

THE POSITIVE SIDE

HEALTH INFORMATION & VIEWS

SPRING/SUMMER 2009

VOLUME 11 ISSUE 1

TO THE RESCUE!

Artist Daniel-Claude Gendron and alter-ego Super Poz team up to battle the virus

SHOUT OUT

Speaking publicly about HIV

BIRTH RIGHTS

Getting pregnant, staying safe

PILLOW TALK

Sex, disclosure and the law



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EDITOR'S LETTER

Having passed through another winter, the warmer weather and budding green of spring remind us that life is about birth and creation, and that living is about growing and evolving. In this issue of *The Positive Side*, we look at the different ways that people with HIV/AIDS (PHAs) in Canada embrace this definition of living and use it to make a positive difference for themselves and others.

On the cover we feature Montreal artist Daniel-Claude Gendron, who uses art to grow emotionally and intellectually. He created HIV-positive superhero and alter-ego Super Poz to help come to terms with his HIV diagnosis. Now he helps others tap in to the healing powers of art.

Others see growth as bringing about a positive change in the people around them. In our feature "Speaking from the Heart," we meet four courageous PHAs who speak publicly about living with HIV. Their goal is to educate and inform others, but they often benefit as well. This theme is carried through in our profile of Ottawa PHA Dave Pineau.

Nothing says birth and growth like a newborn baby. Having children is one of the greatest joys of life for many people, including people with HIV. (We know it's possible and safe for people living with HIV to do so.) In "Birth Rights," we meet a couple looking for help to become pregnant while not passing HIV between them. We learn of the challenges they and other PHAs in Canada are facing and what is being done to remove those barriers.

In our regular columns, we continue our tradition of sharing the experiences of PHAs from across the country. In Ask the Experts, we provide tips on how to get active this summer (and all year long!), and in Chatty CATIE, four PHAs reveal their tricks for sticking with their pill-taking schedule. By sharing our experiences with each other, we grow individually and together—and make a positive difference.

We hope that, like us, you find inspiration and motivation from the stories in this issue. As always, we'd love to hear what you think of anything you read in *The Positive Side*. Send your stars and cherry bombs to dmclay@catie.ca.

—David McLay

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Editor-in-chief

David McLay

Editors

Alain Boutilier, Anna
Kohn, RonniLyn Pustil

Contributors

Albert Martin, Ann
Siversides, Beverly
Deutsch, Darien Taylor,
Derek Thaczuk, Diane
Peters, Sean Hosein,
Tim Rogers

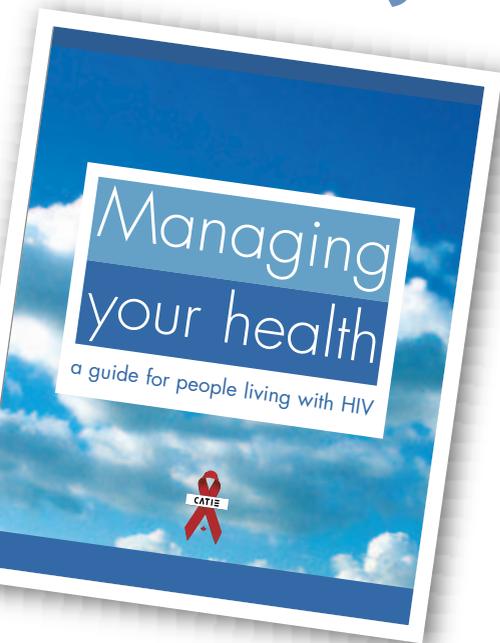
**Creative Direction
and Design**

David Vereschagin,
Quadrat Communications

Cover Images

Daniel-Claude Gendron
photographed by
Pierre Dalpé
Super Poz art by
Daniel-Claude Gendron

Back by Popular Demand



For well over a decade, *Managing your health* has been a faithful friend to positive people from coast to coast. Now CATIE is launching a new edition of its must-read guide to living with HIV. **Alex McClelland** takes you on a tour of the newly renovated CATIE classic.

T rue to its original mantra—that information is the path to self-empowerment—the new-and-improved *Managing your health* (*MYH*) covers a wide spectrum of issues that we people living with HIV in Canada deal with on a day-to-day basis.

Like many other positive Canadians, this was the first resource handed to me when I tested positive back in 1998 at age 19. The red and black tome at first seemed overwhelming, but without it I would have been one lost HIV newbie. It helped me navigate the wide and complex world of life with HIV. *MYH* is the ultimate encyclopedia for living well with HIV—packed with information on coping with your diagnosis, choosing the right meds and managing side effects, eating healthy, starting a family and more. It also includes practical stuff, like legal, money and housing issues, as well as fun stuff, like tips on making sex hot and safe.

To draft the new 340-page guide, CATIE called in the big guns—more than 20 experts, many of them living with HIV, from all over the country. After all, it takes a village to get through all the complexities that we face as people living with HIV. I chatted up a few of these experts to find out more about what to expect from the new *MYH*.

The doctors are in

“HIV therapy is in constant evolution and there is a need for new and updated information,” says internationally recognized Montreal-based HIV scientist Mark Wainberg, who wrote a spirited foreword to the new guide, which he calls a key resource for people with HIV. “*MYH* provides an important service in education and awareness in regard to HIV and AIDS. It provides patients with a sense of security and knowledge about HIV and the drugs used to combat it.”

While the new *MYH* still provides a comprehensive background to HIV treatment and side effects, it also takes into consideration that looking after your health means a lot more than popping your anti-HIV pills.

Check out the chapter “Your healthcare team” by Evan Collins. As a doctor living with HIV, Collins has the inside scoop on how to build a healthy relationship with your physician and other healthcare providers.



Not just for newbies

Now that we’re living longer, the need for *MYH* is greater than ever—whether you’re an HIV newbie or veteran. The new *MYH* includes the chapter “HIV and aging” by Kath Webster of British Columbia Persons with AIDS Society (BCPWA) and Positive Women’s Network. CATIE staffer Darien Taylor, one of the *MYH* editors and a woman who’s been living with HIV for more than 20 years, says, “While reviewing the chapter on aging, I decided to take its advice and get a bone scan to check for early-stage bone loss, which this chapter points out is common in both men and women with HIV as we age. Now I’m supplementing regularly with calcium to protect against further bone loss.” As we all get older (and greyer!), *MYH* will be there to guide us through the ins and outs of living long and well.



Did you know? Though many of us hoped that research would show that “drug holidays”—structured treatment interruptions—would enable us to take an occasional break from HIV treatment and its side effects, clinical trials have shown that treatment interruptions actually increase the risk of serious health problems.



Did you know? It is estimated that up to 12 percent of HIV-positive people in Canada are older than 50, and this number is expected to increase by as much as 20 percent over the next decade.



Ladies first

“As a person living with HIV, I used *MYH* as a daily resource when I was diagnosed 15 years ago,” says Shari Margolese, of the Blueprint for Action on Women and HIV/AIDS and Voices of Positive Women. “*MYH* has allowed people living with HIV, particularly those newly diagnosed, to educate themselves about the virus in a confidential manner and at their own speed.” Margolese, an HIV-positive mom, wrote the chapter “Women and HIV.” It covers issues like the interaction between birth control and anti-HIV drugs and provides information on how HIV and its treatment affect women and men differently. “The new edition is very inclusive of the different populations now affected by HIV,” Margolese says, “and it addresses many new and timely issues.”

MYH now includes sections focused on specific populations, including the chapters “Children and HIV,” also by Margolese, and “Immigrants, refugees and non-status people with HIV” by Dr. Alan Li of the Committee for Accessible AIDS Treatment.



Did you know? Since January 2002, HIV testing has been a mandatory part of the immigration examination for everyone over the age of 15. However, having HIV does not, in itself, make you inadmissible to Canada.

CATIE has added some exciting new features to the guide. Following focus-group recommendations, *MYH* will be spiral-bound in a workbook format. It will include a personal health record so you can track your own health information, write notes and make the book your own. The online version of *MYH*, available at www.catie.ca, will contain interactive links and more.

Order your free copy today through the CATIE Ordering Centre, available online at www.catie.ca or by phone at 1.800.263.1638. CATIE Ordering Centre catalogue number ATI-40215. (The French edition, *Vous et votre santé*, is catalogue number ATI-40216.)

Sex it up

Feeling sexy ain't always easy when you're on the poz side, but AIDS Committee of Toronto staffer John Maxwell encourages us to get it on—HIV and all! (And to put a condom on while we're at it.) The chapter on sexual health seeks to support us positive peeps in having a fulfilled sex life while staying healthy and protecting our partners. Maxwell shares info on relationships, sex toys, sexually transmitted infections and much more. He even tackles the confusion around the link between viral load and infectivity, reminding us that even with an undetectable viral load it is still possible to transmit HIV.

When asked about the grass-roots nature of *MYH*, Maxwell says, “The community-based philosophy of *MYH*—one that is rooted in advocacy, self-determination and empowerment—contributes to the greater and more meaningful involvement of all PHAs within the HIV/AIDS movement. We're not mere passive recipients of services but are actively involved in decision-making with respect to all aspects of our health.” Power to the people!



