

"My AIDS test turned out positive"

My name is Janet Connors. I am a 36 year old married woman and we have a 12 year old son. I have, at times, volunteered as a reading tutor for the Canadian Literacy Council, a Cub leader for 2 years, taught Sunday school, a Christian Education Director. I am a daughter, sister, aunt, in-law and friend. I am also HIV positive.

My husband is a hemophiliac, who received infected blood products and, although we practiced safer sex, I tested positive in 1989, after 2 years of marriage. We all struggle, from time to time, with life's problems and stress, but mix a marriage and family life with HIV and AIDS infection and those problems and stress are added to by an unimaginable amount.

At the time my husband tested positive, I tested negative. We were told not to be too concerned because the medical community was not seeing hemophiliacs developing AIDS, nor were they passing the virus to their spouses. It was suggested that we practice safe sex (as it was then called) and simply get on with our lives. I was tested every 3 or 4 months. After about a year and a half, it was suggested that I only need be tested once a year, because, if I hadn't contacted the virus by then I probably wasn't going to and perhaps I was one of those people that were immune to the virus (we now know that no one is immune to the virus). A few months later, I discovered two

lumps on the back of my head. A few days later, I discovered 3 large lumps in each armpit and many pearl-sized lumps along my collar bone. The next morning, I discovered a rather painful lump on my right thigh. I had been feeling tired, run-down and slightly ill for a couple of weeks. My sister-in-law mentioned that she had had the 'flu' and her glands had been swollen and sore. I immediately decided that I had the flu and sort of forgot about the lumps. A few weeks later, I was due for my annual PAP test and during the visit to my doctor, I mentioned the 'flu' like symptoms, the lumps, and the general fatigue. Since the lumps in my armpit were the largest and most painful, an appointment was made with an internist, to look at the possibility of breast cancer. I mentioned to my doctor, that as it had been a few months since my last AIDS test, I might as well have it done. My appointment with the internist was scheduled for about 4 weeks from that day. The appointment was eventually cancelled. My AIDS test came back positive. On that sunny day in July, 1989, my life changed forever.

During my first Infectious Disease (the field of medicine that treats HIV/AIDS infection) clinic visit, I asked our I.D. doctor for a best case/worst case scenario. He described the progression from HIV to AIDS and death, as it happens to a man. He said, unfortunately, not much was known about HIV in

women except women develop AIDS sooner and die faster than men. Well, I asked!!!

Through the years, I have come to appreciate our I.D. doctor's candor and honesty. With the exception of many, many discussions with our doctor and the infectious diseases clinic staff, I have never really received any counselling. I don't even know what services are available. I read a lot, try to stay involved with AIDS organizations, visit a psychiatrist regularly and meet with others living with HIV/AIDS, especially other infected women.

I believe public education about the treatment of people living with HIV/AIDS has been successful, so far. I have received supportive care and concern from those I have disclosed to, whether family, friends or strangers. (It is difficult to accept sympathy - I think that as a society, we are never taught to accept sympathy - however I understand people's needs to express it to me. The disclosure of HIV infection is very sad news.

Whenever I was tested (and even now, with any required blood work), a number code is used in place of my name. Personally, confidentiality is not the important issue it once was, however it has been a long, thoughtful journey for me to reach this point. The decision, to go public, was one of the most difficult decisions I have ever had to make. I continue to be frustrated by the lack of information

available about positive women. As far as I know there are no clinical research studies, nor had there ever been, into HIV/AIDS in women. I have discussed my concerns with my doctor and clinic nurses. I have participated in a clinical drug trial - not as an HIV positive woman but as an HIV positive person. I agreed to do this article, in part, to raise awareness of HIV infection in women. Women are no longer only affected by this pandemic, in the role of caregivers; we are the newest face to the pandemic. Perhaps if, as positive women, we make enough noise, we'll get some research started. (I wonder and worry sometimes, that perhaps the answer to the mystery of AIDS lies in a woman's body, but no one thought to look.)

