And I want to forgive  
Forgive you for that look  
You give me*

*Forgive myself for thinking  
I deserve this  
I have AIDS  
And it's kicked my ass  
Yet I'm afraid it's just begun  
I have AIDS  
And it's taught me strength  
I never knew  
It's taught me love  
I never had.*

*I have AIDS  
And I want to get married  
Have children... grow old  
I want the same things  
Everybody wants  
But most of all  
I want this voice  
To stop  
The voice that never stops  
Telling me...*

*I have AIDS*

*Linda Peach  
February 21, 1994*

**-- Linda**

**1-800-499-1986**

**[www.cdnaids.ca](http://www.cdnaids.ca)**

**International**

**Women's Day**

**March 8, 2004**