Did you know? There's a growing movement to include people living with HIV in the effort to stop the spread of the virus. Find out more in the new chapter “Positive prevention,” written by David Hoe, a longtime community activist in Ottawa.

The new edition of *MYH* is dedicated to Nitto Marquez, a long-time employee at Toronto People with AIDS Foundation who passed away last year. Just months before he died, Nitto authored the very practical chapter “Money matters.”

Alex McClelland has been involved in many Canadian and international civil society organizations and NGOs working toward and advocating for the support, care and rights of people living with HIV. He spends his time between Montreal and Toronto and is a student at York University.

Adherence Interference

Four PHAs talk about the challenges they faced adhering to their drug regimens—and how they overcame them.

Sticking to your regimen is a must, but it's not easy being perfect *all* the time.

Interviews by **RonniLyn Pustil**

PAUL RUBBEN, 59

Vancouver

Diagnosed with HIV in 1990

CD4 count: 325

Viral load: undetectable

I started taking meds in 1995—AZT, 3TC and d4T. Things were OK but my viral load was still too high. My doctor started to add different protease inhibitors to my regimen, but nothing seemed to work. I went on liquid ritonavir but after three weeks I couldn't handle the gross taste anymore. Saquinivir (Invirase) gave me diarrhea of the worst kind. I couldn't go anywhere without having an accident.

I became very depressed—even suicidal—over the side effects of my meds. I kept my curtains closed and only saw my family and best friend. Some days I spent a lot of time on the toilet. My quality of life ended. My doctor added ddI (Videx) to my regimen but all it did was make me void myself in bed. That was the breaking point.

I decided to stop taking meds altogether. I told my doctor and he advised me not to, but I wanted some life back.

I eventually realized that if I didn't take my meds I would die. It took me three months to decide that I wanted to live, and I went back on meds in 1997. My doctor recommended I see a specialist and things got better. I had a lot of pills to take but at least I didn't have any serious side effects.

I started living again. It was kind of miraculous. I started taking some chances and my whole life turned around. I went out more and got involved with an AIDS organization, and through all of this I met my partner (who's not positive). I had given up on meeting anyone after my diagnosis.



Adherence advice: Do the best you can. Seek help from a professional if you're feeling depressed. If you're having problems with your regimen, ask your doctor if you can change meds. Go to a support group or an AIDS organization. Ask others what they do. Most of all, don't give up! Life is too wonderful.

I eventually realized that if I didn't take my meds I would die.

DEE LYNN, 38

Vancouver

Diagnosed with HIV in 1995

CD4 count: 300

Viral load: 16,000

In 1997 I started a regimen of indinavir (Crixivan), AZT and 3TC. I took all my meds religiously. After a year I developed kidney stones. The doc had told me to drink lots of water—I literally had a two-litre water bottle attached to my arm—but I still got them. I had surgery to get them removed.

I continued on the indinavir regimen until I moved to the UK in 2000. The specialist there asked why my doctor kept me on indinavir after I got kidney stones. He immediately took me off it and put me on Kaletra (along with 3TC and d4T). I was one of the first patients in the UK to start Kaletra and I became part of a research group. I adhered to this regimen with a passion. During that time my CD4 count was 850 and my viral load undetectable.

After six years I began to lose weight rapidly, especially in my limbs, cheeks and face. My specialist kept

telling me to stick to my regimen. Then I got a second opinion from another specialist who said I was taking too much d4T for my weight and it was causing lipodystrophy. I became very frustrated that I'd agreed to be part of the Kaletra research group, where I was assured that I'd be closely monitored, yet the specialist failed to realize the proper dosing requirement for my weight. I began to feel more like a guinea pig than a patient. This tested my trust level with specialists. I had adhered to their advice and knowledge for more than eight years only to end up with complications and side effects.

The d4T caused many side effects: lipo, chronic fatigue, nausea and depression. By 2007, my CD4 count had dropped to 500 and my viral load, which had been undetectable, went up to 10,000. I was so discouraged with the side effects and how my body and emotional/mental state had changed. I

I was so discouraged with the side effects and how my body and emotional/mental state had changed.

no longer had any enthusiasm in taking any meds, so I went on a drug holiday and turned to holistic therapies.

After three months of detoxing from these potent meds, I felt totally renewed and re-energized. My depression was gone and I was very happy and active. My CD4 count steadied at 500. It's been a year and a half, and I don't feel like a guinea pig anymore. Taking the meds can be a hard routine to follow, especially when you

get side effects and then it becomes about fighting a battle of side effects and forgetting about having HIV. One day I may have to go back on meds but not until I am mentally ready.

Adherence advice: Research and learn about the meds you are taking. Write a daily journal on how they are affecting your body, so that if any side effects occur they can be acknowledged right away. Other than that, it is a matter of commitment and belief in longevity—and following the regimen exactly the way the specialist recommends. You need to take responsibility for your own healthcare plan.

DAMIEN CALLICOTT, 49

Vancouver

Diagnosed with HIV in 1986

CD4 count: 640

Viral load: undetectable

I was caring for a friend who was co-infected with HIV and hepatitis C. He'd been a crystal meth addict for the past 11 years that I'd known him. In caring for him, I fell to temptation and became wired to meth.

Until meth was involved in my life, I had always been very good at sticking to my regimen. It's scary how quickly this drug makes you not care about the things that are most important when it comes to taking care of yourself. After about six weeks of daily use, I became so focused on my friend and his care that I started missing doses of my own meds, or sometimes I took my meds twice, because I couldn't remember if I'd already taken them. I kept a chart to show that my friend's meds had been administered. I did not, however, have the insight to do the same for myself.

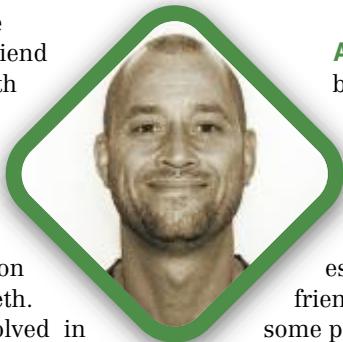
I can't even guess at how many doses of my meds I missed. On some level I was aware of what I was doing, but at the same time it didn't seem to matter much. Eventually I felt as though everything was spinning out of control and I gave up on looking after myself. This went on for about a year.

My friend has been gone now for 14 months and I am clean. Getting away

from the meth was not easy, but I made it through with the support of family and friends.

Right after my friend passed away I was able to return to a regular schedule of meds, with the same regimen. I was very lucky because my counts remained relatively unchanged. To this day I never told my doctor because I was embarrassed by my actions.

Eventually I felt as though everything was spinning out of control and I gave up on looking after myself.



Adherence advice: Don't be afraid to let your friends know you're having a problem; I got more support from them than I expected. Never underestimate yourself or your friends. We all need help at some point in our lives.

KEN MONTEITH, 48

Montreal

Diagnosed with HIV in 1997

CD4 count: 210

Viral load: undetectable

I was diagnosed with a CD4 count of 4, and I had confidence that treatment was going to keep me alive as long as I was adherent. So when I started my first regimen—Crixivan (three times a day fasting), d4T and 3TC—I took it extremely seriously and made adjustments to my lifestyle to accommodate it. I organized meals around fasting times and woke up early to take pills, even on weekends and holidays. I became the poster-boy for treatment adherence.

Then I started to notice significant problems with lipodystrophy, so I



After years of treatment I was no longer ready to change my life to fit my meds.

that will best fit your life. And don't lose sight of why you are taking anti-HIV treatment. The pleasures of the days and years to come make the little hassles worthwhile. +

For more adherence info and tips, read "The Importance of Being Adherent" in the Fall/Winter 2004 issue of *The Positive Side*.



The Comeback Kid

Ottawa PHA **Dave Pineau** has dealt with some serious blows during his life, but his unbreakable desire to help others always brings him back.

By **ASTRID VAN DEN BROEK**

The message was blunt: “We regret to inform you that your blood has tested positive for the HIV virus,” read the letter from the Canadian Red Cross Society. For David Pineau, then 24 years old in the late spring of 1985, the world stopped. “It was like I was frozen in time,” he recalls, “like I was having an out-of-body experience looking down at myself holding this letter in disbelief.”

This life-changing moment was handled with such little care and compassion that Pineau vowed to help others living with HIV and hepatitis C. (He is co-infected with both viruses.) Ever since, he has worked to contribute to the HIV community as best he can. While he occasionally faces a setback, Pineau is definitely a comeback kid who has decided to give back.

Pineau was 18 years old in 1979 when he and his girlfriend left his hometown of Windsor, Ontario to head to Vancouver. Life at home was hard and he had dropped out of school three years earlier after having fallen in with a crowd that pressured him to experiment with drugs, mostly light stuff like marijuana. Life in Vancouver with his girlfriend looked promising at first. “But then I started drinking and things weren’t good for her,” Pineau says. “Eventually, I ended up on the street.”

On the street, Pineau befriended a group of people who were drinking heavily and using harder drugs such as cocaine. “Everybody was into sharing needles at that time,” he recalls. “In those days, HIV wasn’t even a word. It was called GRID—gay-related immunodeficiency disease. Being a heterosexual man, I figured I had nothing to worry about.”