I hope, every day of my life, for a cure; I see that as the only real hope to end this pandemic. Until a cure is found, I believe education is the only prevention. I am living proof that safer sex is not always safer. The time has arrived to stop being uncomfortable and afraid to educate our children. As parents, we need to stop confusing AIDS education with sex education. I believe AIDS education is life insurance for our children. We are willing to do whatever it takes to ensure our children have a safe and happy life but we seem to be nervous about taking the opportunity to possibly save their lives. When my son was a baby and I would imagine the things I would teach him as he grew, AIDS was not something I thought about having to teach him about. I want our son to live and remain uninfected so we teach him life saving techniques, the same way we enroll him in swimming lessons or taught him to cross the street. I feel that young girls must be taught that they have the ability to avoid infection. They must learn that, as they reach sexual maturity, they are valuable and they have the right and the need to demand protection from infection. We must teach our children that safer sexual practices are not always safer. Condoms don't always work; they occasionally break. With all the discussion of safer sex, we tend to forget the importance of birth control. As children become sexually active at younger and younger ages, the educational needs of very young children becomes imperative. I believe in teaching sexual responsibility and the benefits of not be-

coming sexually active, however we must, at the very least, equip children with the knowledge they need to save their lives.

It is not always easy for me to ask for help, and I'm sure many people would say the same about themselves. I have been asked to address that issue. I need to feel that I am still coping, however, there are many times in my life, now, that I don't cope well. I am lucky to have people in my life that, can quietly tell me that perhaps I need a break. There are many people in my life, ready and waiting to step in and help when they see that I am having trouble coping. During my husband's hospitalizations, family members offered to take care of the ordinary things such as cleaning our house or picking up groceries. Everyone we know offers to spend time with our son. To all those people, I am more grateful than you know and I thank you from the bottom of my heart. The help I require from social workers is more specific and I think it is universal for women or anyone trying to cope with AIDS, whether infected or affected. My family (myself, my husband, our son, our parents, our siblings and extended family) is constantly experiencing all phases of grief. This grief overwhelms us. We need help dealing with our grief. I need practical child care solutions, especially when my husband is in the hospital. I often need a somewhat unaffected person to just sit and listen. Mostly, I don't need advice or guidance, I just need someone to listen.

Well, I've been HIV positive for nearly three and a half years now and if nothing else, it has been a real learning and growing experience. My life has become a series of ups and downs. Some days, it seems there are more downs than ups; that simply makes the ups much more precious. I have learned more about medicine and medical care, than I ever imagined I would have to. I have met many wonderful, new friends. Our struggle to deal with the effects of HIV/AIDS has brought my husband and I closer than ever. I have reached a point where I can look forward with hopeful anticipation to the rest of our lives together. I have realized the importance of telling family and friends I love them. A new friend of mine referred to HIV/AIDS as, not a death sentence, but a wake up call.

- The HIV virus does not discriminate against gender, race or age.
- The HIV virus is believed to cause AIDS. Being HIV positive does not mean that you have AIDS however, eventually an HIV positive person will develop AIDS.
- The World Health Organization projects that by the year 2000 there will be 30 to 40 million persons HIV positive and close to 10 million persons with AIDS. (1992)
- Women and youth are the fastest growing group of persons being infected with the HIV virus.
- The World Health Organization estimates 250,000 women world wide have AIDS and that 3,000,000 are HIV positive. (1992)
- Presently in Canada there are 1 in 10,000 people living with AIDS and 1 in 1,000 are HIV positive. (1992)
- Transmission through heterosexual contact accounts for 60% of Canadian women's cases and 2/3 of women world wide.
- To date there has been little Canadian research done with respect to women and HIV/AIDS.
- Women are the most misdiagnosed, underdiagnosed and underserved population in the HIV/AIDS pandemic.
- HIV infection presents itself differently in women than men.
- Many women die before being diagnosed with AIDS because women-specific symptoms are not part of AIDS diagnosis.
- HIV infected women have high rates of gynecological and obstetrical disorders such as pelvic inflammatory diseases, chronic vaginitis and cervical cancer.
- Women living with HIV/AIDS need funding for services and support in order to reduce their isolation and their basic needs.
- Women need to be included in HIV/AIDS education as well as in decision making in all levels of policy and programs affecting women.

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Christmas Luncheons and Dinners will be served on the following dates and Locations :

MARSHALL D'AVARY
December 1, 1992 11:30 am - 1:30 pm

STUDENT UNION BUILDING
December 2, 1992 11:30 am - 2:00 pm
4:30 pm - 7:30 pm

ALL RESIDENCE CAFETERIAS
December 10, 1992 4:30 pm - 6:30 pm

UNIVERSITY CLUB
December 14, 15, 16, 17, 18, 21, and 22, 1992

HAPPY HOLIDAYS!

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