That was the beginning of a dangerous ping-pong game for Pineau. For eight to 10 months at a time, he would live on the streets, seeking drugs and working odd jobs. Then he would stop using, land a job and find a place to live. Sooner or later, there would be a trigger, such as a friend from the street, and he’d bounce back to his street life. And so it went for four years, until he met a woman.

“She wasn’t a street person. She was working full time and came from a good family,” Pineau says. Her influence

was a healthy one—he finished high school and got a job—and the couple moved in together. Life was good as a two-some, and Pineau even started joining her on charity initiatives, such as donating blood.

Then that letter arrived, putting an end to Pineau’s relationship and, he thought, his life. He called the doctor’s number at the bottom of the letter. “I asked her how long I have to live and she said three to five years if I was lucky,” he says. “I asked if there was anything to do to improve my chances. She told me to stop smoking and take a multivitamin. And then she hung up.”

More than two decades later, Pineau still vividly remembers the cold and cruel treatment he endured. With his girlfriend and most of his friends gone, Pineau isolated himself. “I thought I would never have a girlfriend again,” he says. “I really struggled with that and ended up on a downward spiral.” Once again, he turned to cocaine and alcohol and found himself back on the streets. For years, he bounced between Windsor and Vancouver.

In 1992, Pineau decided that he needed to break away again, this time to Toronto. But Toronto provided no escape from his drug dependence, and eventually he landed in a men’s hostel. A year later he turned to the Toronto People With AIDS Foundation (TPWAF) for support. “They helped me apply for disability insurance,” he says, “and I got an apartment through them. Things were looking better for me, even though I was still struggling with addictions.”

As life improved, Pineau began to feel the need to give back to the people who had helped him and get involved in the HIV community. He joined the speakers’ bureau at TPWAF. This volunteer role had him sharing the gritty details of his life story in high school classrooms and auditoriums across the city. The first time was knee-rattling but also enlightening. “I did an excellent job and felt so good about it after I’d finished,” Pineau says. “I thought, ‘Wow, I think I’ve found something here.’”

Pineau continued to speak at high schools and, later, drug and alcohol treatment centres. Not only was he helping others, he was helping himself. Sharing his story

was surprisingly cathartic. “Talking helped me deal with [everything going on in my life], even better than a counselor,” he says. “I thought if I could just reach one person and somewhere along their journey they’d remember my talk, it would be worthwhile—that was my motivation.”

During this time, Pineau was still using drugs, and one unlucky day, police raided his apartment. He was charged and convicted of possession of an illegal substance. However, because he was halfway through a six-month treatment program, his sentence was reduced to a fine. Then, a close friend arranged for Pineau to be moved to an intensive six-month drug treatment program at Toronto’s St. Michael’s Hospital.

The program helped, and Pineau was able to resume what he was good at: telling his story. “One of my goals was to work at TPWAF,” he says, and so he applied for and got the position of outreach worker with the speakers’ bureau. He excelled at his job, eventually taking over as the speakers’ bureau coordinator. In 1998, Pineau undertook a new challenge—helping to set up and coordinate TPWAF’s needle exchange program. It was a team effort involving many players inside and outside the agency. “We consulted with other exchanges in the city as a baseline for developing our program,” he says. “And once the word got out, many of TPWAF’s clients started using our program regularly. It was quite a success.” Indeed, the needle exchange is still operating today.

Then a setback: Clients of the needle exchange were comfortable talking to Pineau because he could relate to

“I thought if I could just reach one person and somewhere along their journey they’d remember my talk, it would be worthwhile.”

their experiences. This included one woman who was heading into a dangerous situation, one that Pineau admits he didn’t know how to handle. “She was on the verge of using with somebody and sharing needles and the guy didn’t know she was HIV positive,” he says. “He also wanted to pay her for unprotected sex. She shared all this with me. I didn’t know what to do, but I couldn’t just let her go.” Pineau decided to help her, but he got too close to the situation and ended up relapsing. Eventually, he lost his job. “I knew that if I stayed in Toronto it was probably going to be the end of me because everywhere I went I was running into dealers or addicts,” he says. “I thought I’d end up dead.”

Once again, Pineau sought to escape the city where he was struggling to live, and in late 2000 he moved to Ottawa. “But there was something missing,” he says. “I needed to get involved again.” He turned to the AIDS Committee of Ottawa, where he received help and started giving talks to schools and community groups. He became involved in the

Survive and Thrive support group, a part of the AIDS Bereavement Project of Ontario, and the group has become an important part of his support network. He tried something new as well, becoming co-editor for the *Choices and Voices of Ottawa* newsletter, a publication for people at risk for HIV and hepatitis C that provides information about harm reduction, safe choices and more.

These days, Pineau enjoys his work as a research assistant on the Positive Spaces, Healthy Places housing research project co-ordinated by the Ontario HIV Treatment Network. The study has multiple sites across the province, including Bruce House, an Ottawa-based HIV residential care centre where Pineau conducts interviews with participants about health and housing issues for people with HIV. Pineau has also taken on work in the hepatitis C community. Through Ottawa’s Sandy Hill Community Health Centre, he’s training to lead workshops delivering information about hepatitis C, its prevention and treatment. Pineau was diagnosed with hep C almost a decade after his HIV diagnosis. “Although I was devastated by my hep C diagnosis, it wasn’t totally unexpected,” he says, because he knowingly shared needles with someone infected with the virus.

In terms of his own treatment, Pineau is taking anti-HIV medications, which he’s been on since 1989. His viral load is undetectable and his CD4 count is between 700 and 800. Pineau admits that adhering to his drug regimen hasn’t been easy, but today he takes his meds religiously, a habit that’s been made easier since treatments are more advanced and regimens more simplified. More advanced treatments means fewer restrictions and limitations, such as having to refrigerate meds or take them with food—requirements that can sometimes be impossible for a homeless person to fulfill. He has not taken hep C treatment due to concerns about the side effects of the therapy (depression, insomnia and flu-like symptoms). “I’m in stage 2 with my liver health—there’s some minor scarring but it’s still relatively healthy,” he says. “I’m waiting for the new treatment to be released, hopefully within the next two years.”

While Pineau finds many ways to give back to the community, he acknowledges that he still struggles with dependence. “I’ve relapsed in the past few years, but I’ve pulled myself out. I think I’m still here because I haven’t yet finished what I’m meant to do,” he says. Through all of his ups and downs, Pineau has come to believe in a motto that helps him through his own hard times and fuels his desire to help others: It is a smart person who learns from their own experiences. However, it is a wise person who learns from the experiences of others. +

Astrid Van Den Broek is a Toronto-based freelance writer who’s written about health, wellness and nutrition for a number of magazines including *Chatelaine*, *Best Health*, *Canadian Living* and *More*. She also writes regularly for *CrossCurrents*, the Centre for Addiction and Mental Health’s journal.

As things are heating up between you and a potential sex partner, you're faced with a dilemma—to tell or not to tell that you have HIV. **Glenn Betteridge** provides some information about what Canada's criminal law says, and doesn't say, about HIV-positive people's obligation to disclose their status before having sex.

Law & Disclosure



Hardly a week goes by without a news report about HIV. Unfortunately, these reports all-too-often concern criminal cases involving people with HIV. Typically, we are told about an HIV-positive person charged by police for allegedly not telling his or her sex partner about his or her HIV status before sex. According to the Canadian HIV/AIDS Legal Network, which tracks HIV legal and policy developments, police have charged approximately 75 people with HIV from 1998 to the end of 2008. The vast majority of those charged have been men who have

had sex with women. Most of these criminal cases do not end well for the accused person. People living with HIV who have been found guilty have been sentenced to jail, some for many years.

Like me, you have probably been shaken to see the mug shot of a person with HIV staring out at you from a newspaper or TV screen. And, like me, you may think, "What about the challenges of living with HIV and the complexity of sexual relationships and HIV disclosure? Why don't we hear about *that* in the media?" You may also be frightened by the possibility that you, or someone close to you, could be criminally charged some day.

WHAT THE LAW SAYS

The criminalization of HIV and sex started in earnest in 1998. That year the Supreme Court of Canada, in a case called *Cuerrier*, decided that a man living with HIV who did not disclose his HIV status before having sex could be found guilty of assault (including sexual assault or aggravated sexual assault) under the Criminal Code. The Criminal Code is a federal law, so it applies all across Canada.

Cuerrier was a starting point that other Canadian legal cases have built on. Here is what the legal cases dealing with HIV, sex and disclosure say:

- A person has a legal duty to disclose his or her HIV-positive status to sexual partners before having

sex that poses a “significant risk” of HIV transmission. Right now, it seems pretty clear that the law sees vaginal and anal intercourse without a condom as a significant risk.

The law is unclear about whether a person with HIV has a duty to disclose his or her status when engaging in sexual acts with a lower risk of HIV transmission (such as vaginal or anal sex with a condom, or oral sex without a condom or other barrier). It could be argued that the risk of transmission is low enough in the case of other activities that it should not be considered a “significant risk,” and therefore the person has no legal duty to disclose. *But courts in Canada have not yet confirmed this.*

- A person can be convicted of aggravated sexual assault and common nuisance for not disclosing his or her HIV status before having sex, *even if the other person does not become infected*. In other words, it is a criminal offence to **expose** someone through sex to a significant risk of getting HIV.
- A person **may** have a legal duty to disclose his or her HIV-positive status before having sex that poses a significant risk of transmission even if he or she knows that the sexual partner also has HIV. There are no decided court cases about this situation. Whether an HIV-positive person has a legal duty to disclose to another person with HIV will likely depend upon the seriousness of the bodily harm that could result if the other person was exposed to re-infection with a different strain of HIV.
- A person who knows there is a real possibility that he or she has HIV (but has not received an actual HIV-positive test result) **may** have a legal duty to tell sexual partners about this risk before having unprotected sex.

MAKING DISCLOSURE COUNT

If you are going to disclose your HIV status to your sex partner, make

When you know what the law says, you can make better decisions and avoid legal problems.

it count. Avoid code words or hints like “poz” and “positive.” It is best to tell your partner: “I am HIV positive” or “I have HIV.” Make sure that your sex partner understands that HIV is a serious health condition that can lead to AIDS, that there is no cure, and that HIV can be passed on during sex.

Under the criminal law, you also have to have an honest and reasonable belief that the person agreed to have sex with you. So you must take reasonable steps to find out if he or she is too drunk or too high on drugs to agree to sex. If the person is too drunk or high to agree to sex, you could be charged with sexual assault. That is the law for everyone, not just for people with HIV.

THE DIFFICULT SITUATION OF PEOPLE WHO MIGHT LIE

Even if you told a person before sex that you are HIV positive, after you have sex the person might lie and say that you didn’t. Judges and juries have decided many of the legal cases about HIV, sex and disclosure based on credibility—whom they believed or didn’t believe. In a court case, it is important to have evidence to show that you disclosed and that the other person knew your HIV status. Here are some strategies for you to consider.

- **Witnesses:** Tell the person you want to have sex with that you are HIV positive in front of a friend (or someone you trust). Your friend becomes a witness who can say that you disclosed your HIV infection.
- **Online correspondence:** If you disclose over Internet chat or by

email, be clear about your HIV status. Try to get the other person to acknowledge in writing your HIV status and that he or she knows what HIV is and how it is transmitted. Save an electronic copy of what you wrote as well as the other person’s response, and print it out.

- **Professional records:** If you are thinking about getting into a relationship, you and the person can go to see a doctor, counsellor or support worker together. During the session disclose that you are HIV positive. Ask the counsellor to record notes of the session.
- **Trust your instincts:** If a person you are thinking about having sex with seems untrustworthy, ask yourself if the sex is worth the risk.

HIV-positive people often tell me that they feel a great responsibility or weight because they are living with HIV. They say that HIV is different than other infections and diseases because it can be transmitted during sex, there is no cure, it can lead to serious health problems and people living with HIV face high levels of stigma and discrimination. This explains, in part, why the law about HIV and sex is very strict, even harsh. When you know what the law says, you can make better decisions and avoid legal problems, which can hopefully lead to a safer and more satisfying sex life. +

Understanding how the law impacts your sex life can be difficult. *HIV Disclosure: a legal guide for gay men in Canada* offers information and practical tips about HIV disclosure and Canadian criminal law. The guide will be available in summer 2009 through the CATIE Ordering Centre at www.catie.ca.

Glenn Betteridge is a legal and policy consultant living in Toronto.

This article is not legal advice. You should not rely on it as legal advice. It contains information about the law. It is not a substitute for getting legal advice.



WILL THE HPV VACCINE GUARD YOU?

Suzanne MacCarthy reports how Canadian HIV researchers are marching to the front lines of the fight against cervical cancer.

IF

it starts with the letter H, then I've either got it or will get it," says Penelope, with a giggle. "Seriously, I know about genital herpes simplex and how common a virus it is among HIV-positive people. But the human papillomavirus (HPV)—and its potentially devastating effects—was not something I was familiar with. My doctor said that my compromised immune system made me more prone to HPV."

Penelope, a 42-year-old Vancouver resident, has been living with HIV for 20 years. "It wasn't until I was pregnant with my son that my doctor noticed the small bump on my genitals," she says. "I knew it was a genital wart but I didn't know the link between warts and HPV." HPV infection is surprisingly common: Approximately 75 percent of Canadians harbor HPV, making it the number one sexually transmitted virus. Most people will never show any signs or symptoms, which means they may unknowingly pass on the virus.

There are more than 100 types of HPV, and about 30 of those can infect the genital tract through skin-to-skin and sexual contact. HPV types 6 and 11 cause 90 percent of genital warts; types 16 and 18 are responsible for an estimated 70 percent of cases of cervical cancer, which claims the lives of more than 400 women a year in Canada.

In women, especially HIV-positive women, HPV can lead to a range of health risks—from the benign, like Penelope's genital warts, to life threatening, such as cervical cancer. Dr. Deborah Money, a specialist in viral pathogens in women and executive director of the Women's Health Research Institute in Vancouver, says, "Not only are HIV-positive women the most vulnerable to HPV, they tend to have more severe viral symptoms, such as larger and harder-to-treat genital warts, than their HIV-negative counterparts."

That's why doctors, including Money, stress the importance for all women, HIV-positive or not, to get regular Pap

tests. “A Pap test looks for abnormal cells and signs or future indications of cervical cancer,” Money says. “It’s a simple lifesaving procedure.” If caught early, cervical cancer is almost entirely preventable. For her part, Penelope follows her doctor’s advice and gets regular Pap tests. She also keeps her stress level down, gets plenty of rest and listens to her body—all of which can help bolster the immune system and prevent a recurrence of warts.

CANADIANS DOCS ON GUARD

In 2006, another tool to help fight cervical cancer was made available to women and their doctors when Health Canada approved Gardasil—a vaccine to protect women and girls against the more common types of HPV (types 6, 11, 16 and 18). The vaccine is currently licensed for girls and women age nine to 26. “When I first heard about Gardasil, I automatically disqualified myself as a vaccination candidate,” Penelope says. “I thought it was merely a prevention strategy for young girls before becoming sexually active.”

While Gardasil is considered most effective if given before any sexual activity occurs, some experts believe that the majority of women could still benefit from the vaccine, as it’s unlikely for any one woman to have been exposed to all four types of HPV that Gardasil protects against.

However, researchers do not yet know how safe or effective the vaccine is in HIV-positive women. Given the possible serious consequences of HPV infection in women with HIV, it’s a question that HIV researchers and clinicians are keen to answer.

That answer may come soon. Dr. Money and a team of 40 researchers across Canada are leading the world’s first study to evaluate Gardasil in HIV-positive women and girls.

CTN 236 is a five-year study recruiting 500 HIV-positive female participants at 16 sites across Canada over a two- to three-year period. Not only is CTN 236 breaking ground by testing the vaccine in HIV-positive women, it is also the first investigator-driven, peer-reviewed and independently funded vaccine study in which all findings of vaccine efficiency and safety will be publicly released. The study is being funded by the Canadian Institutes of Health Research (CIHR) and supported by the CIHR Canadian HIV Trials Network (CTN). Females who have HPV are eligible to participate.

When approached by her doctor about participating in the study, Penelope was enthusiastic because, she says, “This clinical trial seems crucial to all HIV-positive females.” Money echoes these thoughts, saying, “There is an urgent need to evaluate the effectiveness of the HPV vaccine in this vulnerable, high-risk group of HIV-positive girls and women in Canada. More knowledge about how HIV infection impairs the initial immune response to the vaccine and subsequent immune memory would greatly improve vaccine strategies.”

AROUND THE WORLD

The results of the trial may also have a global impact. In 2007, the World Health Organization (WHO) identified a knowledge gap in HPV vaccines, stating that their safety and efficiency have not yet been evaluated in Africa or in populations with a high HIV prevalence. “It’s a groundbreaking study, especially for Africa, where over half of the HIV population is female. The WHO is awaiting these trial results,” says Lisa Venables, the national project manager of CTN 236.

The study will use the same standard dosing schedule and vaccine amount currently being used in HIV-negative women and girls. The vaccine will be administered in three doses over the course of six months and trial participants will make a total of seven clinic visits in a 24-month period.

“Our results should serve to identify HIV-infected individuals who will benefit the most from this vaccine and suggest whether extra doses of the vaccine—booster shots—may be recommended in this population,” Money says. “The knowledge gained in this study will also help researchers assess the vaccine in other immunocompromised populations.”

Penelope, who at press time was awaiting her first vaccination, says that participating in a clinical trial is a necessary step in finding valuable knowledge. Referring to the possibility that being in the study could benefit herself and other women with HIV, she says, “I’ll scratch your back if you’ll scratch mine.” +

HPV PRIMER!

How is HPV spread? The virus can pass during any form of sexual contact—oral, vaginal or anal sex, and even finger-to-genital contact. Remember: You can be infected with HPV and have no signs or symptoms. So even though you or your partner might not see any genital warts, the virus can still pass between you. Condoms reduce the risk of passing the virus but do not eliminate it because the virus may be on a part of the skin not covered by the condom.

You are at an increased risk for HPV infection if you:

- have many sexual partners
- are already infected with another sexually transmitted infection (such as chlamydia)
- have a condition that affects your immune system (such as HIV)

To learn more about CTN 236 and other CTN trials, visit the CIHR Canadian HIV Trials Network database at www.hivnet.ubc.ca or call 1.800.661.4664.

Suzanne MacCarthy is Communications and Information Coordinator at the CIHR Canadian HIV Trials Network (CTN) in Vancouver. Her adventures in HIV have taken her from Swaziland to British Columbia, with a stop in beautiful Cape Breton, Nova Scotia, along the way.



“Stories are the creative conversion of life itself into a more powerful, clearer, more meaningful experience. They are the currency of human contact.”

—Robert McKee

Hollywood screenwriting teacher

Perhaps, like me, you have had the honour of listening to someone speak so compellingly that you swear your life changed as a result of hearing them talk. Was it the words they used, or perhaps the tone? The space in-between their lips, where brilliance seemed to find its way out? The art of storytelling is an age-old method of sharing life stories and imparting wisdom. Sometimes the result is simply a good laugh, other times it is much more powerful.

One of the best ways to fight ignorance, fear and stigma associated with a disease is to put a face to it—and HIV is no different.

Many AIDS service organizations (ASOs) have programs in which people living with HIV/AIDS (PHAs) speak publicly to promote awareness of HIV and AIDS. They’re often known as speakers’ bureaus, although I prefer to call them “the power of the human word” because I am not a fan of structuring what has been organic in many communities and nations since time immemorial.

The people who talk publicly about their lives with HIV—most are volunteers—often speak of the desire to educate, inform and touch someone else’s life and make it better. As a young person who is starting out in sexual health and AIDS services, I have learned a lot just from listening to people speak. That’s also to say that I’ve been challenged, frustrated and didn’t always like what they had to say or even had the patience to sit through it. The “speaks” that really stick out in my mind either made me feel represented or challenged me to critically examine my own perspective. Those were the times when I had the opportunity to grow and change.

Speakers, too, often benefit from their role. Some are compelled by the urge to help people. Others feel a need to give back to a community that has been a support through difficult times. Many claim that there are healing powers in the sharing of the ups and downs of their journeys.

To pay tribute to the power of storytelling embodied in the speakers’ bureaus across the country, I spoke with four PHAs about their experiences as public speakers. (Choosing only four people from across Canada was a difficult task; there are so many speakers with riveting stories.) They spoke to me about their motivation, their satisfaction and their tricks for engaging an audience. In listening to each, I learned that it takes guts to be public about your HIV status. All four people reveal that the key to being an amazing public speaker is “speaking from the heart.”

Speaking from the Heart

Talking publicly about your HIV status can be a scary yet rewarding experience. **Jessica Yee** interviews four courageous PHAs who speak out and discovers how saying “I have HIV” can open hearts and change lives.

ASOs across the country host speakers’ bureaus. If you’re interested in participating, contact your local agency to see if they have a program or check out www.ASO411.ca, a listing of ASOs across the country.

Jessica Yee, founder and director of the Native Youth Sexual Health Network (www.nativeyouthsexualhealth.com), works throughout North America on issues of healthy sexuality, reproductive justice, cultural competency and youth empowerment.



PHOTOGRAPH: BRUNO HENRY

Doris Peltier, 52

Wikwemikong Unceded First Nation,
Manitoulin Island, Ontario
Diagnosed with HIV in 2002
Speaks with Canadian Aboriginal AIDS Network

What gets you fired up?

First of all, I am a woman who was diagnosed at the AIDS stage. This is a trend we are seeing in our community, particularly with Aboriginal women. I think it really speaks to the systemic silencing of the Aboriginal voice, and the impact of this is evident in the high prevalence of HIV among Aboriginal women and youth. I feel that talking can help us to heal as a whole, as a community.

What led you to become a public speaker?

Being diagnosed with AIDS was the moment I found my voice. It was a life-changing moment. My voice came out and it came out powerfully. It was like the Spirit opened my eyes. I feel like all the things that happened to me—the journey that I walked, from the sexual abuse I experienced as a child to all that followed, including many risky activities—had to happen in order for me to get my voice, to jar me into action. This is what I talk about with women—that we need to find our voices and be able to say “no” and say it powerfully.

Where do you draw your inspiration?

In the Ojibway language we say *odebwewin*, which translates to “speaking from the heart.” When you speak truth, it comes from the heart.

Finish the sentence: I know I'm connecting with the audience when...

You can hear a pin drop in the room.

Advice for future public speakers:

Remember that you are not just speaking for yourself; you shouldn't have your own personal agenda. When you step out onto that level and take that one step forward, you are speaking for other people. You are essentially opening yourself up to try to empower other people.

“Being diagnosed with AIDS was the moment I found my voice. It was a life-changing moment.”

“I’m here to say that it’s possible to live with HIV and find a path that allows us to live in a positive way.”

Jacques Gélinas, 63

Victoriaville, Quebec
Diagnosed with HIV in 1992
Speaks with BLITS (Bureau
local d’intervention traitant
du sida)

What inspires you?

What gives me the most enthusiasm is still being alive and in very good health after more than 16 years. I’m here to say that it’s possible to live with HIV and find a path that allows us to live in a positive way. I’m also enthusiastic about believing and realizing that human beings are certainly very complicated but can change and evolve.

True or false: Public speaking is your number one fear.

Public speaking is still a little frightening, especially since we’re talking about an infection like HIV. But the more competent I feel and the clearer my path becomes, the less I am afraid.

Finish the sentence: I know I’m connecting with the audience when...

They allow themselves to ask indiscreet questions and to laugh, or when there is an intensity as we make eye contact.

Advice for future public speakers:

You have to have a tight self-connection, above all with your path in life. And you have to be ready to listen to all kinds of questions and be able to say, “I believe your question is about my private life, and so it isn’t necessary to respond to it.”

PHOTOGRAPH: PIERRE DALPÉ



PHOTOGRAPH: © JAMIEGRIFFITHS.COM 2009

“It’s important that young people are given a chance to tell their stories without being judged.”

Lulu Gurney, 25

Vancouver
Diagnosed with HIV in 2005
Speaks with the Playing it Safe project,
YouthCO in partnership with the National Film
Board of Canada

What made you decide to start speaking publicly?

I understood that I had a story that needed to be told, and I had a strong network of people to encourage me and remind me that positive youth need a voice. There is a lack of storytelling among youth, and this is especially true with positive youth. They feel shame or guilt for contracting the virus and feel that they need to lie about it and not be upfront. I think it’s important that young people are given a chance to tell their stories without being judged.

Speaking really helped me articulate myself as a person. It gave me a new direction to go in—not only is it inspirational

to other people, but it inspired me to clean up my life and make something positive of myself.

What do you get out of speaking publicly?

For me, it’s really about trying to reach out to people and letting myself be known. Even just being an example for other people who need inspiration makes a difference.

Finish the sentence: I know I’m connecting with the audience when...

I’m letting them know things that have hurt me and sometimes still do. I’m being vulnerable to people and it shows how human I am. If I manage to make friendships from a place of doubt, that’s a connection.

Advice for future public speakers:

Take a class in English composition or literature. When I first starting doing this, I was attending school to upgrade and it really helped.

James Lord Edwards, ⁴³

Sorrel Ridge, New Brunswick
Diagnosed with HIV in 1996
Speaks with AIDS New
Brunswick and AIDS Saint John

What gets you fired up?

I'm tired of tip-toeing around words I want to use. The HIV movement has become too polite. Having HIV is not polite. When I was talking with a nursing student who works with gay men, I was about to say, "When you have anal intercourse..." but then I said, no, "When you fuck..."

What drew you to public speaking?

When I became HIV positive I didn't do a lot of HIV work because it was too close to me, but after I returned to the East Coast I got involved with AIDS New Brunswick. I had been supported by different organizations and I wanted to give back. Recently, my reasons shifted when my friend Jocelyn, an Aboriginal activist, passed away from AIDS. I felt a rage with her passing and I needed to turn it into something positive.

True or false: Public speaking is your number one fear.

True. Even though I say I don't care what someone thinks of me, when I see or read people's reactions, especially if they're judgmental, it can affect me. As strong as we may be, we all want to be liked; we don't want to be judged.

Advice for future public speakers:

Sometimes people say things that can trigger negative memories, and next thing you know, it's affecting you in a way you never thought it would. Investigate it. How do you control it? Do you need to put up boundaries? +

"I'm tired of tip-toeing around words I want to use. The HIV movement has become too polite. Having HIV is not polite."

PHOTOGRAPH: BRIAN ATKINSON



We know how to help HIV-positive people get pregnant safely, yet those exploring the idea of having children still too often encounter ignorance and fear. **Diane Peters** reports on fertility options for PHAs and the drive to improve access to fertility services.



Birth Rights

Two years ago, Marie-Josée and her husband, Luc, decided to set aside the condoms and make a baby. She's HIV positive, he's not—but they were willing to take the risk. “This is really high on our list of things we want to do,” says Marie-Josée, who's 38 and concerned she's running out of time to become a mother.

But after 18 months of trying, no baby was on the way. Then, last fall, Luc got some upsetting news: Tests showed a sperm count so low that he's unlikely to be able to father a child. International adoption was out for the Quebec couple—it was too expensive. Besides, they quickly learned that Marie-Josée's status could make international adoption challenging, as many countries require medical examination of the parents and discriminate against people with HIV. A fertility clinic and the use of donor sperm seemed the best alternative.

Marie-Josée called all the clinics in the Montreal area, and heard a string of no's. “We don't deal with HIV-positive women for safety and security reasons,” one secretary told her. Marie-Josée knew these reasons had little scientific basis, but meanwhile, she was getting little support. Her HIV specialist did not want to be involved in her quest to become a mom, saying that reproductive health issues were beyond his expertise. He also told her: “I'm not supposed to know you're having unprotected sex. I don't want to have this conversation with you.”

But Marie-Josée knows that for the past decade it has been both possible and safe for people living with HIV (PHAs) to have children. Doctors know how to dramatically reduce the risk of the virus passing from mothers to newborns (this is called perinatal, mother-to-child or vertical transmission).

Preventing HIV transmission between partners often also requires medical help, but unfortunately in Canada that help can be hard to find—services are few and education among medical practitioners and the general population is lagging. However, a push for change is gaining momentum—community members and healthcare professionals, including obstetrician/gynecologists and infectious disease specialists, are joining forces to improve access to services for PHAs like Marie-Josée who want to get pregnant.

Baby boom

The desire to procreate among PHAs is on the rise. “I'm getting more and more referrals for couples who want to conceive,” says Dr. Mona Loutfy, an infectious disease specialist and the director of the Women and HIV

Research Program at the Women's College Research Institute in Toronto. Women, in particular, are keen. A recent survey found that 30 percent of young HIV-positive women in British Columbia hoped to become pregnant in the future. Researcher Gina Ogilvie, associate director of the division of STI-HIV prevention for the BC Centre for Disease Control, says these intentions are just seven percent lower than those of women in the HIV-negative population. “We can no longer assume that just because women have HIV they are not interested in having children,” she says.

Medical innovations have triggered this growth in a desire for kids. Thanks to a decade of experience and research—and resulting new protocols—the transmission rate of HIV to babies during pregnancy, childbirth and breastfeeding has dropped dramatically since the early 1990s, when rates were around 25 percent. “The risk is not zero, but with the right care it can be less than 1 percent—a risk that couples are usually willing to take,” says Dr. Deborah Money, an obstetrician/gynecologist who heads up the prenatal program at Oak Tree Clinic in Vancouver, which specializes in treating HIV-positive women.

Now doctors are seeing PHAs go through with their fertility plans. Money says that one-third of the HIV-positive pregnant women she treats have planned their pregnancies. Not that prospective parents are making the decision lightly. Like Marie-Josée and Luc, many educate themselves

about the risks to both themselves and the baby before setting aside birth control. They worry about transmission, the impact of a pregnancy on their health and how their illness or a shortened lifespan might affect a child.

As well, many of the young HIV-positive people in Canada are recent immigrants from countries where the disease is endemic, and cultural issues affect their fertility needs. "Some cultures place a huge weight on motherhood—it's a pinnacle to achieve," Ogilvie says. In many cultures, particularly African cultures, becoming a mother is equated with being a woman. If these couples haven't disclosed their status to other family members, they must often cope with strong social pressures to have a baby and prying questions about why it's taking so long or why the couple is using fertility services.

Safe options

Infertility is not the underlying reason why most PHAS come to a fertility clinic, according to Dr. Mathias Gysler of the Isis Regional Fertility Centre in Mississauga, Ontario. Instead, they are looking to prevent transmission of the virus between partners. "So, at a fertility clinic, these couples should do well," he says.

However, infertility does affect about 10 percent of the general population, and people with HIV might be at higher risk. The reasons for this are not clear but might include previous genital tract infections (in either sex) and sperm problems in men. Couples with fertility difficulties have various options. They may need ovulatory drugs, which stimulate a woman to release an egg. Or perhaps they'll undergo intrauterine insemination (IUI)—where sperm is placed inside the woman's uterus using a thin tube inserted into the vagina. They may even undergo in vitro fertilization (IVF)—in which the woman's eggs are fertilized in the lab and then inserted into her uterus.

When it's the woman who's HIV positive, a couple can often get pregnant at home. But, doctors do not recommend unprotected sex. For a safer option, these couples can try IUI at home by inserting semen into the vagina. Dr. Mark Yudin, an obstetrician/gynecologist at St. Michael's Hospital in Toronto who has a special interest in HIV, gives his patients empty syringes and helps them map out their menstrual cycles to determine when they are most fertile. "They

don't need assistance," he says. "They maybe just need advice." With IUI, there is about a 15 percent chance of pregnancy per cycle for all women, which is roughly the same or a little lower than it is for couples having regular intercourse.

When it's the man who has HIV, a couple does require a doctor's help: The virus transmits twice as easily from men to women, and unprotected sex carries on average a one in 1,000 chance of male to female infection per sex act. The best approach is IUI using washed sperm in a fertility clinic. This process involves a lab removing all the seminal fluid—where most of the virus lives—from around live sperm before insemination. Sperm washing costs about \$400 per procedure and IUI costs a similar amount, taking the total per try to \$800. If this fails, doctors can try IVF with washed sperm, which costs about \$6,000 per cycle. However, since sperm washing reduces the effectiveness of sperm, many clinics recommend using intracytoplasmic sperm injection (ICSI) during IVF. In this process, sperm is injected directly into a woman's egg in a lab dish using a microscopic needle, so fewer healthy sperm are needed. ICSI adds an additional \$1,200 to the cost of IVF.

While washed sperm has been used for the past decade thousands of times around the world with no incidents of HIV transmission to women or infants, there is still a theoretical concern. "I don't think you can eliminate the risk," Gysler says. To minimize the risk, doctors perform IUI with washed sperm just once every cycle.

For couples in which both partners are HIV positive, having safer sex is still important, as it is possible to reinfect each other during unprotected sex. The woman is more likely to become reinfect, and if reinfection occurs at the same time the woman becomes pregnant, her body would face these two health issues at the same time. Yudin says these couples might feel the risk is worth it. A safer but costlier choice is sperm washing and insemination at a fertility clinic.

While not recommended by doctors, couples who choose to forgo condoms often take other precautions to reduce the risk of infection. One of the most important is suppressing HIV in the positive partner. Research has shown that having an undetectable level of virus in the blood generally, but not always, means a lower level of virus in the semen and vaginal fluids. Lower levels of virus generally mean a lower risk of infection.



When it's the man who has HIV, the best approach is intrauterine insemination using washed sperm in a fertility clinic.

First steps

While the science already exists to help people with HIV have a baby, few Canadian clinics actually offer these services to PHAs. In a first step toward addressing this situation, Yudin and Loutfy recently surveyed fertility clinics across the country. Of the 23 that responded, only four offered a full range of services to HIV-positive people (many clinics don't offer sperm washing) and five said they do not help PHAs at all. "There's a big disconnect here," Yudin says. "It isn't right." The survey also found that HIV fertility services are not equally dispersed across the country. "We're doing well in Ontario and Alberta, but provinces like BC, Quebec, Manitoba and Nova Scotia aren't," Loutfy says. PEI, Newfoundland and the territories have no fertility clinics.

This patchwork of coverage is largely due to the fact that it has been the choice of individual doctors and clinics to offer their services to people with HIV. At Isis in Mississauga, Gysler and his colleagues began helping HIV-positive women and men about two years ago because they believed that ignoring the need could do harm—something that goes against their mandate as doctors. "If an HIV-discordant couple decides to have unprotected intercourse, that presents a greater risk than us helping them," Gysler says. Isis brought in an infectious disease expert to ensure that the clinic was being extra safe with its protocols. So far, the clinic has assisted in more than a dozen successful pregnancies in couples with HIV, some of them in people who had been trying for nearly a decade.

Labour of love

As has been the tradition in HIV activism, the community is fully involved in the effort to raise awareness and demand access to fertility treatments. Along with Loutfy, Yudin and Gysler, PHA and longtime community member Shari Margolese has been spearheading several initiatives aimed at addressing the gaps in understanding and the lack of services. Most pivotal is the National HIV Pregnancy Planning Guidelines Initiative, which is consulting with community and medical experts across the country to develop guidelines for healthcare professionals around safe practices for dealing with HIV during pregnancy planning and fertility treatments. "They will be the first comprehensive guidelines of their kind in the world,"

says Margolese, who is co-lead on the initiative. "And they will be for all HIV-positive people, not just for women with HIV."

In Quebec, community members are also taking the lead in ensuring that PHAs are able to become parents in that province. In the winter of 2008, HIV-positive women joined forces with healthcare professionals to create a committee to investigate the current state of policy, law and practice related to reproductive health and adoption for PHAs in Quebec. The committee, supported by provincial HIV organization COCQ-Sida, expects that its research will highlight where the most urgent changes need to be made.

What's motivating everyone in taking on this new work is a shared sense that the current situation is simply not fair and that access to fertility services should be offered to everyone, no matter what their HIV status.



Cautious optimism

Fortunately for Marie-Josée, in January the fertility clinic at the Royal Victoria Hospital in Montreal accepted her as a client. (The clinic, however, can't help HIV-positive men, as it doesn't offer sperm washing.) Her new fertility doctor told her and Luc that their case—female seropositivity and male infertility—was not as complex as they might think.

Now Marie-Josée is getting needles and ultrasounds as part of a fertility work-up and is facing the reality of fertility treatment. "The medicalization bothers me," she admits. "I'm already at the doctor more than I ever was in my previous life before HIV." As well, getting fertility help is costly—and there's no guarantee she'll have a baby in the end. "We're cautiously optimistic," she says. "We're not elated." When will she get excited? The day she holds a healthy baby in her arms. +

For more info about HIV and pregnancy, check out *You can have a healthy pregnancy if you are HIV positive*, published by Voices of Positive Women and CATIE and available through the CATIE Ordering Centre at www.catie.ca or 1.800.263.1638.

Diane Peters is a Toronto-based writer and teacher who has written extensively about health, parenting, women's issues and business for several national publications. She has two young children and gets very teary-eyed about baby-related happy endings.

ASK THE EXPERTS

Get answers to your treatment questions



WORK IT!

With the nice weather calling me outside, I've decided I want to get a bit more active this summer. I know exercise is good for everyone, including people with HIV, but I'm wondering if there is anything in particular I should know before I break a sweat. – RR, Peterborough, Ontario

RYAN COOPER

Physician, Northern Alberta HIV Clinic
Edmonton

The fact that more PHAs are asking about fitness shows how far we've come. Anti-HIV drug therapy has transformed a deadly disease into a chronic, manageable condition for most people in Canada. Instead of worrying about dying, people are getting on with their lives.

However, some of these lifesaving drugs can cause

side effects like high cholesterol, high blood pressure, abdominal weight gain and diabetes. All of these can

increase the risk of heart problems. What's more, HIV itself may increase your risk of cardiovascular disease and your long-term risk of heart attack.

For a number of reasons we are just beginning to understand, people with HIV (PHAs) seem to have thinner bones than the general population. We give PHAs the same advice about osteoporosis that we give everyone. Get enough calcium and vitamin D in your diet and perform

**CONSULT
A DOCTOR BEFORE
STARTING A VIGOROUS
EXERCISE PROGRAM.**

weight-bearing exercises, such as jogging, walking or stair climbing, to build your bone strength and density.

Consult a doctor before starting a vigorous exercise program. Most of the time, your doctor will review your medical history, ask about past injuries and then heartily encourage you to start exercising. But if you have severe heart disease or diabetes, your doctor may refer you to a cardiologist to make sure exercise is safe.



**YOUR NUTRITIONAL
NEEDS MAY CHANGE
WHEN YOU START
EXERCISING.**

DIANA JOHANSEN

Registered dietitian, Oak Tree Clinic
Vancouver

Ten years ago, we did not advise people with HIV to lose weight because of the concern of wasting syndrome—uncontrolled weight loss. But wasting is much less of an issue for people taking effective anti-HIV therapy.

For patients who are obese but with otherwise stable health, I now recommend losing weight because obesity can lead to all kinds of serious diseases. Being overweight, as opposed to being obese, doesn't pose the same health risks, but if you are overweight, you don't have to fear shedding a few pounds.

The BMI (body mass index) is one tool for finding out if you are obese or overweight. You are obese if your BMI is 30 or greater and overweight if your BMI is between 25 and 30.

Your nutritional needs may change when you start exercising. This will depend on your individual health and exercise or weight goals, so I recommend consulting a dietitian. Most HIV clinics have one on staff. To have plenty of energy, fuel up with carbohydrates one hour before exercise and bring along a snack if you're working out intensely for more than an hour.

Exercise can boost energy, but it takes time to start feeling energized after starting an exercise program. At first, you may feel more tired, so you need to stick with the program for about a month to reap that reward.

I tell clients to think about getting fit as a lifelong project because it stops them from getting too discouraged when they fall off the wagon for a few days. For detailed information about nutrition, weight loss and exercise, see CATIE's *Practical Guide to Nutrition*. The guide also contains a chart that can help you quickly determine your BMI.

TEMMI UNGERMAN SEARS

Certified Iyengar yoga instructor,
Director of YogaBuds Studio
(www.yogabuds.com)
Toronto

Therapeutic yoga is a branch of yoga that seeks to heal or treat the root causes of illness or injury. In our studio, all of our classes, including therapeutic yoga sessions, are taught in the Iyengar system of yoga, which seeks to achieve unity of mind, spirit and body—along with a meditative state—through breathing techniques and a system of *asanas* (poses).

Iyengar practitioners are trained to work with people with medical conditions and believe that certain poses benefit certain conditions. For example, chest openings and inversions can aid

a compromised immune system by increasing lymphatic flow and reducing stress. And someone with gastrointestinal problems may benefit from poses that increase circulation to the pelvic area or cause the abdominal organs to relax.

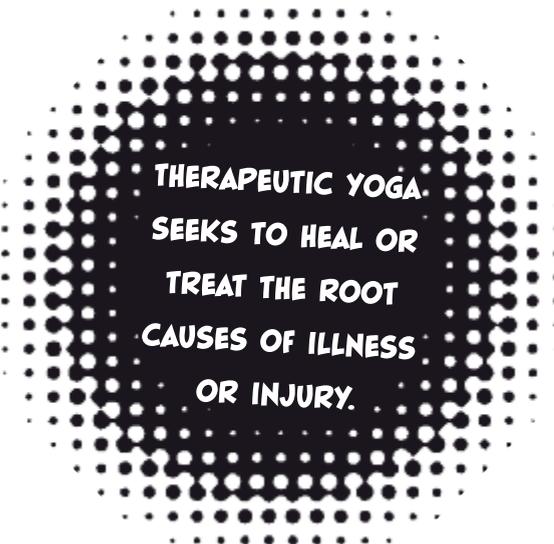
For a student who is a beginner or is limited by pain, fatigue or another condition, yoga teachers can use props such as ropes, blankets or chairs, to modify poses and so allow the student to experience postures more fully. The props also help the students hold poses for longer, which allows the deeper therapeutic benefits of yoga to happen.

DANIEL DEMONTIGNY

Personal trainer
Montreal

If someone comes to my gym with central fat accumulation, cardiovascular exercise is more important to start with than resistance training (lifting weights). Keep in mind that it takes a little exercise to be healthier and happier, but a lot more to burn fat. But even if you aren't losing weight, you can still derive benefit from keeping active, so start exercising at a comfortable level. Just start moving!

While exercise relieves stress, improves your mood and speeds weight loss, it can also help with serious health issues, like osteoporosis,



**THERAPEUTIC YOGA
SEEKS TO HEAL OR
TREAT THE ROOT
CAUSES OF ILLNESS
OR INJURY.**

WHEN BEGINNING
AN EXERCISE PROGRAM
KEEP YOUR HEART RATE
IN THE SAFE ZONE.

potential heart problems, diabetes and high blood pressure. However, these conditions can actually make exercising dangerous if you are not aware of them. Many people do not get the counselling and supervision they need at a gym, which may put them more at risk. Fortunately, you don't need a gym to exercise, just the go-ahead from your doctor and some simple guidelines to help keep your workout safe:

- If you have heart disease, diabetes or high

blood pressure (above 140/90 mmHg), or your resting heart rate is abnormally fast (over 100 beats per minute), check with your doctor before starting a vigorous exercise program.

- When beginning an exercise program, start conservatively and keep your heart rate in a safe zone (which is 45 to 60 percent of your maximum heart rate). You'll be less fatigued and actually start enjoying it!
- The first week of your program, start by exercising for 10 to 15 minutes two to three times per week. Progressively increase the duration and frequency (times per week), but

BY JENNIFER MCPHEE

As Joseph van Veen sprinted toward the finish line, he began to cry. His friends, parents and future husband, Bruce Edwards, were cheering wildly from the sidelines. The dance hit "You're a Superstar!" blared from the loudspeakers. It all felt overwhelming, and no wonder—van Veen wasn't even supposed to be alive. But 17 years after testing positive for HIV, he was on the verge of conquering the 2003 Ironman Triathlon in Madison, Wisconsin, one of the longest and most challenging triathlons in the world.

Van Veen was just 21 years old and living in Toronto when he was diagnosed with HIV in 1986. His doctors gave him three to five years to live. Seeing no point in getting an education, he dropped out of school and began spending money like Paris Hilton. By the time his 35th birthday rolled around, debt collectors were hounding him so often that he ended up declaring bankruptcy. At the same time, he was out of shape and roughly 20 pounds overweight. By day, he survived on caffeine and nicotine. By night, he ate fast food in bed while watching television. Looking back, he realizes he was depressed.

In 2000, van Veen stumbled across a fitness website geared toward a general audience and full of "before and after"

LIVING FOR THE TOMORROW

FOR IRONMAN JOSEPH VAN VEEN,
THE FINISH LINE WAS JUST THE BEGINNING!

PHOTOGRAPH: JACOB PETERS

not the intensity. Increase intensity when you are able to exercise for 30 minutes or longer. For example, if you were walking, you may start a slow run, or increase intensity to the 60 to 85 percent maximum heart rate zone. Eventually, you should exercise for 35 to 40 minutes at least three times per week.

- If you feel pain anywhere, rest and consult your doctor. Exercise can make injuries worse. +

Jennifer McPhee is a freelance writer based in Toronto. After finishing her first article for *The Positive Side* about getting fit, she finally started working out regularly again.



To calculate your maximum heart rate, subtract your age from 220.

To calculate your target heart rate (HR), you will need your age, your resting heart rate (in beats per minute) and the percentage of maximum heart rate you wish to reach (as a decimal, for example, 0.45 for 45%). Calculate the target heart rate like this:

$$\text{Target HR} = [\text{Target \%} \times (220 - \text{Age} - \text{Resting HR})] + \text{Resting HR}$$

There are several heart rate calculators online. Search for Karvonen heart rate calculator.



photographs that looked too good to be true. He was skeptical, but decided to commit to the 12-week program designed by U.S. fitness guru Bill Phillips. It opened him up to the idea of taking care of himself and completely transformed his body. “For the first time in my life, I set a goal and finished it,” he says. “That was a huge ego boost.”

Not long after, he began dating someone—his future husband Bruce Edwards. Edwards wanted to mark his own 40th birthday with an Ironman Triathlon. Van Veen started training with him and soon realized he was capable of taking on the race too. He signed up for the 2003 Ironman in Wisconsin and began selling kilometres to raise money for Casey House, a Toronto hospice for people with HIV/AIDS (he raised almost \$15,000).

Despite pouring rain and Toronto’s notoriously hot and humid summer weather, van Veen trained every day during the 13 weeks leading up to the September race, increasing his distances on weekends. “You never actually do the full race distance, but you build your stamina and strength so you are able to do it,” he says. “It’s about tricking your body into expecting something more the next time.”

The hardest part was sticking to his gruelling training schedule. Compared to that, the actual race was easy. Well,

maybe not easy. The Ironman begins with a 3.8-km swim, followed by a 180-km bike ride, and finally a 42.2-km run. “I got stung in the armpit by a wasp during the bicycle ride,” he says. “I grabbed it with my first, clenched it and squeezed it to death. And I said, ‘This is an Ironman. I’m in pain and I just keep going.’”

Van Veen’s goal was to finish the triathlon in 15 hours. But at the beginning of the run, he realized his heart rate was dangerously high and so he began alternating between running and walking. His goal seemed out of reach.

But then, a kilometre before the finish line, he realized he still had seven minutes to spare. “I don’t know where it came from, but I sprinted through the last kilometre,” he recalls. His final time was 14 hours, 58 minutes and 14 seconds.

The *Toronto Star* ran a half-page story about him in the sports section on the day of the race. “I didn’t even know there was a sports section,” he quips. “I go from the Living section to the Entertainment section.” Soon after, the Canada Africa Partnership on AIDS (CAP AIDS) asked him to raise more money by cycling across Africa. Van Veen said yes, and cycled 6,600 kilometres from Nairobi to Cape Town (roughly the equivalent of cycling from

Halifax to Vancouver), helping to raise \$25,000. But that’s another story.

These days, van Veen remains focused on his future, not on death. He got married two years ago and recently bought a condo. “You know the expression: Live each day as if it was your last?” he says. “I did that. I spent all my money. I did everything that I wanted to do. And I was out of shape. I’ve decided that expression is not good enough for me. I need to live each day as if there is a tomorrow.”

“FOR THE FIRST TIME IN MY LIFE, I SET A GOAL AND FINISHED IT. THAT WAS A HUGE EGO BOOST.”

Now 43, van Veen isn’t ruling out another Ironman, but he’s not committing to one either. “If I make it to my 50th birthday, I will need to mark it with something that screams ‘I’m alive,’” he says. “But that could mean an all-night party on a beach in Greece—who knows?” +



Cerebral Cortex
Super Poz and Virus



Your visit
ends here,
Virus!



Super Poz, you always
end up finding me! But
what have I ever done
to you?



YOU HAVE
TAKEN MY
PLACE...

UNMASKED!

Who is that man in the red tights?

Daniel-Claude Gendron, the artist behind the hero Super Poz.

INTERVIEW BY ALBERT MARTIN

I

had stopped drawing for about 10 years. Then, in 2004, during a particularly bad time, I asked myself what I could do to feel better. To be more specific, one night when my spirits were in the gutter, I said to myself, "Why not do the things you used to do?" I liked to draw when I was younger, so I started up again.

It did me a world of good to put pencil to paper. It made me understand that I had resources within me that I could use to improve my health. I also realized that I had forgotten how much I loved to draw. Since that day, I express myself through my drawing at



every difficult turn. Drawing has been my new therapy since 2004.

After I had been drawing for a year, I was still trying to understand what I was going through. One day, while analyzing the drawings I had created, I discovered that they contained some of the answers I was looking for. I learned that I could explore the issues I was facing through my drawings.

How did Super Poz come to be?

When I drew my first drafts of Super Poz in 2005, I had already been working in the HIV community for about three years (I received my HIV diagnosis about six years before that). I was often in contact with people living with HIV and was talking a lot with them. I found it a bit heavy to be discussing HIV 24 hours a day; it's not exactly a fun subject. As a remedy for my sadness, I drew a hero who fights HIV in a mask and red tights—Super Poz—because I wanted to laugh about it. I really needed to de-dramatize what was happening around me.



THIS STORY WAS ORIGINALLY INTENDED FOR ME AND SO THE ADVENTURE TAKES PLACE INSIDE MY BODY.

Is Super Poz you?

My goal was to be him (*laughter*), and I wanted to poke fun at that goal. As HIV-positive people, our situation is an odd one. We pay a lot of attention to our health, and the simplest things, like what we eat and drink, can take on huge importance. In my case, I became extremely fixated on myself and my health. My ultimate goal was to become the model HIV-positive man who eats well, exercises and looks after himself to perfection.

Things had really become blown out of proportion, so I wanted to make fun of the situation and show that such a goal is unattainable. I will never be Canada's perfect HIV-positive man, which was what the character Super Poz was representing for me at that time. Ever since I decided to laugh about life with HIV, being not perfect is much easier to accept.

So this "comical" character finally allowed you to assert yourself?

Things have changed a lot since 2005. At that time, I was simply having fun with a personal project. I had no intention to show my drawings to other people. I was amusing myself with my pencils and paper, but then I came to realize that my character's quest and my own were the same.

Eventually I decided to tell the adventures of Super Poz to my friends and colleagues. As I told his stories, I wondered to myself: "Who else but an

HIV-positive person could imagine such a character?" Clearly, I was asserting myself as much as my character. For me, creating a comic book about HIV was an exercise in disclosing my HIV status.

Has telling your hero's adventures helped you evolve?

From the moment I decided to make a "real" comic book out of Super Poz, I naturally became concerned about telling a story that everyone could understand. People living with HIV will certainly understand things differently because the action is taking place inside their own bodies. It's very narcissistic, obviously (*laughter*), but this story was originally intended for me and so the adventure takes place inside my body.

At the beginning of the story, we meet the character Cannabinol who has an appointment with Cerveau to present a project to Psyché. However, so everyone can understand, there's no talk of viral load, CD4+ counts or complex medical stuff; it's purely a world of fantasy. I think that HIV-positive people will still identify with the story and see the truth within the fantasy world.

When you remove your superhero mask, you work with HIV-positive people at Montreal's Maison Plein Cœur, helping them with all sorts of creative endeavors. What do you think they get out of it?

When I realized that I was feeling much better since I had begun to draw again, I wondered if there weren't other people out there like me who have neglected their artistic talents. That's where I got the idea for the project Zone+, a creative drop-in centre where, regardless of their skill level, people can rediscover their passion for creative activities in order to find answers and comfort.

I have been told by a lot of people that the mere fact of devoting time to a creative project has helped them become aware of their communication problem. Being creative has enabled them to express emotions that they aren't able to express verbally—to a counsellor or support worker, for example. This isn't exactly art therapy, but it certainly has a therapeutic effect.

Where is Super Poz in his adventures now?

My first draft of Super Poz was a bit all over the place. All my thoughts about myself, HIV and the world were jumbled together in a story that was too long and complex. In recent years, I have tried to create an issue entitled *Métabolisme*. It's ready to go as soon as I find some money to publish it. +

Albert Martin is chair of the organization *Fréquence VIH*. An HIV-positive writer and activist, Martin believes that art teaches us a great deal about the experience of living with HIV.

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IMPORTANT: Decisions about particular medical treatments should always be made in consultation with a qualified medical practitioner knowledgeable about HIV-related illness and the treatments in question.

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